

FIRST NATIONS HEALTH POLICY AND FUNDING: CONSEQUENCES FOR THOSE LIVING WITH  
HIV/AIDS

by

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A dissertation

presented to Ryerson University

in partial fulfilment of the  
requirements for the degree of

Doctor of Philosophy

in the program of

Policy Studies

Toronto, Ontario, Canada, 2019

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## Author's Declaration

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First Nations Health Policy and Funding: Consequences for those Living With HIV/AIDS

Doctor of Philosophy, 2019

Sean A. Hillier, Policy Studies Program, Ryerson University

## Abstract

In 2014-2015 Indigenous Peoples represented 17.5% of all HIV infections in Canada, yet accounted for only 4.3% of the population. In 2008, Indigenous Peoples accounted for an estimated 3.2% of people living with HIV in Ontario, while comprising 2.4% of the population. From 2009 to 2011, 2.7% of new HIV diagnoses in Ontario were Indigenous Peoples, of whom 7.2% were women. This research study sought to assess the efficacy of funding for HIV/AIDS treatment, services, programming, and care within Ontario First Nations communities. This research will improve understanding of services available to people and communities affected by the HIV/AIDS epidemic.

The Indigenous based method of storytelling and freedom of information requests were used to capture data. Ontario First Nations people who were at least 16 years of age and living with HIV/AIDS (n=29) participated. Participants were asked five open-ended questions related to their use of and access to healthcare services. Stories were transcribed and analysed using NVivo. Transcriptions also form the bases of re-written first-person stories, detailing the life and experiences of the participants and their experiences of living with HIV/AIDS and accessing treatment, services, programming, and care.

It was found that the federal government drastically underfunds HIV/AIDS treatment and services. This is given context by powerful stories of the impact limited funding has on Indigenous people living with HIV/AIDS. Participants experienced issues with access to care and

supports with many forced to leave their northern communities, either permanently or temporarily, due to limited access to care. HIV-related stigma played a role in access to prevention, testing, and care. Participants indicated difficulties with HIV education either in understanding their own HIV status or in the lack of education within the broader community. Historical traumas (residential schooling and the 60s scoop) and discrimination were central themes to many stories, seriously affecting the lives of participants and their overall health outcomes.

The dissertation/project culminates in a list of recommendations aimed at informing a process to improve access and quality of health care for Indigenous Peoples living with HIV/AIDS. Greater access to community-based, holistic care in northern First Nations communities is urgently required.

## Acknowledgments

I want to begin this dissertation by thanking the people living with HIV who have generously shared their time, experiences, and bodies for the purposes of this research. Much of the fight against HIV and AIDS relies upon people living with HIV continuing to put themselves forward and this research and our fight against HIV and AIDS is indebted to those past and present. This research would not have been possible without the work of community partners, the Ontario Aboriginal HIV/AIDS Strategy (OAHAS) and Two-Spirited People of the First Nation. I am forever in your debt. I also acknowledge the many other organisations who helped with recruitment and offered space and resources whenever needed. I wish to acknowledge the traditional territories on which this research took place. This land has helped to ground the knowledge I have gained through this process, and I will be forever grateful.

I wish to extend my heartfelt gratitude to my Supervisor, Dr. Lynn Lavallée. Without her guidance, support, and encouragement, I would not have been able to finish this program. I also wish to recognize the support of Dr. Neil Thomlinson who spent many an hour reviewing my work and providing guidance on not only this work, but on my career and larger questions about life. I thank Dr. Julie Tomiak for taking a chance and agreeing to come onto my dissertation as a committee member fairly late into the process. She provided fundamental feedback that helped to shape the critical approaches found within this work. This research would not have been possible without the funding provided by the Canadian Institutes of Health Research through a priority doctoral award in Indigenous HIV/AIDS of \$105,000.

I wish to thank my partner, Cameron (and our dog Ceres) for his support and encouragement in the final years of this very long journey. To my friends, who number far too many to list here I say Thank-You! I wish to specifically highlight Jon, Dave, Heather (Win), Kay, and Adil. Without their love, support, and encouragement over the past seven years, this would not have been possible. They were the cornerstones I was always able to turn to in order to vent, talk things through, seek sound and sometimes profound advice, and just a group who would always want the very best for me!

Finally, I wish to thank those who have supported me for not just the past decade, but who have been the cornerstone of my life. My mom, who sacrificed so much so that I could finish high school in Toronto, who always knew and said I would go on to great things. She is a role model like no other. My father has always been a rock, ready with steady advice no matter the issue. He deserves this PhD as much as I, for he has spent the past 12 years proofreading assignments, essays, and acting as a sounding board for all of my ideas. My brothers and sisters, Kyle, Jessica, Taylor, and Keegan - who all helped to keep me grounded (both literally and figuratively) throughout life.

## Dedications

I dedicate this dissertation to all the brave Indigenous Peoples who are living with HIV/AIDS and are fighting for their recognition and equal rights within this land that is their own. May this work help you to continue your fight.

I wish to acknowledge Tony Nobis, who passed away while I was completing this research. As the Executive Director of the OAHAS, he was instrumental in getting this research off the ground. He was the first person I met in community regarding this project and he dedicated a great amount of time and guidance to ensuring that it got started and I was able to recruit research participants. Without him, this research would not have been. I will be forever grateful for his mentorship and the impact he has had on my work as an academic.

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## List of Abbreviations

2-Spirits	2-Spirited People of the First Nation
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
ASO	AIDS Service Organisation
BNA	British North America
CAD	Canadian Dollars
CBAO	Community-Based AIDS Organisations
ED	Executive Director
FN	First Nation
FNIHB	First Nations and Inuit Health Branch
FOI	Freedom of Information Request
HCV	Hepatitis C Virus
HARRT	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
IPLWA	Indigenous People Living with HIV/AIDS
IDU	Injection drug users
LEP	Laboratory Enhancement Program
MSM	Men who have Sex with Men
DHW	National Department of Health and Welfare
NIHB	Non-Insured Health Benefits Program
OAHAS	Ontario Aboriginal HIV/AIDS Strategy
ODSP	Ontario Disability Support Program
PrEP	Pre-Exposure Prophylaxis
PTO	Political Territorial Organisation
PI	Principle Investigator
PHAC	Public Health Agency of Canada

REB	Research Ethics Board
STBBI	Sexually Transmitted Blood-Borne Infections
USD	United States Dollar

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## Definitions

This paper will use the non-colonial term *Indigenous* when referring to and discussing First Nations, Métis, and Inuit peoples as a group. However, given the subject matter, “First Nations” here means the people described in the definition listed below. Periodically, throughout this paper the terms *Indian* and *Aboriginal* will be used, but only when there is a direct reference to these terms through policy or other direct quote.

Legal definitions from the Government of Canada for these terms and others are provided below:

**2-Spirit:** The term 2-Spirited means many different things, to different people. In our culture, before the Europeans came to North America, 2-Spirit referred to an ancient teaching. Our Elders tell us of people who were gifted among all beings because they carried two spirits: those of male and female. It is told that women engaged in tribal warfare and married other women, as there were men who married other men. These individuals were looked upon as a third gender in many cases and in nearly all of our cultures they were honored and revered. 2-Spirit people were often the visionaries, the healers and the medicine people, respected as fundamental components of our ancient culture and societies. This is our guiding force as well as our source of strength. Today. The term 2-spirit may also be used by Indigenous People who identify within the broader ranges of the LGBT community and may not have any direct connection to culture or spiritual understanding.

**Aboriginal peoples:** “*Aboriginal peoples* are the descendants of the original inhabitants of North America. The Canadian Constitution recognizes three groups of Aboriginal people: Indians, Métis, and Inuit. These are three separate peoples with unique heritages, languages, cultural practices, and spiritual beliefs” (Aboriginal Affairs and Northern Development Canada, 2012, Para #2).

**AIDS:** *Acquired Immune Deficiency Syndrome* is when the body can no longer fight infection as a result of HIV infection. At this point, the disease has progressed to become AIDS (Government of Canada (b), 2014).

**First Nations:** First Nations peoples are original inhabitants of the area now known as Canada. Within this population there exist many distinct cultural groups or nations, including 630 distinct communities and approximately 60 different languages. (National Collaborating Centre for Aboriginal Health, 2013)

**HIV<sup>1</sup>:** 1) Human: Can only be passed between humans; 2) Immuno-deficiency: It makes the immune system deficient (not work properly); 3) Virus: Infectious agent that copies itself only

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<sup>1</sup> **TRANSMISSION:** HIV needs an entry way into the bloodstream, which can occur in these ways: Blood to Blood: Intravenous drug use or other drug equipment; Sexual Fluids: Semen or vaginal fluids during vaginal, anal, or oral sex; Vertical Transmission: during pregnancy, birth or through breast milk when the mother is HIV-positive; Once inside the body, HIV attaches itself to white blood cells (CD4 cells are the ones that fight off infection).

**STAGES OF INFECTION:** Immediately following initial contraction of HIV: The virus multiplies quickly, individuals are HIGHLY infectious; Three Month Window Period: HIV not detectable in tests (test for anti-bodies); Asymptomatic:

within a living host. The virus is only transferred through human body fluids such as blood, semen, vaginal secretions, and breast milk. (Ontario Aboriginal HIV/AIDS Network, 2015)

**HIV/AIDS:** A simplifier of the combined terms to refer to one or both HIV and AIDS.

**Indian:** “*Indian* people are one of three cultural groups, along with Inuit and Métis, recognized as Aboriginal people under section 35 of the Constitution Act. There are legal reasons for the continued use of the term *Indian*. Such terminology is recognized in the Indian Act and is used by the Government of Canada when making reference to this particular group of Aboriginal people” (Aboriginal Affairs and Northern Development Canada, 2012, Para #10).

**Inuit:** Inuit peoples are original inhabitants of the Arctic regions of the area now known as Canada. The majority of the 59,445 Inuit people in Canada live in their traditional territories in four regions collectively known as Inuit Nunangat. These regions are: Nunatsiavut (Labrador), Nunavik (northern Quebec), Nunavut, and the Inuvialut Settlement Region in the Northwest Territories. Close to 70% of the Inuit people speak Inuktitut, although the number of people reporting it as their first language is declining. (National Collaborating Centre for Aboriginal Health, 2013)

**Métis:** In French, the word “Métis” translates as “mixed.” There exists some debate over who is considered Métis, with some taking a broader definition than outlined by the Métis National Council (MNC). The MNC defines Métis people as individuals who self-identify as Métis, are of historic Métis origin (mixed First Nations and European heritage, descendants primarily of 18th century fur traders and First Nations in the area known as the Métis Homeland) and are recognized by the Métis Nation (Métis National Council, n.d.). Métis people have a distinct culture, traditions and language (Michif) which contribute to their collective consciousness and nationhood (ibid). (National Collaborating Centre for Aboriginal Health, 2013)

**Remote Reserve:** A *remote reserve* is a reserve with a geographic Zone of 3 or 4. A zone 3 reserve is “located over 350km from the nearest service centre with year-round road access.” A zone 4 is a “First Nation that has no year-round road access to a service centre and, as a result, experiences a higher cost of transportation” (Aboriginal Affairs and Northern Development Canada, 2014, Para #21).

**Reserve:** “A *reserve* is a tract of land, the legal title to which is held by the Crown, set apart for the use and benefit of an Indian *band*” (Aboriginal Affairs and Northern Development Canada, 2012, Para #25).

**Status Indian:** “*Status Indian* is a person who is registered as an Indian under the Indian Act. The act sets out the requirements for determining who is an Indian for the purposes of the Indian Act” (Aboriginal Affairs and Northern Development Canada, 2012, Para #11).

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Virus slows down, gets comfortable in body, there are no symptoms; Symptomatic: If HIV is not treated with anti-retroviral medication one can progress to a diagnosis of having AIDS. This progression leaves the body vulnerable to more infections than normal due to lowered immune function and if left untreated can eventually lead to death. (Ontario Aboriginal HIV/AIDS Network, 2015)

## Chapter I: Introduction

“Two thirds of that last generation to attend residential schools has not survived. It is no coincidence that so many fell victim to violence, accidents, addictions and suicide. Today the children and grandchildren of those who went to residential schools also live with the same legacy of broken families, broken culture and broken spirit” (Chief Councillor Cootes, cited in Royal Commission on Aboriginal Peoples, Government of Canada, 1996, p. 22).

Striking health disparities exist amongst Indigenous Peoples across Canada. These disparities have been well documented for more than three decades (Kurtz, Nyberg, Tillaart, & Mills, 2008). “On many health indicators, First Nations, Inuit, and Métis peoples continue to show a disproportionate burden of disease or health disparities. These disparities are often rooted in health inequities” (National Collaborating Centre for Aboriginal Health, 2013, p. 3). Indigenous Peoples in Canada are experiencing ill health, including major health problems, at rates far higher than in the non-Indigenous population. These disparities can be seen among virtually every facet of health, including but not limited to: high infant and young child mortality; high maternal morbidity and mortality; heavy infectious disease burdens; malnutrition and stunted growth; shortened life expectancy; diseases and death associated with cigarette smoking; social problems, illnesses and deaths linked to misuse of alcohol and other drugs; accidents, poisonings, interpersonal violence, homicide and suicide; obesity, diabetes, hypertension, cardiovascular, and chronic renal disease; and diseases caused by environmental contamination (National Collaborating Centre for Aboriginal Health, 2013, p. 4). These gaps are paving the way for some of the shortest life expectancy rates of any one

identifiable group within Canada. In 2017, the projected life expectancy of an average Canadian was 79 years of age for men and 83 years for a woman. However, when looking at the Indigenous population, that falls dramatically to 73-74 years for men of Métis and First Nations descent and 78-80 for women. Even more dramatic is that the Inuit have the lowest projected life expectancy in Canada at 64 years for men and 73 years for women (Government of Canada, 2017b).

Health disparities faced by Indigenous Peoples in Canada have been directly linked to centuries of traumatic policy imposed upon them. These policies have resulted in a history of cultural genocide and colonisation. Colonialism is at the heart of power structures within Canadian bureaucracy, which in turn has sought to suppress Canada's Indigenous Peoples since first contact. As a result, this has created "social, political and economic inequalities that 'trickle down' through the construction of unfavourable, intermediate and proximal determinants" (Reading & Wien, 2009, p. 20). This leaves Indigenous Peoples "suffering from the worst social, economic and health conditions in Canada" (MacDonald, 2007, p. 321).

The impact of structured and deliberate practices to remove and kill the language and culture from Indigenous Peoples is still felt today. The reserve system, residential 'industrial' schooling, the 60s scoop<sup>2</sup>, over-incarceration of Indigenous men and women, and the continued over-apprehension of Indigenous children by the state to be placed in foster care all play a part on the continued role in the ill health of Indigenous Peoples. This is important, because as Axelsson, Kukutai, and Kippen (2016) argue, "[w]hile there continues to be a

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<sup>2</sup> The 60s scoop in this context relates to a period from the 1940s-1970s in which thousands of children were apprehended by the state. Issues surrounding the continued apprehension of Indigenous children in what is known as the 'millennium scoop' will be addressed later in this section.

proliferation of research on the contemporary health outcomes of Indigenous Peoples, colonisation or colonialism rarely figure as part of the explanation. On the rare occasion that colonisation is mentioned, it is usually situated as an historical event rather than an ongoing process that continues to impact negatively on Indigenous health outcomes” (Axelsson, Kukutai, & Kippen, 2016, p. 3). The focus of this research is to ensure appropriate voice is given to the impact colonisation has on Indigenous Peoples’ health today.

In total, colonial policies, attitudinal and systemic racism, combined with socio-economic disparities all present significant barriers to creating an ideal healthy environment for Indigenous Peoples in Canada (Smylie, Williams, & Cooper, 2006). Canada is a settler colonial nation-state, one that is balanced upon white supremacy and heteropatriarchy (Arvin, Tuck, & Morrill, 2013). For more than five hundred years, Western law has functioned as a core tenet of the practices of European settler colonialism (Morgensen, 2011). Settler colonialism must also address the interaction of colonialism racism, gender, class, sexuality and desire, capitalism, and ableism (Snelgrove, Kaur Dhamoon, & Corntassel, 2014). Racism at its core is a multi-layered phenomenon, it must be investigated through a structurally layered approach in order to understand its true impact on health (Juutilainen, Miller, Heikkila, & Rautio, 2014). Additionally, this research will provide a critical analysis of heteropatriarchy – as research shows that Indigenous women are reporting higher rates of HIV infection than Indigenous men, in addition to experiencing a disproportionate likelihood of being the victim of violence (Browne et al., 2016).

## Background

The Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) are disproportionately impacting Indigenous Peoples in Canada. However, there is limited data on the true impact HIV and AIDS are having on this key population, given significant issues with HIV data collection and reporting. Some of the latest data available are from the year 2011. According to Negin, Aspin, Gadsden, and Reading, with data taken from 2011, “Among Indigenous Peoples in Canada, HIV has become a generalized epidemic and diagnosis rates are considerably higher among Indigenous Peoples compared to non-Indigenous Canadians. Indigenous Peoples make up 4.3 % of the Canadian population yet accounted for 12.2 % of new HIV infections and 18.8 % of reported AIDS cases” (2015, p. 1722). Specifically, in Ontario, Indigenous Peoples are at greater risk (1.7 times more likely) to acquire HIV than the general population, however, while Ontario may appear to have fewer cases, HIV testing rates are also significantly lower amongst this population (Ontario HIV Treatment Network, 2014). Indigenous women are also more likely to be diagnosed with HIV than the general population, with new data suggesting that up to 40% of new infections are among Indigenous women. Modes of exposure for women are mainly from sexual contact with men (at 59% of infections) and exposure through injection drug use (35% of infections). For men, the greatest risks are from injection drug use (32%), followed by sexual contact with men (28%), and exposure through both drug use and sexual contact with men (20%), while only 16% reported transmission via sexual contact with women (Ontario HIV Treatment Network, 2014). Additionally, up to 60% of Indigenous Peoples living with HIV are also living with hepatitis C, a

rate that is over 3.5 times that found within non-Indigenous populations (Ontario HIV Treatment Network, 2014).

The largest number of people with Indigenous ancestry in Canada live in Ontario (242,495) compared to 1,172,785 in all of Canada. Almost half (48%) of the 181,524 registered Indian population in Ontario lives on 207 reserves and settlements, and there are 126 bands, with over 23,000 speakers of Aboriginal languages in the province (Government of Canada, 2018c). HIV statistics in Ontario are limited due to a lack of demographic tracking of new infections, but it was estimated in 2008 (the last date data are available) that Indigenous Peoples accounted for 853 (3.2%) of the 26,628 people living with HIV in Ontario. In Ontario from 2009 to 2011: 43 (2.7%) of 1,573 new HIV diagnoses were in Indigenous Peoples (Government of Canada, 2016c). In a new 2016 report, Indigenous Peoples made up 2.5% of new infections between 2001-2016, with Indigenous women representing 7.4% of new diagnoses by race (The Ontario HIV Epidemiology and Surveillance Initiative, 2016). Therefore, based on these limited data we can estimate that approximately 853 Indigenous Peoples are diagnosed as living with HIV/AIDS in the province of Ontario.

## Study Overview

While the HIV/AIDS epidemic affects all Indigenous communities, the scope of this research will be specifically looking at status First Nations people and reserve communities. This is because the federal government has direct responsibility for “Indians and Lands reserved for the Indians,” as detailed in the British North American Act (section 91.24). The policies detailed below all specifically relate to this specific population.



The impetus for this research is derived from the significant dearth of academic literature on this critical issue. Past studies of First Nations health funding have not analysed how the policies and funding arrangements concern HIV/AIDS. Additionally, throughout the literature there is a lack of understanding or analysis of how funding is having an impact upon First Nations people living with HIV/AIDS and their communities.

This research will be grounded in an Indigenous theoretical framework, from which the data was collected and analysed. This research utilizes Indigenous ways of knowing and methodological approaches to examine the central question to be answered in this dissertation - how and to what extent does policy have an impact upon funding and/or programming, care, treatment, and service delivery for people living with HIV/AIDS in First Nations communities in Ontario, Canada?

The research sub-questions to be explored are as follows:

1. What policies are in place that affect First Nations' health care?
2. How much funding for HIV/AIDS treatment/policy/services do communities receive? Where does this funding come from?
3. How and to what extent does funding and/or service delivery affect people living with HIV/AIDS?
4. What processes/actions can be taken by the federal/provincial governments and First Nations communities to re-evaluate current practices of funding and service delivery to improve any inefficiencies that may be found?

This dissertation will help answer these central questions through the analysis of four major components. First, a comprehensive literature review was conducted to assess the landscape of published policy work in the field of HIV/AIDS, specifically in relation to Indigenous Peoples living with HIV/AIDS. Second, a detailed review of policy was conducted. The review highlights the formation of all colonial acts related to health care within Canada. Significantly, there were issues with inter-jurisdiction and the impact this had on Indigenous-specific policy

formation. This results in there being no policy in Canada that notes HIV/AIDS as an exceptional illness for Indigenous Peoples. Consequently, policies relevant to the formation and delivery of healthcare services to First Nations Peoples in Canada will be examined from the macro, meso and micro level, specifically how Treaties, the Royal Proclamation, The British North American Act, the Indian Act, Canada Health Act, Indian Transfer payments, and Constitution Act piecemeal together a healthcare system for First Nations Peoples. Third, this dissertation will report on the results of primary research with First Nations people living with HIV/AIDS (n=29). Through a traditional storytelling method, participants described their life living with HIV/AIDS; how they access care, treatment, and services for their HIV status; their perception of the quality and availability of those services; and provide recommendations on how better access to treatment, services and care could improve their quality of life. Fourth, freedom of information requests were submitted to the federal government asking for all data related to funding HIV treatment, services, and care for First Nations People living with HIV/AIDS in Ontario. Additionally, a request was made to determine the number of individuals who had accessed any form of HIV/AIDS drug treatment through the Non-Insured Health Benefits Program (a program offered to status First Nations people).

## Literature Review

The literature review is broken down into nine major themes: Indigenous health broadly within Canada; prevalence of HIV/AIDS within specific populations; injection drug use and risks of HIV infections; stigma faced by Indigenous Peoples in relation to HIV; cultural impacts and holistic health; HIV treatment and access; HIV prevention; supports for people living with HIV; and policy. An evaluation of the settler state's injustices perpetrated against Indigenous

Peoples for their own capital gain as expositied through gendered and racialized privilege (Simpson, 2007) will lay the foundation of the analysis of this chapter and others to come.

Through a search of the literature, it was found there is an overall dearth of information in all areas related to Indigenous HIV in Canada. Specifically, there was no literature identified which directly addresses the issue of funding for HIV/AIDS services, care, or programming for First Nations people living with HIV/AIDS or within First Nations communities. There is a marked increase in the number of new HIV infections within the Indigenous community (Duncan et al., 2011; Hoffman-Goetz, Friedman, & Clarke, 2005; Hogg et al., 2012), and this presents a clear concern and need for further research. While treatment and supports are widely available today, there are clear gaps in access for both Indigenous Peoples in general (Baiju, Gunraj, & Hux, 2003) and, more specifically, for those living with HIV/AIDS (Worthington, O'Brien, Myers, Nixon, & Cockerill, 2009). This is particularly apparent when looking at Indigenous women and straight men, who seem to be virtually absent from the literature. There is a clear gap in the literature related to how HIV/AIDS is an exceptional Indigenous health issue that warrants specific policy creation. The dearth of policy related literature about Indigenous Peoples living with HIV/AIDS is also highly problematic given the varying inter-jurisdictional issues at play.

## Research Methodology

The chapter on research methodology is broken down into two major sections. The first is a discussion of Indigenous knowledges and worldviews, and the second describes the methodological approaches used within this research. Within the section on Indigenous knowledges and worldviews, there are discussions related to how to define Indigenous knowledge, what Indigenous worldviews are and how they are applied to this research.

However, it starts with highlighting the colonisation of Indigenous Peoples and examining the impact this has had on Indigenous ways of knowing and being. The process of colonisation left Indigenous Peoples without a voice (Wilson, 2003). However, there has been a steady move towards embracing Indigenous ways of knowing and being within the academy. While Indigenous knowledge holds identifiable characteristics and processes, there is no single understanding of Indigenous knowledge, or how we come to know. These processes of knowing can come from connection to the land and spiritual systems, the processes through which we learn through listening, viewing, sharing, and engaging with one another, and how understanding is grounded in the timing and environments of the particular experience. This section will explore how the methods chosen were respectful of the variety of participant backgrounds and how their ways of passing on knowledge could differ from participant to participant.

The second section seeks to answer these questions through the use of two methods. First, storytelling was used with 29 participants, who identified as First Nations and were living with HIV/AIDS. A holistic approach to this research was deemed to be critical given my own approach to conducting health research but also given the incorporation of Indigenous methods and ceremony within the research. I also determined that taking a holistic approach was required given the subject matter of this research and interaction with participants who are living with HIV/AIDS. Therefore, this research first used a storytelling method. Stories can be used to remind us of who we are and how one belongs within a community. When people talk about their stories they talk about their knowledges while at the same time signifying their relationships (Kovach, 2009). Storytelling, as a method, is a collaborative process that

acknowledges the researcher is also in the position of being a participant within this process of storying and then re-storying – the process by which the narrative is actually created. Second, this chapter will report on the results of the freedom of information requests from the Canadian federal government regarding funds provided to First Nations in Ontario with relation to HIV/AIDS, including funding source(s) as well as the number of Non-Insured Health Benefits users accessing treatment or services for HIV/AIDS within the province of Ontario.

### Policy Review

At the heart of colonisation is policy (Jackson, 2009). Policy is the tool that has been used to suppress Indigenous Peoples, whether it be through the creation of residential schools, the direction to remove Indigenous children from their communities and place them in foster care or up for adoption, or through the forced assimilation and enfranchisement of tens of thousands of Indigenous Peoples (Armitage, 1995; Jasen, 1997). Canada has a long history of colonial policy leading to adverse health effects among Indigenous Peoples. This also extends to a lack of action by the government in dealing with urgent health needs, as is the case with Indigenous Peoples living with HIV/AIDS. The act of choosing not to act is the conscious creation of policy.

As a result, this chapter starts with a brief overview of policy studies and the determination of not conducting a policy review. A finding of this research is that there is no policy in Canada which directly sets out funding for HIV services and or programming for First Nations people living with HIV/AIDS. The federal government has traditionally avoided making exceptional policy for disease-specific issues. This has meant that there has been no creation of policy related to funding or service delivery for First Nations people living with HIV/AIDS.

Instead there are significant jurisdictional issues that plague policy development in the area of healthcare for First Nations Peoples. Therefore, I highlight the policy context of healthcare delivery more broadly in Canada.

The policy review uses the macro, meso, and micro framework to structure the policy issues explored. The orientation of the macro frame is the policy context that established the ability for government action within the healthcare field. At this level, healthcare exists largely conceptually and is meant to be understood as an umbrella that vastly impacts all Canadians. Whereas, the meso frame is where health policy takes shape as a way to conceptualize funding and delivery. This is where we see Indigenous healthcare delivery begun to take shape as more than a concept or area of jurisdictional dispute. Given the fragmented nature of healthcare policy related to Indigenous Peoples in Canada, this framework makes the most sense for understanding the role the Government of Canada plays in the delivery of healthcare services. At the micro level, we see an absence of policy that directs the continuum of care or funding for Indigenous People living with HIV/AIDS.

However, this framework does not address (through classification) the significant colonisation that has and continues to take place as a result of these policies' existence. Therefore, I further classify the frames of macro, meso, and micro through a decolonial lens. To this day, Indigenous policy is created under the guise of recognition and respect, however, Indigenous policy continues to entrench the patriarchal systems created and propped up by the Indian Act, 1876 and its subsequent amendments. In recognition of this, the first half of these policies will be labelled macro policies of assimilation, and the second half as meso policies of accommodation. Taken together, this policy section will use this framework to understand how

policy has been set out to deliver healthcare in Canada, both in general and specifically related to First Nations people living with HIV/AIDS.

The macro policies of assimilation create an overarching framework from which healthcare delivery to First Nations and Inuit Peoples are derived. These detail the colonial history of Canadian policies, which sought to destroy Indigenous ways of life, culture and language. Policies related to Indigenous Peoples have meant horrendous outcomes across virtually every aspect of life. Historians refer to early government interventions as well-intended assimilatory policies (Palmater, 2014). These policies include, the Royal Proclamation (1763), British North American Act (1867), Treaties (1871), Indian Act (1876), the White and Red papers (1969 and 1970, respectively) and the Constitution Act (1982).

The meso policies to follow detail how the government has continued to place their own needs before that of First Nations and Inuit Peoples. This section brings together the aforementioned section to create a framework from which policy delivery can be accomplished in Canada. These policies include the Indian Health policy (1979), Canada Health Act (1985), Indian Health Transfer Policy (1989), Primary Health Care Transition Fund, and Jordan's Principle. The policies detailed through this chapter denote a transformation over time from being assimilative in their intent and goal to being encouraging of First Nations having control and autonomy over their affairs, particularly when it comes to healthcare. The most recent policies highlighted in this section which concern healthcare, have been designed to transfer certain resources and control over to the communities. However, many communities have been, and remain, concerned that this action, through policy, is merely the federal government

acting in its own best interests. The clear absence of micro policies related to funding delivery and responsibility of care further obfuscates these problems.

Overall, Canada has a complex set of policies that give the federal government jurisdiction and authority for status First Nations and Inuit Peoples and First Nations and Inuit communities. The Royal Proclamation confirmed that the Indigenous Peoples of Canada were never a conquered people. Through both of these sections, it is argued that the federal government has recognized and affirmed its unique constitutional obligations to First Nations and Inuit Peoples. However, the federal government has never officially acknowledged that it has a legal obligation to provide health services to First Nations Peoples. Instead, the federal government argues that it has a special relationship with the First Peoples of this land and, through its unique constitutional relationship with them, it is committed to preserving that special relationship, and that means offering health services on reserves as a matter of goodwill. Significant jurisdictional gaps leave First Nations People and their communities struggling to address their basic healthcare needs, including addressing the need for HIV/AIDS strategy. Therefore, we continue to be left questioning who truly has jurisdiction for First Nations health? Is this an 'Indian' issue which must be viewed as a federal issue, or is it merely a health issue that the province must deal with, or is this a federal matter which must override provincial jurisdiction?

## Findings and Discussion

The findings chapter highlights the results of storytelling with 29 participants who are First Nations and living with HIV/AIDS. There was an almost equal distribution between male (n=13) and female (n=12) participants, and two-spirited (n=4) participants. The majority of



participants self-identified their sexuality as straight / heterosexual (n=22), two identified as two-spirited, one as gay, and one as not straight. The average age of participants was 48 years old with an average monthly income of \$1,362 (all participants received supports from the Ontario Disability Support Program). Through storytelling, 17 major themes emerged along with a set of recommendations that was participant-focused. These 17 major themes represent some 143 individually coded nodes. The major themes include: diagnosis, treatment, health, access, community, family, culture, education, addictions, sex and sex-work, homelessness, incarceration, life, death, discrimination, trauma, and criminalisation. Additionally, twenty-six participants provided feedback on recommendations they believe would best serve them and others living with HIV/AIDS.

The findings chapter also highlights the results of three freedom of information requests that were made to the Canadian federal government via Health Canada. The responses provide insight into the numbers of people accessing treatment and therefore in need of services in the province of Ontario. The responses also allow for an understanding of what funding the government is providing to communities and other First Nations organisations within the province. Specifically, given the information received I was able to draw a relatively accurate picture of the diagnosed HIV epidemic within First Nations communities in Ontario. Based on this information, there were a total of 427 status First Nations people receiving treatment for HIV within the province. This number encompasses 316 people who are registered to a First Nation in Ontario, with the remaining 111 being from First Nations outside the province of Ontario but accessing treatment within the province. This number is higher than the estimated epidemiological figures posted by both the provincial and federal governments. Additionally,

requests to detail funding for services and programming related to HIV in First Nations communities was sought. There were significant funding increases between the years of 2011 and 2014 (see Table 24), especially when it came to funding directed to First Nations bands themselves. However, between 2014 and 2016, there has been funding stagnation. Given that there are 126 bands in Ontario, if this funding were allocated equally across all bands (which it is not), it would amount to \$7,920.27<sup>3</sup> in funding being available directly for communities to deliver HIV services and programming (minus treatment) in their community.

## Contributions

This dissertation fills a clear void in the literature by creating an anti-colonial framework from which to view policy. Namely, a framework that places policy within the context of assimilation-based macro policies, accommodation based meso policies, and decolonial micro policies. This dissertation reviews policies to explain the framework from which HIV/AIDS funding and service delivery takes place. The findings of this research will also inform new discussions about the quality of HIV programming for Indigenous Peoples, and how funding can have a silent impact on how people receive care. Finally, it will provide clear participant-driven recommendations about how the government, AIDS service organisations, and communities can work to better support and treat people living with HIV in Ontario

The contribution of this dissertation to the policy area is that it details, for the first time, that policy, or a lack thereof, is directly tied to a lack of funding for treatment, care, services, and programming for Indigenous Peoples living with HIV/AIDS in the province of Ontario. I

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<sup>3</sup> This funding is representative of all services and programming offered to First Nations People living with HIV/AIDS in Ontario. This does not include funding for treatment.

therefore conclude this clear lack of policy creates no incentive to deal with the problem at hand. Therefore, through a lack of coordination and funding, First Nations people across the north experience a lack of access to HIV testing, education, and harm reduction. This has directly contributed to the ongoing HIV crisis across the north and within rural and remote First Nations Communities.

## Chapter II: Literature Review

### Introduction

The literature on the issue of Indigenous health policy and Indigenous Peoples Living with HIV/AIDS (IPLWA) is limited. After a comprehensive search, there was no literature found which directly addresses the issue of funding for HIV/AIDS services, care, or programming for First Nations people living with HIV/AIDS or within First Nations communities. Additionally, there are major gaps in what little literature there is in such areas as Indigenous health policy (Boyer, Lavoie, Kornelson, & Reading, 2016; Lavoie, 2013) and healthcare funding and service delivery within reserve communities (Masching et al., 2016). Due to various social and political issues faced by Canada's Indigenous Peoples, funding for healthcare is derived from multiple sources, including the federal government (First Nations and Inuit Health Branch, Health Canada, Public Health Agency of Canada), provincial governments, local bands (through development and business funds), and private sector partnerships. The way in which most of this funding is distributed and used by the government has lacked openness and transparency (Henderson, 2012).

Colonialism, which has been suppressing Canada's Indigenous Peoples for hundreds of years, has played a significant role in the power structure of the Canadian bureaucracy. This has created "social, political and economic inequalities that 'trickle down' through the construction of unfavourable, intermediate and proximal determinants" (Reading & Wien, 2009, p. 20), which have Indigenous Peoples "suffering from the worst social, economic and health conditions in Canada" (MacDonald, 2007, p. 321). Similarly, Indigenous Peoples are facing an HIV/AIDS epidemic within their communities. This includes Indigenous Peoples having experienced a 13% incidence increase in HIV infection between the years 2014 and 2016 (CATIE, 2016). Saskatchewan has the highest rates of HIV infection in the country, mainly focused in First Nations communities (Woroniuk, 2017). This has resulted in the pressing need for further research within this topic area.

### Analytical Approach

Today, there is significant discussion of decolonisation and reconciliation. This is often framed within the context of postcolonialism – or the legacy of colonisation and imperialism within the world. However, within a Canadian context, this makes little sense because, as will be shown through the research presented herein, the process of colonisation is still alive and active. For Byrd and Rothberg (2011), the 'post' in postcolonialism is problematic, given that this infers that events have occurred in the past. To place postcolonialism in context, we will examine the previous literature (through this review), health policies, and finally participant stories – all of which will detail and describe the ongoing hardships Indigenous Peoples face, including: detachment from culture, language, and community, systemic abuses, lack of access to healthcare and other services, and violence and murder. These serve to suppress not only

their voices but also their indigeneity. There are many scholars who often discuss postcolonialism including: McClintock (1992); Shohat (1992); Silva (2004); Smith (2012); Womack, Weaver, and Warrior (2006), amongst others, and while at times this may be productive, continued narratives of colonisation being in the past gives others the power to disavow themselves of their present actions and guilt of their own colonial acts (Tuck & Wayne Yang, 2012).

Lawrence and Dua (2005) argue that postcolonial and antiracist theorists have begin to take Indigenous decolonisation seriously as a result of Canada working to suppress the voice of Indigenous Peoples through policy and direct violence, including police surveillance and direct military actions. There are many Indigenous individuals who are reluctant to associate themselves with postcolonialism, which may be largely due to the fact that confronting the ongoing colonisation of Indigenous lands through policy remains a top priority for Indigenous Peoples (Byrd & Rothberg, 2011). There must be recognition that Indigenous Peoples have not laid down and died, but as a people persist – to re-establish nationhood and sovereignty against settler colonial policies (Simpson, 2011). This will again become evident through the description of participant resilience in later chapters – many of whom were told they would be dead in a short time, who were lost and forgotten within an unjust system, but lived to tell their story for the hope of empowering others. For Arvin et al. (2013), we seek not to have equality or civil rights, instead we look to achieve independence from western nation states, so as to allow for nations to decide independence on their own terms. This will lay the foundation of the policy and analysis chapters to come. It will provide an evaluation of the settler state's continued

injustices against Indigenous Peoples for their own capital gain as expositied through gendered and racialized privilege (Simpson, 2007).

### Background / History of HIV

The first confirmed case of AIDS in Canada was announced in February 1982 (Duffin, 1994; Hoffman-Goetz et al., 2005). In 1993, the Government of Canada announced there were 7,282 AIDS cases in Canada with a total of 4,685 deaths (Duffin, 1994). Since 1995, there has been a slowing in the number of reported cases of HIV and AIDS across Canada (Hoffman-Goetz et al., 2005). Hogg et al. (2012) note that there are 3,300 newly diagnosed cases of HIV in Canada each year. At the end of 2011, an estimated 71,300 people were living with HIV, of whom 25% were unaware of their status (Ha et al., 2014). HIV can be contracted through unprotected sexual intercourse, drug use involving the sharing of intravenous syringes, contaminated blood products, and through perinatal transmission from mother to child (Hoffman-Goetz et al., 2005). Since the beginning of the HIV epidemic, men who have sex with men (MSM) have faced the largest burden of HIV and AIDS infections in North America (Hoffman-Goetz et al., 2005; Hogg et al., 2012). Today, nearly half (48%) of new infections take place among MSM (Duncan et al., 2011; Hogg et al., 2012), whereas in 1989 it represented 79.9% of all cases (Hoffman-Goetz et al., 2005). Injection drug users (IDU) are at a substantially increased risk of infection today. In 1985, IDUs represented just 8.9% of new cases (Hoffman-Goetz et al., 2005), but today they make up more than 17% of new infections (Duncan et al., 2011). There has also been an increase of infection among women, heterosexuals, and Indigenous Peoples (Duncan et al., 2011; Hoffman-Goetz et al., 2005; Hogg et al., 2012). More specifically, there has been a

marked increase in the HIV infection of heterosexual Indigenous women (Ontario HIV Treatment Network, 2014).

The main focus for public health officials from the 1990s into the early 2000s was on preventing the spread of HIV (Aggleton et al., 2018; Hoffman-Goetz et al., 2005; Worthington et al., 2009). Prevention includes education, the use of condoms during sex, avoiding the utilisation of a used needle, screening of blood products and testing and treatment for pregnant mothers (Hoffman-Goetz et al., 2005). While preventing the transmission of the virus remains a main focus today, there has been significant change over the past decade with the advent of pre-exposure prophylaxis (PrEP)<sup>4</sup>. This new prevention method allows a person who is at high risk of HIV to take a pill once a day to reduce the possibility of contracting the virus. Additionally, HIV is actively being combatted using post-exposure prophylaxis (PeP)<sup>5</sup>. However, since the beginning of the AIDS crisis, Hogg et al. (2012) note an untreated infection will eventually lead to progressive immune system failure. As a result of immune failure, opportunistic infections and cancers will ultimately result in a person's death within 10 to 15 years from the onset of infection. There has also been a drastic change in the outcomes of HIV infection. Outcomes today with treatment are substantially better than just a decade ago. However, even with better life outcomes, people living with HIV experience a wide range of

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<sup>4</sup> Pre-exposure prophylaxis (or PrEP) is the use, by people at high risk for HIV, of HIV medicines daily to lower their chances of getting infected. PrEP can stop HIV from taking hold and spreading throughout a person's body. It is highly effective for preventing HIV if used as prescribed, but it is much less effective when not taken consistently. Daily PrEP reduces the risk of getting HIV from sex by more than 90%. Among people who inject drugs, it reduces the risk by more than 70%. The risk of getting HIV from sex can be even lower if PrEP is combined with condoms and other prevention methods (U.S. Department of Health & Human Services, 2017).

<sup>5</sup> PEP (post-exposure prophylaxis) means taking antiretroviral medicines (ART) after being potentially exposed to HIV to prevent becoming infected. PEP should be used only in emergency situations and must be started within 72 hours after a recent possible exposure to HIV. (U.S. Department of Health & Human Services, 2017).

disabilities, including body impairment, limitations to activity, and limits to their social participation (Worthington et al., 2009).

Overall, the face of HIV has been changing from one of almost certain death to one of long-term management of a chronic illness. A major issue, however, is that there is unequal access to treatment and services within provinces in Canada. In general, access to care for those living with HIV is substantially easier for those who live in the urban areas of Ontario, Quebec and British Columbia, where 90% of all physicians reside in the main urban centres and work within hospitals, out-patient care or within an HIV specialty clinic (Worthington et al., 2009). This presents clear barriers for populations outside of those centres who will either have limited access or be required to travel for access to services and care.

#### Data Search Criteria

In order to come to the findings listed below, an initial search was conducted in the fall of 2014. At that time, a total of eight databases were searched: (a) Scholars Portal, (b) ProQuest Social Science, (c) PubMed, (d) ProQuest Dissertation and Thesis Database, (e) Quick law, (f) LexisNexis Academic Universe, (g) Worldwide Political Science Abstracts, and (h) Canadian Research Index, in addition to an extensive search of the grey literature (a term explained below). After excluding articles not matching the below noted inclusion search criteria, a total of 101 references were found. Upon further review of those references, 78 articles were deemed appropriate for use in the initial review of the literature. This review formed the basis of the research questions presented and of the dissertation proposal.



A further review of the literature with revisions was conducted in the winter of 2017. This review was performed to include any new materials that may have been published in the past three years. The selection of texts for review on Indigenous HIV and policy within Canada was conducted in two phases. Phase I consisted of academic database searches. Phase I began with searching for peer-reviewed articles focusing on the following populations: "Aboriginal", OR "First Nations", OR "Métis", OR "Inuit", OR "American Indian", OR "Indian" (omitting Indian from India), OR "Native American", OR "Indigenous" while using the following combinations of topic terms, ""HIV", "AIDS" AND "Canada"; (no population search); "HIV", "AIDS" AND "policy" AND "Canada"; (no population search); "HIV", "AIDS" AND "Canada"; (with population search); "HIV", "AIDS" AND "policy"; (with population search); "HIV", "AIDS" AND "policy" AND "Canada"; (with population search); and "HIV", "AIDS" AND "policy" AND "Canada" AND "Reserves"; (with population search) in the article abstract, or identified keywords. This new search was conducted using only six databases: (a) Scholars Portal, (b) ProQuest Social Science, (c) PubMed, (d) Google Scholar, (e) Web of Science, and (f) Worldwide Political Science Abstracts.

A search of the six databases yielded 13,468 possible texts. Texts were then initially selected for inclusion in Phase I of the study based on meeting the following criteria: (a) was directly and substantially applicable to Indigenous Peoples; (b) dealt substantially with the subject matter being discussed; (c) peer-reviewed article; (d) published within the past 15 years; and (e) English language. There were 116 texts which met this review.

Phase II of the review consisted of grey literature searches. Phase II began with searching for articles, websites, and reports with focusing on the following populations:

“Aboriginal”, OR “First Nations”, OR “Métis”, OR “Inuit”, OR “American Indian”, OR “Indian” (omitting Indian from India), OR “Native American”, OR “Indigenous” while using any of the following combinations of topic terms, “HIV”, “AIDS” AND “policy” AND “Canada” AND “Reserves” in the title, abstract, or body. The search was conducted using Google, searching specific Indigenous agencies and organisations, and through previous knowledge of the researcher and supervisor (i.e., knowledge of specific communities doing work in this area). Thirteen texts were selected for inclusion in Phase II of the study based on meeting the following criteria: (a) was directly and substantially applicable to Indigenous Peoples and dealt substantially with the subject matter being discussed; (b) from a reliable, accredited, or recognized source; and (c) English language.

This resulted in a total of 78 articles from the first search and 129 articles from the second being included for review. A total of 207 articles were accessed for inclusion and subjected to a second review for inclusion. There were 27 duplicates discarded upon this review, and an additional 46 articles were removed after the second review. Therefore, 134 articles were reviewed, and they comprise the totality of this literature review.

## Indigenous Health

The 2016 census<sup>6</sup> showed that 1,673,785 Indigenous Peoples are living in Canada, representing 4.9% of the total Canadian population (Government of Canada, 2016a). Of that

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<sup>6</sup> There are numerous problems associated with using census data pertaining to Indigenous Peoples. These include access to appropriate sample size, given the low overall and sub-sample size this can result in large sampling errors; and the definition of who is an Indigenous person, meaning people may not self-identify as Indigenous (Wright, 1993).

total, 301,425 (21.5%) reside in Ontario (Government of Canada, 2015). A significant amount of data and literature exists on the health of Indigenous Peoples in Canada, indicating that many of whom have significant health issues. In fact, the health of Indigenous Peoples had been in steady decline since their first contact with Europeans [going back over 400 years], and since that time, various health crises have taken the lives of untold numbers of Indigenous Peoples. It has only been in the past several decades that statistics have shown an improvement in the health of Indigenous populations, though many still fall significantly behind the general population in overall health (Young, 2003). Many of the poor healthcare outcomes Indigenous Peoples face are directly linked to issues of intergenerational trauma, trauma experienced through residential schools (Barlow, 2009), and many forms of abuse experienced by generations of Indigenous Peoples. Moreover, this cycle of abuse appears to be continuing (Christian & Spittal, 2008).

A major theme within the HIV literature was discussing the health status of Indigenous Peoples within Canada, including rates of disease, mental health and sexually transmitted blood-borne infections (STBBIs). Discussing HIV within an Indigenous context cannot be done without highlighting the historical background of Indigenous Peoples in Canada generally, and therefore this was substantially highlighted within much of the literature, including: Baiju et al. (2003); Eyles, Birch, and Chambers (1994); Majumdar, Guenter, and Browne (2010). Indigenous Peoples in what is now called Canada have been living in third world conditions on reserves, in what has been referred to as the “embodiment of inequality” (de Leeuw, Greenwood, & Cameron, 2009, p. 284). This is particularly the case of Indigenous populations living in remote communities across Canada's north. Northern Indigenous communities tend to have poor

access to, or ineffective, primary care. In more remote communities, physician services may not be routinely available on-site; therefore, all primary care is typically delivered through nursing stations (Baiju et al., 2003, p. 801). Baiju et al. (2003); Shah, Gunraj, and Hux (2003) argue that, as a result, this population has a higher hospital admission rate for ambulatory care-sensitive conditions – or conditions that are potentially preventable – while having a lower rate of physician referral care-sensitive cases. This problem is exacerbated by a lack of family physicians within northern Canada, physicians unwilling to travel into remote communities for work, and a high turnover rate of physicians.

The literature predominantly highlights that disease is having a disproportionate and adverse impact upon Indigenous Peoples in Canada. Further, “In general, Canada’s Aboriginal people tend to have poorer health outcomes than the non-Aboriginal populations” (Majumdar et al., 2010, p. 449). These poorer health outcomes are directly linked to the disproportionate rates of chronic disease faced by most communities, with Type II Diabetes and various cancers being of the most significant concern (Baiju et al., 2003; de Leeuw et al., 2009). Overall, Indigenous Peoples are at risk of having a higher prevalence of diabetes, hypertension, cigarette smoking, coronary artery disease, heart disease, asthma, mental health disorders, circulatory disease, cancer and respiratory disease (Baiju et al., 2003; Frohlich, Ross, & Richmond, 2006; Majumdar et al., 2010; Shah et al., 2003). According to de Leeuw et al. (2009), Indigenous Peoples’ life expectancy falls well below that of non-Indigenous Peoples in Canada. This can be attributed to high rates of disease and accidents within this population, which is leading to an overall lower life expectancy.

The systemic disadvantage has played a significant role in how Indigenous Peoples, especially those throughout the north, can access healthcare. Eyles et al. (1994) argue there is becoming an ever-increasing recognition of the "relative disadvantages and lack of opportunities facing native populations as compared to their non-native counterparts. Relative to non-native populations, natives tend to have lower incomes, higher rates of unemployment, and poorer housing and are at greater risk of dependency on government transfer payments" (p. 801). There is considerable concern about how services are delivered to these communities and about the appropriateness of those services. Many programs currently taking place in communities may not reflect the actual needs of the populations they are intended to serve (Baiju et al., 2003). This is related to a lack of coordinated policy which would centralize healthcare funding at a national level allowing for community advancement of their own needs. Eyles et al. (1994) argue that the way the government funds services for health care in First Nations communities is not proportionate to what is needed, resulting in the clear decline of health within this population. A combination of individual and government financial issues, individual socioeconomic status, and geographic isolation all play a significant role in the health status of northern Indigenous populations (Baiju et al., 2003).

Sexually Transmitted Blood-Borne Infections have been a prominent aspect of HIV research but have been seen as a background topic to that of HIV. STBBIs are discussed in more detail in a number of studies, including: de Leeuw et al. (2009); Devries and Free (2010); Devries, Free, Morison, and Saewyc (2009); Ontario HIV Treatment Network (2014); Shaw, Jolly, and Wylie (2014). Hepatitis C Virus (HCV) appeared the most within the research related to HIV (Ontario HIV Treatment Network, 2014; Sadler & Lee, 2013; Shaw et al., 2014; Steenbeek,

Bailey, & Simandl, 2013; Wu et al., 2007). As of 2007, there were over 240,000 chronic cases of HCV in Canada, and this continued through 2011, however firm data on national prevalence are lacking (Sadler & Lee, 2013). In 2014, Ontario reported 7,184 cases of Indigenous Peoples living with HCV. This is a 3.0% prevalence within the Indigenous population equating to a prevalence of HCV that is 3.5 times higher in the Indigenous population than in the general public (Ontario HIV Treatment Network, 2014). According to Sadler and Lee (2013): “A sad indicator of the disenfranchised status of Canadian Aboriginals is that they are proportionally over-represented in populations living on the street as well as those who are incarcerated. Both of these populations are well known to have a significantly increased prevalence of HCV infection” (p.335). It is problematic that there have been very few studies focusing on the impacts of HCV on overall health, especially when compared to research involving HIV (Shaw et al., 2014; Steenbeek et al., 2013). Those who are living with HCV, especially those who are Indigenous, are much more likely to be injection drug users (Shaw et al., 2014; Wu et al., 2007). Additionally, rates of chlamydia, gonorrhoea, and syphilis have been substantially higher within Northern Canada, with rates up to 10 times the national average (Steenbeek et al., 2013). Infectious diseases such as hepatitis, chlamydia, and HIV/AIDS are all either more prevalent or increasing within First Nations across Canada (de Leeuw et al., 2009). This poses a substantial risk as not only do these infections increase the risk exposure of HIV acquisition and transmission but also pose a much more serious threat to people who are already immune-compromised (Steenbeek et al., 2013). Increased risk of STBBIs within Canada's Indigenous populations continues to pose a risk for all communities, but especially those in the north.

Further studies are needed to identify the impact of these infections on public health and overall Indigenous health and should be more prominently featured in HIV research.

Mental health also was featured throughout the literature. Indigenous Peoples were argued to be experiencing mental health problems at a disproportionate rate when compared to the general population (de Leeuw et al., 2009; Firestone, Tyndall, & Fischer, 2015; Frohlich et al., 2006; Sadler & Lee, 2013). Overall, Indigenous Peoples are facing specific and significant mental health issues – which includes high rates of suicide (particularly in youth), alcoholism, substance abuse, violence, feelings of demoralisation, self-destructive and violent behaviours – at a greater rate than is found in the general population (de Leeuw et al., 2009; Firestone et al., 2015; Frohlich et al., 2006). According to Frohlich et al. (2006) "the suicide rate among First Nations was 27.9 deaths per 100,000, compared with the Canadian population's rate of 13.2 per 100,000" (p. 136-137). These results, taken into context with other mental health problems faced by Indigenous Peoples leads to suicide and self-inflicted injuries being the leading cause of death for those between the ages of 10-19 and 20-44. Mental health continues to play a role in HIV research as many of the participants within these research studies were compounding their HIV diagnoses with additional mental health concerns. There appears to be a correlation within the literature between mental health issues, especially addiction issues, and a person's HIV infection. Similarly, there is a causal effect that people who are diagnosed with HIV are more likely to develop or be affected by mental health issues.

The reasons for the disproportionate health burden faced by Indigenous Peoples in Canada also constitute a major theme in the literature. There is no one reason presented that is agreed upon, however many authors argue that socioeconomic status plays a significant role in

this burden (Antoniou, Zagorski, Loufty, Strike, & Glazier, 2012; Firestone et al., 2015; Frohlich et al., 2006; Majumdar et al., 2010; Ross & Richmond, 2008; Tang & Browne, 2008). Additional factors that come together to affect the health of Indigenous People in Canada include:

- a) socio-economic deprivation (Firestone et al., 2015),
- b) marginalisation (Firestone et al., 2015),
- c) persistent impacts of historical trauma (Firestone et al., 2015),
- d) race (Tang & Browne, 2008),
- e) substance issues (Tang & Browne, 2008),
- f) food insecurity (Antoniou, Zagorski, et al., 2012),
- g) inadequate and insufficient housing including a lack of basic sanitary infrastructure (Frohlich et al., 2006),
- h) high-risk behaviours (Majumdar et al., 2010),
- i) unhealthy lifestyle choices rooted in structural factors such as:
  - a. poverty,
  - b. low educational attainment,
  - c. unemployment,
  - d. the intergenerational effects of residential schools, and
  - e. societal discrimination (Majumdar et al., 2010),
- j) the breakdown of close-knit social supports, a breakdown in social norms, values and expectations held at the family and community levels (Ross & Richmond, 2008),
- k) environmental health, lifestyles and behaviours, and material deprivation (Frohlich et al., 2006) .

All of these factors come together to affect the health of Indigenous Peoples in Canada. The literature does not point to any one solution to effect change towards Indigenous health or HIV, but this must be seen as part of a larger societal issue of how Indigenous Peoples, especially those that live in rural and remote areas of the country are treated and viewed.

### Colonisation of Indigenous Peoples and Health

Colonisation has played a major role in the health outcomes of Indigenous Peoples. For de Leeuw et al. (2009), colonial policies have a long history of violently intervening into the living and structures of Indigenous Peoples. As a result of these interventions, Indigenous Peoples face elevated risks of addictions and mental health issues. Colonisation has occurred



through many varying means in Canada, including the *Indian Act*, residential schools, oppressive policies, theft of lands, and through branches of government, such as child welfare systems through the 60s scoop, and the criminal justice system (Oliver et al., 2015). Neo-colonial and racist contexts within Canadian society have served to create particular dangers for Indigenous women when it comes to violence and their risk of being diagnosed with HIV/AIDS (Varcoe & Dick, 2008). This is because a history of colonial abuse has left Indigenous women living in poverty and disconnected in many cases from their family and communities (Varcoe & Dick, 2008).

The burden of health disparities faced by Indigenous Peoples in Canada is fundamentally rooted in colonisation and in its historical positioning with the social service system (Frohlich et al., 2006; Mill, Lambert, Larkin, Ward, & Harrowing, 2012). Health disparities are manifested in a long history of oppression, systematic racism, and discrimination, all of which can be linked directly to a lack of resources, be it education, employment, social services, or control over Indigenous land and governance (Frohlich et al., 2006). These institutions are also understood to be about social control and regulation. Significantly, Tang and Browne (2008) found that Indigenous People are treated differently (negatively) when they access health care service, typically because of their racialisation and low socio-economic status.

When it comes to HIV/AIDS, Barlow (2009) argues that there is both a direct and indirect correlation between HIV/AIDS and residential schooling in Canada. Additionally, in that study, a considerable number of survivors indicated that having attended a residential school had serious impacts on their overall health (Barlow, 2009). Through the Cedar Project et al. (2008), it was found that traumatic life experiences, which include sexual abuse, when placed within

the context of being colonized, leads to lower health outcomes and places people at a higher rate of mental, sexual, and drug-related vulnerabilities. The impacts of intergenerational trauma are felt by many Indigenous Peoples living with HIV/AIDS (Bingham, Leo, Zhang, Montaner, & Shannon, 2014; Flicker et al., 2008; Larkin et al., 2007). Bingham et al. (2014) argues that Indigenous women's HIV is directly correlated with the intergenerational effects of colonisation and racial policies which seek to suppress and "other" them within society.

## HIV Prevalence

### Background

HIV is presented throughout the literature as disproportionately affecting Indigenous Peoples. A number of authors agreed that one of the main causes for this overrepresentation is the result of marginalisation of Indigenous Peoples within Canada and their varying social determinants of health (Cedar Project et al., 2008; Klakowics, Zhang, Colley, Moore, & Tu, 2016; Negin et al., 2015). Moreover, Duncan et al. (2011); Klakowics et al. (2016); Negin et al. (2015) have argued the key determinant to HIV infection is economic: people living in poverty and destitution. Economic determinants directly relate to a person's biological susceptibility to acquiring HIV through taking part in high-risk actions, such as sex work, not being able to afford condoms, and IDU (Duncan et al., 2011; Mill et al., 2012; Negin et al., 2015). Sexual abuse was also a major theme for HIV risk, as those who reported being sexually abused as children had a higher rate of HIV diagnosis (Cedar Project et al., 2008; Negin et al., 2015). Monette et al. (2011) argue Indigenous HIV patients are more likely to be "younger, female or transgender women, less educated, unemployed, and homeless or unstably housed" (p.215). These demographics substantially correspond with related research which highlights the fact that

people with these characteristics are more likely to have low socioeconomic status and suffer poorer health. Kendall et al. (2014) argue more than half of those with HIV have at least one other physical condition which will have a drastic impact upon their overall health, especially women, who have a higher prevalence of comorbidity<sup>7</sup> and multimorbidity.<sup>8</sup>

There are a series of issues addressed in the literature when it comes to the prevalence of HIV in Canada and in certain demographics. Cain et al. (2013); Ontario HIV Treatment Network (2014); Wardman, Quantz, and Clement (2006) argue access to testing and testing rates for Indigenous Peoples in Canada is an issue. Cain et al. (2013) claim, "A recent study of HIV testing experiences of Aboriginal youth in Canada found that the majority felt they were treated with respect, but often experienced apprehension or shame as a result of the testing experience." (p.816). This research correlates to other studies which find Indigenous Peoples are less likely to go and seek out testing for HIV, especially those who live on reserve (Wardman et al., 2006). Within Ontario, all HIV diagnostic testing is performed by Public Health Ontario. All testing can be requisitioned without charge by any physician in the province. However, this system creates a pervasive public health surveillance, which requires mandatory reporting of all identified communicable diseases in the province (O'Byrne & Bryan, 2013). However, people in Ontario can also access free anonymous rapid HIV testing, which limits tracking of HIV cases if a person does not follow up for formal testing. However, access to rapid testing is dramatically limited to major urban centres within Ontario, with only 50 locations offering such services. O'Byrne and Bryan (2013) note "individuals who reported a preference for, or use of,

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<sup>7</sup> the simultaneous presence of two chronic diseases or conditions in a patient.

<sup>8</sup> the presence of two or more chronic medical conditions in an individual.

anonymous HIV testing were more likely to have reported having: (a) been tested for, and diagnosed with, STIs; (b) prior STI/HIV diagnosis; and (c) a self-reported history of anal sex" (p. 35). This highlights how surveillance can have an impact on HIV testing and how people seek out care and management within Ontario, especially those who feel they are at greater risk and are more concerned about surveillance mechanisms. However, a major drawback of this system is that no demographic information is collected on positive HIV results aside from the age and sex of the person and the risk factors for an infection they presented to a physician (Ontario HIV Treatment Network, 2014). These limitations have dramatically affected the ability of researchers to collect a detailed and comprehensive understanding of who is HIV-positive in the province of Ontario.

#### Problems with Diagnosing HIV in Indigenous Populations

HIV diagnoses within the Indigenous population is of rising concern within the broader world of public health. However, Santo and Lyons (2004) argue that there is an 'undiagnosed iceberg' within the Indigenous population due to the unreliability of data collection. This unreliability becomes especially evident when looking at rural and northern settings (Ontario HIV Treatment Network, 2014; Santo & Lyons, 2004). CATIE (2016) argues that we must use caution when drawing a conclusion about HIV and Indigenous Peoples in Canada because we require an adequate description of the problem and we do not have an accurate sense of Indigenous HIV statistics due to incomplete and inaccurate ethnicity data. Specifically, only 38% of HIV cases in Canada had any ethnic data available. There are no data available for either the province of Ontario or Quebec (CATIE, 2016). This undiagnosed iceberg is also exacerbated by the fact that Indigenous Peoples tend to be diagnosed with HIV at a much later age in life (Cain

et al., 2013); they tend to come from more rural areas, negatively affecting their ability to access testing and care (Ontario HIV Treatment Network, 2014; Steenbeek et al., 2013); there is concern from people within small communities about the confidentiality and anonymity of testing (Steenbeek et al., 2013); and HIV is not perceived by communities as much of a concern to them, as HIV is still portrayed as a gay man's disease within many Indigenous communities (Hoffman-Goetz et al., 2005) therefore leading people to assume they are safe and not at risk of contracting the virus (Steenbeek et al., 2013). These problems create significant barriers to being able to assess the number and scope of HIV cases within the Indigenous populations in Ontario and Canada more broadly.

#### HIV Prevalence in Canada

Nationally, approximately 65,000 people are living with HIV. Of that, 48% of infections are among men who have sex with men with the majority residing in British Columbia, Ontario, and Quebec (Belvedere, Miller, & Hogg, 2012). When looking at Indigenous-specific cases, caution must be used due to the lack of demographic data. There are 1,400,685 Indigenous Peoples in Canada, with an estimated 6,850 Indigenous Peoples infected with HIV in 2014, making up 9% of HIV infections in Canada (CATIE, 2016). This has been an alarming increase in HIV infections in the Indigenous population over the past decade when, in 1993, only 1.3% of HIV infections affected this population. By 2006, 27.3% of all new diagnoses were Indigenous (Duncan et al., 2011). According to Hogg et al. (2012), more than 1 in every 100 Indigenous Peoples over the age of 15 is living with HIV. A disproportionate number of these infections are related to IDU and female (Duncan et al., 2011; Hogg, Strathdee, Kerr, Wood, & Remis, 2005; Shea et al., 2011). Additionally, Jaworsky et al. (2012) note that, at the time of diagnosis,

substantially more Indigenous Peoples had a viral load which would suggest a potential later stage diagnosis for this population.

### HIV Prevalence in Ontario

Within Ontario, Ontario HIV Treatment Network (2014) notes the provincial government estimated in 2008 that Indigenous Peoples accounted for 3.2% or 853 people of the 26,628 people living with HIV in the province. From 2009 to 2011, a new Laboratory Enhancement Program (LEP) questionnaire was employed within the province. This new LEP included for the first time, questions related to the patient's ethnicity. During this period, 91% of the 11,729 new HIV diagnosed individuals filled out the survey. During this period, 2.7% or 43 of those new diagnoses were in Indigenous Peoples (Ontario HIV Treatment Network, 2014). "According to the LEP data, 28 (64%) of the people diagnosed were exposed to HIV sexually; while 15 (35%) were exposed through injection drug use" (Ontario HIV Treatment Network, 2014, p. 18). Therefore, there are no clear answers to questions of HIV prevalence of HIV infection in Indigenous populations in Ontario. Of note, the higher rate of IDU presented issues of co-infection of HCV, with 37% (314) of Indigenous Peoples in Ontario being co-infected with HIV and HCV (Ontario HIV Treatment Network, 2014) in comparison to 20% nationally (Klein et al., 2013).

### Prevalence for MSM

Men who have sex with men represent the largest percentage of those currently infected. This includes gay and bisexual men, but also men who do not identify as gay, but have sex with other men, possibly working in the sex industry to survive (Barlow, 2009). Between 1979 and 2006, MSM accounted for more than 30% of all AIDS cases within the Indigenous

community in Canada (Barlow, 2009). Ontario HIV Treatment Network (2014) notes that 28% of infections in Ontario were through MSM. However, as with all statistics presented given the issues with HIV surveillance, there is no definitive number of how prevalent this would be.

### Prevalence for Women

Indigenous women are notably underrepresented within the literature about HIV. This underrepresentation is concerning given that the number of HIV infections is growing more rapidly among Indigenous women than men (Clarke, Friedman, & Hoffman-Goetz, 2004). However, given the historical neglect and subordination Indigenous women have faced, this is unsurprising. According to Ontario HIV Treatment Network (2014), from 2009 to 2011, 40% of new HIV cases in Ontario were among women, with 59% from heterosexual sexual contact and 35% through IDU, a finding supported by studies conducted by Barlow (2009); Bingham et al. (2014). These figures are in contrast to the general population where 78% of infections are attributed to heterosexual sex and just 20% to IDU (CATIE, 2018). Bingham et al. (2014) argue that due to colonial effects, Indigenous women are overrepresented in street-based sex work and thus are placed at higher risk of IDU and HIV infection.

### Prevalence in Youth

There is little research discussing the prevalence of HIV among Indigenous youth (Canadian Aboriginal Aids Network, 2010; Larkin et al., 2007; Teengs & Travers, 2006; Worthington et al., 2010). However, it is a concerning issue for Indigenous leaders (Cedar Project et al., 2008). As of 2002, it was estimated that 41.2% of all Indigenous cases of HIV were among people under the age of 30 years old, with the leading cause of infection in this demographic being IDU (Cedar Project et al., 2008). The reasons for this are not clear, but the

prevalence of sex work performed by those in this age demographic along with sexual abuse experienced by younger people may be leading to increased IDU and sex work (Cedar Project et al., 2008; Ha et al., 2014). Additionally, over 50% of the Indigenous population is under the age of 30 years of age, which may influence the higher demographic representation.

### Discussion on Men who have Sex with Men

There was substantial discussion throughout the literature related to HIV in MSM, with 63% (85) articles discussing this subject. As the majority of the research and forthcoming review will address the many issues affecting MSM, I will only provide an overview of the literature in this section. MSM are disproportionately affected by HIV in Canada, and this is generally attributed to high risk sexual behaviour and a high concentration of the virus in a small sub-population (Burks, Robbins, & Durtschi, 2011). Indigenous gay and bisexual men account for a significant portion of HIV infections within the community (Hogg et al., 2005). There is a dearth of literature about the relationship of male sex work and HIV infection within the MSM category and particularly within Indigenous men who perform sex work. Additionally, there were 22 articles (16%) that discussed two-spirited people, which will be discussed in a section below. However, there was a clear gap in discussing how two-spirited people seek out HIV treatment and care (Barlow et al., 2008; Burks et al., 2011; Ontario HIV Treatment Network, 2014; Teengs & Travers, 2006). The clear lack of discussion regarding the role heteropatriarchy plays in the continued subordination of men who have sex with men and the risk factors this may lead to is concerning. There is a need for critical literature which explores the role colonisation plays in the risk factors of Indigenous men who have sex with men, as colonisation may heighten the power of heteropatriarchy, homophobia, and sexism.



## Discussion on Women

The impact of HIV on women was a clear overall gap within the literature. There were 25 (18%) articles which predominantly addressed the issue of Indigenous women and HIV. While a number of these articles looked at varying issues faced by women with HIV, there were two clear themes that emerged: First, the stigma women faced with regard to their HIV status and how this is compounded further by their racialisation; and second, HIV-positive women and pregnancy/motherhood.

There are indications within the research that Indigenous women are of increasing risk of acquiring HIV infection within Canada. Logie, James, Tharao, and Loufty (2012); Mehrabadi, Craib, et al. (2008) discuss that Indigenous women are becoming overrepresented amongst new HIV cases, especially those in the sex industry and among injection drug users (Shannon, Bright, Gibson, & Tyndall, 2007; Wang et al., 2012). Indigenous women also have a pronounced rate of multimorbidity and thus a shorter life expectancy (Kendall et al., 2014). As of 2008, close to 50% of new infections are among Indigenous women, which compares to just 19% who are non-Indigenous women (McCall, Browne, & Reimer-Kirkham, 2009). This overrepresentation appears to be complicated by the ongoing notion that women are not at risk of HIV transmission. There is a widespread misunderstanding within Indigenous communities that HIV continues to be a white male and/or gay disease (Fernandez, Keigher, & Stevens, 2008; Hoffman-Goetz et al., 2005). This misconception of risk is resulting in a lack of testing and a lack of precaution being taken by women who perceive their risk as low.

The issue of stigma played a significant role in the literature, especially when discussing women. The larger role of stigma will be addressed later in this review. There were a total of 8

articles that discuss the impact that stigma has on HIV-positive women (Masching, Archibald, & Jackson, 2009; Mill et al., 2009; Varcoe & Dick, 2008). Mill et al. (2009) argue women may generally experience more severe forms of stigma related to their HIV status than men. Women who are HIV-positive are seen as “dirty, diseased and undeserving” (Loufty et al., 2012, p. E48169) and are labelled as sexual deviants. There is no one all-encompassing iteration of the forms of stigma women face. Stigma can take the form of being “symbolic, internalized, and enacted, and ... associated with marginalized identities: HIV-positive serostatus, female gender, sex worker, sexual minority, transgender, and ethnic minorities” (Logie et al., 2012, p. E1001124). Critically, women tend to face issues of stigma within health care settings. This is affecting their ability to access appropriate health care services, as they feel their environments are unsafe or they do not provide the services that they require (Fernandez et al., 2008; Logie et al., 2012; McCall et al., 2009). Indigenous women in Canada face particular issues with stigma, as this is complicated by colonisation which continues to affect their lives (Masching et al., 2009; McCall et al., 2009; McCall & Lauridsen-Hoegh, 2014). “Intergenerational trauma, caused by the poverty, displacement, and discrimination that are attributable to colonisation has contributed to the high burden of substance use and addiction” (McCall & Lauridsen-Hoegh, 2014, p. S73). These compounded factors have presented a unique problem for Indigenous women, who experience higher rates of sexual abuse, sex work, and IDU, which further continues to marginalize them and to lead to an overall higher risk of HIV infection. Additionally, Indigenous women who are HIV-positive face higher risks of violence, especially those who live in rural areas (Varcoe & Dick, 2008).

Motherhood was also a significant theme when looking at the studies discussing women living with HIV. There were five articles that discussed this theme (Hwang, Raffa, & Gill, 2012; Jones, 2004; Kennedy et al., 2014; Lindau et al., 2006; Masching et al., 2009). Jones (2004) notes that Indigenous women in Canada are seven times more likely to test positive for HIV than the general population. An Ontario based study found that of the 504 HIV-positive women in the province, 20% of them were Indigenous (Kennedy et al., 2014). Women are less likely to seek out testing for HIV but instead are more likely to be diagnosed via population screening such as when pregnant (Hwang et al., 2012). Kennedy et al. (2014) argue that there has been little research on the importance of motherhood to HIV-positive women, but instead, most research focuses on fetal well-being. There are also significant issues of the stigma attached to Indigenous mothers, especially if they choose to have children after their HIV diagnosis and those that are IDU (Lindau et al., 2006; Masching et al., 2009).

The literature captured in this search was largely absent in relation to colonial forces and their impacts on women and their HIV status. There are three articles which discuss the issue of Indigenous women and HIV with the concepts of heteropatriarchy or patriarchy, Boyer (2011); Matiation (1999); Oliver et al. (2015) all discuss this aspect in varying ways. However, the significant imposition upon women at the hands of colonial practices and policy has largely been ignored or avoided within the literature reviewed.

### Discussion on Youth

The discussion of youth was presented in the literature 18 times, comprising 13% of articles. Those articles substantially focused on four sub-themes. First, youth experiences with IDU and housing/being transient (Ahamad et al., 2014; Cedar Project et al., 2008; Masching et

al., 2009); second, the impact colonisation/marginalisation has on youth and their outcomes (Christian & Spittal, 2008; Larkin et al., 2007; Teengs & Travers, 2006); third, the vulnerabilities of youth who are HIV-positive (Ahamad et al., 2014; Cedar Project et al., 2008; de Leeuw et al., 2009); and finally, HIV prevention among youth (Flicker et al., 2008; Larkin et al., 2007; Worthington et al., 2010).

Indigenous Peoples aged 0-29 years of age, made up over 32% of all Indigenous HIV-positive diagnoses between 1998 and 2006 (Masching et al., 2009). Indigenous youth are highly overrepresented among street youth (36%) (Jongbloed et al., 2015; Masching et al., 2009). Youth who are transient or homeless are much more likely to be injection drug users (Ahamad et al., 2014; Cedar Project et al., 2008; Jongbloed et al., 2015). “Transience may exacerbate injection-related risk as young people use injection drugs to self-medicate the pain of trauma or deal with the stress of housing instability” (Jongbloed et al., 2015, p. 129). Miller et al. (2006) argue youth who inject drugs are four times more likely to be HIV-positive. Youth who are IDU were more likely to have been denied housing and to perform sex-work (Ahamad et al., 2014; Mehrabadi, Craib, et al., 2008; Mehrabadi, Paterson, et al., 2008; Miller et al., 2011). Many of the youth who work in the sex industry were sexually abused as children (Cedar Project et al., 2008; Jongbloed et al., 2015). This also has resulted in a disproportionate increase in the risk of coinfection with HCV for youth (Firestone et al., 2015; Mehrabadi, Paterson, et al., 2008; Miller et al., 2006).

Youth who have been affected by a trauma in their life (through colonisation or in other ways) may be at a greater susceptibility to HIV infection. While youth today may not have been directly exposed to the traumas of residential schools or the 60s scoop, their legacies have had

a lasting effect. According to Christian and Spittal (2008) “high levels of youth suicide, HIV/AIDS, addiction, social dislocation, discrimination, human-rights violation, children in care of the state and poverty” (pp. 1132-1133) can all be traced back to issues of colonisation. There are five articles which specifically address the issues of colonisation and historical trauma and their impact on youth and their risk of acquiring HIV (Christian & Spittal, 2008; Larkin et al., 2007; Majumdar, Chambers, & Roberts, 2004; Majumdar et al., 2010; Oliver et al., 2015; Teengs & Travers, 2006). Christian and Spittal (2008), in their study, revealed “links between generations of trauma—such as that suffered by parents and grandparents in residential schools, and the sexual abuse of second-generation and third-generation children and grandchildren early in life—and negative health outcomes, including vulnerability to injection and non-injection drug use and a two-fold risk of acquiring HIV infection” (pp.1132-1133). In a study conducted by Larkin et al. (2007), Indigenous youth strongly linked their own experiences of colonisation with their HIV status, while making direct reference to material deprivation they have experienced. The role women play within Indigenous society has changed as a result of colonisation. Young people in a study conducted by Oliver et al. (2015) argue it is vital in understanding how gender intersects with race and colonisation to create experiences of oppression that demean women’s roles and bodies. Majumdar et al. (2010) argue that, in order to efficiently deal with the issue of high HIV rates among Indigenous youth; we must address the socioeconomic issues which place youth at risk of sexual abuse, violence, and oppression. Additionally, there are youth – especially two-spirit youth – who leave communities to find more accepting places in major cities, but instead they tend to find racism, poverty, and sexual exploitation (Teengs & Travers, 2006). The role of girls and women in communities, sexual abuse, the need to leave the

community, and the history and ongoing legacy of colonisation are all working together to burden youth disproportionately resulting in increased risks of HIV.

The notion of Indigenous youth as vulnerable was an evident sub-theme within the literature, especially when looking at their HIV status (Ahamad et al., 2014; Cedar Project et al., 2008; Clarke et al., 2004; de Leeuw et al., 2009; Teengs & Travers, 2006). Flicker et al. (2008) argue Indigenous youth face systemic inequalities which make them vulnerable to acquiring HIV. Overall, there are a number of authors who refer to youth that acquire, or are at risk of acquiring, HIV as 'vulnerable' (Ahamad et al., 2014; de Leeuw et al., 2009; Teengs & Travers, 2006). This vulnerability particularly extends to youth who have been victims of, or exposed to, sexual abuse as children (Cedar Project et al., 2008). This idea of vulnerability appeared to both describe systemic risk factors youth face but also to create a sense of infantilism, and thus a group needing extra protection.

Prevention methods to address the surging rate of HIV infections amongst Indigenous youth was also a sub-theme explored by three authors (Flicker et al., 2008; Larkin et al., 2007; Worthington et al., 2010). Flicker et al. (2008) argues that "as a result of social and economic inequities, Indigenous youth globally are disproportionately vulnerable to HIV/AIDS" (p.176). Therefore, there is a clear need to target this group due to their high risk of acquisition. It is important to point out, based on the notion of the vulnerability of youth due to their age and/or life circumstances, that this group faces issues unlike those faced by many others. Prevention must be specifically geared towards the diverse issues they face. Therefore, prevention methods undertaken must differ, given that this specific demographic is unique among others covered in the literature.

## IDU

Injection drug use was a major theme within the literature. Many of the authors discussed IDU prevalence and the impact it has on the HIV epidemic, especially within the Indigenous population (Ahamad et al., 2014; Barlow et al., 2008; CATIE, 2016; Duncan et al., 2011; Fernandez et al., 2008; Firestone et al., 2015; Loufty et al., 2012; Ontario HIV Treatment Network, 2014). IDU is a significant risk factor for the transmission of HIV and Hepatitis C (Ahamad et al., 2014; Brown Jr et al., 2006; Fernandez et al., 2008). Barlow (2009) argues needle sharing IDU is the greatest risk factor for contracting HIV. This is concerning given the increasing trend within Indigenous communities and amongst Indigenous Peoples to use injection drugs (Fernandez et al., 2008). According to Firestone et al. (2015) “among people who self-identified as Aboriginal, an estimated 66% of new HIV infections were attributed to injection drug use, similar to the estimation of 63% in 2005” (p. 1118). This presents an alarming situation in terms of strategies to combat the spread of HIV, as typical HIV prevention methods have focused primarily on MSM and sexually-based transmission. Wardman et al. (2006), in their study focusing on British Columbia, found that Indigenous Peoples living off reserve were much more likely to be using illicit drugs than those on reserve. Additionally, research has found Indigenous Peoples who use injection drugs have a burden of HIV infection that is significantly elevated compared to other groups of IDUs (Duncan et al., 2011; Wood et al., 2008). More concerning according to Miller et al. (2011) is “young Aboriginal women were twice as likely to inject drugs as men, and participants who injected drugs (both men and women) [...] were more than twice as likely as those who did not to be involved in sex work” (p.1147). This is substantiated by Ahamad et al. (2014); Ontario HIV Treatment Network (2014)

who note young Indigenous females are more likely to use drugs than other females in their age category. According to Mehrabadi, Paterson, et al. (2008), there is need for harm reduction programs that specifically target women at a young age and also work to address the very complex traumatic intergeneration experiences that are highly associated with childhood sexual abuse experienced by this population.

As previously mentioned, the most substantial factor for HIV transmission is the sharing of used needles. As Ciccarone and Bourgois (2016) note, “program restrictions limiting access to syringes [...] exchange may have interfaced with a complex conjunction of historical, geographic, political, economic and cultural forces and physiological vulnerabilities to create an extraordinary HIV risk environment” (p.36). There is a clear requirement to tackle the issues surrounding needle sharing within IDUs, also known as harm reduction. Other research has found “Indigenous women were significantly more likely than Indigenous men to report passing on used needles and acidifiers to someone else” (Ontario HIV Treatment Network, 2014, p. 46). Unsurprisingly, given the literature discussed, “injecting drug use was commonly reported as a form of pain relief or alleviation of past trauma and abuse and was often associated with sex work” (Negin et al., 2015, p. 1729). Therefore, the need for targeted harm reduction techniques is vital when conducting IDU outreach.

Injection drug use has been on the rise within the Indigenous population, and the types and frequency of drug use have also been an area of research within the literature. Barlow (2009) argues IDUs typically use highly potent drugs. The result is users having to use multiple injections per day to maintain their high, promoting their risk of needle sharing and HIV infection. Long et al. (2014) note that low average monthly incomes are associated with



patterns of higher intensity addiction and HIV risks. Firestone et al. (2015) asked Indigenous participants in their study about drug use in the past 12 months and the major non-prescribed drugs consumed were: “cannabis; hallucinogens, including LSD, magic mushrooms, PCP, and Special K; amphetamines, including crystal meth, speed, and ecstasy; cocaine or crack; sedatives or sleeping pills; heroin, opioids; and inhalants, such as solvents, glue, and gas” (p.1116). One of the major findings was related to the vast number of different drug types being used for injection. Ontario HIV Treatment Network (2014) notes that there are clear differences between the types of drugs Indigenous Peoples vs. non-indigenous people inject. The main difference included “morphine (65% vs. 58%), oxycodone/OxyContin (64% vs. 53%), Ritalin (34% vs. 20%), benzodiazepines (12% vs. 7%), barbiturates (9% vs. 4%), and a combination of Talwin & Ritalin (10% vs. 5%)” (pg. 41). What is substantially missing from the literature is an analysis of the role alcohol plays in HIV transmission. A study by Masching et al. (2016), found nearly half of their Indigenous participants reported alcohol played a role in becoming HIV-positive. Therefore, across the literature, there seem to be differing perceptions of HIV within the IDU community versus that of other groups.

## Stigma

A major theme present in the literature was stigma. This included a discussion of general HIV stigma (Antoniou, Zagorski, et al., 2012; Eustace & Ilagan, 2010; Jackson et al., 2008; Loufty et al., 2012); HIV stigma which affected negatively access to healthcare (Donnelly et al., 2016; Ha et al., 2014; Mill, Edwards, Jackson, MacLean, & Chaw-Kant, 2010); and Indigenous experiences of stigma (Hoffman-Goetz et al., 2005; Loufty et al., 2012; Morgensen, 2008).

Stigma has a substantial impact on those who consider themselves at high risk of, or who have been diagnosed with, HIV. Stigma is considered one of the most significant barriers to health and well-being for people who are living with HIV (Loufty et al., 2012). According to Harris and Larsen (2008) “receiving an HIV diagnosis is often experienced as devastating and emotionally overwhelming” (p. 402). As a result of diagnoses, people continue or even increase their high-risk behaviours, which places themselves and others in danger (Harris & Larsen, 2008). HIV stigma is made more difficult when other inequalities compound it. Therefore, patients experience greater forms of stigma when their marginalisation intersects across race, class, gender, and sexual orientation (Loufty et al., 2012).

There is a general lack of understanding of HIV within society. While little research has been conducted in this area in Canada, studies conducted in the United States show that 75% of ‘Americans’ do not believe they know anyone who is HIV-positive and a further 90% say they are not related to anyone who is HIV-positive (Sileo & Sileo, 2008). According to Jackson et al. (2008) “initial depression associated with an HIV diagnosis was made worse by stigma and an accompanying fear of disclosure” (p. 6). Self-disclosing of an HIV diagnoses can bring about risks of blame, shame, fear and scapegoating (Eustace & Ilagan, 2010), and generally elicit negative reactions from family, friends or lovers which generates fear of “rejection for sex, loss of romance, separation, divorce, and negative labels such as handicap or sickness” (Eustace & Ilagan, 2010, p. 2099). Those who are diagnosed with HIV are susceptible to depression, as a result of “isolation, dissatisfaction with others or disconnection from people, communities, and culture, rather than in terms of psychological feelings of sadness or hopelessness” (Jackson et al., 2008, p. 6). Stigma plays a large role in how people cope with their HIV diagnoses and their

ability to seek out adequate care. This is particularly true of heterosexual males who, Antoniou, Loufty, Glazier, and Strike (2012) argue are left out of the HIV conversation and relegated to the margins. There are no specific programs geared towards HIV-positive heterosexual males and they, as a group lack the social capital to benefit from, or to improve their standing within the HIV health and services fields. This is unlike gay and bisexual men and marginalized women who have traditionally been disproportionately affected by HIV thus leading to significant resource and program allocation, much of which has been the result of group organisation and advocacy, which is not seen within the population of HIV-positive heterosexual males.

### Indigenous Stigma

Throughout the literature, there was a discussion of the stigma HIV-positive Indigenous Peoples face in Canada. There is no one clear answer on how stigma is viewed within Indigenous communities or where the stigma is focused, given the vastly different demographics and mode of transmission experienced by this particular group of people. Loufty et al. (2012) note that gender and race interact with each other to change how stigma is experienced, particularly in racialized women who tend to experience higher rates of stigmatisation. Additionally, lower stigma was seen within those who are older, who are part of the LGBTTIQQ2S<sup>9</sup> community, or who have a higher education (Loufty et al., 2012). Clarke et al. (2004) argue there are no particular emphases on homosexuality but instead fear experienced by Indigenous Peoples is related to rejection by family, neighbours, friends, health care workers, and the broader Indigenous community. Donnelly et al. (2016) argue that feelings of

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<sup>9</sup> Lesbian, Gay, Bisexual, Transsexual, Transgendered, Intersexual, Queer, Questioning, 2-Spirited

shock, disbelief, and anger are less apparent among Indigenous Peoples. This has resulted the ways in which culture, the history of colonisation, the perceived access to health care, and/or religious beliefs, intersected in order to shape how Indigenous Peoples can cope with their life situation(s).

Particular forms of stigma faced by Indigenous Peoples are varied. Hoffman-Goetz et al. (2005) argue there is a clear connection between stigma and media coverage in Indigenous communities that associates HIV with MSM. This has resulted in many still believing HIV mostly affects MSM and almost never impacts heterosexual people. However, according to Loufty et al. (2012) drug use is associated with a lower level of HIV-related stigma. Therefore, while we continue to see stigmatisation of HIV in Indigenous communities in Canada (Jackson et al., 2008), where and how the stigma is perceived may not fit with the actual reality of the risk or situation. For many, HIV is still a 'gay disease' which provides a different form of stigma than if someone was an IDU. However, because HIV is still substantially attached to gay men, many IDUs may be stigmatized due to perception rather than actual transmission method. This can result in overall negative impacts on mental health and well-being.

### Health Care Stigma

The literature presents HIV-related stigma as a significant barrier to accessing health care, before and after diagnosis (Donnelly et al., 2016; Mill et al., 2012). Ha et al. (2014) argue that stigma is a key factor in people not seeking out testing for HIV. Furthermore, stigma plays a role in compromising treatment, care, and support for HIV-positive people (Donnelly et al., 2016; Loufty et al., 2012). There is fear of having HIV status disclosed based on purchasing or taking antiretroviral drugs, thus leading to problems with adherence to treatment (Loufty et al.,

2012). A research study conducted by Donnelly et al. (2016), notes that participants experienced stigma from the moment they received their diagnoses. Therefore, this influenced their perception of wanting to seek out additional assistance and treatment post diagnosis. Mill et al. (2009, p. 168) note “participants’ experiences of stigma and discrimination were shaped by the organisational policies (universal precautions, models of care) and design (physical layout) under which care was provided”. Additionally, Mill et al. (2010, p. 1469) note that participants in their study “described both active and passive social control mechanisms: shunning and ostracizing, labelling, and disempowering health care practices” (p. 1469). These actions can lead to behaviour on the part of health care providers that appears to be forgiving in nature towards participants who may not be doing as they would expect for a person who is HIV-positive. These negative experiences also correspond with research conducted by Donnelly et al. (2016) which showed that HIV-positive patients experienced greater stigma and mental distress within emergency departments, walk-in clinics and at dentist offices. Overall, the literature indicates that there is an apparent problem with stigma within the healthcare profession towards those living with HIV, and that it results in an impact on patients’ desire or ability to access prevention or treatment care. The literature was absent on any discussion related to stigma in healthcare settings in its relation to the colonisation of Indigenous Peoples. There was no peer-reviewed literature discussing power dynamics between Indigenous patients and the medical professionals.

### Cultural Impacts

The impact culture has on HIV diagnoses and treatment was only briefly touched upon within the literature, however was relevant enough to be mentioned. Flicker et al. (2015) argue

“Indigenous worldviews privilege holistic interconnectedness, collaboration, reciprocity, spirituality, and humility, in contrast to Western notions of dichotomous thinking, rationality, and individualism” (p.1149). They argue that research, especially HIV research, ought to be done using Indigenous research paradigms in collaboration with Indigenous Peoples. Jackson et al. (2008) argue that traditional approaches to research and care can be helpful for many participants. This cultural-based work can help to establish social and cultural connections that, many times, are not present otherwise. There is also an ongoing need to blend both traditional and western ways of knowing and doing research to adequately support Indigenous Peoples living with HIV (Jackson et al., 2008; Levers, 2006). In fact, Ross and Richmond (2008) argue health issues are better understood if we draw from holistic frameworks to do research, as it connects with not only the individual but also the family and communities, all of which are affected.

Traditional healers and the use of elders has been a staple of Indigenous culture since time immemorial. Santo and Lyons (2004) argue that using traditional healing alongside western medicine is vital to many of their participants. This included “healing circles, sweat lodges, and seeking treatment from traditional healers” (Santo & Lyons, 2004, p. 16). Marsh, Coholic, Cote-Meek, and Najavits (2015) argue “treatment interventions must honour the historical context and history of Indigenous Peoples” (p. 1). Specifically, when looking at HIV, we must take into account the healing which stems from the intergenerational trauma and substance abuse faced by Indigenous Peoples (Marsh et al., 2015). Flicker et al. (2015); Hankard (2013) both argue the importance of Elders in the healing process, as both the knowledge keepers and guides for Indigenous Peoples. However, the choice of traditional treatment and

supports is dependent mainly on access and availability to these very resources, including whether there are elders who would be willing to support people living with HIV/AIDS (Hankard, 2013; Santo & Lyons, 2004).

## Treatment

HIV treatment has made significant strides since the 1980s. HIV will no longer automatically develop into AIDS, a disease from which many will die, but rather it is now a chronic condition with which people die, sometimes from other causes (Braithwaite et al., 2005). Research shows that the majority of deaths of individuals living with HIV are from non-attributable causes and therefore not linked to their HIV status (Braithwaite et al., 2005). Overall, new treatments allow people to manage the illness better, resulting in a change of care strategies from “end of life” to “healthy-living”. This has resulted in an increased duration of life which in turn has an impact upon the nature of the care and services required and received by individuals (Barlow et al., 2008).

Early detection and treatment of HIV was a significant theme throughout the literature. This is unsurprising given the new focus of the United Nations on its 90-90-90 campaign which seeks to achieve 90% of people with HIV being diagnosed, 90% of those on treatment, and 90% of those to be virally suppressed by the year 2020 (Bolsewicz, Debattista, Vallely, Whittaker, & Fitzgerald, 2015). The literature was broken down into a number of sub-themes, including early detection (Barlow et al., 2008; Cain et al., 2013; Ha et al., 2014); antiretroviral treatment (ART) and highly active antiretroviral therapy (HAART) (Belvedere et al., 2012; Bolsewicz et al., 2015; Samji et al., 2013); issues with non-adherence by Indigenous populations to treatment (Anema

et al., 2013; Chongo, 2011; del Amo et al., 2013; Lefebvre, Hughes, Yasui, Saunders, & Houston, 2014; Martin, Houston, Yasui, Wild, & Saunders, 2011); and treatment plans which showed improved health outcomes (Duran et al., 2010; Klakowics et al., 2016; Marsh et al., 2015; McCall & Lauridsen-Hoegh, 2014; Tu et al., 2013).

Early detection of HIV is considered essential as it leads to early treatment and slows the spread of the virus (Ha et al., 2014). Those who are diagnosed earlier after first contracting HIV benefitted from having improved health outcomes (Ha et al., 2014). However, there is concerning evidence that Indigenous Peoples are being diagnosed much later for HIV than other Canadians (Barlow et al., 2008; Cain et al., 2013). Late detection includes many Indigenous women being diagnosed at the AIDS stage (Barlow et al., 2008). Late stage detection will result in the delayed use of antiretroviral treatment (ART) and therefore results in an overall higher mortality rate (Barlow et al., 2008; Cain et al., 2013) and a higher likelihood of passing on the virus.

Antiretroviral treatment is the standardized treatment for those who are HIV-positive. In Canada, ART is free of charge and universal (Bolsewicz et al., 2015). The concept of ART treatment is that “effective HIV therapies suppress viral replication and reduce blood plasma concentrations of the virus to levels below detection, thereby prolonging the health of the immune system” (Kalichman et al., 2006, p. 401). ART treatment is used as a means of reducing the progression of HIV to AIDS and also of improving the overall health and well-being of patients. Also, it helps in the reduction of the spread of the virus (Bolsewicz et al., 2015). ART consists of highly active antiretroviral therapy (HAART), which has been available since 1996 (Belvedere et al., 2012). The use of HAART has resulted in a substantial reduction in HIV-related



morbidity and mortality (Hogg et al., 2012) and meant a shift from viewing HIV from simply a high mortality rate to one that is treated as a manageable chronic condition (Belvedere et al., 2012; O'Neil et al., 2012). Research now shows that the life expectancy of a person on therapy is approaching that of an uninfected individual (Hogg et al., 2012) and in some studies is exceeding that of HIV-negative persons (Samji et al., 2013).

Those who have high adherence to treatment not only benefit individually from overall healthier outcomes, but the public also benefits from the reduction in risk of transmission and economically from reduced hospitalisations (Bolszewicz et al., 2015). Hogg et al. (2012) argue “for each 10% incremental increase in HAART coverage in the provinces of British Columbia, Ontario, and Quebec, the rate of new HIV diagnoses decreased by 8%” (p. E47260). This reduction is the result of HIV viral suppression which has a prevention effect. Critical research demonstrates that a person with an undetectable viral load, which is suppressed using ART, has never infected another person (Kalichman et al., 2006).

While the research and literature on ART are promising, there was clear indication within the literature that the same benefits are not being felt by the Indigenous community. There is clear evidence to show that there is a slower and lower uptake of ART among Indigenous populations (Klakowics et al., 2016; Wood et al., 2006). Additionally, in recent years there has been increased access to highly active antiretroviral therapy, which is resulting in an increase in life expectancy and decreased morbidity within Canada (Martin et al., 2011). However, again, when it comes to Indigenous Peoples, a number of studies have noted a decreased uptake and adherence to HAART therapy (Hogg et al., 2005; Klakowics et al., 2016; Martin et al., 2011). According to Belvedere et al. (2012), Indigenous women in their study were

not experiencing the same decline in morality after taking ART as Indigenous men; this was attributed to a lower uptake in ART.

Martin et al. (2011) argue Indigenous groups experience overall more significant all-cause mortality when compared to every other group, even after they have started HAART. The most important indicator of this all-cause mortality is IDU. Those who use ID have a lower uptake rate of ART (Klakowics et al., 2016; Martin et al., 2011; Wood et al., 2006), at just 29.2% for Indigenous Peoples versus 53.7% for non-Indigenous participants (Wood et al., 2006). This lack of uptake and non-adherence to HAART is resulting in reduced life expectancy of Indigenous patients (del Amo et al., 2013; Hogg et al., 2005), the opposite of the non-Indigenous populations. Of note, Barlow et al. (2008); Braithwaite et al. (2005) argue a major obstacle to adherence to HIV drug regimens is a lack of culturally competent services providers. Service providers must consider corresponding problems such as substance abuse when they recommend a treatment plan, with an understanding of the histories Indigenous Peoples have faced in Canada leading to widespread IDU.

The issue of uptake was not the only issue presented. Also, adherence to taking medication appeared to be a significant problem within Indigenous populations (Chongo, 2011; O'Neil et al., 2012). There is a high level of adherence required when on ART and HAART to derive the sustained, long-term benefits of the treatment (O'Neil et al., 2012). McCall and Lauridsen-Hoegh (2014) argue historical and contemporary trauma experienced by Indigenous Peoples is associated with decreased adherence to ART.

Trust issues and addictions appear to be barriers for people from seeking out treatment (Burks et al., 2011; McCall & Lauridsen-Hoegh, 2014). “The higher mortality of HIV-positive First Nations people in Canada [...] is likely to reflect social and health inequalities, including cultural discrimination, higher unemployment, lower incomes, higher rates of imprisonment, lack of access to adequate healthcare, and higher ART discontinuation rates” (del Amo et al., 2013, p. 1808). Additionally, Lefebvre et al. (2014) argue Indigenous patients have poorer treatment outcomes after starting ART than do Canadian-born non-Indigenous patients.

Given these poorer health outcomes within the Indigenous population, there have been a number of studies which look at how to overcome these outcomes. Klakowics et al. (2016) suggest that clinical and health services interventions can directly affect outcomes, primarily when used with culturally appropriate care. Additionally, Duran et al. (2010) note successful prevention and treatment is predicated on combined medical, support, and education services being reliably available to at-risk Indigenous populations. Marsh et al. (2015) state “there appears to be strong evidence that strengthening cultural identity, community integration, and political empowerment can enhance and improve mental health and substance use disorders in Aboriginal populations” (p. 1). This is corroborated by McCall and Lauridsen-Hoegh (2014) who argue medical staff must establish partnerships with their patients and that this is based on fostering respectful, holistic care based on trust and respect. Finally, Tu et al. (2013) argue that a “chronic care management approach to HIV care in a marginalized, largely Aboriginal patient population led to improved disease screening, immunisation, ART uptake, and virological suppression rates” (p. 650). Overall, the literature argues Indigenous Peoples are facing issues

in the uptake and adherence to ART, and therefore, a culturally respectful way to treat this population group must be used to ensure the best results.

## Prevention

HIV prevention is presented as a central theme throughout the literature. However, there has been limited research published on surveillance and prevention (O'Byrne & Bryan, 2013). HIV prevention was comprised of: a general discussion around HIV prevention efforts (Eustace & Ilagan, 2010; O'Byrne & Bryan, 2013; Wardman et al., 2006); HIV strategies and plans which were not effective (Burks et al., 2011; Duncan et al., 2011; Mill et al., 2012; Orchard et al., 2010; Santo & Lyons, 2004); considerations and effective prevention programs (Devries et al., 2009; Duncan et al., 2011; Edwards, Mitchell, Gibson, Martin, & Zoe-martin, 2008; Majumdar et al., 2010; Nelson & Tom, 2011); and education as prevention (Riley, 2013; Sileo & Sileo, 2008; Tingey et al., 2015).

Since the start of the HIV epidemic in the 1980s, there have been numerous prevention and public health interventions initiated to stop the spread of the virus (Eustace & Ilagan, 2010). Remis (2013) argues Canadian data on the incidence and prevalence of HIV reveal a lack of success in preventing and controlling the spread of HIV in this country. HIV prevention strategies have historically been focused on the interruption of the virus prior to infection (Mill et al., 2012). This approach has been slowly changing and now includes the continuing adoption of new and innovative techniques for the prevention of HIV, including strategies to promote early diagnoses and disclosure of HIV status (Eustace & Ilagan, 2010; Mill et al., 2012). These prevention methods include the use of widespread public health surveillance systems whereby

anyone tested in Canada is required to have their positive results communicated to public health officials (O'Byrne & Bryan, 2013). The ability of the HIV surveillance system to act as a form of prevention is called into question with the rise of widespread anonymous HIV testing. Anonymous testing is increasingly being sought out due to perceived stigma within healthcare settings (O'Byrne & Bryan, 2013). Additionally, issues of respect, discrimination, and confidentiality of HIV testing are barriers for people, especially Indigenous Peoples, who want to seek out testing (Wardman et al., 2006; Worthington et al., 2010). There has been no evidence-based interventions that have evaluated the effectiveness of HIV prevention programs for American Indians in the US (Tingey et al., 2015). There are similarly limited results in Canada; which only compounds prevention issues given the lack of awareness and risk factors present in Indigenous communities (Wardman et al., 2006).

The literature highlighted that many of the prevention strategies currently being undertaken with Indigenous populations are failing to have the desired outcomes, including condom distribution, traditional education methods, PreP, and active testing (Burks et al., 2011; Duncan et al., 2011; Mill et al., 2012). Prevention efforts may be hampered by the fact they are incompatible with the cultural norms, knowledge, and behaviour patterns of those they are meant to target (Burks et al., 2011). This is especially true of Indigenous Peoples who use illicit drugs (Duncan et al., 2011), Indigenous women, and youth (Orchard et al., 2010). There are also numerous issues with conducting prevention measure in Indigenous communities, as recruiting participants to take part in HIV research is more challenging due to confidentiality, stigma, and discrimination (Mill et al., 2012). Additionally, prevention programs are not effective when they fail to take into account socio-cultural beliefs, especially when there is widespread perception

in a community that homosexuality does not exist there, or that IDU is not a problem in their community, therefore designing programs around these issues will not be an effective approach (Santo & Lyons, 2004). That is, it is reported in the research that there are Indigenous communities that do not believe any of their members are homosexual. There are other communities which state IDU is not a problem affecting their communities. This leads to barriers when trying to implement an effective prevention program from a public health perspective. However, there was also a gap in the literature related to an analysis of how colonisation has led to issues of homophobia and IDU within communities. The literature is almost wholly absent on the discussion of how prevention must systematically review the roles of heteropatriarchy and colonisation and the impact it has had in Indigenous communities.

Prevention of HIV in Indigenous communities as a high priority (Majumdar et al., 2010) was a leading theme within the literature, along with recognizing that, to work, strategies that are put in practice must be culturally sensitive. Duncan et al. (2011) argue that, in order to be genuinely useful, there must be approaches that look beyond surface level issues, and instead address a history of sexual abuse and the apprehension of children from their families and communities. Working to combat issues of depression faced by HIV-positive Indigenous Peoples has had a positive effect on adherence to treatment and in prevention efforts (Joan, Browne, Roberts, & Gafni, 2005). Edwards et al. (2008) argue that a practical approach to preventing the spread of STIs within northern communities requires an intervention which is grounded in a community-based approach, including working with community leaders and elders in its development and implementation (Santo & Lyons, 2004). Intervention and prevention methods must take into account community and participant culture and spirituality (Fernandez et al.,

2008; Hyshka, Strathdee, Wood, & Kerr, 2012; Majumdar et al., 2010) and must meaningfully include those who the measure seeks to involve, including youth and IDUs (Jongbloed et al., 2015; Mill et al., 2012; Nelson & Tom, 2011). When approaching prevention from this aspect, the change can have an impact upon people who then become self-empowered. This is done by having a strong emphasis on the importance of Indigenous cultures and spirituality, and specifically prevention approaches must recognize the interconnectedness of the mind, body, and spirit (Fernandez et al., 2008).

A critical area of preventive care as discussed in the literature is around education. Riley (2013) argues the importance of “creating a community-based training curriculum designed to build capacity and foster new knowledge in support of HIV/ AIDS education” (p. 42). This perspective is reinforced by Burks et al. (2011); Majumdar et al. (2010) Sileo and Sileo (2008); Tingey et al. (2015) who argue that a lack of proper HIV education is resulting in a marked increase in the transmission of the virus.

## Supports

The ability of HIV-positive people to receive supports was a theme discussed throughout the literature. Supports, as described within this section, include both the notion of lack of support and also how supports, especially how culturally based supports, can improve overall health outcomes. There was also a general discussion of the lack of supports available to Indigenous HIV-positive people (Brondani, Moniri, & Kerston, 2012; Joan et al., 2005; Newman, Woodford, & Logie, 2012; Varcoe & Dick, 2008). A lack of supports is especially felt by people living in a rural setting, who find it more difficult than those in urban areas to access supports

(Joan et al., 2005; Varcoe & Dick, 2008). Brondani et al. (2012) argue that, due to the high level of stigma people face, they become disconnected from their support networking—including their families and partners – which compounds their inability to come to terms with their diagnosis. Therefore, giving people hope is a vital part of providing support, as this helps people eliminate high-risk behaviours (Harris & Larsen, 2008). Additionally, when supports are available, they tend to be fragmented and not to be ‘one-stop’ shopping for the varying needs of people (Brondani et al., 2012).

The impact of positive supports was noted within the literature. Having supports that are more spiritual can assist with easing emotional burdens (Brondani et al., 2012). Also creating supports within healthcare and community facilities helps people feel more comfortable accessing those services and supports (Donnelly et al., 2016). Joan et al. (2005) argue that most “clients found the community-based AIDS organisations (CBAO) drop-in, individual, and group counselling services helpful, reporting reduced sense of isolation, increased knowledge of their illness and how to live with it, and improved quality of life as a result of using the services” (p.47). Additionally, there needs to be greater emphasis placed on changing the types of supports for people to reflect the changing reality that people are living longer with HIV (Joan et al., 2005). However, it does appear that the programs and supports being offered by CBAOs are serving Ontario’s most at risk and vulnerable people living with HIV and ensuring they are entering and retaining medical care and supports (Williams et al., 2005).



## Policy

Policy was an important theme within the literature. There were varying policy issues presented, including: how policy has failed to address the overarching issues underlying HIV infections within Canada (Frohlich et al., 2006; McCall et al., 2009; Teengs & Travers, 2006); issues of HIV-disclosure policies (Canadian HIV-AIDS Legal Network, 1999; Eustace & Ilagan, 2010; Young, 2014); drug policy (Anema et al., 2013; Brown Jr et al., 2006; O'Shaughnessy, Hogg, Strathdee, & Montaner, 2012; Vogel, 2010); and how policy can be used to target specific HIV demographics (Antoniou, Loufty, et al., 2012; Hankard, 2013; Jaworsky et al., 2012). However, there was no literature which highlighted HIV policy in Canada as a larger subject, but instead focused on specific areas where policy has had an impact upon HIV/AIDS prevalence, treatment, or prevention in Canada.

HIV-disclosure laws in Canada remain a challenge, as discussed earlier in this chapter, because disclosure laws can be a barrier to HIV testing (Eustace & Ilagan, 2010). Additionally, Canada has moved towards the criminalisation of HIV, which means “an increasing tendency to use the criminal law as a means of enforcing norms of safe sex and disclosure among the HIV-positive population” (Young, 2014, p. 113). In Canada, failure to disclose an HIV+ status to a sexual partner can, in certain circumstances, lead to criminal charges including aggravated sexual assault. According to the Canadian HIV/AIDS Legal Network, “criminal law is a blunt instrument to deal with complex issues such as disclosure or the root causes for HIV in Indigenous communities” (2016, p. 3), this is particularly true for Indigenous Peoples who are at high risk of violence as a result of their disclosure – the law does not take this into account. The issue of HIV criminalisation continues to be a developing area of jurisprudence, with new court

cases, including Supreme Court of Canada decisions, shaping and defining the notion of risk and criminality<sup>10</sup>. Issues of criminalisation however continues to prevent people from wanting to seek out testing which can lead to further discrimination (Canadian HIV/AIDS Legal Network & Canadian Aboriginal AIDS Network, 2016). This is especially true for young people, racialized people, women, and sex workers (Canadian HIV-AIDS Legal Network, 1999).

Policy around illicit drugs and injection drug use was a prominent theme throughout the literature, and the policies behind various harm reduction measures have also been prominent. There is evidence that the so-called “war on drugs” is not doing anything to prevent the spread of HIV but only exacerbating the problem (Vogel, 2010). Debeck and Kerr (2010) argue “implementing evidence-based policies can be particularly challenging in some environments” (p. E169), including dealing with issues when legal norms come up against public health issues. Policy decisions are being made around implementing decisions that are sub-optimal and not based on science but public pressure, which is having an adverse effect on both illicit drug users and in trying to prevent the spread of HIV (Debeck & Kerr, 2010; Hyshka et al., 2012). Health policy must focus on the many interconnecting issues faced by IDUs to develop policies to combat the issue. The city of Vancouver has implemented harm reduction policies which look not just at drug use harm reduction but also access to addiction services, improved housing, and mental health programs, in addition to their needle exchanges (O'Shaughnessy et al., 2012).

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<sup>10</sup> Under the current state of the law, it is safest to assume that individuals have an obligation to disclose before: 1) Vaginal or anal sex without a condom; and 2) Vaginal or anal sex with a condom unless you have a low viral load (less than 1500 copies/ml) (Canadian HIV/AIDS Legal Network, 2016).

HIV policy can also be used to target health outcomes for specific groups. Antoniou, Loufty, et al. (2012) argue that, when creating policy geared toward MSM; they should be involved in helping to craft that policy. Hankard (2013) advocates for creating policies that would allow access to traditional healers to provide additional services. Additionally, there is a need to explicitly look at creating policies that would create safer working conditions for Indigenous sex workers, as they face an increased risk of infection and policy refocus could address culturally safe HIV-prevention programs designed around their needs (Bingham et al., 2014).

There has been a lack of success in the fight against the spread of HIV in Canada as a direct result of the lack of both policy and leadership in the area (Remis, 2013). Importantly, there must be a focus on developing health policy that seeks to tackle the determinants of health rather than just the health disparities themselves (Frohlich et al., 2006; McCall et al., 2009; Santo & Lyons, 2004; Teengs & Travers, 2006). Likewise, governments must make policy changes that increase access to programs, education, and positive social interaction at the family and community levels (Ross & Richmond, 2008). More specifically, there needs to be a detailed intergovernmental policy, steeped in research and supportive infrastructure (Nowgesic, 2010) on how to tackle the issue of HIV in both rural and urban communities across Canada (Masching, 2009).

## Conclusion

There is an overall dearth of literature in all areas related to Indigenous HIV in Canada. There are significant barriers to being able to assess the number and scope of HIV cases within

the Indigenous populations in Ontario and Canada more broadly. Given reported data, there is a clear increase in the number of new HIV infections within the Indigenous community (Duncan et al., 2011; Hoffman-Goetz et al., 2005; Hogg et al., 2012), which presents a clear concern and need for further research. This is in addition to a lack of research conducted in the area of HCV, especially within Indigenous communities, which are disproportionately affected by the virus (Shaw et al., 2014; Steenbeek et al., 2013). Stigma was also presented as a barrier, but there is no one clear indication of how stigma is viewed within Indigenous communities or where the stigma is focused, given the vastly different demographics and modes of transmission experienced by this particular group of people.

A lack of research has implications for communities, service providers and policy makers. While treatment and supports are widely available today, there are clear gaps in access for both for Indigenous Peoples in general (Baiju et al., 2003), for Indigenous Peoples in rural and remote locations (CATIE, 2016), and especially for those living with HIV/AIDS (Worthington et al., 2009). The treatment gap is even more concerning given the change in HIV from being an inevitable death-sentence to being one of long-term management, which requires greater care and overall supports (Worthington et al., 2009). These gaps in treatment and service provision become even more apparent when looking at Indigenous women and straight men, who seem to be virtually absent from the literature. There is a lack of knowledge about how to combat the spread of HIV within these populations, as typical HIV prevention methods have focused primarily on MSM and sexually-based transmission. Additionally, while the research and literature on ART indicates promising results, there was clear indication within the literature that the same benefits are not being felt by the Indigenous community. There is clear evidence

to show that there are adherence issues and a slower / lower uptake in care and ART among Indigenous populations (Klakowics et al., 2016; Wood et al., 2006).

There is a clear gap in the literature around policy and how or whether it affects HIV statistics in Canada. As has been noted, there has been a lack of success in the fight against the spread of HIV in Canada as a direct result of the lack of both policy and leadership (Remis, 2013). There continues to be a need for a detailed intergovernmental policy, steeped in research and supportive infrastructure (Nowgesic, 2010) on how to tackle the issue of HIV in both rural and urban communities across Canada (Masching, 2009). The dearth of policy related to HIV and Indigenous Peoples more specifically is problematic given the varying interjurisdictional issues at play and the very legislated and codified role of government within the lives of Indigenous Peoples.

While the discussion of colonisation comes up throughout the literature, it is almost always in a passive or surface-level context. There are significant gaps in how the literature addresses the issue of colonisation in relation to HIV within Indigenous communities. There is no substantial literature with a focus on the issues of paternalism, heteropatriarchy, patriarchy or the power imbalances faced by Indigenous individuals trying to access services and care. There is also a lack of critical engagement within the literature of the reasons behind the risks faced by two-spirited people based on stigma and community rejection.

Therefore, further research is required in the area of Indigenous HIV in Canada. This includes research in the area of prevalence, access to care and supports for Indigenous Peoples living with HIV/AIDs, especially those living in rural and/or remote communities. There is a clear

requirement to detail how people access treatment through the varying levels of government and analysis of the policies that the federal government has in place to address the HIV epidemic within First Nations peoples. This dissertation may be placed squarely into that gap.

## Chapter III: Health Policy's control of HIV-Related Service Delivery

### Introduction

Fundamental to the operation of western democracy is the use of public policy. Policy and its subsequent analysis is used in order to provide direction and maintain the efficiency of the bureaucracy within a state. According to Jenkins (1978), policy is “a set of interrelated decisions taken by a political actor or group of actors concerning the selection of goals and the means of achieving them within a specified situation where those decisions should, in principle, be within the power of those actors to achieve” (p. 15). However, in the creation of policy, there is no requirement to have any form of direct action taken by a political actor(s), in order for a policy to be created. Dye (1972) argues that a policy is “anything a government chooses to do or not to do” (p. 2). Similarly, Pal (1997) argues that a policy can constitute “a course of action or inaction chosen by public authorities to address a given problem or interrelated set of problems” (p. 2). This understanding is of vital importance to the discussion in the following section.

For the past 300 years, there has been no codified policy that explicitly and concretely sets out any form of goals and objectives for dealing with First Nations healthcare in Canada. This includes having no clear path towards achieving a unified or clear healthcare delivery system for First Nations and Inuit peoples in Canada. Hofstad (2002) argues that a “policy by many analysts is taken to be the actual behaviour of some authority, and the objectives that can be inferred from these actions. The discrepancy between expressed policy and actual behaviour may be due to a number of reasons, some perfectly justifiable – others tend more in

the direction of deception” (p. 50). Therefore, it can be argued that an absence of detailed policy in the area(s) of First Nations and Inuit health has been a conscious decision by policy makers and therefore does, in itself, constitute a policy decision. Additionally, while there is a lack of broad, overarching policy creation (“Big ‘P’ policy as described below), it is possible to critique the act of funding allocation. The federal government’s detailed involvement in funding prevention, treatment, programming, and services, is clearly an act of policy making (“small ‘p’ policy as described below). Given that the federal government controls funding allocation for Indigenous healthcare and, more specifically, funding for HIV/AIDS-related treatments and services for Indigenous Peoples, this is a form of policy creation in and of itself.

This dissertation sought to conduct an analysis of policies that affect HIV/AIDS service and program delivery to status First Nations people and communities. In this case, policy was defined as any “public decisions, positions, and statements/announcements of government direction by an elected or senior government official. A policy may be created as a result of legislation, other legal documents (court case, treaty), or simply because of an identified organisational need” (Lavoie & Gervais, 2010, p. 121). There are different types of policy; as Lavoie and Gervais (2010) note, there are Big-‘P’ and Small-‘p’ policies. For the purposes of this dissertation, Big-‘P’ policies are referring to macro and meso or systemic policies, including national or provincial policies, while small-‘p’ policies are sectoral or micro policies, including the internal functioning policies of departments or health organisations. For clarity of this dissertation, Big ‘P’ policy will focus around health in general, but not about HIV/AIDS in particular. However, to understand the situation of HIV/AIDS prevention and treatment, it is necessary to look briefly at the Big ‘P’ policies, since programs and services related to HIV/AIDS



are forced, in the absence of specific policies, to operate under these overarching health policies.

The lack of a formal policy analysis within this dissertation is a result of a lack of any Big-‘P’ policy that deals specifically with First Nations HIV/AIDS treatment or services in Canada. When conducting a policy analysis; it is necessary to identify and understand what the goal, impact, and efficiency of a given policy is. Given the absence of specific Big ‘P’ policy in this field, this type of analysis is not possible. Therefore, this dissertation will focus on a review of macro, meso, and micro policies and how they work together to form the basis of how First Nations HIV/AIDS care is delivered and funded within this broader health system.

## HIV Policy

After conducting an exhaustive search of current federal laws and policies, no direct policy or policy provision(s) related to the delivery of HIV funding, care, or services to First Nations people or communities was discovered. This search included reviewing federal and provincial (Ontario) legislation for the mention of ‘HIV’ or ‘AIDS’ and ‘First Nations.’ Additionally, there was a search of literature for the topic of HIV and policy, the results of which supported the conclusion that there were no specific HIV/AIDS policies related to First Nations populations. Beyond this search, contact was made with the Office of the Chief Medical Officer of Public Health for the Department of Indigenous Services; Director of Communicable Disease Control Division at Health Canada; and the Director of Nursing for the Ontario Region of the First Nations and Inuit Health Branch. Subsequently, a request was made for any known internal or external policies or directives (ministerial or otherwise) related to how funding is

distributed, access to services and care, or treatment is allocated when provided at either the community or the individual level. These offices were also asked how funding is determined/allocated and what direction has been given to create programs or services related to HIV in First Nations communities. From these follow-up conversations, it was determined that there are no policies that provide for the delivery of healthcare related to HIV prevention and treatment in First Nations communities or for status First Nations people regardless of where they live. All funding and service delivery is determined by the bureaucracy in its day to day workings (micro policies) and is covered by the overarching mandate giving Indigenous Services Canada authority to provide service and care to these populations. Therefore, with no direct policy goal or specific policy direction about First Nations HIV funding in Canada, conducting a regular policy analysis was not possible.

#### HIV Exceptionalism and Policy

A lack of policy is important because HIV/AIDS is considered by experts as an exceptional health issue, that warranted specific policy direction, as its transmission ability was unlike other diseases (Smith & Whiteside, 2010). The idea of HIV as an exceptional health issue first appeared in the literature in the early 1990's, whereby Bayer (1991) argued HIV/AIDS has to be treated differently in both policy and law from other diseases, including other sexually transmitted, infectious, and lethal diseases. HIV exceptionalists place a focus on the human rights of people living with HIV/AIDS in the areas of privacy, confidentiality, and autonomy. Specifically, exceptionalism is primarily driven by the stigma faced by people living with HIV/AIDS. Without exceptional policy to deal with issues of autonomy and criminality

surrounding HIV, then this would dramatically impact the work of public health and how to control the spread of the virus.

However, governments were and continue to be reluctant to create disease-specific policy. This was particularly true of HIV/AIDS treatment (or prevention campaigns) because they viewed HIV/AIDS as a “health issue” that should be addressed routinely by health policy (the treatment part) and by public health (the prevention part) (Herek, 2006). In terms of public health, HIV/AIDS is unique, and the global response has been unlike any other disease. Its impact has been wide-spread and lasting, including major social, economic, and political impacts (Smith & Whiteside, 2010). HIV/AIDS challenged this model of general health policy covering all (in non-Indigenous as well as in Indigenous communities), but governments were extremely slow to recognize the need for “exceptionalism.” The federal government was finally shamed into creating the AIDS Secretariat and the federal Initiative to Address HIV/AIDS in 2012 that specifically addressed the issue of HIV/AIDS in society and directed resources to fighting the continued spread of it (Government of Canada, 2012a). Similarly, at the provincial level, we see the AIDS Bureau of Ontario doing this exceptional work. There remains ongoing debate within North America as to whether HIV/AIDS should continue to be seen as exceptional (Bayer & Fairchild, 2006). This is rooted in the idea that prevention methods have largely worked, medication has advanced to the point that HIV is no longer resulting in AIDS, individuals are no longer dying from the virus but are living long productive lives (Liu et al., 2014), and the stigma has largely been reduced within society.

However, both levels fail to address the exceptional nature of HIV/AIDS within Indigenous and/or First Nations communities specifically. With First Nations communities falling

under the jurisdiction of the Federal Government, it's exceptional HIV/AIDS policy, the Federal Initiative to Address HIV/AIDS in Canada: Strengthening Federal Action in the Canadian Response to HIV/AIDS in Canada, is all but absent of discussing First Nations Peoples. The urgent need to continue the argument that HIV/AIDS is exceptional for Indigenous People living with HIV/AIDS, is that as this research will demonstrate that issues of stigma, privacy, confidentiality, treatment, and autonomy continue to plague communities and the efforts to address the increase of new infections. That is to say that there is no policy to address the issue of HIV/AIDS treatment and programming, and that the broad policy wasn't capable of dealing with the exceptional challenges that have come with HIV/AIDS. What we continue to see is governments that refuse, or are reluctant, to solve the problem with an "exceptional" policy.

As a result, this chapter provides a more general analysis of the various policies that affect healthcare delivery as the most effective way to understand, at a comprehensive level, how policy, or the lack thereof, has affected HIV healthcare and service delivery. This chapter is meant to be descriptive in nature, it will therefore not deal with any of the substantial critiques of the policies presented, this will instead be integrated with the research and covered in the discussion chapter.

## Background of Indigenous Health Policy

Colonisation and forced assimilation have been the precursor to any form of policymaking related to Indigenous Peoples since the time of contact. The Canadian Constitution Act, 1982 recognizes three groups of Aboriginal people: Indians (now called First Nations), Métis, and Inuit peoples (1982). First Nations describes all Indigenous Peoples in

Canada who are not Inuit or Métis and can be either status or non-status, residing on reserve or off. The Métis People “emerged as a distinct people or nation in the historic Northwest during the course of the 18th and 19th centuries” and are of mixed settler and Indigenous blood (The Métis Nation, 2018). Inuit Peoples are Indigenous Peoples who typically have resided across northern Canada. Colonisation has had an impact upon all aspects of life for Indigenous Peoples across Canada, especially when it comes to healthcare (Kurtz, 2011). Before colonisation, Indigenous Peoples relied on and managed their healthcare through holistic practices, including using traditional medicines and healing (Kurtz, 2011). Healthcare is, and always has been, viewed from a good health perspective, whereby there is a balance and harmony involving the body, emotions, mind, and spirit (Gabel, 2012; Hyett, Marjerrison, & Gabel, 2018). In the 1700s, when mass European expeditions arrived in Canada, many times a physician accompanied the crew. Through contact and trading, physicians offered health care to Indigenous Peoples they met, and in later years, Indigenous Peoples would share their health practices with settlers who had been left behind to survive in the new world (Kurtz, 2011).

The Royal Commission on Aboriginal Peoples notes that it is the policies implemented by the federal government that have created the health crisis taking place amongst Indigenous Peoples in Canada today (Boyer, 2011). Boyer (2011) argues that the failure of health policies geared toward Indigenous Peoples is because they were based on a set of false assumptions: “that Aboriginal people were inherently unhealthy and inferior; that they were therefore biologically predetermined to vanish; and that their traditional cultures caused them to pursue harmful lifestyles” (p. 150). Also, non-health policies had a significant impact upon Indigenous health by limiting traditional practices including, hunting and fishing, which led to additional

suffering, starvation, and death of Indigenous Peoples (Boyer, 2011). At its core, health care services that are accessed by Indigenous Peoples are powerful colonial forces that affect how people seek out and access care (Boyer, 2011).

It is important to articulate that the Government of Canada has never acknowledged that Indigenous Peoples have a right to access healthcare. Instead, the courts have recognized the fiduciary responsibility the federal government has for First Nations and Inuit peoples, which is seen to include their overall health (Lanine & Deo, 2006). This lack of acknowledgment, which happened over generations, has left Indigenous Peoples experiencing some of the worst health disparities in the western world (Boyer, 2011; Pierre, Pollack, & Fafard, 2007). Today, contributing to the problem of Indigenous health is the lack of a clear understanding of the health situation faced by Indigenous Peoples, as this understanding is complicated by the jurisdictional issues present within our complex healthcare system<sup>11</sup>. To that effect, there is no one level of government that provides continued, streamlined, frontline access to care to First Nations and Inuit peoples in Canada, and that is one of the main factors complicating this issue (Boyer, 2011). The Federal government, in recent years, has “focused on improving availability and access to health care and providing health programs and services for First Nations on-reserve and Inuit communities” (Pierre et al., 2007, p. 7). However, these initiatives have been piecemeal and have not resulted in any substantial change in Indigenous health over the last decade.

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<sup>11</sup> Jurisdictional issues will be discussed in Constitution Act (1867) and subsequent sections.

In 1904, given the deplorable health conditions that prevailed across reserve communities, the federal government hired a General Medical Superintendent. Through this new superintendent came the formation of the mobile nurse program in 1922, with the first nursing station opening in Fisher River, Manitoba in 1930 (Boyer, 2011). Shortly after that, the government created the National Department of Health and Welfare (DHW) in 1944 and tasked it with delivering health care to Indians. By the 1950s, DHW comprised some 33 nursing stations, 65 health centres, and 18 small regional hospitals which were designated to serve both Indian and Inuit peoples (Boyer, 2011). Nursing stations provided free health care based on humanitarian grounds, and this became the standard for the delivery of healthcare on reserves until the establishment (explained below) of the universal national healthcare system in 1970 (Lavoie, 2004). While nursing stations continue to deliver care across First Nations and Inuit communities today, they have been complemented by health centres in communities. These new health centres are funded separately by the federal government. However, a patient who requires additional or tertiary care or any medical emergency would have to seek care from a provincial centre, while being billed to the federal government (Lavoie, Forget, & Browne, 2010).

The Canadian healthcare system is a complicated grouping of varying agreements between the federal government, the ten provinces, three territories and First Nations and Inuit in Canada (Kurtz, 2011). Today, there remains a number of policies that direct how, when, and where, healthcare services can be provided and by whom. To understand the policies that have been created to control most aspects of Indigenous Peoples and their lives, we must examine the various acts that give authority, and therefore power, to the various levels of

government and their respective agents. These policies are captured below under the heading of Macro Policies of Assimilation and include the Royal Proclamation (1763), the British North America (BNA) Act (1867), the Indian Act (1876) – and subsequent amendments, Numbered Treaties (1870-1921), the Constitution Act (1982) (including Section 35, which recognizes Aboriginal People's Inherent Right to Self-Government). Expressly, the BNA Act (1867) – which is now included in the consolidated Constitution Act of 1982 – stipulates which level of government is responsible for the delivery of services to Canadian citizens. Within the Act, it stipulates the division of powers between the federal and provincial governments in sections 91 and 92. In section 92(7), it gave provinces jurisdiction over hospitals, which would later be interpreted to mean health care more generally, while at the same time, in section 91(24), it made the federal government responsible for Indians and the lands reserved for Indians. Through this set up, it allowed for both levels of government to claim the other level of government had responsibility for dealing with Indigenous health care in Canada. Out of this Act, have come many of the funding agreements and policies which stipulate who can, and how they can, deliver healthcare across Canada including the Indian Health policy, Canada Health Act, Health Transfers, and Jordan's Principle. Together, these policies lay the foundation for healthcare delivery for First Nations and Inuit people and communities in Canada.

### Policy Framework and Categorisation

Within various policy and public administration studies, there are numerous frameworks to understanding policy instruments and evaluation – however, I find the use of macro, meso, and micro to frame a health or policy issue to be most useful in this particular case. Caldwell



and Mays (2012) use a similar framework analysis to review policy implementation at the macro (national policy), meso (national programme), and micro (North West London) levels within their research. However, as seen above, this framework has traditionally only been used with reference to specific aspects of policy (e.g., design, instruments, implementation) (Howlett, 2009) rather than as a categorisation of overall policy. Given the fragmented nature of healthcare policy related to Indigenous Peoples in Canada this framework makes the most sense for understanding their role.

However, this framework does not address (through classification) the significant colonisation that has and continues to take place as a result of these policies' existence. Therefore, I propose to further classify the frames of macro, meso, and micro through a decolonial lens. To break down the varying policies, Lavoie et al. (2010) have previously analysed Indigenous health policy development in Canada as occurring in four distinct waves: pre-1860 through early contact; from 1860-1920 post-confederation protective paternalistic policies; from 1920-1960 through assimilative paternalistic policies; and from 1960-present through policies that respect cultural identity and political autonomy. Alternatively, Kelly (2011) has more broadly described policy development related to Indigenous Peoples as happening in two eras: 1) policies of assimilation and 2) policies of recognition.

This dissertation rejects the assertion that policies starting in the 1970s are no longer assimilative or paternalistic in their nature. To this day, Indigenous policy is created under the guise of recognition and respect, however, they continue to entrench the patriarchal systems created and propped up by the Indian Act, 1876 and its subsequent amendments. In recognition of this, the first half of these policies will be labelled policies of assimilation, and the

second half as policies of accommodation. In this context, “policies of accommodation” can be understood as the Government of Canada entering into convenient arrangements that continue to favour itself over First Nation and Inuit communities. At its most basic understanding accommodation can be defined a “convenient arrangement; a settlement or compromise” (Oxford Dictionary, 2018, para. 2). The continued engagement of convenient agreement between communities and the federal government holds true through today and will be demonstrated throughout this section.

Taken together, this policy section will use the following framework to understand how policy has been set out to deliver healthcare in Canada, both in general and specifically related to First Nations people living with HIV/AIDS:

The orientation of the macro frame is the policy context that established the ability for government action within the healthcare field. At this level, healthcare exists largely conceptually and is meant to be understood as an umbrella that vastly impacts all Canadians. Additionally, macro policies are the tool which have been used to operationalize colonisation and genocide, thus they will be known as the policies of assimilation or accommodation. Within this frame, the following policies are included: 1) Royal Proclamation (1763), 2) British North American Act (1867), 3) Treaties (1871 – 1921), 4) Indian Act, 1876, 5) White Paper (1969), 6) Red Paper (1970), and 7) Constitution Act, 1982.

The meso frame is where health policy takes shape as a way to conceptualize funding and delivery. This is where we see Indigenous healthcare delivery become more than a concept or area of jurisdiction dispute. However, because meso policies continue to be convenient

arrangements that favour the federal government, these will also be known as policies of accommodation. At this level the policy starts to take on specific scope and deliverables. Within this frame, meso policies are: 1) Indian Health Policy (1979), 2) Canada Health Act (1985), 3) Indian Health Transfer Policy (1989), 4) Primary Health Care Transition Fund, and 5) Jordan's Principle (2007).

Finally, the micro frame is the operationalisation of meso policies through understanding their objectives and goals. This includes the categorisation of funding allocation, programming, services, and treatment delivery. This is also where communities have the ability to offer treatment, services, and programming, that is based on traditional knowledge and therefore decolonising in nature. Within this frame, there are no micro policies explored. If there were policies related to Indigenous HIV/AIDS, they would be captured within this section.

### Macro Policies of Assimilation

Macro policies of assimilation create an overarching framework from which healthcare delivery to First Nations and Inuit Peoples are derived. The Royal Proclamation (1763) is the foundation to the many numbered treaties that proceed from it. Through these treaties, we find the rights relating to healthcare. The British North America Act (BNA) (1867) outlines the responsibility of the federal government to Indians, which subsequently allows for the creation of the Indian Act (1876). The Indian Act then works to more specifically outline the roles and responsibilities of healthcare within First Nations communities. Finally, through the Constitution Act (1982), Indigenous rights, including healthcare rights, become entrenched

within the constitution and are not able to be overridden by the government of Canada. These acts form the bedrock for all health policy in Canada today.

### Royal Proclamation (1763)

Treaties are the foundation of many of the claims espoused by First Nations in Canada. Treaties were entered into by the Crown and First Nations from the late 1700s through to 1921, in which First Nations gave up large swaths of land to the crown in exchange for “reserve lands, annual payments, fishing and hunting rights, schools and educational resources, farm equipment and animals, and other material goods” (Kelly, 2011, p. 2). Treaties were entered into based on the Royal Proclamation of 1763, which stated “the Indigenous Peoples of Canada were not a conquered people and retained title to their ancestral territory. Any encroachment on the part of the settlers was to be approved by the Crown, negotiated through the treaty process and duly compensated” (Gabel, 2012, pp. 135-136). The Royal Proclamation, also known as the ‘Indian Magna Carta’ or ‘Indian Bill of Rights’ was an attempt by the Crown to create an alliance with Indigenous Peoples to ensure the sovereignty of the British Crown after the Seven Years War (Lavoie, 2004). Following the enactment of the Royal Proclamation, the Crown entered into agreements with First Nations across what is now known as Canada. Today, treaties are widely discussed within a ‘historical’ context, however, treaties are living documents and agreements. Treaties are in no way historical, other than the fact they were created some decades ago. They remain valid and living agreements that are actively used to ensure Indigenous rights within Canada.

## British North America Act (1867)

Prior to the creation of the British North America Act (1867), Canada was wholly governed by the British Crown. By way of an act of the British Parliament, that is the enactment of the BNA Act (1867) on July 1, 1867, Canada became a dominion of Britain. It was not until 1982 that Canada became a fully independent state, following 115 years of evolving powers. Through this time, Canadian dependence on Britain was gradually reduced until, in 1982, the final power was transferred: the right to amend the Canadian constitution.

Health is a complex issue under the constitution, as it involves issues related to prisons, crime, labour issues, national emergencies, Indigenous Peoples, and local issues (Matiation, 1999). Importantly, the BNA Act (1867), and subsequent amendments are relatively silent on the issue of legislative power over health and healthcare (Boyer, 2011; Matiation, 1999). In 1867, health was not considered a matter of vital importance that rose to the level of constitutional intervention. Instead, health was considered a private or local matter (Boyer, 2011). The state was expected to intervene only during times of emergencies, such as an epidemic. Otherwise, health was of private or municipal concern. However, health started to evolve as an area of prominence as the country developed, and the question of responsibility started to emerge and become more prominent. Within the Act, the constitutionally mandated powers of governance were established. Namely, this included the division of power between the federal and provincial governments.

While no one level of government is wholly responsible for health, sections 91 (federal powers) and 92 (provincial powers) of the Constitution Act (1867) still preserve substantial

impact on Indigenous Peoples and, by default, their healthcare, through the federal government's delineated powers. Under section 91(24), the federal government has the exclusive authority and responsibility for "Indians and Lands reserved for the Indians." However, under section 92(7), the province is responsible for "the establishment, maintenance, and management of hospitals, asylums, charities, and eleemosynary institutions in and for the province, other than marine hospitals," and, under 92(16), for "generally all matters of a merely local or private nature in the province" (Government of Canada, 1867). These provisions have generally been interpreted to mean that the BNA Act (1867) conferred "provincial legislatures authority over public health and the provision of health services as a local or private matter and over the establishment and management of hospitals" (Matiation, 1999, p. 16).

Jurisdictional overlap clearly occurs when dealing with Indians and lands reserved for the Indians. The federal government has exclusive authority within this area, and therefore provincial legislation cannot apply to Indians "if the laws directly overlap and impair the core of federal authority over —Indians, and Lands reserved for the Indians - as set out in s. 91(24) of the Constitution Act, 1867" (Boyer, 2011, p. 222). Through the provisions of the Constitution Act (1867), the Indian Act (under federal jurisdiction) details the federal government's responsibility for delivering medical treatment and health services to Indians. Through the Indian Act, under section 6, service provision applies only to status Indians and those residing on reserves. However, the Constitution Act remains silent on the issue of healthcare more broadly.

This silence has resulted in healthcare not being assigned, as a constitutional responsibility, to either level of government<sup>12</sup>, and therefore it is the subject of ongoing negotiations between both the federal and various provincial governments. “Because the Constitution Act is silent on health, the courts have defined (and continue to define) how governmental powers should be distributed to meet health needs and concerns” (Boyer, 2011, p. 209). In relation to First Nations’ healthcare, the matter continues to evoke contentious debate between both levels of government over responsibility for the delivery of care and who shall be responsible for paying for it.

Because the federal government is responsible for Indians and Indian land, the definition of to whom the federal government is actually responsible to deliver healthcare has been limited by the courts. The courts have understood the federal responsibility to mean Indians with status and those who live on reserve lands (as created and recognized through the Indian Act) and Inuit Peoples. As a result, the federal government has therefore “focused its activities on status Indians living on reserve and some Inuit communities” (Matiation, 1999, p. 10), with provincial governments having responsibility for non-status Indians, status Indians and Inuit peoples living off reserves/community, and Métis people. This has led to infighting amongst Indigenous nations and Indigenous Peoples about who is considered an ‘Indian’ under the *Indian Act* and therefore entitled to benefits. There remain divides over who should be entitled to recognition and benefits arising therefrom. The politics of recognition must be recognized for what it is: a set of colonial policies meant to further divide and tear apart

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<sup>12</sup> The BNA Act, 1867 does state navy hospitals and the power to quarantine vessels fall within federal jurisdiction. Additionally, s92.7 states provincial authority over the establishment, maintenance, and management of hospitals in and for the province.

families, communities, and nations. As Coulthard (2014) argues, settler-colonialism in Canada maintains a goal of dispossessing Indigenous Peoples from their lands and creating factions between them. Furthermore, contemporary politics of recognition seeks to reproduce colonial power structures and cause division that Indigenous Peoples have sought to transcend (Coulthard, 2007)

Today, as a result of decades of health policy and some judicial interventions, most citizens would view their provincial government as maintaining jurisdiction over the direct administration of healthcare. However, the federal government, under section 91, also has considerable influence through its exercise of spending powers. The federal government contributes significant money to the provinces for healthcare delivery, which allows it to indirectly exercise control over healthcare delivery otherwise not directly within its purview (Boyer, 2011). This control can be viewed today through the federal government's control of healthcare through the Canada Health Act (1984).

These nuances in policy, created by the Constitution Act (1867), are the foundation of many of the access issues Indigenous Peoples face in Canada. The overlap between federal responsibility, with the federal government's limited ability to deliver care, and the provincial government's expertise in delivering care to the rest of the population has created a two-tiered system which disadvantages those who live on reserve and rely on limited federal responsibility.



## Treaties (1871 – 1921)

Following confederation in 1867 a total of eleven numbered treaties were recognized by the Canadian government, which had been previously entered into by the British Crown. When it comes to healthcare, there is only one treaty with the Crown that is said to deal with some provision of health. Treaty No. 6 was entered into by the Crown and the Plains Cree people, whereby the Crown gave the “promise of a medicine chest” (Kelly, 2011, p. 2). The medicine chest clause has since been interpreted by many to mean the promise of the delivery of healthcare to the Plains Cree people. The federal government has worked actively, over the past century, to limit the scope and influence of the Royal Proclamation and the impact the treaties have on Canada (Lavoie, 2004). This is the starting point of healthcare policy in Canada and provides jurisdictional context for federal responsibility to deliver health care to First Nations Peoples in Canada.

## Indian Act, 1876

The Indian Act is Canada’s continued colonial policy that regulates most aspects of Indigenous Peoples’ lives. There are two significant aspects when looking at the delivery of healthcare to First Nations (Kelly, 2011). The first is by defining who is within the federal government's jurisdictional boundaries, and the second is determining how and when services are provided.

First, the federal government has set out the framework and rules for who is considered an ‘Indian’ in Canada. The federal government does this by assigning status to First Nations

people. Through that assigned individual status, the federal government takes responsibility for aspects of their healthcare and what accessibility and coverage they will receive (Lavoie et al., 2010). Under the Act, one's status is a complicated categorisation based on the timing of receiving status, and one's parents' perceived Indian lineage. Indians are categorized as being "6(1)" or "6(2)" (Government of Canada, 1985b). Section 6(1) of the Act denotes who is eligible for status. Section 6(2) dictates who is eligible for status based on having previously lost status or on having a parent who is registered as a status Indian. Being a 6(1) status Indian means that a person has the ability to pass along status to their children no matter with whom they procreate. However, the children of 6(2) status Indians who procreate with someone who is non-status will no longer be eligible for status under the Act. However, if two 6(2) Indians procreate, their child would convert to 6(1) status. Through this process, the Act "determines which individual or group has the right to Indian-specific federally funded health care programs and services, individualized health and social services, or no services at all" (Lavoie et al., 2010, p. 86). This system is complex and continues to perpetuate stereotypes and discrimination about who is, in fact, an Indian in Canada. Substantively, having status affects how a person accesses services and care.

The Indian Act also established the reserve system, which is yet another mechanism used by the federal government to define its jurisdictional boundaries (Kelly, 2011). The federal government, under section 18(2) of the Act, has been able to dictate that the Minister may authorize the use of reserve lands for "Indian Health Projects" (Government of Canada, 1985b, p. 23). Through this system, the federal government has carefully crafted who is and who is not eligible for healthcare services under its jurisdiction. Through this policy, the government has

created a system of rules that has caused confusion related to how people access care and services and how communities can improve their people's health.

Second, the Indian Act sets out in general terms how and when healthcare services are provided. This is done by dictating that, to receive services, a person must be a status Indian and/or reside on a reserve. The Act only mentions health on three separate occasions. The first, having already been discussed above in relation to the Indian Act, allowed for reserve lands to be used for Indian health projects. Under the Act, the Governor in Council may also make regulations under section 73(1)(g) “to provide medical treatment and health services for Indians” (Government of Canada, 1985b). This section has been used in order to establish access for the Non-Insured Health Benefits program (to be discussed later in this section) and other health entitlements. Section 73(1)(g) has also allowed for the establishment of nursing and other medical facilities, which are administered by the federal government. Additionally, section 81(1)(a) denoted the Powers of a Band Council, noting: “The council of a band may make by-laws not inconsistent with this Act or with any regulation made by the Governor in Council or the Minister, for any or all of the following purposes, namely, (a) to provide for the health of residents on the reserve and to prevent the spreading of contagious and infectious diseases” (Government of Canada, 1985b). This section allows for bands to take charge of providing healthcare services directly to their people but doesn’t guarantee any transfer of funds to help that to happen. This provision of services to their people has facilitated the establishment of community health service centres in First Nations. Communities now have the ability – if not the means – to take responsibility for the delivery of healthcare within their territory, under the direction of the federal government, but this shift is typically allowing for

more culturally based and competent service delivery. Overall, the Indian Act limits federal responsibility while, in the same stroke, gives it almost ultimate control over the funding and delivery of healthcare services to First Nations and Inuit Peoples.

### White (1969) and Red (1970) Paper

The Hawthorn report, commissioned in 1963 and released in two parts (October 1966 and October 1967) was the first major study to evaluate the health and social conditions on-reserves (Lavoie, 2004). The 1969 White Paper was put forward by the federal government in response to the Report. The objective of the White Paper was to repeal the Indian Act, notably to remove status Indian provisions and the special services that came along with them (Kelly, 2011; Lavoie, 2004). Implementation of the White Paper would have also meant the repeal of the reserve system and all lands being transferred to provincial control. The White Paper received widespread objection from Indigenous leaders. While Indigenous leaders were consulted during the development of the paper itself, their input was not reflected in its contents (Kelly, 2011). Harold Cardinal, a founder of the National Indian Brotherhood (precursor to the Assembly of First Nations) called it “a thinly disguised programme of extermination through assimilation.” (Cardinal, 1969, p. 1) In response to the White Paper, Indigenous leaders created and released the Red Paper in 1970. The Red Paper sought to emphasize that healthcare was the responsibility of the federal government and the continued desire for First Nations to have control over their health programs. The Red Paper resulted in the White Paper being withdrawn by the federal government, based mainly on the strength of arguments put forth by Indigenous leaders relating to the federal government’s responsibility

under the Royal Proclamation (Lavoie, 2004). Both the White and Red Papers played a vital role in assisting in the push for more open and transparent policymaking with First Nations (Kelly, 2011). Notably, as a result of these papers, the government moved away from policies with the intended goal of assimilation and moved towards creating policies that recognize the inherent rights of First Nations.

### Constitution Act, 1982

The Canadian Constitution was patriated in 1982. In addition to the BNA Act (1867), which is re-named the Constitution Act (1867), it includes the Constitution Act (1982), Part I of which is the Charter of Rights and Freedoms, and Part II (section 35) of which is “Rights of the Aboriginal Peoples of Canada.” Section 35(1) provides that: “The existing aboriginal and treaty rights of the aboriginal peoples of Canada are hereby recognized and affirmed,” while section 35(2) says “In this Act, ‘*aboriginal peoples of Canada*’ includes the Indian, Inuit and Métis peoples of Canada” (Government of Canada, 1982). The Supreme Court of Canada interpreted this section of Constitution Act and had set forth its limitations through the Sparrow Test (Boyer, 2011). According to Boyer (2011), “For Aboriginal health, constitutional supremacy means that the constitutional reform of 1982 and the judicial interpretations that affirm Aboriginal and treaty rights must be upheld no matter what. No federal, local or provincial government can violate them or pass laws to diminish them” (p. 217). Given the inclusion of section 35 and preceding judicial interpretation, legal and policy directions must conform to protecting and securing Indigenous rights. Substantially, this has meant that protections have been extended to the jurisdiction of First Nations and Inuit healthcare.

Additionally, the many treaties into which Canada has entered have been recognized by the courts to include health and health practices. Therefore, governments do not have the ability to simply override these protections by either direct action or, similarly, through their own inaction (Boyer, 2011). Boyer (2011) notes, “[a]mong the Aboriginal and treaty rights to be protected and secured, Aboriginal rights to health are paramount. In essence, Aboriginal people have the same rights to good health as other Canadians; in addition to those rights they possess constitutionally protected Aboriginal and treaty rights to health” (p. 217). These protections under the Constitution Act (1982) have continued to evolve over the past 36 years and continue to ground arguments by First Nations related to their access to healthcare and continued treaty rights.

### Meso Policies of Accommodation

The meso policies to follow detail how the government has continued to place their own needs before those of First Nations and Inuit Peoples. This section brings together the aforementioned section to create a framework from which policy delivery can be accomplished in Canada. This policy framework allows for the creation of the Indian Health Policy which set to restore the health of First Nations Peoples through changing how and by whom healthcare is delivered. This policy created the skeleton for the establishment of the Health Transfer Policy (1989). However, in 1985 the Canada Health Act was enacted along with the federal department, Health Canada. Health Canada is subsequently assigned responsibility of specific aspects of healthcare for Indigenous Peoples. After the creation of Health Canada, the federal government created the Health Transfer Policy which was designed to transfer all

administrative authority in relation to community health services to First Nations communities living below the 60<sup>th</sup> parallel. Subsequently, the First Nations and Inuit Health Branch via Health Canada was tasked to work on the implementation of healthcare services to First Nations and Inuit communities.

### Indian Health Policy (1979)

In Canada, only two national Indigenous health policies are publicly available, the Indian Health Policy (1979) and the Health Transfer Policy (1989) (Lavoie & Gervais, 2010). The Indian Health Policy was released on September 19, 1979 and was a two-page document that was meant to radically change the direction of First Nations' health in Canada. The policy intended to restore "Indian health through community development, a reaffirmation of the traditional relationship of Indian peoples to the federal government and by improving the relationships within the Canadian health care system" (Gabel, 2012, pp. 128-128). The policy came about as a result of the recognition of the poor health outcomes of First Nations people across Canada and the realisation that First Nations themselves have to be involved in any changes if they hoped to combat those outcomes (Kelly, 2011). For the first time, there was now a focus on the involvement of First Nations and Inuit communities<sup>13</sup> in delivering health services to their people (Pierre et al., 2007). This change in approach is significant because, through the Indian Health Policy, the federal government "acknowledged its role to be to advocate on behalf of

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<sup>13</sup> In 1954, the Advisory Committee on Northern Development of the Department of Northern Affairs and National Resources developed a Northern Health Services Branch which co-ordinated health care for Inuit throughout the north. Since that time, the federal government has been recognized as having responsibility for the delivery of healthcare services to Inuit peoples when there is a lack of care provided by provincial or territorial governments (Duffy, 1988, pp. 59-61)

Indians to the larger Canadian society, promote capacities of Indian communities, and provide public health and health promotion activities on-reserve” (Kelly, 2011, p. 2). The policy sets out the foundation for further advancement in First Nations and Inuit health through the Health Transfer Policy (1989). This policy pre-dated the arrival of the AIDS epidemic, but its thrust was very much in keeping with the notion of ‘health care’ as an umbrella under which all health needs could be organized.

The Indian Health Policy was a broadly-defined policy consisting of three overarching pillars. The first pillar, also viewed as the most significant, is community development in First Nations communities. This includes socio-economic and cultural/spiritual development, which are being created through mechanisms generated and maintained by communities themselves (Gabel, 2012; Lavoie & Gervais, 2010). The second pillar of the policy is the “traditional relationship of the Indian people to the federal government”, and to promote the capacity of communities to achieve their aspirations (Lavoie, 2004, p. 8). This pillar was intended to assist in strengthening the traditional and new relationship(s) between the federal government and First Nations communities. Through this, the federal government is to serve as an advocate for the interests of communities and to assist them in achieving their aspirations (Gabel, 2012). The third and final pillar is the Canadian Healthcare System. The third pillar is the recognition that the Canadian healthcare system is one that is highly specialized and an interrelated mix of responsibilities assigned to federal, provincial, and municipal governments in conjunction with First Nations and private sector actors (Gabel, 2012). This pillar is to assist in increasing the capacity of communities to play a positive and active role in the decisions and delivery of healthcare to their people (Lavoie & Gervais, 2010). Overall, the objective of the Indian Health



Policy of 1979 was to “achieve an increasing level of health in Indian communities, generated and maintained by the Indian communities themselves” (Lavoie, 2004, p. 8). The primary mechanism of this policy is the creation of the Health Transfer Policy of 1986, which will be discussed later in this section. Through this policy, the federal government finally acknowledged that its system of healthcare was not working and specifically recognized the necessity to have communities take responsibility for the delivery of their health systems in order to combat the ongoing issues they were facing. It did not imagine, however, exceptional circumstances of the sort exemplified by the AIDS crisis.

#### Canada Health Act (1985)

Canada’s national healthcare system was established in 1970. The current system is encapsulated in the Canada Health Act (1984), since renamed the Canada Health Act (1985). This system is a “publicly financed, publicly administered, and partially privately delivered system, managed by the provinces under the umbrella of the Canada Health Act” (Lavoie et al., 2010, pp. 88-89). The Act sets out an insurance program that would provide services with no assigned user fee (Kurtz, 2011). The Act sets out and establishes standards for the delivery of healthcare service nationally. However, the Act does not specifically address First Nations healthcare or set out any jurisdiction for such a group (Kelly, 2011). The jurisdictional breakdown contained in the Act itself defines any person as being insured under the Act, if they are a resident of a province other than if they are “members of the Canadian Forces or Royal Canadian Mounted Police, federal inmates, or residents of the province who have not completed a minimum period of residence” (Government of Canada, 1985a). However, while

the Act is silent on First Nations health, MacIntosh (2008) argues “provinces have agreed to deliver insured health services to all persons normally resident in the province, which includes Aboriginal [sic] residents regardless of whether they live on or off reserve” (p. 86). Through the use of the Canada Health Act, the federal government has created the federal department called Health Canada. The role of Health Canada is to deliver care to persons for whom it has responsibility under the Act and more broadly to all Canadians through policy, regulation, and health promotion.

Health Canada is set up to support First Nations in the delivery of various health programs which are based on both the Canada Health Act and the Indian Health Policy (Office of the Auditor General of Canada, 2015). Under these various programs, Health Canada is responsible for funding the delivery of healthcare services to First Nations communities. Within Health Canada, there exists the First Nations and Inuit Health Branch (FNIHB), first created in 1989, which is directly responsible for the delivery of care to First Nations and Inuit people. Federal policy in relation to healthcare is silent on the Métis and those who are not eligible for status under the Indian Act, as the federal government does not view them as being its responsibility. “Health Canada supports funding transfers, health promotion programs and some services for mental health and chronic conditions through its First Nations Inuit Health Branch” (Palmer, Tepper, & Nolan, 2017, p. 8). The mandate of FNIHB includes ensuring “availability of, or access to, health services for First Nations and Inuit (FNI) communities; assisting FNI communities in addressing health barriers [...]; and building strong partnerships with FNI to improve the health system” (Government of Canada, 2012b). The branch provides services to those who live in First Nations and Inuit communities and who are either defined as

Indians under the Indian Act (i.e., status Indians) or who belong to Inuit communities (Boyer, 2011).

On-reserve services were intended to complement the provincial healthcare system. Therefore, they are generally limited to public health and health promotion initiatives by the federal government. However, in more remote and isolated communities, services are broader in scope and include primary healthcare delivery (typically delivered by nurses through a network of nursing stations), intermittent physician services, and local paraprofessionals (Lavoie et al., 2010). “[In 2011] FNIHB provide[d] \$500 million per year to five major health programs: Community Health Services, Environmental Health and Surveillance, the National Native Alcohol and Drug Abuse Program, Hospital Services, and Capital Construction” (Gabel, 2012, p. 130). The branch also administers a sixth program called the Non-Insured Health Benefits Program (NIHB). This program ensures basic healthcare needs are available to those who are registered status Indians if they are not met by other private or public health insurance plans (Boyer, 2011). The plan covers prescription drugs, dental care, medical supplies and equipment, vision care, transportation to medical services, and short-term/crisis mental health counselling (Government of Canada, 2018b). The Canada Health Act also mandates the Canadian Health Transfer, which sets out to provide cash and tax transfers directly to provinces and First Nations and Inuit communities, so they have reliable and predictable funding for delivering care (Gabel, 2012). Through the Act, Health Canada delivers almost all health services (or funding) on First Nation reserves and provides status Indians additional health benefits through its various programming. These services are intended to mimic comparable services received by non-Indigenous Peoples in the provincial system.

## Indian Health Transfer Policy (1989)

The Indian Health Transfer policy was first introduced in 1986 and is the most tangible outcome of the prior Indian Health Policy of 1979 (Matiation, 1999). The Indian Health Transfer policy is designed to transfer all administrative authority in relation to community health services to First Nations communities living below the 60<sup>th</sup> parallel. The transfer occurred in gradual phases and requires “specific mandatory public health programs to be provided, gives communities flexibility to allocate funds according to community priorities, and limits funding, by way of a non-enrichment clause, to health care delivery costs at the time of transfer” (Kelly, 2011, p. 3). The aim of the Indian Health Transfer policy, broadly speaking, was to work towards communities having greater involvement and say in the delivery of healthcare services to their people. The policy was officially implemented in 1989 and laid out the opportunities single First Nations communities and Tribal Councils had in assuming responsibility for the planning and delivery of services (Lavoie & Gervais, 2010).

The Indian Health Transfer policy stated three broad objectives. The first, to empower “Indian Bands to design health programs, establish services and allocate funds according to community health priorities”. The second, to “strengthen and enhance the accountability of Indian Bands to Band members”. And finally, to “ensure public health and safety is maintained through adherence to mandatory programs” (National Health and Welfare, 1989, p. 1). Through the Indian Health Transfer policy, there were three distinct tiers of healthcare that could be transferred through the FNIHB at Health Canada: “first level (community - direct service delivery), second level (zone - coordination, supervisory) and third level (regional - consultant,

advisory)” (Gabel, 2012, p. 141). Through the policy, First Nations communities were able to participate in the planning and delivery of services that were designed to reflect on-the-ground local needs and priorities, with the considerable potential to actually improve health outcomes. However, the policy evolved into a complicated set of funding formulae which were not regularly revisited. This resulted in per capita funding that did not accurately reflect the needs of communities or the emergence of greater participation in community programs (Lavoie, Forget, & O’Neil, 2007).

As a result of these funding concerns, there are now two additional types of transfers (known as contribution agreements) for the transferring of health programming to First Nations. In 1994, FNIHB broadened the opportunity for community control with a second funding approach. This approach introduced the Integrated Community-Based approach, whereby a community would have less control overall than that of the one-size-fits-all health transfer model, but instead, communities were provided a more flexible funding alternative (Lavoie et al., 2010). Through this approach, communities “may not create new programs outside the FNIHB mandated services. However, communities are able to make some program adjustments to reallocate resources and set up health management structures that receive funding on an on-going basis” (Gabel, 2012, p. 145). Many small communities were also not eligible for the larger health transfer agreement of years prior, given their overall population and economic size. Therefore, this new approach gave communities an opportunity to participate in their health planning. Communities that accepted this approach felt it was less infringement on their treaty rights and was lower risk, allowing the opportunity to learn how to manage their health portfolio before entering into more substantial transfer agreements

(Gabel, 2012). Finally, the government also set up the Consolidated Contribution Agreement in 1999. Through this agreement, communities could be given funding for specific programming, generally of no more than one year in duration. However, the community would have no authority to redirect the funding to other programs but had to deliver the program as noted in their agreement (Gabel, 2012; Government of Canada, 2017a). Overall, these transfer agreements meant that communities could finally start to take control of the health of their own people and start to have a say in how health services were being provided within their communities. This was a significant step forward from the policies of the past.

#### Primary Health Care Transition Fund

In 2000, the Government of Canada announced the establishment of the Primary Health Care Transition Fund. This fund saw \$800 million allocated over a six-year period from 2000-2006. The fund was open to provinces, territories, First Nations and Inuit Communities, Health organisations, and not-for-profit non-governmental organisations to assist in reforming primary healthcare within their jurisdiction (Government of Canada, 2007b). This funding provided to First Nations and Inuit communities was designed to respond to the needs of the community.

The objectives of the Primary Health Care Transition Fund were listed as promoting more productive and cost-effective primary health care service delivery through the integration of existing services and resources; enhancing coordination of service delivery between Health Canada, provincial and territorial governments, and First Nations/Inuit communities and health organisations; enhancing the ability of federal, provincial, and territorial systems to be accountable to each other and to their publics through collaborative information development;

improving the quality of services delivered to Aboriginal peoples, including cultural appropriateness; and improving linkages between primary health care services and social services. (Government of Canada, 2007b, p. 2)

The First Nations and Inuit envelope of the Primary Health Care Transition Fund had a total commitment of \$35 million and was comprised of two components: health system renewal, which was to be a significant scale project with the intent to renew entire health systems; and health systems enhancement, which sought to focus on niche areas to improve on the delivery of primary health care for First Nations and Inuit peoples (Government of Canada, 2007b). The program helped to create/fund ten unique initiatives and/or programs including the Northern and Aboriginal Population Health and Wellness Institute; Nursing Strategy Initiative; A Tool to Help People from Far Away-The Ikajuruti Inungnik Ungasiktumi Telehealth Network; and a Aboriginal Midwifery Education Program (Government of Canada, 2007c). This funding envelope has been completed and is no longer available for communities to secure funding.

#### [Jordan's Principle \(2007\)](#)

On October 22, 1999, Jordan River from Norway House Cree Nation in Northern Manitoba was born with a rare neuromuscular disorder. Throughout his life, he had complex medical needs that could not be supported on his home reserve, resulting in his transfer to Winnipeg. While in care in Winnipeg he would become wheelchair-bound, ventilator dependent, and unable to speak. In 2001, after being diagnosed with Carey-Fineman-Ziter syndrome, Jordan was to be discharged to a specialized foster home near his home reserve.

This foster care home specialized in the healthcare needs Jordan required in order to improve his quality of life. However, the federal and provincial government fought over who was responsible for paying for this care. These jurisdictional fights continued for two years before Jordan eventually died at the age of five while awaiting medical care (Boyer, 2011; Boyer et al., 2016). This case brought national attention to the issue Indigenous Peoples face in trying to access care and funding. It resulted in the articulation of Jordan's Principle, which consists of five overarching principles: 1) that the government of first contact must pay for the services required and disputes would be dealt with later (Government of Canada, 2018a; Palmer et al., 2017); 2) that it applies equally to all First Nations children, whether residing on and off reserve; 3) that it is meant to ensure there are no gaps in any government services provided to children; 4) that service assessments that go beyond the normative standard of care shall be evaluated by the government of first contact to determine where the requested service should be provided; and 5) that Jordan's Principle is a broad principle that applies even when there is not a jurisdictional dispute taking place (Government of Canada, 2018a).

Cindy Blackstock, a leading advocate for First Nations children and the executive director of the First Nations Child and Family Caring Society, extensively advocated for the adoption of Jordan's Principle. It was Blackstock, along with the Assembly of First Nations, who lodged the original complaint with the Canadian Human Rights Tribunal in 2007, alleging the Canadian government was discriminating against First Nations children by underfunding the child welfare system for children on reserve, in violation of Jordan's Principle (Cossette, 2017).

On December 12, 2007, the House of Commons unanimously passed Private Members' Business M-296 [moved by Jean Crowder (NDP: Nanaimo-Cowichlan) and seconded by Judy



Wasylycia-Leis (NDP: Winnipeg North)] “That, in the opinion of the House, the government should immediately adopt a child first principle, based on Jordan's Principle, to resolve jurisdictional disputes involving the care of First Nations children” (Government of Canada, 2007a). There were attempts to enact Jordan’s Principle in legislation. Subsequently, there were various Acts which went before Parliament but did not pass, including: C-249: First Nations Children's Health Protection Act: An Act to ensure that appropriate health care services are provided to First Nations children in a timely manner. This Private Member’s bill was introduced by Pat Martin (NDP: Winnipeg Centre) multiple times, first in 2008 and most recently in 2011. Additionally, in June of 2008 Bill C-563: First Nations Children’s Health Protection Act, also a Private Member’s Bill was introduced by Tina Keeper (NDP: Churchill) but did not pass. In 2008 the federal government established an \$11 million fund to cover costs of care during a dispute (O’Brien, Maynard, Moreau, Bernstein, & Wolff, 2015). However, a 2016 film documentary by Alanis Obomsawin titled *We Can’t Make the Same Mistake Twice* argues that the federal government has fought applying Jordan's Principle to such a degree that an \$11-million fund set aside to cover its costs was never used.

Since its implementation, the Canadian Human Rights Tribunal has ruled on three separate occasions that the federal government is purposely interpreting and applying the principle too narrowly (Palmer et al., 2017). In a Tribunal ruling on January 26, 2016, the federal government was ordered to adopt the measures within Jordan’s Principle fully. In its most recent ruling the Tribunal found “delays in providing health equity for Indigenous children was linked to youth suicide in Wapekeka First Nation in northern Ontario” (Palmer et al., 2017, pp. para. 9-12). The Tribunal’s ruling of May 26, 2017, expanded the definition of Jordan’s Principle:

In recognition of Jordan, Jordan's Principle provides that where a government service is available to all other children, but a jurisdictional dispute regarding services to a First Nations child arises between Canada, a province, a territory, or between government departments, the government department of first contact pays for the service and can seek reimbursement from the other government or department after the child has received the service. It is a child-first principle meant to prevent First Nations children from being denied essential public services or experiencing delays in receiving them (Government of Canada, 2018a, p. 1).

Since 2016, the federal government has committed to invest 382 million dollars in implementing the application of the principle (Boyer et al., 2016). In that time, there have been more than 70,000 requests for services, supports, and products (including mental health supports, medical equipment, speech therapy, and educational supports) which have been approved for First Nations children under the Principle (Government of Canada, 2018a).

However, there continues to be sporadic implementation of the principle across Canada:

“Although Jordan’s Principle was passed unanimously by the House of Commons in 2007 and adopted by most provinces and territories, its implementation has been limited and inconsistent. A 2015 Research Report found that jurisdictional confusion among provincial, territorial and federal governments still results in First Nations children being denied care, and that Jordan’s Principle is not being applied” (Canadian Paediatric Society, 2016, p. 1).

Additionally, the third non-compliance order issued by the Canadian Human Rights Commission issued in May 2017 found that the Government of Canada continued to repeat “its pattern of conduct and narrow focus with respect to Jordan’s Principle.” Twenty-two additional legal orders in regard to Jordan’s Principle were made at this time. This demonstrates that the work of implementing a clear principle politicians of all political parties talk about embracing, is a complex task.

## Policy Assessment

### Federal Departmental Policies

The delivery of healthcare services and funding flows from federal, and to some extent provincial, Ministries and Departments. The following are examples of micro policies, including department or health organisational internal functioning policies. However, these micro policies lack clear policy goals and evaluative measures that could be used in standard policy analysis. HIV services and care for First Nations and Inuit peoples is managed through Health Canada, Indigenous Services Canada (formally, Indigenous and Northern Affairs Canada), and Correctional Services Canada. Each of these departments plays a critical role in the coordination of an effective HIV/AIDS strategy for Indigenous Peoples. Substantially, for First Nations healthcare, especially on-reserve, all funding comes from Indigenous Services Canada (formally though Health Canada until January 2018) via the First Nations and Inuit Health Branch. Within Indigenous Services Canada, funding for HIV programs and services comes from some of the following funding envelopes: communicable diseases, chronic diseases, prevention, and home and community care. Almost all education funding comes from a proposal-driven process through FNIHB. Relying on all funding to come from one division in Indigenous Services Canada creates numerous problems. Employees in the department feel as though it's hard to deal with Indigenous portfolios (including getting action on political and jurisdictional issues); interdepartmental coordination is challenging given working relationships, personnel changes, and a high level of bureaucracy; and finally, other government departments at the federal level tend to not perceive the importance of their own specific role in relation to HIV/AIDS funding

and service delivery (Matiation, 1999). Departmental infighting and a general lack of will on many of the Indigenous portfolios remains an ongoing concern for First Nations who are at the mercy of these decision-makers. Additionally, Lavoie (2013) argues, “federal and provincial/territorial legislative and policy frameworks fail the test of seamlessness. They also fail to address shifts in jurisdiction related to changes in legislation, decentralisation, self-government activities, or as a result of other arrangements” (p. 5). In addition to this fragmentation, over the past decade, we have seen the federal government systematically and unilaterally start to devolve its historical responsibility for funding health care services for status on-reserve peoples to the provinces (Lavoie et al., 2010). The provinces have been actively resisting having to fund and manage healthcare services on reserves. Overall, there are apparent barriers within and between departments at the federal level and between the varying levels of government themselves.

Funding problems are being exacerbated currently by a change in responsibility for Indigenous healthcare from Health Canada to a newly created Ministry called Indigenous Services Canada. This Ministry, along with the newly created Crown-Indigenous Relations and Northern Affairs, is being carved out of the old Ministry of Indigenous and Northern Development Canada. This new federal ministry will be devoted to improving the delivery of all services in Indigenous communities. Both the Minister of Health and the Minister of Indigenous Services received mandate letters that do not directly address the issue of HIV/AIDS or how their respective departments should go about dealing with this pressing health concern. In the Minister of Health’s Mandate Letter from the Prime Minister in 2017, Minister Philpott was instructed to work closely with the Minister of Crown-Indigenous Relations and Northern

Affairs and the Minister of Indigenous Services, to help make systemic change in the government's provision of health care services to Indigenous Peoples and to reduce the health inequities between Indigenous Peoples and non-Indigenous Canadians. This includes supporting the Minister of Crown-Indigenous Relations and Northern Affairs as she undertakes consultations relating to the anticipated transfer of responsibility for the First Nations and Inuit Health Branch from your portfolio to that of the Minister of Indigenous Services. (Government of Canada, 2017c)

Indigenous communities have been accessing and dealing with Health Canada for over four decades. This transfer of responsibility can cause significant disruption to communities when new funding envelopes, employees, and processes are put into place by a new ministry. At this stage, it is unclear what this new ministry will entail (Palmer et al., 2017). However, the Mandate letter provided to the Minister of Indigenous Services notes that the Minister will:

Lead work to create systemic change in how the federal government delivers health services to Indigenous Peoples in collaboration with the Minister of Health and the Minister of Crown-Indigenous Relations and Northern Affairs. Specifically, I would ask that you take an approach to service delivery that is patient-centred, focused on community wellness, links effectively to provincial and territorial health care systems, and that considers the connection between health care and the social determinants of health. You should also work with the Minister of Crown-Indigenous Relations and Northern Affairs to develop governance models that bring control and jurisdiction back to Indigenous communities. (Government of Canada, 2017d)

It is expected the new ministry will work to set up a task force or expert committee to design the goals and eventual outcomes of its work (Palmer et al., 2017). Given the absence of any specific direction related to HIV or communicable diseases in the mandate letters, it is not known what priority will be given to the area in the coming months and years. The significant task of this new ministry is to create a more fluid process for communities to access funding for

health care and services, all while ensuring it can be done in a culturally appropriate manner. The one major challenge that is not yet apparent is how the provinces will be engaged in this new process by the ministry. By failing to mention the provinces in the mandate of the new ministry, it continues to leave them off the hook for actually assisting or delivering any services to First Nations also in their jurisdiction.

## HIV Funding

There is a dearth of literature on the topic of HIV funding in Indigenous communities. Matiation (1999) argues that problems with HIV funding for Indigenous organisations are similar to those experienced by other HIV organisations, noting that many HIV/AIDS organisations across the board are underfunded. Strategic funding is almost always proposal-driven, and therefore communities must spend considerable time preparing applications for new and renewed money (Minore & Katt, 2007) and accounting for money received and spent via previous proposals. Generally, Indigenous HIV/AIDS funding emerges only as an afterthought, or funding is based on the needs and policies of other non-Indigenous HIV/AIDS groups. Funding also varies momentously across the country based on additional funding that is sometimes received by service organisations from their provincial government (Matiation, 1999). Indigenous-specific HIV funding comes from program-specific funding envelopes within the Ministry of Health via Health Canada. Each of these envelopes have different lines of accountability, and it has its own format of assessment, design, and allotment processes (Minore & Katt, 2007). The result is a time-consuming bureaucracy that communities must navigate to apply for funding for HIV education, prevention, treatment, services, and

programming. Almost all HIV funding given to communities is based on short-term funding envelopes that must be consistently renewed. This gives communities little assurance that their funding, and thus their initiatives, will continue beyond the fiscal year, making it extremely difficult to attract and retain highly talented and trained staff (Minore & Katt, 2007). Funding initiatives for HIV/AIDS within First Nations communities are a complicated and complex mix of arrangements offered by varying divisions and portfolios within Health Canada, making access to funding all the more difficult.

### Adequacy of Healthcare and HIV Funding

Accessing funding for healthcare and service delivery can be a complicated and gruelling task for many First Nations communities. Lavoie (2004) notes that First Nations are not equitably funded, compared to provincial services, when existing inequalities and the overall cost of service delivery are taken into account. Matiation (1999) argues that jurisdictional issues related to healthcare funding and delivery have been happening for decades. The issue of HIV/AIDS as an exceptional healthcare issue has significantly played into this. There have been exceptional policies in place at the provincial level to deal with HIV/AIDS, thus resulting in overall coordination and funding. However, at the federal level, there is no exceptional policy for Indigenous Peoples living with HIV/AIDS that would permit specific funding or service delivery for this health crisis. These jurisdictional difficulties have led to funding problems and barriers to coordination and collaboration for healthcare for Indigenous Peoples. Access to primary healthcare services in First Nations communities has been an ongoing problem, with communities relying heavily on secondary and tertiary healthcare services for many health

conditions within communities (Lavoie et al., 2007). This continues today with healthcare funding coming from a set sum of money given to communities when they sign agreements with the government. These funding requests are generally based on historical data and do not represent the ongoing or changing needs of a community (Lavoie, 2004; Minore & Katt, 2007). Lavoie et al. (2013) note, “[f]unding for health services is, however, calculated on the basis of the population actually served only in communities where services are provided by Nursing Stations. In all other communities, FNIHB funds communities for services delivered to registered Indians only” (pp. 5-6). Therefore, sub-populations on reserves, may not be receiving the same form of, and access to, care as others who are living in the same community.

There remain significant funding issues when evaluating the ability of First Nations to deliver healthcare services to their people. Significant issues were reported by the Auditor General of Canada Report of 2015, which found that Health Canada has not taken into account the actual health needs of remote First Nations communities when it is allocating its funding and supports (Office of the Auditor General of Canada, 2015). The report also found the federal government was not meeting its objective of providing comparable access to clinical and client care services as would be used by other residents living in the same province and with a similar geographic location. Health Canada must take into account the needs of First Nations communities when allocating services and funding, and the department must conduct an analysis of what comparable services are offered to similar residents not in First Nations communities (Office of the Auditor General of Canada, 2015). Additionally, Boyer et al. (2016) note that culturally appropriate healing services and healthcare delivery is in its infancy, on reserve, across the north, and in urban areas. Healthcare services that are provided on reserve



are severely underfunded and the primary player in advancing culturally competent care. The Aboriginal Healing Foundation, was defunded in 2014 (Boyer et al., 2016). This has been in addition to the defunding of the National Aboriginal Health Organisation in 2012. Under both organisations, justification for defunding was the need to protect monies that went directly to communities and their funded services. In the case of the National Aboriginal Health Organisation, it advocated for the advancement of health within First Nations, Métis and Inuit people through research, reports, databases, journals, and video footage of elders providing Indigenous teachings.

### Jurisdictional Issues

The federal government has recognized and affirmed its unique constitutional obligations to First Nations and Inuit Peoples. However, the federal government has never officially acknowledged it has a legal obligation to provide health services to First Nations peoples (Kelly, 2011). Instead, the federal government argues that it has a special relationship with the First peoples of this land and, through its unique constitutional relationship with them, it is committed to preserving that special relationship, and that means offering health services on reserves as a matter of goodwill (Kelly, 2011). However, many of the health policies and guidelines that affect Indigenous Peoples' health today are reminiscent of the wardship model of Crown/Indigenous relations (Boyer et al., 2016). As noted above, under Section 73 of the Indian Act, the federal government has the ability to enact regulations in relation to various areas of health for First Nation, but, at the same time, it does not provide any sufficient authority for the creation of a comprehensive health services framework on First Nations

reserves (Lavoie & Gervais, 2010). Overall, what is visible today is the federal government using the full weight of its constitutional powers over 'Indians' and accepting responsibility to provide and deliver healthcare services on reserves. This has also been extended to provide funding for cost-sharing programs with provinces for contracted services and other health care premiums for status Indians.

Provincial governments have responsibility for the delivery of almost all healthcare services in Canada. This division, as defined by the Canada Health Act (1985) denotes what access and services provinces are expected to maintain. Métis, off-reserve registered Indians, non-registered Indians, and Inuit living outside of their traditional territories fall under the purview of territorial and provincial governments. Beyond this, as Lavoie and Gervais (2010) note in their work, there are a number of provincially-developed Aboriginal-specific health policies and frameworks. In Ontario, the Aboriginal Health and Wellness Strategy in 1990, and later, the Aboriginal Health Policy in 1994, sought to provide direction to the provincial Ministry of Health in assisting with the bridging of the health gaps faced by First Nations people in the province. This is seen as one of the most comprehensive frameworks for Indigenous health in Canada. The framework also outlines the emergency procedures for an influenza pandemic and clarifies the roles of the Ontario Ministry of Health and Long-Term Care, First Nations and Inuit Health Branch, and First Nations communities in responding to such an emergency.

Jurisdictional issues are further exacerbated by provincially-supported programs, which provide limited access and funding for HIV services. In Ontario, the province has opted to support Indigenous HIV/AIDS initiatives through the establishment of the Aboriginal Health Office. The province indicated that it would not allow jurisdictional issues to compromise and

undermine the response to HIV/AIDS. The Ontario provincial AIDS Bureau accepts proposals related to HIV/AIDS healthcare initiatives from both on- and off-reserve Indigenous organisations. Such initiatives include the Ontario Aboriginal HIV/AIDS Strategy, which provides services to Indigenous Peoples both on- and off-reserve (Matiation, 1999). Additionally, some provinces have opted to create agreements with the federal government and First Nations for the delivery of healthcare services. These have been used as tools for clarifying jurisdiction issues, especially when communities have self-government agreements already in place (Lavoie & Gervais, 2010). Lavoie and Gervais (2010) note that “a number of intersecting federal, provincial, and territorial legislation, policies, and authorities with shifting and blurred responsibilities contribute to ambiguities and gaps” (p. 126). Healthcare delivery is a jurisdictional nightmare for many First Nations communities to navigate, and this is, in part, the reason why the federal government has promoted, and continues to promote, First Nations having control of their own health services as the preferred methods of fixing the inequalities that they currently face.

### Suppositions on Indigenous Health Policy

Policies related to Indigenous Peoples have meant horrendous outcomes across virtually every aspect of life. Historians refer to early government interventions as well-intended assimilatory policies, but we now know the reality is of a much darker picture (Palmater, 2014). For Lawrence and Dua (2005) the settler state is founded on extermination, displacement, or assimilation policies – all with the intent to make Indigenous Peoples disappear. In the case of Canada, the intended objective of Indian policies was to capture land and resources and at the

same time reduce any government obligation to Indigenous People (Palmater, 2014). The government did this by creating scalping laws, forced sterilisations, and residential school and cultural prohibitions through the Indian Act, all of which, Palmater (2014) argues, were clearly meant to eliminate, rather than assimilate, Indians. Today the status quo of colonial order still works to target Indigenous People and to place them in a category of legal and cultural extinction while at the same time taking their remaining land and resources (Lawrence & Dua, 2005). For Simpson (2011), Indian sovereignty is linked directly to settler governmental forms, charters, and philosophical systems which must be dismantled in order to be overcome. However, the Canadian government has worked to keep Indigenous Peoples busy trying to survive so that the government can avoid the issues of treaty implementation, self-determination, and addressing land and resources claims (Palmater, 2014).

The policies detailed above have attempted to transform over time from being assimilative in their intent and goal to being encouraging of First Nations having control and autonomy over their affairs, particularly when it comes to healthcare. The most recent policies concerning healthcare, starting in the 1970s, have been designed to transfer certain resources and control over to the communities. However, many communities have been and remain concerned that this action is merely the federal government acting in its own best interests (Kelly, 2011). The new emphasis on policies that aim to respect cultural identity while providing greater autonomy has brought the creation of frameworks that form institutions that are specially designed to address the unique needs of First Nations people. However, at the bases of these policies remains the Indian Act, and by extension, status. Furthermore, communities

remain tightly controlled when it comes to audits of their finances and programming, thereby limiting their actions and returning them to a paternalist structure.

By 1996, after the introduction of the Indian Health Transfer Policy, some 141 First Nations had assumed administrative responsibility for their healthcare services. Another 237 were involved in pre-transfer processes of gaining administrative responsibility either individually or collectively through multi-community agencies or tribal associations (Boyer, 2011). Today, almost three-quarters (599) of First Nations and Inuit communities have current agreements which present some form of self-determination related to the health of their people (Minore & Katt, 2007). However, there continues to be an unequal balance between communities and the federal government. There is an ongoing need for reciprocal accountability between all parties. Currently, transparency occurs only from a top-down approach, with communities entirely at the mercy of decision-makers who approve or reject their proposals and funding. The federal government has set up policies of accommodation, whereby it is viewed as bowing down to and supporting First Nations and Inuit communities when, in reality, it limits almost all autonomy communities have through stringent direction and accounting of all funding and programming. Instead, the goal should be a relationship where healthcare responsibilities are equally balanced and accountable. Only when historical assimilative policies, such as the Indian Act are removed, will there be community-based healthcare thriving in communities.

## Conclusion

Canada has a complex set of policies that give the federal government jurisdiction and authority for status First Nations and Inuit people and First Nations and Inuit communities. The Royal Proclamation confirmed that the Indigenous Peoples of Canada were never a conquered people. Through the execution of treaties, First Nations people negotiated health care benefits in exchange for land and other goods. However, with the creation of Canada and the BNA Act (1867), First Nations people and their land became the sole responsibility of the federal government, thus starting the struggle over jurisdiction in relation to healthcare. The enactment of the Indian Act saw the Canadian government set up extensive limitations on the lives of Indigenous Peoples across Canada. The Indian Act set forth who was an 'Indian' in Canada (through the use of status) and further limited the responsibilities of the federal government to Indigenous Peoples through the creation of the reserve system. However, after decades of oppressive colonial actions, the White Paper was a turning point for Healthcare discussions in Canada. First Nations leaders rejected the premise of the White Paper, which was to dismantle the Indian Act, along with the reserve and status systems. Instead, through the creation of the Red Paper, First Nations leaders made it known that healthcare fell under the purview of the federal government and that they expected to contribute in bringing about change to the health of their people. The Red Paper brought about the creation of the Indian Health Policy where, for the first time, there is a fundamental change in Indigenous Healthcare policy in Canada. The Indian Health Policy affirmed First Nations rights to have autonomy over the delivery of services to their people. The Indian Health Policy was the precursor to the creation of the Indian Health Transfer Policy, which finally put into action the creation of

community-led agreements that would allow single or collaborative groups of First Nations communities to be in charge of their own healthcare and delivery systems on their territory. At the same time, through the creation of the Canada Health Act, Health Canada was created. The department was set up and given authority to assist in the delivery of healthcare to First Nations in Canada. Health Canada subsequently established the First Nations and Inuit Health Branch and, under this new branch, delivers services on-reserve complementary to those offered off-reserve or, in the cases of remote communities, also offered primary healthcare services. The branch also established the Non-Insured Health Benefits program, to be used by all status First Nations people, regardless of whether they resided on reserve. In 2017, Indigenous Services Canada took over responsibility for First Nations health from Health Canada. This new ministry has an aim of delivering specialized service directly to Indigenous Peoples in a culturally competent way.

However, none of the policies explored in this chapter directly deal with the issue of HIV/AIDS in First Nations communities. Instead, First Nations Peoples face a labyrinth of inter-jurisdictional issues that piece together a healthcare framework for delivery services to First Nations Peoples across Canada. There is no policy to direct care, services, or funding to First Nations communities that are facing an HIV epidemic. This lack of policy can be tied back to a lack of policy action by the federal government. Furthermore, it is likely that non-exceptionalism of HIV/AIDS has worked to ensure that First Nations Peoples are not being prioritized for policy creation around an illness that is otherwise being deemed as exceptional. Could this also be a case of continued colonial inaction, with the federal government hoping that this problem will continue to spill into provincial jurisdiction? Overall, the choice to use

First Nations and Inuit Health Branch as the policy instrument to deliver healthcare services for First Nations people living with HIV/AIDS is entirely problematic given that they are still required to lump HIV/AIDS in with every other health issue they must oversee and scrutinize.

Therefore, it must be understood that, through the federal government, Indigenous Services Canada is responsible for internally deciding how and where funding and services are provided to First Nations in relation to HIV/AIDS. Until this point, the evidence shows that the system has been an uncoordinated, gruelling, and complicated jurisdictional mess for First Nations to navigate in trying to access funding for their healthcare needs. This continuation of policy making by Ottawa does not bode well for First Nations, as community policies with directed and coordinated funds to tackle the increase in HIV/AIDS diagnoses is the most practical and decolonizing approach that could be taken. Therefore, the continuation of bad policy formation along with inappropriate and ineffective policy instruments must stop and the federal government must make a concerted effort to recognize HIV/AIDS as an exceptional illness that needs to be addressed in a holistic and decolonial way.



## Chapter IV: Indigenous Knowledge and Methodologies

### Introduction

This chapter will highlight the understanding of Indigenous knowledges and worldviews. This understanding will underpin much of what is to come within this dissertation. The goal of this chapter is to show how this research forms a comprehensive Indigenous research paradigm, which Wilson (2008) refers to as research that is made up of Indigenous ontologies, epistemology, axiology, and methodology. In order to accomplish this, given the diversity of stories presented in the research, I present overarching notions of each of these and how they are incorporated into this work. Indigenous worldviews are critical to this process and to the understanding of how this research was conducted and how it is to be understood. Understanding Indigenous worldviews will allow for a discussion of how Indigenous Peoples, come to know and understand what happens around us. This will also set out the theoretical position for this dissertation.

Situating oneself within a specific context allows others to understand the worldview from which they come. This is important, so as to note the distinctive nature of Indigenous Peoples across this country and the individual histories and practices they have. Across the country we recognize Indigenous Peoples within three broad categories of First Nations, (status and non-status), Inuit, and Métis people (Government of Canada, 2014). Additionally, these broadly defined groups of people consist of smaller groups that associate by region/territory, language, cultural practices, etc. and each one of those groups “maintain unique heritages, languages, cultural practices and spiritual beliefs, as well as unique current and historical relationships with Canada” (Bartlett, Iwasaki, Gottlieb, Hall, & Mannell, 2007, pp. 2371-2372).

The research conducted for this dissertation focused on just one specific group of people, status First Nations Peoples coming from northern Ontario reserve communities. This research was conducted within a specific timeframe, and therefore it is essential to understand not only a person's worldview but to learn and understand the worldview of the people and communities in the time and place in which the research is conducted.

As a queer Mi'kmaw person, I come to this research with my own developing understandings and worldview, which was gained throughout my life – from stories as a young boy, my educational background, elders, mentors, living on the land, and many other experiences. Each person has a particular worldview, from which research will be conducted. Brannick and Coghlan (2007) argue that conducting 'insider research' (research which is completed by members of their own communities or people as opposed to outsiders) is taboo within academia. The dominant approach to research has been positivism, which has the view that there is an external reality in which an "independent, value-free researcher can examine this reality. In other words, they adhere to an objectivist (realist) ontology and an objectivist epistemology. Positivists adopt a methodological approach toward reflexivity and concentrate on improving methods and their application" (Brannick & Coghlan, 2007, p. 62). For Smith (2012) positivism seeks to apply views about how we can examine the natural world, which is the idea that coming to understand the world can somehow be equated to some form of measurement. As we become fixed on issues of measurement, the focus of our understanding becomes interconnected and more concerned with and about procedural problems and validity. Similarly, Wilson (2001) discusses how positivism and post-positivism have similar ontological foundation that there is only one true reality – and it is a researcher's job to explore

that reality. Unlike positivist epistemological frameworks which claim that researchers should be objective and neutral, Lavallée (2009) argues we need to come into research willing to discuss our individual views and biases. This allows researchers to be grounded by having an understanding of their biases and objectivity, to be open with the communities they are researching, and it allows for the growth of the researcher throughout the research process. For Wilson (2001), our systems of knowledge are built on and around the relationships that we have with people and objects, as well as the cosmos, the ideas, concepts and everything that is around us. Lavallée (2009) argues researchers are able to benefit from the research they conduct and are “inevitably affected by the research undertaken. For me, the research project became a tremendous learning journey that included growing spiritually, exploring my identity as an Aboriginal person, and receiving an indescribable amount of knowledge from the community” (2009, p. 26). As such, instead of locating oneself within the research to identify biases, Bastien (2005) and Lavallée (2009) argues that we do so in order to connect with community and to understand our own way of knowing which may differ from that of the community or peoples we are researching.

With this in mind, I begin by identifying myself and my relationship to this research. I am both of Mi'kmaw<sup>14</sup> and Settler blood. My nation, the Qualipu Mi'kmaq First Nation was recently ‘legally’ defined into existence and accepted as a full Nation under the Indian Act. Questions of identity and belonging continue to be problematized in communities within Western Newfoundland. With the creation of the Qalipu Band in 2009, founding membership was given

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<sup>14</sup> Mi'kmaw referring to the singular and Mi'kmaq referring to the larger group of people.

to some 10,000 individuals, including me. However, after 2009 some 120,000 applications were received for enrolment in this new band – leading the federal government to create a new enrolment process, sending all applications back for review. Through this process, new evaluation criteria were enacted, including the requirement that someone must live in an identified community or have substantial links to it. Through this process, I was deemed to not meet the criteria, as I had not lived in my community since 2006, when I moved to Ontario to pursue post-secondary education. This left my entire family maintaining their membership as founding members, however, I was denied. This took a significant toll of my own identity and connection with my community. All of these activities have meant the continued suppression of most cultural practices and traditions.

My family has always had a rich history of identifying as Mi'kmaw, however, derogatory terms such as 'jackatar' were used to suppress this identity, as no one wanted to be labelled as such. The term referred to a Newfoundlander who was of mixed French and 'Micmac'<sup>15</sup> Indian descent and was highlighted by the speech of people in the community. Jackatar's were known to mix English, French, and the Mi'kmaw words together when they spoke. The suppression of this rich culture has had an impact on my own way of knowing and gaining Indigenous knowledge.

Over the past decade, I have started to learn the way of my ancestors through my family and community. As I started to learn from Mi'kmaw elders, I found many of their underlying meanings were present in stories I had heard as a young child from older family members.

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<sup>15</sup> The term Mi'kmaq has been used interchangeably with the anglicized word Micmac throughout the east coast.

Growing up in rural Newfoundland, I always hunted, fished, picked berries, grew fruit and vegetables, and participated in community events. We lived in a community of sharing, whereby one member would always share their excess with family and friends, to ensure we all thrived, during what was a trying economic time in the province. These early experiences helped to solidify the way I have come to learn and know that reading a textbook or sitting in a lecture is only but one small aspect of the education I received.

### Indigenous Knowledge and Worldviews

Indigenous knowledge has flowed through our people and communities since the beginning of time. However, Indigenous voices and knowledges have historically been suppressed and forgotten. According to Wilson (2003), non-Indigenous Peoples became experts on Indigenous Peoples and these experts (anthropologists, physicians, psychologists, professors, etc.) all felt qualified to pass on their learning of Indigenous Peoples. This left Indigenous Peoples without a voice, with others only speaking of them and occasionally for them, thereby making the Indigenous voice unnecessary or even impossible to be heard (Wilson, 2003). However, it has only been in recent history that traditional knowledge, which has been used by our communities for centuries, has begun to be acknowledged, in however limited ways, within Western academia. Since the early 1990s Indigenous scholars and educators have been working to affirm and activate holistic paradigms of Indigenous Knowledge which have been systematically excluded from history through contemporary educational institutions and by Eurocentric knowledge systems (Battiste & Henderson, 2009). This acknowledgement of Indigenous knowledge has allowed for communities and researchers to more openly use traditional ecological knowledge to empower and support themselves

within mainstream academia (Simpson, 2001). For generations, policies such as the Indian Act banned virtually all forms of ceremony and knowledge sharing (Government of Canada, 1985b). Westernisation, the process of converting Indigenous Peoples' practices, traditions, laws, etc. to a European way of doing and being – or of imposing a European way of doing and being – has suppressed Indigenous knowledge as 'less than' or 'primitive' in comparison to Eurocentric knowledge and ways of knowing (Porsanger, 2004). For Kovach (2009) "the reproduction of colonial relationships persists inside institutional centres" (p.28) and this is manifested through western-based policies and practices that governs the research at Universities. Similarly, Battiste (2002) argues that few universities across Canada have made any attempt to make Indigenous education a priority, while often treating Indigenous knowledge as matter of multicultural or cross-cultural education as opposed to its own distinct knowledge system. Walker (2004) has argued that the power exerted by the dominant culture (coloniser) has allowed Western methods and concepts to become institutionalised and to be imposed forcefully upon Indigenous worldviews. In recent years, however, there has been an observable trend to create new ways of knowing within the academy (although these are not new within Indigenous communities), which favour moving away from western theories and methods to more traditional way(s) of gaining knowledge, done in a community based and engaged way.

This chapter will start with a cursory examination of what Indigenous knowledges are and how they are created, how/where do various Indigenous knowledges stand in comparison to non-Indigenous knowledge and its perception of Western ways of knowing. It will also include an overview of Indigenous worldviews and how Indigenous Peoples come to

understand and have the knowledge we acquire. This discussion will support the ontological, epistemological, and axiological views used in the creation of this research.

### Western and Indigenous Knowledge

Western research methodologies and ways of gaining knowledge have many similarities to Indigenous approaches to gaining knowledge. A significant difference is that western tools can be limiting and non-encompassing of the holistic worldview to which many Indigenous Peoples and communities adhere. “The Western paradigm for research articulates theory and scientific methods, which are chosen in order to explain a particular phenomenon and guarantee an objectivity of research, [...] in order to create a desired result” (McMutcheon, 1997 as cited in Porsanger, 2004, pp. 109-110). Surely, for Smith (2012) one cannot discuss research methodologies and Indigenous Peoples together without first addressing the ways in which our pursuit of knowledge is embedded in varying levels of imperialism and colonial practices. Through a western process of theorizing and scientific measurement, society has come to determine what is acceptable within the scientific field. This has resulted in the notion that research and its application must be natural or objective in all aspects of its existence. However, in recent decades there has been a rise in scholarship that aims to break down this linear construct, including both feminist and critical race theorists (Kovach, 2009; Smith, 2012).

Western research takes on a systematic process in order to be considered valid and objective. Knowledge, for Kovach (2009), when positioned from a positivist paradigm assumes “objective neutrality can exist with research so long as lurking variables are controlled” (p.32) and that with qualitative research is built upon an interpretative presumption which assumes

that subjectivity within research is consistent. Porsanger argues that this process happens whereby researchers will collect information about their subject, they then revise their accepted theories based on the new facts they have found, and then promote practical applications for the new or revised theories or laws they have created. Therefore, this rigorous systematic process works by implying “discovery, observation, collection, investigation, description, systematisation, analysis, synthesis, theorizing and codifying by means of the language of theory, comparison, verification, checking hypotheses, etc.” (Porsanger, 2004, p. 106). However, this type of systematic process may not always align with, or adhere to, an Indigenous framework, nor does it necessarily support the varying ways of Indigenous Peoples knowing and being (Chilisa, 2012; Kovach, 2009). In fact, according to Smith (2012), Indigenous Peoples have been, and continue to be, oppressed by theory. However, new ways of theorizing, especially by Indigenous scholars, are grounded in a clear sense of, and with sensitivity towards, what it means to be an Indigenous person.

Over the past several centuries, research has been used systematically to discover, evaluate and ‘other’ Indigenous Peoples and their lands. At the same time, colonialism has been used to bring disorder to Indigenous Peoples with the intent of disconnecting them from their histories, lands, languages, their traditional social relations, and most importantly their own way of thinking, feeling, and interacting with the world (Smith, 2012). Research has been, and continues to be, used as a tool of colonialism. Simons and Christopher (2013) argue that the decolonizing of research is becoming one of the most discussed issues in Indigenous research. This is especially true among the growing generation of Indigenous researchers and their peers who are seeking to explore topics related to Indigeneity. Quanchi (2004) likewise argues that



Indigenous leaders are scholars trying to combat the continued Eurocentric hegemony and to assert Indigenous wisdom within research and the academy. In recognizing the monopoly which Western knowledge has reserved for itself, it is important to understand that there is a new quest for a transdisciplinary balance between European and Indigenous ways of knowing. “This academic effort seeks to identify relations between the two generalized perspectives of Eurocentric modernism (and postmodernism), and Indigenous knowledge (and post-colonialism)” (Battiste, 2002, p. 10). Until recently, Indigenous approaches to theorizing have been denied by Western science because intrinsically Indigenous theories were being evaluated from Western academic knowledge and epistemology by scholars who were only exposed to these worldviews (Porsanger, 2004). In order for change to take place, greater knowledge, understanding, and research must take place both within and outside of the academy to find understanding and support for ways of knowing and understanding that go beyond Western worldviews.

### Background of Indigenous Knowledges

In order to examine the approach used for this research, it is vital to understand what Indigenous knowledges are out there and how we come to acquire these knowledges in a good way. However, we must recognize the colonial history of knowledge formation across Turtle Island.<sup>16</sup> In a colonial context, research and knowledge creation has been about power and domination over Indigenous Peoples (Smith, 2012). Henry and Pene (2001) argue there are philosophical debates which continue today regarding what knowledge is true or what is real,

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<sup>16</sup> Is an Indigenous reference to North America, often found within traditional oral stories.

where this knowledge can take place, whether it can take place across time and place, and how it can reflect both intellectual and political struggles. These debates are critical to understanding Indigenous knowledges because, by participating within them, we as Indigenous Peoples expand our own understanding of how Western ways of knowledge differ from our own. This assists in giving legitimacy and rigour to our own ways of knowing and being. We must also recognize the loss to Indigenous knowledges through colonisation. Indigenous knowledges have been subjected to narratives of being “less than” and colonial education has placed a positional superiority over knowledge within a western and imperial context (Smith, 2012). Battiste (2002) and Hart (2007b) argue that, while Indigenous knowledges are not readily recognized or respected within Western societies, they do in fact exist. Indigenous knowledges contribute to the overall wellbeing of both Indigenous nations and the population at large (Hart, 2007b). Battiste and Henderson (2000) also argue that given the diversity in knowledge systems, there is no short answer to being able to explain what Indigenous knowledges are as they each are grounded in their own distinct knowledge system. Hart (2007b) continues that while there are connections between Western and Indigenous knowledge systems, there are many variations between the methods, concepts, experiences, and values used and therefore, there are important and significant differences between the interpretations and applications of Indigenous knowledges. Furthermore, the gathering of Indigenous knowledges has not always been fair and equitable, nor has it always been done to the benefit of the communities who have participated. The fundamental use and understanding of Indigenous knowledges and knowledge systems along with culturally appropriate methods will assist in protecting against the many abuses and misuses that occurred in the past and continue to occur in the present. It

is therefore “essential to establishing a balanced, consent-based system for sharing Indigenous knowledge” (Brascoupé & Mann, 2001, p. 20).

There are a number of authors (Battiste & Henderson, 2000; Hart, 2010; Kenny, Faries, Fiske, & Voyageur, 2004) who argue that there is no consensus about the nature of knowledge. In fact, Battiste and Henderson (2000) state that “attempting to define Indigenous knowledge is inappropriate because such efforts are about comparing knowledges and that there are no methodologies existing to make such comparisons” (as cited in Hart, 2010, p. 4). It is argued that instead of defining any one Indigenous knowledge, it is more important to understand the process of gaining knowledge. In order to understand a particular knowledge, inquirers must be open to accepting different realities, no matter how it is seen from their own view or perspective (Hart, 2010).

Additionally, to understand what an Indigenous knowledge is, it is first vital to understand that knowledge not a singular concept. There is no one pan-Indigenous knowledge system or way of knowing. “No single Indigenous experience dominates other perspectives, no one heritage informs it, and no two heritages produce the same knowledge” (Battiste, 2002, p. 28). Similarly, “it is important to note that an umbrella Aboriginal worldview does not exist and that pan-Indigenous references should only be seen as stepping stones in Indigenous Peoples’ progress” (Hart, 2007a, pp. 83-84). Therefore, the arguments to follow should be viewed within a particular context and the fact that they will be presented using a variety of different worldviews and ways of coming to know Indigenous knowledge. This section will be informed by my own ways of knowing, which have been developed through my teachings and understanding of Mi’kmaq ways of knowing, but those much more broadly through the

experiences to which I have been exposed through my studies, research work, and interactions I have had with Indigenous communities from across Canada. It is vital to understand that no one way of knowing is more important, or correct, than another but this section will be curated by varying perspectives that have become known to me through these experiences.

### Definition of Indigenous Knowledge(s)

Throughout this section, a variety of perspectives of Indigenous knowledge, which have been acquired from around the world, will be presented. These understandings have created a grounding for how I have approached this research and the research questions. Kurtz (2013) argues that Indigenous knowledge spans across cultures, histories and geographical spaces that are beyond the physical work and strongly centred in the spiritual. With this in mind, all of the perspectives presented are valid and they will be drawn upon in order to form a final understanding of Indigenous knowledge.

The ways in which we come to know are central aspects of this research and what led to the use of the storytelling method (to be described later). It is critical that the storytelling process frame the storytellers' understanding of ceremony, their relation to the world, and that it places their stories within the context of time and place. For Battiste (2010) learning as Indigenous Peoples is "holistic, lifelong, purposeful, experiential, communal, spiritual, and learned within a language and a culture" (p.15). What guides the learning of Indigenous Peoples is our spirit that guides us as we walk along the earth (Battiste, 2010). Martin and Mirraboopa (2003) argue that ways of knowing are directly related to the entities of "Land, Animals, Plants, Waterways, Skies, Climate and Spiritual systems of Aboriginal groups" (p. 9). These entities are learned and reproduced through various processes, such as: listening, sensing, viewing,

reviewing, reading, watching, waiting, observing, exchanging, sharing, conceptualizing, assessing, modelling, engaging, and applying. In addition, any way of knowing expands and contracts according to “social, political, historical and spatial dimensions of individuals, the group and interactions with outsiders” (Martin & Mirraboopa, 2003, p. 9). The learning takes place within a specific context and process as well as within a certain time, which all affect the knowledge gained (Martin & Mirraboopa, 2003). Similarly, Battiste (2002) articulates Indigenous knowledge as inherently tied to the land; in particular “landscapes, landforms, and biomes where ceremonies are properly held, stories properly recited, medicines properly gathered, and transfers of knowledge properly authenticated” (p. 13). This knowledge is passed from generation to generation through the structure of Indigenous languages, through modelling, practice, and animation, instead of by written word. For Kovach (2010) “Indigenous knowledges comprise a specific way of knowing based upon oral tradition of sharing knowledge” (p. 40). Battiste (2002) argues that complete and accurate transmission of knowledge depends not only on ceremonies but also on maintaining the integrity of the land itself. In Canada, Battiste (2002) argues the government treats ceremony as art rather than science. Both views of Indigenous knowledge contribute a solid foundation to the understanding of what it is and how it is gained. Indigenous knowledges are grounded within the land, ceremony and culture of Indigenous Peoples and are gained through a variety of processes, and are affected by the specific social, political and historical contexts of the participant and his community. This will ground the research method used within this research. The following discussion will build upon this understanding, in order to create a more complete understanding.

Brascoupé and Mann (2001) have argued that there are thousands of knowledge systems in existence. They define Indigenous knowledges as “an ancient, communal, holistic and spiritual knowledge that encompasses every aspect of human existence” (Brascoupé & Mann, 2001, p. 3). They state that there should be an emphasis on wisdom rather than on knowledge as understood within a western context. Furthermore, Indigenous knowledge must be understood from a spiritual realm, as knowledge cannot and should not be separated from the spiritual aspect of life. Bartlett et al. (2007) argue that Indigenous knowledge begins with narratives (stories and/or myths) “that must be experienced before one can be said to have truly gained personalized or experiential knowledge” (p. 2375). This understanding is in contrast to the grounding of Western knowledge of facts and data, which are then synthesized into abstract information. From an Indigenous perspective, knowledge is grounded in community, and thus it is crucial within Indigenous research that it should remain that way (Bartlett et al., 2007).

Hart (2010) also discusses Indigenous knowledge from a variety of perspectives. This ranges from people’s interaction with nature within a common territory to “the established knowledge of Indigenous nations, their worldviews, and the customs and traditions that direct them” (Hart, 2010, p. 3). Indigenous characteristics of knowledge are identified as “personal, oral, experiential, holistic, and conveyed in narrative or metaphorical language” (Hart, 2010, p. 3). Maurial (1999) identified three characteristics of Indigenous knowledge: local, holistic, and oral (as cited in Hart, 2010). Therefore, spiritual and holistic ways of knowing are critical to Indigenous knowledge. The idea of a holistic approach to knowledge will be discussed later in this section, but it is a vital part of understanding Indigenous knowledge systems.

Ceremony plays a significant role in the creation and dissemination of knowledge. For Wilson (2008), when Indigenous Peoples do research, we are doing ceremony, that allows for a raised level of consciousness and provide new insight into our world. Ceremony is also at the foundation of the participant-based research method used in this dissertation. Lavallée (2009) argues that Indigenous epistemology seeks to acknowledge how there is an interconnectedness between the physical, mental, emotional, and spiritual aspects of all individuals. Further, this interconnectedness is associated with all living things as it is with the earth, star world, and universe. Lavallée (2009) continues that many ways of knowing rely on both the physical and nonphysical realms and that we must accept the fact that nonphysical reality cannot always be quantified. Brant-Castellano (2000) argues that Indigenous knowledge encompasses three processes: “empirical observation, traditional teachings, and revelation (spiritual)” (as cited in Lavallée, 2009, p. 22). However, empirical observation cannot be based on a controlled setting, but instead, Indigenous knowledge is a representation of varying perspectives that come from the different vantage points of a person over time that happen in real-life-situations and settings (Lavallée, 2009). Lavallée (2009) similarly argues that Indigenous knowledge is passed on through familial and community generations. Knowledge can be acquired through various revelations, including: “dreams, visions, and intuition, [which] is sometimes regarded as spiritual knowledge,” where this knowledge is understood to be coming from the spirit world and our ancestors (Lavallée, 2009, pp. 22-23). Spiritual knowledge is not a commodity that can be observed by physical means and, as a result, we cannot measure or quantify it, thus often leading to its dismissal by Western researchers. Additionally, no single way of knowing is seen

as more important than any other, but all ways are seen to be equally valid and interconnected (Lavallée, 2009).

Hart draws upon Battiste and Henderson (2000) in discussing the changing ecosystem and how this can be seen as the ultimate source of knowledge. “Indigenous knowledge lies in the vibrant relationship between the people, their ecosystem, and the other living beings and spirits that share the land” (Hart, 2007b, p. 85). Knowledge can be developed through our attempts to understand the relationships within our local ecosystems. Therefore, when we discuss Indigenous ways of coming to know about the world, they are directly related to the space, place and time in which they happen (Hart, 2007b). The ecosystem is the key to a holistic base for Indigenous knowledge. Knowledge is argued to be holistic, which encompasses the personal, social, and is all highly dependent upon the local ecosystem. Therefore, this holistic perspective is larger than any one person or area, but it is also intimately linked to matters of spirit (Hart, 2007b). Spiritual ceremonies are significant, if not vital, pathways to gaining, demonstrating, sharing, and/or respecting knowledge. These ceremonies are what create a direct and dependent link between knowledge and the earth (Hart, 2007b). Kenny et al. (2004) also argue that any true Indigenous framework for research will only be legitimate if it employs a holistic attitude to which it subscribed. Battiste (2002) argues that Indigenous academics must activate the holistic paradigm of Indigenous knowledge in order to reveal the wealth and richness of languages, worldviews, teachings, and experience. Therefore, using a holistic base, Indigenous knowledge is not separated into disciplines, but instead systems like religion, philosophy, art, physical sciences, and social sciences, and all are looked at and addressed together (Hart, 2007b). Understanding of the world comes from seeing these as mutually



dependent upon one another, and therefore, it would be irrational and damaging to divide them. “Knowledge is developed on a personal level through subjective reflection and participating in ceremonial and stage-based processes” (Hart, 2007b, p. 84). Therefore, we gain our knowledge through our experiences, senses and instincts. From a social level, we see knowledge being localized and based upon the current environment and situations that are encountered by the learners present (Hart, 2007b).

### Discussion of Indigenous Knowledge

Indigenous knowledge holds identifiable characteristics and processes that have come from our ways of knowing, including connection to the land and our spiritual systems, the processes through which we learn through listening, viewing, sharing, and engaging with one another, and how we ground our understanding based on the timing and environments of the particular experience. Some of these processes are similar to European ways of knowing. However, there are many distinctions and there is a need for those distinctions to be recognized, developed, and supported (Hart, 2007b). Agrawal (2002) argues that there was an initial attempt to underline the difference between Indigenous and scientific knowledge along with a variety of methodology and contextual criteria. However, most academics have now come to accept that there is no simple or realistic way to do this. Indigenous knowledges and ways of knowing are continuing to gain momentum within the academy and are becoming more accepted within mainstream academia, where they are used alongside Western ways of knowing in a framework, which is becoming widely used, known as “two-eyed seeing.”

The notion of two-eyed seeing was coined by Albert Marshall, a Mi’kmaq elder, many years ago, as a guiding principle of Mi’kmaq knowledge. Bartlett, Marshall, Marshall, & Iwama

note: “Two-Eyed Seeing adamantly, respectfully, and passionately asks that we bring together our different ways of knowing to motivate people, Aboriginal and non-Aboriginal alike” (as cited in Martin, 2012, p. 21). Within this framework, Indigenous knowledge and western sciences are able to interact allowing for an opportunity to learn diverse ways of understanding the world (Martin, 2012). However, Battiste (2002) notes the blending of Indigenous knowledge with Western knowledge raises continuing issues of the extent to which each knowledge is validated and accepted. The use of two-eyed seeing has become normalized within research today and is widely discussed in the context of Indigenous research. The use of two-eyed seeing is not being framed within this dissertation. This is not as a result of its construction or grounding, but rather of my own personal concerns about its wide-spread use. There are ongoing controversies within Indigenous communities about the widespread use of the approach by non-Indigenous scholars who are using the two-eyed seeing approach to circumvent real, sustained, and ethical engagement with Indigenous communities. This research has taken a deliberate approach of engaging with Indigenous communities, through the creation of the project and its research questions, to what methods were used, how participants were recruited and how we analysed the results and wrote the recommendations which are to be found within. It is my contention that there has been a co-opting of the two-eyed seeing approach by non-Indigenous scholars as a way to frame their research as Indigenous-ish, while lacking real connection to communities and Indigenous ways of knowing and being. I have found there is ongoing emphasis being placed on this framework, but it is being done in a way that only reinforces colonial and western academic attitudes. I contend, by using two-eyed seeing, there is a real and present danger of not recognizing Indigenous research knowledge

and methods as valid. Instead, by using this approach, it gives the view of Indigenous methods and ways of knowing as needing to be supported and backed-up by Western methods. As a scholar, I have rejected both notions. Some published scholarship has used a two-eyed seeing approach but has placed western theories and/or methods before that of the Indigenous ways of knowing and methods and, by giving such prominence to the western theory and method, has implied a greater validity to them than to the Indigenous methods. Therefore, this research seeks to move away from such frameworks, which seek to bolster Indigenous knowledge with western knowledge, and instead allow it to stand on its own merits.

Throughout this section, it has been argued that Indigenous knowledges do exist, however there is no short answer to explaining, in any concise form, what they comprise. The process of gaining Indigenous knowledge is understood to be more critical to this research than the ability to define it outright. As such, the spiritual and holistic ways of knowing are vital to understanding Indigenous knowledge. Knowledge has been said to be holistic, encompassing the personal and social, and is highly dependent upon the local ecosystem. The holistic perspective is intimately linked to matters of the spirit. As such, ceremony plays a significant role in the creation and dissemination of knowledge. Therefore, it makes sense to look at knowledge from the three ways of knowing: through empirical observation, traditional teachings, and spiritually. Thus, using a holistic base, Indigenous knowledge will not be separated into disciplines familiar to Western pedagogy (e.g. art, physical sciences, etc.) but will be addressed together in a culturally appropriate way.

## Worldviews

Throughout this chapter thus far, the discussion of worldviews has been mentioned only passively. This was purposeful, as this discussion relates to the next chapter, which addresses the approaches and methods used within this research. Walker (2004) discusses worldviews as the deeper level of culture, the beliefs and values that shape all behaviour. Worldview is the “underlying, hidden level of culture ... a set of unspoken, implicit rules of behaviour and thought that controls everything we do” (Walker, 2004, p. 528). Similarly, Hart (2010) discusses worldviews as mental lenses that are entrenched ways of perceiving the world. “Worldviews are cognitive, perceptual, and affective maps that people continuously use to make sense of the social landscape and to find their ways to whatever goals they seek” (Hart, 2010, p. 2). Worldviews develop through socialisation and social interaction over a person’s lifetime (Hart, 2010). Hart (2010) also argues that there appear to be many commonalities between various Indigenous worldviews, because of the close relationship many peoples have with the environment. Worldviews are critical to an individual’s understanding of time and place, but researchers must not only be aware of their own worldview but also of the various worldviews of the participants who are partaking in the research. Simpson (2000) provides an outline of the seven principles of Indigenous worldviews:

First, knowledge is holistic, cyclic, and dependent upon relationships and connections to living and non-living beings and entities. Second, there are many truths, and these truths are dependent upon individual experiences. Third, everything is alive. Fourth, all things are equal. Fifth, the land is sacred. Sixth, the relationship between people and the spiritual world is important. Seventh, human beings are least important in the world (as cited in Hart, 2010, p. 3).

The ecological worldview discussed by Kenny et al. (2004), says that Indigenous Peoples thought of the Earth and their life on it as an interconnected web of life, which is a complex

functioning ecosystem of relationships. Kenny et al. (2004) argue that knowledge is not meant to be a description of reality but instead an understanding of the processes of change within ecology (e.g., insights about diverse patterns or styles of flux taking place). We cannot look at life as static but as something, which is always changing, and in flux. If we see things as permanent, it is to see things in a confused way. Therefore, an alternative, according to (Kenny et al., 2004), is to create harmonies of interdependence through all the various alliances and relationships amongst all forms and forces within the work. Having this web of interdependence, will create a never-ending source of wonder by Indigenous minds and by others who contribute to the harmony. An Indigenous worldview acknowledges the complexities of a holistic, interconnected life and embraces change.

Indigenous worldviews differ from Western worldviews in a number of ways. Walker (2004) states that western worldviews include: “a unilinear, present-centered conception of time; an analytic rather than holistic conception of epistemology; a human-over-human conception of human relations; and a human-over-nature conception of relations to nature” (p. 529). Indigenous worldviews, on the other hand, would include a circular conception of time along with being holistic in their epistemology, be non-hierarchical, have shared-power within human relations; and believe that humans are responsible for caring for nature. It is essential to be cognizant of the differences in these worldviews and how they are approached and understood within the research context. It applies heavily within this research context through the relationships gained through the community-engaged nature of the research. It grounds the notion of equality between the researcher, community, and participants – which is to allow for not just an equal voice for all but to give a greater voice to the participants and communities.

## Methodological Approaches

This section will discuss the use of a number of methodological approaches as well as their context to Indigenous research. It is important to note; these methods are not labelled qualitative. As Kovach (2009) argues, Indigenous methodologies can be considered from a qualitative approach or not. However, Indigenous methodologies are guided by Indigenous epistemologies and knowledge, whereas western methods are not. Therefore, this research will not be using the traditional Western approaches to research. Increasingly, Indigenous researchers reject the notion of contextualizing Indigenous methods under the headings of qualitative, quantitative, and mixed methods. Lavallée argues it is important that our Indigenous way of knowing “resist being categorized under Western concepts, including qualitative inquiry. Indigenous research is not qualitative inquiry; however, the methods used may be qualitative. Indigenous approaches or research frameworks encompass far more than just the methods. An Indigenous approach is an epistemology” (2009, pp. 36-37). Lavallée notes that although a method may be qualitative in nature, it can also have quantitative aspects and not fit within a western understanding of a research method. This is an important point that should not be overlooked. Indigenous research is about moving away from colonial practices and ways of knowing. Kenny et al. (2004) have also argued that there is a slant to qualitative data within Indigenous communities. However, there is also a need for quantitative analysis as this provides much-needed information for communities, their leaders and funders. The combination of both quantitative and qualitative methods produces results, which can provide a holistic picture of the research context, which is an important aspect of Indigenous research and why it is discussed here.

The problem with qualitative research within a modern context is the assumption that the researcher and the research can and should be objective and neutral. Lavallée (2009) however argues, “Indigenous research is not objective, nor does it see itself as unbiased” (p.23). She argued that there is no possible way that research can be objective, as individuals are interconnected with everything they do and influence and/or are influenced by their experiences. Therefore, researchers conducting research will be connected to the ideas, locations, and individuals being researched (Lavallée, 2009). Having this connection is an important aspect to both recognize and understand. From its core, research has developed to be a specific western-based way of approaching the empirical world. Kenny et al. (2004) argue that qualitative research is appropriate for research because it reveals the identities and stories of the people and the meaning behind those stories, which empowers the participants and community. They continue that this process can be decolonizing because it gives back the power to the population who are taking part in the research. Qualitative research methods from a Western perspective, such as interviews, focus groups, and participant observation “are relevant to the oral traditions and personal interactions in the Native [sic] community” (Kenny et al., 2004, p. 19). Qualitative research seeks to understand ‘how’ things happen and not only ‘what’ happens (Kenny et al., 2004), and approaches such as thick description are set up with the deliberate intent to provide a foundation for further examination. However, qualitative research can be very time consuming and labour intensive when it comes to analysis, transcripts, coding, etc. Overall, qualitative research can be used within Indigenous research and can be used in conjunction with Indigenous approaches to research in order to create a holistic approach to the research question. However, I think it is critical for researchers to

exhaustively review existing Indigenous methods and ways of knowing first, to see how a traditional method may already exist to answer their questions before jumping to a Western method.

Quantitative research has benefits for many Indigenous communities. Many Indigenous communities rely on the 'hard' data received from quantitative methods in order to assist them in understanding their community better, to show empirical evidence of change to funders and others. However, there are also numerous drawbacks to quantitative methods. "Although quantitative research provides the framework and facts, the gathering of information through survey forms has not always resulted in an in-depth understanding of the issues" (Kenny et al., 2004, p. 12). Quantitative methods tend not to consider the life or worldview of a particular individual or community in the collection of data, thus limiting their holistic capabilities. Additionally, significant sampling numbers are generally required for data collection, which can be difficult to achieve as community sample sizes tend to be small. Therefore, making generalisations across large groups of people as diverse as Indigenous Peoples is a difficult task that can be easily critiqued, and it increases the chances of damaging a community or larger group of people.

Mixed methods is research that includes both quantitative and qualitative methods. Using multiple methods with a variety of capabilities allows a researcher to gain a fuller understanding of the research question(s) being explored. The method allows one method to compensate for the weakness of another. "Many Aboriginal people are suspicious of just becoming another number in a statistical study out of context from their lives and communities" (Kenny et al., 2004, pp. 32-33). When a mixed method approach is used, it has



the ability to fulfil the needs of the research by taking into account context that may not otherwise be present. This is especially true when research is accompanied by stories of Indigenous Peoples lives (Kenny et al., 2004). There is a substantial advantage, when coming up with a research design, to using this approach, as it has the ability to gain greater knowledge and benefit for a community.

### Holistic Research

In order to bring this dissertation research to fruition, taking a holistic approach was required. Taking a holistic approach is critical given both my own understanding of approaches to conducting health research but also given the incorporation of Indigenous methods and ceremony. I also determined this was required given the subject matter of this research around participants who are living with HIV/AIDS. “Indigenous knowledge is both empirical (this is, based on experience) and normative (this is, based on social values). It embraces both the circumstances people find themselves in and their beliefs about those circumstances” (Battiste, 2002, p. 19). Different groups understand holism differently, however its overarching theme is that there is a need for the research to take on an integrated approach that seeks to address the human relationships and practices within both the social and physical ecology. Therefore, holistic research can use a wide range of varying methods for both the collection and analysis of data (Kenny et al., 2004). In particular, a holistic approach is useful for health and social justice research, and taking a holistic approach when it comes to policy research is central because when we evaluate the consequences of social issues, health issues, and the public policies attached to them, we experience them as interconnected. Kenny et al. argue that “this balance

of relationships can neither be revealed by a fragmented research approach nor best served by fragmented policies that seek to address singular aspects of individuals' lives or community processes" (2004, p. 15). Policy research generally does not analyse an issue from a holistic perspective. However, a study that conducted a policy analysis using a holistic approach showed that using such an approach allowed the researchers to collect data using a variety of methods, while also understanding the issue from a variety of perspectives and being able to make policy recommendations that were directly taken from the community (Kenny et al., 2004). Therefore, within this research it is a priority to ensure a holistic approach is used as a way to gain knowledge from each of the participants and to understand the circumstances of each of their lives and communities from which they come. This research also seeks to use a modified framework, viewing policies from a macro, meso, and micro frame while at the same time reviewing them from their inherent colonial base.

Generally, researchers have struggled to gain access to data from government agencies and departments. Since 1985, Canadians have had somewhat better access to government information via the *Access to Information Act (R.S.C., 1985, c. A-1)*. However, this access still remains limited, as it took more than 12 months past the legislated deadline to receive the ministry responses to the access requests contained in this paper. Given the past secrecy of government actions, Freedom Of Information requests (FOIs) can now be used as "an important lever when dealing with the traditionally secretive agencies of the public sector" (Brown, 2009, p. 88). Savage and Hyde (2012) argue FOIs are a powerful tool for social science researchers, even though they are more typically used by investigative journalists. Walby and Larsen (2011) argue that the use of FOIs is often overlooked as a research tool for useful data production.

They argue that the entire premise of Freedom Of Information laws “is that citizens can request information that has not previously been made a matter of the public record and that requests of this kind facilitate information access in a participatory and democratic manner and reinforce government accountability” (Walby & Larsen, 2011, p. 31). While data garnered from FOIs may not be complete, information is made available that can provide substantial context to research questions. However, FOIs can only be helpful when the research questions are appropriate for this type of data collection, as they are meant to complement research designs not be the primary focus of them (Savage & Hyde, 2012).

Further to this discussion is the meanings and implications of conducting community-based research. Kenny et al argue that “a community approach is reasonable given the tribal nature of Indigenous communities, and that an understanding of this reasoning can help guide the research process. Community members are empowered with rights and responsibilities” (2004, p. 22). The approach is vital to identifying, examining, and resolving current issues within communities. However, it could also be argued that, by taking on a holistic Indigenous worldview this would inherently take place, and therefore, placing the title of community-based or engaged research on research is unnecessary as this should already have been taken into account. “A decolonizing framework and methodology, that privileges Indigenous ways of learning/ knowing, brings increased efficiency and effectiveness to the research process, including the process of collective data analysis” (Bartlett et al., 2007, p. 2375). For this research, a decolonizing framework was about understanding the needs and wants of the communities I was working with, and ensuring that they had a prominent say in all aspects of the research, from start to finish, whenever possible. It was interweaving ceremony through

the research process, and giving agency to participants in every way possible, including having their stories published in whole. When completing research of this nature, it is vital for researchers to understand the community in which they are entering – understanding the people, history, culture and political climate of the community – as all of these will affect and influence the results of the research they are conducting. This was more difficult for me, as a researcher coming from a Mi'kmaq community and working with agencies that served First Nations people from across Ontario. However, I had conducted research in this area before, and I extensively relied on my community partners who had staff imbedded in all of the areas in which research was conducted to guide me through local understandings and customs before I met with participants. Additionally, I also felt a personal connection with many participants and the community organisations as a gay man, relating to the issue of HIV/AIDS and the shared history of colonisation we had all faced in varying ways. Therefore, through this process all of these aspects are integrated throughout this research project.

Storytelling, as a method, is similar to the Western concept of narrative inquiry. The goal of storytelling is to gain knowledge through an individual's oral story. It is predicated on the importance of the story. The importance of storytelling is the "validation of 'story' as a critical component of personal experience methodology" and is, therefore "valid within the context of undertaking research with Aboriginal peoples because it provides people with the opportunity to engage in an oral tradition compatible with their Aboriginal traditions" (Saini, 2012, p. 17). Storytelling encourages a researcher to go out and gather stories in a respectful manner. The researcher should then turn these stories into a text that can be analysed, shared, and archived (Kenny et al., 2004, p. 28).

There is an importance to storytelling as it “is connected to our Homelands and is crucial to the cultural and political resurgence of Indigenous nations” (Cornetassel., Chaw-win-is., & T’lakwadzi., 2009, p. 137). storytelling is not something that can be observed from a distance, but it is about peeling back the layers of a life to gain the teachings and learnings Indigenous Peoples have (Ornelas, 2014). For Kovach (2009) “Stories remind us of who we are and of our belonging. Stories hold within them knowledges while simultaneously signifying relationships” (p. 94). Saini (2012) argues storytelling is an effective mechanism for capturing Indigenous ways as it is the traditional way oral societies passed on their knowledge. Storytelling is an Indigenous method that takes on a cultural role involving medicines, the spirits, and reflection, to create the story and its process. “Research participants become involved in the process of collaboration, of mutual storytelling and re-storying as the research proceeds...a relationship in which both stories are heard” (Bishop, 1999, p. 6). Storytelling, as a method, is a collaborative process that acknowledges the researcher is also in the position of being a participant within this process of storying and then re-storying – the process by which the narrative is actually created.

The use of storytelling was necessary in order to ensure ceremony could be conducted one-on-one with each participant. Ceremony within this research consisted of the use of tobacco, prayer, smudging, and sharing of stories – participants had the option of being involved with some or all of these aspects, with some not wanting to take part in any. It was determined early in the research with my community partners that ceremony was an important part of the healing process for Indigenous Peoples who are living with HIV/AIDS and therefore necessary in order to record their lived experience in a good way. Using this method allowed

participants to discuss what is happening within their community related to the HIV/AIDS epidemic and what policy recommendations they would offer to improve the situation. Kenny et al. (2004) note the use of storytelling was recently completed in a research study and allowed for the stories to be analysed for their values, themes, secondary themes and implied themes, and importantly, their policy recommendations. This form of inquiry also provides for an appropriate research method due to the context in which the stories are given - which is often a more natural mode of communication for participants (Kenny et al., 2004). From the study used by Kenney et al., in that particular analysis, there were sixty-three policy recommendation collected from the data, allowing the research team to then be able to condense them into one primary overarching recommendation that was decided with, and agreed upon by, the communities involved (Kenny et al., 2004). This process of storytelling takes on many of the objectives and characteristics sought for this research, is deemed to be culturally-appropriate, and was feasible given the community connections and funding provided for completion of this research project.

## Chapter V: Research Methods

### Overview

This chapter will speak to the methods used within the research project. This will start by explaining the ethical approval used for this research. It will be followed by a detailed description of the recruitment process. This section finally highlights the four methods used for data collection and analysis. That includes discussion of Freedom of Information Requests, demographic surveys, storytelling, and the process by which the storytelling was coded using a software program and embedded within an understanding of Indigenous ways of knowing and being.

To the extent possible, this research was conducted with, and alongside, 2-Spirited People of the First Nation (2-Spirits) and the Ontario Aboriginal HIV/AIDS Strategy (OAHAS). It was essential to be respectful of, and to use positively, the knowledge conveyed to me by the participants to assist in giving agency to their stories. The first stage of this research project involved a detailed literature review of the subject area, which has been previously discussed and described. Second, an extensive analysis of government policy that affects First Nations healthcare and funding from both federal and provincial levels of government was conducted. Included in this policy review was determining which level of government is responsible for healthcare delivery/funding, how health care is delivered/funded, and by whom it is delivered. The review of literature and the policy review assisted in answering the first three sub-questions posed within this research (listed in the section below) by providing the necessary information to determine the policies currently in place that allowed for the determination of

what role each level of government has in service delivery and funding for First Nations people living with HIV/AIDS.

In the next phase, given ethical and logistical concerns about recruiting HIV-positive people directly from First Nations communities, participants who had been diagnosed with HIV/AIDS had left their First Nations, and were now in urban centres, were sought for participation. Data were obtained through use of a Storytelling method. The data sought were about the impact of HIV/AIDS on the participants' lives while living within their First Nation community and whether there are any mitigating factors related to their HIV status that led them to leave their community to come to an urban centre. These data were then transcribed and coded via the software program NVivo. This aspect of the research assisted in answering the last two sub-questions.

### Research Questions

This study will explore the policies and funding arrangements for HIV/AIDS prevention and treatment in First Nations communities. Particular attention will be given to the origin of funding/services, how those services are utilized, and the specific role the federal and provincial levels of government play in the funding and delivery of services.



The central question to be answered is: How and to what extent does policy have an impact upon funding and/or service delivery for people living with HIV/AIDS in remote First Nations communities in Ontario, Canada?

The research sub-questions to be explored are as follows:

1. What policies are in place that affect First Nations health care?
2. How much funding for HIV/AIDS treatment/policy/services do communities receive? Where does this funding come from?
3. How and to what extent does funding and/or service delivery affect people living with HIV/AIDS?
4. What processes/actions can be taken by the federal/provincial governments and First Nations communities to re-evaluate current practices of funding and service delivery to improve any inefficiencies that may be found?

## Ethics

Before any participant-based research began, I consulted extensively with OAHAS and 2-Spirits in relation to the research questions, methods, and ethics. After their approval, an application was made in October 2015, to the Ryerson University Research Ethics Board (REB) for approval to conduct research with human participants (see Appendix 1). Research ethics approval was received in November 2015. The entire research process was done following Chapter 9 of the Tri-Council Policy Statement and Ownership, Control, Access, and Possession Principles. The chapter dictates that researchers are to engage with individuals and communities when conducting research involving First Nations, Inuit and Métis peoples. Additionally, communities are to have a role in shaping the research projects that affect them so as to conserve, reclaim, and develop knowledge which is specific and of benefit to them (Government of Canada, 2018d). The policy has three overarching principles: Respect for

persons through ensuring free, informed, and ongoing consent of all participants and communities; Concern for the welfare of participants' physical, social, economic, and cultural environments and for the community; and Justice which ensures researchers understand the power imbalance at play in research and to take steps to ensure no harm is done (Government of Canada, 2018d). For this research, community partnerships were entered into with 2-Spirited People of the First Nation and the Ontario Aboriginal HIV/AIDS Strategy. These community partnerships officially entered into formal research agreements during a meeting in September 2015 (see Appendix 2). These partnerships were for a duration up to and including Jan 1, 2018. The Executive Directors (ED) of my community partners were the co-researchers who assisted in designing the research questions and methods that were used within this project. However, two years into the project during the data collection phase both organisations lost their EDs. Throughout the remaining research, and specifically within the data collection phase, the community partners (through their Board of Directors, EDs, and/or staff) were continuously engaged, to ensure the research was done in an ethical and appropriate manner, and in a way that will be beneficial to their communities.

Community partners were informed of how data was to be collected, stored, and disseminated, and were assured of the confidentiality of the data and protection of the participants. Due to the inherent risks in recruiting participants from a local community, collaboration with Indigenous HIV/AIDS organisations was undertaken to recruit participants for this project. The most significant risk that limited recruitment was concern that, as a researcher going into small communities, I could be easily identified as a researcher, and community members could easily identify my area of research. Therefore, there was concern that anyone

seen meeting with me would be assumed to be HIV-positive. Additionally, after several months of recruitment via posters and emails produced no participant volunteers, it was determined that assistance from community partners was needed. Community partners were directly involved in recruitment of their members for the study. Community partners requested their counsellors and support workers to reach out directly to members to inform them of the study. This presented another layer of complication to confidentiality. Therefore, partners would only refer participants to me, I would then follow up with them. Community partners were never informed whether their referrals participated. Additionally, at no time did they have access to any identifiable data or information about participants.

Consent was sought once participants indicated they were interested in taking part in the research (see Appendix 3). I, as principal investigator (PI), reached out whenever possible to potential participants, explaining the research and offering to email a copy of the consent form to them for their review. I provided a paper copy of the consent form at the start of the interview and went over the form and research project with each of the participants. The consent form was covered in detail at the start of the meeting with participants, so they fully understood the project and all risks related to the research. The complete consent and interview process was scheduled to take between 45-90 minutes, depending on how much or how little any single participant wished to share (see appendix 4).

Once the consent form was explained, participants were given the option to give written consent on the form or accept tobacco as a method of consent (research as ceremony). "Some researchers have suggested that the practice of presenting tobacco bundles could replace the written informed consent process entrenched in our ethical review processes at the

universities” (Lavallée, 2009, p. 28). Tobacco is a sacred medicine in many Indigenous communities and is “offered in every ceremony and in many other circumstances. Tobacco is used in funerals, weddings, for praying over and offering food, for picking medicines, for hunting, for thanking people, asking for help, praying for information, and sharing stories” (Struthers & Hodge, 2004, p. 217). In addition to the listed uses of tobacco in research, it is also used to ask for help and to share stories (Ellis & Earley, 2006). Participants who were unaware of the teachings of tobacco were told what accepting tobacco meant and were guided through the process. Once participants consented, they were given their incentive for participating, which was \$50.00 CAN in cash. It was then reiterated to participants that they had the right to leave the meeting at any time, to skip any questions they do not want to answer and/or to stop participation at any time without fear of reprisal. Even if they wished to stop, they would keep their incentive to participate.

Participants had the option to review their transcripts/stories after they were transcribed. If they elected this option, they would have six (6) weeks to review it for completeness and accuracy. If they wanted this option, they had to provide an email or mailing address. This process allowed participants to withdraw certain sections of their story or to withdraw from the study altogether. One participant opted to withdraw from the study a day after participating and has since had all personal data removed and destroyed as part of the research.

Research locations were initially scheduled for Toronto, Hamilton, Chatham, and Ottawa. In September 2016, an amendment was submitted to the Ryerson Research Ethics

Board (REB) noting that interviews were to be conducted in both Thunder Bay, North Bay, and Sudbury and including a list of 'counselling resources' for those locations.

### Recruitment & Consent Process

In order to participate in this study, participants had to meet the following criteria:

- 1) be at least 16 years of age; and
- 2) have been diagnosed with HIV/AIDS; and
- 3) be from an Ontario reserve.

As noted above, recruitment was conducted in partnership with 2-Spirited People of the First Nation (2-Spirits) and the Ontario Aboriginal HIV/AIDS Strategy (OAHAS). These two organisations provide support and assistance to Indigenous Peoples who have been diagnosed with HIV/AIDS. Both agencies agreed to send out recruitment materials to their listservs and to pass along the recruitment materials by making direct contact with members who they believed would meet the recruitment requirements. This research relied heavily on snowball recruitment, which is allowing other participants and community members to send the recruitment notice to their contacts and networks. The recruitment materials were also included in an email script (see Appendix 5). Recruitment posters were also put up in a variety of locations around Toronto, and other urban centres where interviews would be taking place.

In November 2015, OAHAS and 2-Spirits distributed the approved ethics recruitment flyer and email (see Appendix 6) throughout their networks. Staff at 2-Spirits posted the flyer on their website and on Facebook. The first interview was scheduled in November, with a second in December 2015. After a substantial amount of time with no participant recruitment,

a meeting was held with the Executive Director of OAHAS in July 2016 who then connected with regional OAHAS offices and some outside community contacts to distribute research materials.

Subsequently, there was a contact who worked in the Indigenous HIV/AIDS field from Thunder Bay and who did work with OAHAS and was interested in assisting with recruitment in the region. Recruitment materials were distributed through several local Thunder Bay agencies, and contact was made with a number of individuals who wanted to participate in the research. OAHAS staff in Thunder Bay were able to conduct an initial screening interview prior to the meetings, in order to ensure that individuals met the requirements. This became necessary given that most of these individuals were not accessible by phone or email. We were able to secure five participants and set up interviews over two days at a local agency in downtown Thunder Bay. A total of four participants consented and were interviewed.

OAHAS staff in Sudbury distributed flyers through several local agencies and made contact with many of their members. They were able to secure nine participants from their outreach. Again, these staff went through the screening interview prior to the meeting, and they set up interview times. Meetings took place over four days in OAHAS offices in downtown Sudbury. A total of six participants consented and were interviewed.

In November 2016, an email was sent to 18 HIV organisations across the province with a copy of the flyer and email script. In January 2016, printed flyers were posted in a number of LGBT and Indigenous businesses and agencies in downtown Toronto with their permission. These included the 519, ACT, The Village Pharmacy, Glad Day Book Store, and Maple Leaf Clinic Pharmacy. During the same month, an email was received from an individual, and an interview

was scheduled at the OAHAS Chatham office. In January 2017, an OAHAS south-west region staff member confirmed two participants in the London Area. All three interviews were conducted on the same day in February. An OAHAS Hamilton staff member had an additional two persons interested, so interviews were scheduled and subsequently conducted at the Hamilton OAHAS office.

Additionally, from January to March 2017, I made contact with 15 individuals who were in the Toronto region and expressed interest in participating. During this time, 13 participants consented to be interviewed, and meetings were conducted at Ryerson University.

In total, there were 30 participants ( $n=30$ ) who consented to be interviewed, were paid, were interviewed, and took part in all aspects of the research. Following the completion of one of the interviews, one participant withdrew consent from the study, not wanting the individual story shared. All of that individual's research materials were withdrawn from the study. Therefore, a final total of 29 participants took part in the research.

## Methods

### Freedom of Information Requests

In order to assist in answering sub-questions three and four, it was necessary to submit a Freedom of Information Request (FOI) to the Government of Canada to access funding data. Funding information was requested from the Access to Information and Privacy Division of Health Canada. There were three separate requests submitted. The first and second requests were related to funding provided to First Nations in Ontario with relation to HIV/AIDS, including funding source(s) (see Appendix 7). The first request was submitted in September 2015 with an answer received in November 2015, and a subsequent (second) request was submitted in

December 2016, and was answered in September 2017. Given their responses, it was possible to compile HIV/AIDS funding allocations for First Nations in Ontario. Additionally, this also allowed for the separation of overall health care funding provided from specific funding and/or expenditures for HIV/AIDS programs or treatment within the province. The third request related to the number of Non-Insured Health Benefits users who were accessing treatment or services for HIV/AIDS within the province of Ontario (see Appendix 8). This request was submitted in December 2016 and answered in September 2017. These data will allow for a funding breakdown per person infected as well as a rough comparison number based on estimated figures of First Nations persons receiving treatment for HIV/AIDS in Ontario.

### Self-Identified Information

Participants (n=29) were asked to complete a short demographic survey. This identified essential demographic information from the population being researched (see Appendix 9). The demographic breakdown of the research participants are as follows:

*Table 2: Participant Demographics*

	<b>Straight</b>	<b>2-Spirited</b>	<b>Gay</b>	<b>“Not Straight”</b>	<b>Total</b>
<b>Female</b>	11	1	0	0	<b>12</b>
<b>Male</b>	11	2	0	0	<b>13</b>
<b>2-Spirited<sup>17</sup></b>	0	2	1	1	<b>4</b>
<b>Total</b>	<b>22</b>	<b>5</b>	<b>1</b>	<b>1</b>	<b>29</b>

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<sup>17</sup> The term 2-Spirited means many different things, to different people. In this context, it was used by participants to describe both their gender identity (found in the vertical columns) as well as their sexuality (found in the horizontal columns).



## Storytelling

Within this research, all 29 participants identified as living with HIV/AIDS and identified as status First Nations who had moved from or left a remote reserve in Ontario. Storytelling was used to discuss the impact that HIV/AIDS has had on their lives, including access to services/treatment while living within their remote community and whether there were any mitigating factors that influenced their decision to leave their community (if applicable). After accepting tobacco, which was a critical part of the ceremony of the method, participants were paid their incentive, and told they were free to leave or stop answering any questions at any time or pass if they did not want to answer a particular question. At this point, the recording device was turned on, and the five overarching research questions were asked of the participant (see Appendix 10). These questions were open-ended and allowed the participants to answer as specifically or as broadly as they felt comfortable answering. This open-ended process allowed for transcription of specific answers for analysis, but they were also structured to allow for the removal of the interviewer's voice. The removal of this voice allowed the participants' answers to be merged to create a story highlighting the participants' lives while living with HIV. At the end of the meeting, participants were reminded of the counselling resources contained in the consent form they received. Additionally, they were told that if they had any concerns, they could reach out to one of these resources or the Ryerson REB. At the end of the meeting, the recording was turned off, encrypted and sent to an external transcriptionist for transcription. After transcription, all the transcripts were de-identified and given to a number of Ryerson undergraduate students who were asked to re-story these transcripts and remove the interviewer's questions and comments. These stories were re-

formatted and edited by the researcher to allow for a set of uniform first-person stories (see annex 1) which detail the experiences of each of the participants' lives while living with HIV/AIDS.

### NVivo Coding

Upon completion of storytelling, the audio-recordings were transcribed and uploaded into the software program QSR\*NVivo 2017. The transcripts were then coded within the software program. This process was chosen at the request of the community partners, as to better understand (in a quantifiable way) the issues facing First Nations people living with HIV/AIDS. This was especially true the recommendations that came from the participants, with community partners recognizing that not every recommendation would or could be implemented, so they desired an understanding of what were the most pressing needs so they could advocate for issues that impacted the most participants. You will find in the results of this research, that each of the themes are followed by the number of times that theme was mentioned across all stories and the number of stories it appeared in. This process and information was deemed to be helpful for the community organizations to further advocate for additional funding from funders.

QSR NUD\*IST VIVO (NVivo's less commonly used full name) was launched in 1999 and "was named for 'in vivo' coding – that is, naming a category directly from a participant's own words" (Bringer, Johnston, & Brackenridge, 2004, p. 248). Researchers have a substantial variety of choices in the tools they use within the NVivo program which allow them the ability to code and dissect their research.

In NVIVO there are many options for document preparation (plain text, rich text with sections, audio clips, pictures), coding (e.g., inductive or deductive, in vivo or researcher defined, manual or automated), retrieval (e.g., by node [category], by document, text searches, matrix searches, refined by attributes), dynamic links to memos, documents, and nodes, and visual representations (e.g., coding stripes, models). (Bringer et al., 2004, p. 249)

This variety allows the researcher the ability to organize data and its analysis efficiently, including the quick processing of large amounts of data and fast retrieval of keyword searches. Additionally, “QSR-NVivo is a powerful tool that, if used appropriately, can facilitate many aspects of the [research] from the design and early sampling procedures, through to the analysis of data, theoretical development and presentation of findings” (Hutchison, Johnston, & Breckon, 2010, p. 283). The use of this program also keeps detailed audit records of the research process at every stage of the analysis (Bringer et al., 2004). The particulars around this specific method of storytelling allowed the use of Indigenous ways of knowing to form the basis of how it was used in this research. It allowed Indigenous worldviews to be incorporated and our understanding of knowing and being to be used as the basis of how the data were framed and then coded. The importance of a holistic balance including the mental, physical, emotional, and spiritual all helped to frame how the coding was brought forward and the importance of what was conveyed in the stories.

Carrying out the coding for this research started by creating analytical codes and categories from the data. This is the “analytical process through which concepts are identified, and their properties and dimensions are discovered in the data. These should be representative of the data itself [sic] and cover a wide range of observations” (Hutchison et al., 2010, p. 284). The data analysis process started by reading the transcripts and coding each statement,

concept, or idea that emerged from the story, thereby highlighting and labelling them as a 'node' within NVivo. "Nodes are similar to codes in constant comparison analysis (described in detail below). Thus, nodes are what a researcher uses to place meaning on different parts of the text" (Leech & Onwuegbuzie, 2011, p. 74). After the coding process started, I created a description for each of the nodes in order to ensure there was a clear understanding of its context and use for subsequent coding.

The coding of the transcripts allowed the making of systematic comparisons. "Making comparisons at every stage of the analysis (e.g. within and between cases or over time) helps to establish analytical distinctions by identifying variations in the patterns to be found in the data" (Hutchison et al., 2010, p. 284). This can be done using 'tree nodes.' "Tree nodes are groupings of nodes. As more nodes are created, the researcher can organize the nodes into tree nodes" (Leech & Onwuegbuzie, 2011, p. 74). This then allowed the creation of axial coding (Corbin & Strauss, 1990). This is the process by which a researcher can relate categories to other categories and their subcategories (Kendall, 1999). "The purpose of axial coding is to begin the process of reassembling data that were fractured during open coding. During axial coding the initial codes are scrutinized to ascertain how some of the identified categories relate to one another and to the overall phenomenon" (Hutchison et al., 2010, p. 291). Eventually, after coding 19 transcripts, density and/or saturation was achieved. "It is commonly accepted that there must be evidence of theoretical density or depth to the observations presented" (Hutchison et al., 2010, p. 284). After saturation was achieved, the remainder of the transcripts were coded and compared for themes and density of opinion.

## Conclusion

Indigenous worldviews are critical to understanding how this research was conducted and how it is to be understood. Only through a detailed understanding of Indigenous worldviews can I proceed with a discussion of how, as Indigenous Peoples, we come to know and understand what happens around us. Our Indigenous ways of knowing have informed the methods used within the research project. While methods such as Freedom of Information Requests, NVivo, and demographic surveys are used within this research, the overall framework is built upon a foundation of Indigenous knowledge systems and methods, mainly the storytelling method, and the process by which the storytelling was coded using a software program and embedded within an understanding of Indigenous ways of knowing and being.

## Chapter VI: Research Findings

### Introduction

This chapter will be broken down into two sections. The first will address the findings gleaned from the use of storytelling with participants. Through the storytellers' perspective of living with HIV/AIDS, their journeys –both the positive and negative aspects of living with HIV – are detailed. The first part of this section also looks at the results of demographic data, highlights the 14 major themes and their sub-themes that were present throughout the stories, and finally, the lists the recommendations from the storytellers. The second section will address the findings of the freedom of information requests submitted to the Government of Canada.

### Storytelling

#### Demographics

There were 29 participants who took part in this research, with an almost equal distribution between male (n=13) and female (n=12) participants, and a smaller number of two-spirited (n=4) participants (see Table 2). The majority of participants self-identified as straight / heterosexual (n=22), and two identified as two-spirited, one as gay, and one as not straight. The average age of participants was 48 years old (there is a detailed age breakdown provided in Table 2). The average monthly income of a participant was \$1,362CAN, with all participants identifying as being the recipient of supports from the Ontario Disability Support Program. Education varied between participants, with a significant number (n=11) not attaining higher than grade 9, completed grade 10 or 11 (n=3), completed high school (n=5), completed some college (n=3), and completed a college or university degree (n=7). Of note, all participants who identified as two-spirited had a college/university level education.

Table 2: Detailed Participant Demographics

	Gender Identity		
	Female	Male	2-Spirited
<b>Age</b>			
Highest	65	63	60
Mean	50	45	51
Lowest	41	31	43
<b>Income</b>			
Avg. Monthly Net Income (CAD)	\$1,329	\$1,214	\$1,942
<b>Sexual Orientation</b>			
Straight	11	11	-
2-Spirited	1	2	2
Gay	-	-	1
Not Straight	-	-	1
Total	12	13	4

## Major Themes

Through the use of storytelling, participants were able to describe and detail their life while living with HIV/AIDS. The open-ended questions allowed them to share what they felt comfortable sharing. Through this process, 17 major themes emerged (see Table 3) along with a set of recommendations that was participant-focused. These 17 major themes represent some 143 individually coded nodes<sup>18</sup> which detail the specifics of each story. The 17 major themes include diagnosis, treatment, health, access, community, family, culture, education, addictions,

<sup>18</sup> A node is a collection of references about a specific theme, place, person or other area of interest. The references are gathered by 'coding' sources such as interviews, focus groups, articles or survey results.

sex and sex-work, homelessness, incarceration, life, death, discrimination, trauma, and criminalisation. These themes are broken down into their node classification to provide greater context to the higher-level themes that inform them. Below the findings of each major theme, there is a breakdown of the major theme (in dark-gray), sub-themes (in light-gray), and the nodes which inform them (in white).

*Table 3: Themes, Sub-Themes, and Nodes*

Nodes	Aggregate number of coding references	Aggregate number of items coded
<b>Diagnosis</b>	181	29
How and When Story	37	25
Drug Use	22	16
Heterosexual Sexual Contact	7	7
Sexual Assault	4	3
MSM	3	2
Risky Behaviour	2	2
Got it in the city	1	1
Transplant	1	1
Assault	1	1
Needle Prick	1	1
When were you diagnosed	33	27
Location	6	5
Prognosis	8	8
Very sick	5	4
AIDS	1	1
Results mixed up	1	1
Pregnant	1	1
Shock	10	9



Wanted to die	8	6
Traumatizing	7	5
Scary	4	4
Depressing	4	4
Self-Blame	3	3
Lonely	3	3
Coming to terms with Sexuality	2	2
Got supports	3	3
<b>Treatment</b>	<b>95</b>	<b>28</b>
Bad Doctor	10	8
Don't have children	4	3
Not enough treatment	2	2
Problems getting Medications	8	7
No Choice in Meds	5	5
Non-Adherence	4	4
Beneficial	4	4
Looking Healthy	1	1
Addictions	4	3
Research	3	3
<b>Health</b>	<b>29</b>	<b>17</b>
Hep C	12	11
Problems	11	10
Co-Morbidity	4	4
<b>Access</b>	<b>219</b>	<b>29</b>
Access to Services	56	24
Service Organisations	23	11
Service Organisations - Location of access services	13	9
Service Organisations - Used Drop-ins	5	4
Services - Not enough for women	3	3
Services – No straight Male Info	3	3

Addiction Treatment	4	4
Positive Experience	11	7
Easy to access services	3	3
Cultural	55	23
Cultural\Access - Indigenous Specific	21	15
There are no services	42	25
There are no services - Nothing on reserves	26	19
Negative	4	4
No Transport	9	8
Confidentiality	6	5
<b>Community</b>	<b>70</b>	<b>24</b>
Left	19	14
Running Away from Home	2	2
Not wanting to go back	12	10
No Treatment in Home Community	15	13
Hasn't gone home	2	2
Returned Home	4	4
Would return if they could	3	3
Safe - In the city	4	4
<b>Family</b>	<b>44</b>	<b>21</b>
Not a good parent	7	6
Partner or Spouse	6	4
Supportive	4	3
Story of Family Member	2	2
<b>Culture</b>	<b>51</b>	<b>20</b>
Creator	5	4
Elders	4	4
Language	1	1
<b>HIV Education</b>	<b>64</b>	<b>25</b>
Lack of HIV Knowledge	35	22

In community	14	12
Going to or speaking at Conferences	10	8
<b>Addictions</b>	<b>74</b>	<b>27</b>
Drugs	51	23
Drinking	14	10
Drugs - types	5	5
<b>Discrimination</b>	<b>80</b>	<b>25</b>
Stigma	67	25
Stigma - Violence	6	4
Homophobia	3	3
Racism	10	9
<b>Trauma</b>	<b>57</b>	<b>23</b>
Residential Schools	12	9
Taken from community	11	8
Colonisation	7	5
Colonisation - Christianity	6	4
Violence	14	8
<b>Criminalisation</b>	<b>16</b>	<b>9</b>
Non-Disclosure of HIV status	10	7
<b>Sex and Sexuality\Sex-work</b>	<b>5</b>	<b>2</b>
<b>Homelessness</b>	<b>8</b>	<b>8</b>
<b>Incarceration</b>	<b>5</b>	<b>4</b>
<b>Life - It's been hard</b>	<b>10</b>	<b>5</b>
<b>Death</b>	<b>11</b>	<b>6</b>

## Diagnosis

*Table 4: Coding for Diagnosis*

Nodes	Aggregate number of coding references	Aggregate number of items coded
<b>Diagnosis</b>	<b>181</b>	<b>29</b>
How and When Story	37	25
Drug Use	22	16
Heterosexual Sexual Contact	7	7
MSM	3	2
Sexual Assault (Female)	3	2
Sexual Assault (Male)	1	1
Risky Behaviour	2	2
Got it in the city	1	1
Transplant	1	1
Assault	1	1
Needle Prick	1	1
When were you diagnosed...	33	27
Location	6	5
Prognosis	8	8
Very sick	5	4
AIDS	1	1
Results mixed up	1	1
Pregnant	1	1
Shock	10	9
Wanted to die	8	6
Traumatizing	7	5
Scary	4	4
Depressing	4	4
Self-Blame	3	3
Lonely	3	3

Coming to terms with Sexuality	2	2
Got supports	3	3

\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

One of the major themes that came out in every transcript was related to the stories of when and how participants were diagnosed with HIV. The node ‘how and when story’ (see Table 4) captured the entire story of a participant’s diagnosis. An example of a story that highlights the nature of this theme is the story of Yvonne, who detailed the events around their diagnosis:

I would have to say when I first found out that I was HIV there was a big mix up with my status. The lab had screwed up the names and gave another woman my test results and it gave me hers. So, for 30 days I ran around not knowing I had the HIV virus or even what it was. They had a mix-up and anyway I got annoyed, I was I wanted you know I felt hurt, angry, alone. It was like I didn’t have anybody, I couldn’t turn to anybody, I didn’t know how to tell anybody. Really scary. I was up and down crying all the time. Thought about my children. They didn’t know – they still don’t know today that I’m HIV. So that is still a problem for me. I finally got all my test results were positive. I became angry. I wanted to die. That day. So, I drank myself silly for the longest time. Just drank every day for a long time. And finally, I went to the doctors and talked to the doctors. They put me on meds. And through over the years with my meds I’ve been having a lot of hard time with them. Because I forget or I’m too busy partying to remember to take them. Or I leave them at home, and I go places and stay there, and I don’t have them with me. I always have these difficulties. I’ve had a lot of medications over the years since I was diagnosed. It’s been a long hard road for me. I still can’t face the fact that one day I have to tell my children that I am HIV. Soon, I hope. I have been trying to work on it over the years to ask people to help me how I can do this and how I can connect with all of them [...]. My son ignores me. He’s pissed off at me so. So anyway, that’s pretty much I don’t know what else to say. That’s how I felt when I was diagnosed. I was angry, pissed off at the world. Mad at everybody.

The stories depicted within this overarching theme of ‘how and when’ encompasses every other node within this section (see Table 4). The node of how and when essentially forms the

entire basis of each diagnosis story. As can be seen from the above story node, many of the nodes listed below are included within it.

The nodes that flow from diagnosis are the details of how participants describe learning of their HIV-status. Some participants did not speak of the transmission mode and others noted multiple possible instances where they could have been exposed to HIV. Participants noted injection drug use (n=16) as an exposure category. There were participants who noted heterosexual sexual contact (n=7) as possible modes of transmission, and while being sexually assaulted (n=2 female, 1 male) was also described as a cause. Further, three participants noted they were men who had sex with other men, two noted they engaged in 'risky behaviour', one person through a transplant, one through a needle prick, and another through committing a physical assault.

Issues surrounding IDU are complicated and multifaceted. There was no one reason identified for a person to start injecting drugs. One of the major underlying themes that correspond to drug use is traumatic experiences faced by participants. These traumatic experiences compounded over time and led to drug use (the theme of addictions will be explored later in this chapter). This is highlighted in Bee Dabum's story:

They [the medical staff] had asked me about risk factors and what not. Had I ever been promiscuous, had I ever engaged in injection drug use to which I felt like every time they asked me a question, my head was just sinking lower and lower. Ya know? Yes, yes, yes, yes. But for me the scariest thing when I was told, because I was in the hospital in intensive care, and they were finally able to tell me what I had and they asked me at that time had I ever been tested for HIV and I said yes before my partner and I got together we both shared the fact that we were both former injection drug users. That was my coping mechanism for sexual abuse and that led me down a pretty destructive path from drinking to popping pills to injection drug use to cocaine on the street, which I had never done before.

Previous abuse, or a traumatic stressor, were common themes throughout the interviews with people who self-identified as IDUs. Participants stated that they understood the risk factors associated with IDU (n=7) but proceeded to use anyway, due to varying compounding factors.

Sexual assault was also a theme discussed by many participants, but only three interviews placed it in the context of stating that a sexual assault may have been a factor in becoming HIV-positive. These stories were graphic and violent in their nature. Singing Medicine Water details how abuse experienced in early life led to relocation to the city, where there ensued a struggle to be accepted for being two-spirited:

I was a little messy. I was at the bar just giving er' on the dance floor, high as a kite. We were drunk and that was the first time I ever experienced GHB. I had no idea what it was. Within 7 minutes of me taking it, it was like a whole different, I don't know, the music changed, and I basically blacked out. And what I wanted to do was hide in a cubicle in a toilet. You're safe there, you can lock yourself in, but it's so not the case. [...] the bouncer, big fellow, god bless him found me in the washroom being raped by 6 guys. And yeah, I wasn't even breathing. So pretty traumatic. [The bouncer] told me a couple months later that he had to pull me out of the bathroom, pull my pants back up and threw me over his shoulder like the firefighters do and did a bee line to the front door. He went down 2 flights of stairs, well one flight of stairs because the dance floor was upstairs. And it was February, I do remember coming to in a snow bank and all I could hear was come on buddy just breathe! And somebody put some snow around my neck and that was when I first took my first breath. Yeah it was traumatic. Something I wouldn't wish on anybody. Because it took something.

Sexual assault for all of the participants was a traumatic experience that led to multiple negative emotions and turning to negative coping mechanisms, such as drugs and alcohol to deal with the events, which further increased their risk of transmission.

Participants also detailed within their stories when they were diagnosed. Within this theme, nodes included the location of diagnosis, the prognosis they received, how sick they

were when they were diagnosed, along with other matters. The majority of participants discuss when they were diagnosed with HIV, with a large segment of participants noting diagnosis before 2009. One participant was diagnosed in 1989, 10 in the 1990s, seven in the early 2000s, eight from 2010 to 2015, and one in the past two years.

Participants discuss the prognosis they were given when they were told they were HIV-positive (n=8). All eight participants note negative, life-debilitating, and life-ending prognoses from their physicians when they were told of their status. Many notes: “He says, ‘I’m sorry to tell you this, but you’ve got HIV, you’re dying’. I told him, ‘You should be dying!’ My God, I had to go on medication here or I’d end up with AIDS”. Additionally, Skywalker states: “Well I was diagnosed in Dec of 1990, I was told to get my affairs in order because within 5 years I was going to get sick. That was 27 years ago”. The doctor said: “you better get your affairs in order you’ve got 2 years to live, tops. So that was about it”. All eight participants thought they were going to die when they were told their diagnosis. This led to negative emotions and uneasy feelings about the medical system. Blessing Water details the reaction to what the doctor told them:

Get your affairs in order and yeah. They were speaking in a language of organisational speak that I didn’t understand. Even though I was traumatized from some of the PTSD [post-traumatic stress disorder] of my life, I still knew what they were doing to us, it was wrong and could have been done way better.

This part of their story highlights the complex feelings expressed by many. With diagnosis, there was a clear onslaught of emotions, with many being left alone and isolated to deal with them.

The next major theme relates to participants’ emotions after being informed of their diagnosis and how that may have been conveyed. Generally, these nodes revolve around the



theme of shock. All participants note some form of negative emotion when told of their diagnosis. Whether this was saying they were shocked, traumatized, scared, depressed, lonely, blamed-themselves or for six participants, that they wanted to die upon finding out they were HIV-positive. Participants discussed some or all of these nodes at the same time.

In several instances, participants were expressing all of these emotions at once. Brant stated: “I was still in shock, like after shock, and I couldn’t sleep, I couldn’t - I was hardly eating. I had quit my job because I thought well there’s no hope here. Lost hope. And still today there’s lost hope”. Likewise, Yvonne stated: “I felt hurt, angry, alone. It was like I didn’t have anybody, I couldn’t turn to anybody, I didn’t know how to tell anybody. Really scary. I was up and down crying all the time. [... I] was angry, pissed off at the world. Mad at everybody”. Others turned to blaming or questioning their own actions and how they may have contributed to becoming HIV-positive. Rick stated, “I was very shocked and y’know just didn’t understand what I had done wrong or yeah know, I just couldn’t figure it out”. Some of these feelings turned to thoughts of self-harm and suicide. Nora stated “My experience started off rough. Because I didn’t know what’s wrong with me when I was first diagnosed. I thought of suicide. I thought about all kinds of stuff. I continued to use drugs for a couple of years”. Similarly, Yvonne said “I became angry. I wanted to die. That day. So, I drank myself silly for the longest time. Just drank every day for a long time”. No participant mentioned having access to immediate and ongoing services for their new diagnosis or proper mental health care. This lack of immediate support appeared to exacerbate an already highly emotional and damaging time. Brant detailed “always trying to attempt suicide [...] you know this happened like 20 times [...] trying to jump off bridges and slice my wrists and hang myself. I had a tough journey living with HIV and not

having enough resources”. Through the interviews, only three participants noted that they felt they were supported during the diagnosis process; however, this was done by outside agencies or friends/family who supported them with coming to terms with their diagnosis and often bleak prognosis.

## Treatment

*Table 5: Coding for Treatment*

Nodes	Aggregate number of coding references	Aggregate number of items coded
<b>Treatment</b>	95	28
Bad Doctor	10	8
Don't have children	4	3
Not enough treatment	2	2
Problems getting Medications	8	7
No Choice in Meds	5	5
Non-Adherence	4	4
Beneficial	4	4
Looking Healthy	1	1
Addictions	4	3
Research	3	3

\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

The theme of treatment was prominent within the stories, with almost all participants (n=28) discussing how they accessed treatment or problems they faced with their treatment. Substantially, eight participants note negative experiences with their doctors (labelled in Table 5 as ‘bad doctor’). The theme of ‘bad doctor’ came from participants referring to them as such. An additional three separate participants noted that their doctors have told them to not focus or worry about having children because they were HIV-positive, with all of them expressing

discomfort and shock at this advice. Nora noted that she does not like her doctor because “He’s rough. He’s rough with some of us women”. Sammy stated: “I don’t like my doctor at all. A lot of people have a lot of complaints [...]. He’s no good, because he doesn’t believe in homeopathic medicine”. Additionally, Bee Dabum stated: “I had a bit of an issue with him at first. [...] when I was diagnosed and I still wanted to have children and when I brought it up to him, he said you should be focusing on your illness, not having more children. So, I found that was very negative”. Through these experiences, participants noted that they were less likely to want to attend follow-up appointments or to take the advice of the medical staff they encountered.

Throughout the stories, participants highlighted issues with getting access to treatment and medication, both Western medicine (i.e., ART) and traditional medicine(s) for their HIV treatment. Participants similarly highlighted having little or no choice in their medications, due to limitations on which drugs are covered/funded by Non-Insured Health Benefits. This results in participants having to deal with significant side effects that they felt could have been otherwise avoided. Dominique described how it was difficult to access required medication:

One of the things that happened for me for my HIV was I had come to the end of my treatments and there were no more options available for me and this was about probably around 2004-2005. My virus was starting to show immunity to the medications that they had and there were no new treatments. There was only this one treatment they have which is called fusion and I would have to inject myself twice a day but that was the only option I had. The problem with it is it wasn’t covered [by Non-Insured Health benefits] so they asked me to see if my band will cover it, and they wouldn’t cover it. I was on ODSP, so the province wouldn’t cover it. I actually had to go to the Chiefs of Ontario and write a letter to them and go get them to lobby for me to get it covered. As a result of that, I did end up getting covered, but I can’t say it was through my band.

Of importance, this participant highlights how they were forced to 'out' themselves to many people in their band, to the Chiefs of Ontario, ODSP, etc in order to try and access medications. Others had trouble accessing medication when they missed doctor appointments and their doctors were unresponsive to them. Therefore, they would go for periods of time with no access to their medications. Additionally, Little Wolf noted limited access to traditional medicine because elders did not know how to fight these new diseases that were never here before colonial contact:

The creator promised this medication will work for this and this. But these are diseases that these Indians have never heard of. It wasn't until the white man came here that these diseases came. When the Indians were here originally there was no disease here. It wasn't until all these white people came that you got all these other diseases that are here now that were never here when they were here. And now all the elders are saying, what's going on to our world? These people brought this, and why would they bring this? They still rely on their old medications and you can't rely on old medications when they don't know about these diseases. A lot of them don't believe in the medications that the white man have come across with, so they're dying. They [HIV-positive people] won't take them. Because according to our beliefs there was no sicknesses when my great-grandfather was here, and your great-great-great-grandfather was here. So according to our legend we can use this herb, and this sweat, and this healing medicine woman and it will all go away. And that's not the way it is anymore. They need to step out of that and say ok we have to fight a white man's disease, so we need a white man's medication. Now we're dealing with diseases that eat our bodies away and you looking like a leopard. And they [elders] don't know what it's all about.

There was concern from five participants about the types of medications available to them.

Mukada Mukaa stated: "they want to put you on this medication, but nobody talked about what the side effects would be. Nobody told you you're going to be vomiting, gonna have pains in your legs, you're going to get welts". Brenda stated: "I really didn't have a choice when it came to medications. If I had my choice, I wouldn't have gone on the pill myself". These five

participants all discussed how they lacked or the perception of lacking agency in the decisions regarding going on medication and the impacts those medications could have on their bodies. Rick described his scepticism about the medications being funded for Indigenous Peoples and questioned if they have worse access because of who they are: "I think that being Aboriginal, I'm not able to get the more maybe proper medicine that's available. So maybe because of the money costs". There is clear suspicion on the part of some participants about the level and quality of care they receive, this perception can in turn create a level of reality for some. There was real apprehension about the reason they were placed on medication and the types of medication they are given. This raised concern about their adherence to the medication schedule. Four participants note they were non-adherent to their medications. Bear stated:

When I got out of jail and they found out I was HIV and they knew I was sick they all, my sister showed up first. Because they all live in Manitoba, so she showed up first all worried because I was really sick at the time and I wasn't taking my meds I wasn't even seeing an HIV doctor and my sister came and thinking I was really sick and I'm gonna die from this. Because they don't know anything about HIV, how it progresses. So, they all came and then my mother and my other sister showed up after my other sister left. My mother and sister showed up also, thinking the same thing. She's really sick. Something is gonna happen to her. I did end up in the hospital after they left. But they were all like, all crying, crying at the doorway. Because they're all thinking I'm gonna die. It was a little sad. But little bit like settle down, it's not like you think it is.

And Brant stated: "I struggle every day to take my medication. I came from [...] 3 pills and now [...] I only take one pill and that's really coming from living with HIV for so many years". This non-adherence was due to a number of reasons but provides concerns about resistance and other complications as a result.

## Health

*Table 6: Coding for Health*

Nodes	Aggregate number of coding references	Aggregate number of items coded
<b>Health</b>	29	17
Hep C	12	11
Problems	11	10
Co-Morbidity	4	4

\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

The health problems of participants came up in 17 of the stories. These were always in an adverse health context. There were 11 participants (see Table 6) who stated they were co-infected with Hepatitis-C. An additional 10 participants noted that they had other major health problems in addition to their HIV-positive status. Irene described the effects of poor health:

I've gotten sick a couple of time where I've ended up in the hospital and people are coming to see me to say goodbye. Ya know. And the first time when I got sick, I remember being in there and I remember my son coming in and he was so afraid, he didn't know what to expect. But I could see him. And he was jumping around, acting out, but we just let him because he needed to let it out somehow. He just knew mommy was sick. He didn't understand the whole, the everything about what it was mommy was sick with. But and then there was my mom, I remember my mom coming in to see me and I could just see the hurt and I was really weak at that point. I was down to maybe about say 90lbs. and my everything was out of whack. My mind, spiritually I didn't have anything ya know. I was so messed up.

Four separate participants specifically mentioned they have co-morbidity health issues, which included cancer in two participants and diabetes in another two. Overall, 14 participants are living with and managed major health issues in addition to living with HIV, including six who had significant liver issues, two who required organ transplants, and four who had major infections requiring hospitalisation.

## Access

*Table 7: Coding for Access*

Nodes	Aggregate number of coding references	Aggregate number of items coded
<b>Access</b>	<b>219</b>	<b>29</b>
Access to Services	56	24
Service Organisations	23	11
Service Organisations - Location of access services	13	9
Service Organisations - Used Drop-ins	5	4
Services - Not enough for women	3	3
Services – No straight Male Info	3	3
Addiction Treatment	4	4
Positive Experience	11	7
Easy to access services	3	3
Cultural	55	23
Cultural\Access - Indigenous Specific	21	15
There are no services	42	25
There are no services - Nothing on reserves	26	19
Negative	4	4
No Transport	9	8
Confidentiality	6	5

\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

The most prominent theme to come out in the research was about access to services and care. There were 24 participants who said they have accessed or were actively accessing HIV services. The node ‘access to services’ (see Table 7) denotes any time a participant discussed accessing services, and thus overlaps with many of the nodes mentioned below it.

Additionally, all service organisations and their locations were coded, but are not detailed in these research findings. Substantially, this section details participants' experiences when accessing services. Three participants noted there was a lack of HIV services for women to access across the province. An additional three male participants noted there were no straight male-specific services for them to access, noting the majority of programming has a focus on women and gay/bi men.

Seven participants discussed positive experiences in accessing HIV services, either in the past or currently. Participants found these positive experiences to be supportive in nature and a reprieve from their daily lives. Rick said "I belong to an agency here in the city. So, you know it has a lot of open doors for me. A lot of support, meetings, group meetings and possibly outside training out of town. Just to get away" and that these services were "welcoming, caring, if you're needing to talk to somebody, they'll have the time to talk". Bee Dabum stated: "They're an integral part of my life and I'm grateful they exist". Additionally, Brenda highlighted a number of nodes, stating:

I've been very lucky being around here when I got sick because there's so many, well I can't say there's a lot of agencies, there's a lot of agencies for HIV people for food and stuff like that. Some of the agencies they actually, not stigmatize, but some certain ones, they look for the gay men, there's more gay than there is, and there's nothing wrong with that but it's not just always them and woman. But I don't know. My experiences have been pretty good, like I said.

Three of the same participants also noted that they found it easy to access services when they required them.

The sub-theme of 'culture' is found in this theme, the sub-theme is used in relation to accessing healthcare services and came up in 23 of participant stories. The importance of



culture was present throughout the discussion of access to services, with 15 participants saying they had accessed Indigenous specific services or care for their HIV-status. Participants noted wanting to access culturally-based services because they were HIV-positive or that they participated in cultural activities and this helped them heal. Nora said:

I went drumming last night, I've been going drumming. I started drumming not too long ago. I got interested. First, I went singing. I used to go to singing practice with the ladies. And then just this year I made two drums. One small drum and a big one. So, I started drumming. I'm thinking this helps, the culture ways. The traditional ways help.

Rick also stated:

I've been to the local agency here, [name of agency] access through medicine healer and a sweat lodge and an elder and there's a counsellor there so we talked about everyday challenges, dealing with this lifestyle I have now. It's been a lot of getting good results from there too. Bettering myself, trying to heal myself, trying to make it good for me. Strong. Strong life.

Sammy discussed access to a traditional healer:

I also see a traditional healer which is a medicine man that we – he's not in our community. He's off our community. We have to travel. I see him and he gives me medicines and all like homeopathic medicines that I take. I take four. I take cedar tea, I take raspberry root, I was taking chaga, I stopped taking chaga because it turned out to be an opiate like a morphine type of medicine. So, I got off of that. Then I started oak cherry tree root I started that, so I've been on quite a few medicines. They're doing the work but some days I feel they don't but they're there. And all I do is I drink it. I make a tea and I drink it. I don't have to eat it like bad salad. I just make it into a tea. Yeah, I go to sweats, I go to ceremonies. I go to a sweat lodge. And what that does is you don't necessarily need to sweat you can sit out and it's a sacred fire and you open up around that fire if you're comfortable you open up. And if you're not comfortable well what you do is you just sit down – they hand the feather to you and you talk with the feather in the circle. And if you don't feel comfortable speaking you just say pass the feather, you don't take it at all. You just keep going. So that's part of the ceremony. Right now, I'm fully traditional, aboriginal, I believe in the creator and a lot of these sweats and sacred circles. [...] And I'm glad they're there because if they weren't there I'd be lost. I find they're important to me because the information I've learnt through them how to get through to where I am today. Because if I didn't know any of this

information, I would be learning it all over the streets and learning it from hear say everywhere. And it wouldn't be the right information that I want to know.

Access to culture and traditional ways and medicine is vitally important. It also helps people cope with their sexuality, while also living with HIV. Singing Medicine Water said that a two-spirited counsellor:

[...] really gave me a sense of what an honour it is to be two-spirited and she gave me some information on how two-spirited people were and acknowledges medicine and healers. Back in the day, years ago. That our society had put being gay, two-spirited, as a negative thing. So, a lot of people that were two-spirited lost that identity. It's only been recently, the last 15 years that it's really overcome barriers and they've really made a movement [...] I'm aboriginal, I can be proud to be aboriginal, I can be proud of having HIV and now that's put it to better use. I was thankful that I was introduced to the [organisation]. And met a lot of people through that. Was able to travel a bunch of places and do personal stories so yeah. Made some good friends there. Yeah. And that's kind of where I've been picking up my culture is through going to difference conferences and learning the new ceremonies and what each ceremony represents and why they do so many ceremonies for so many different things which is beautiful because I never grew up with that so to learn it and to see the elders giving a piece of them, it's like ya know history that's coming out their mouth, it was a proud moment. I'm gonna say [organisation] has been the best. Not only just for the HIV but for the cultural. They gave me a sense of identity. Where do I fit into this world? And it made me feel welcomed so. Yeah. It's nice to have a group like that.

However, while cultural access to services and programs has been available to some, there remains a significant gap in the ability for some to access any form of services. Many want to access basic services, and they could only dream of being able to access culturally competent HIV-care. This is highlighted by 19 participants who noted that there was no access to HIV care or services within their First Nation. This would have forced them to leave their communities if they wished to access care. An additional six participants stated that they could not access services even once they were off reserve because there were no services available or due to a lack of service choices being known to them. Mukada Mukaa stated: "It's almost non-existent.

Have to leave, even living rural, we have to go to Toronto. We have to drive 3 and a half hours there just for an appointment". This is echoed by Irene who said: "Unfortunately there's not [any services]. There never was. And there's probably never going to be. Unfortunately. And it's too bad that ya know that we can't have somebody there". Access issues on-reserve and off-reserve present significant problems for participants who require them. Eight participants said they lack proper transport to access required services and treatment. Yvonne discussed how they have to go to an outlying city at least once a week to get medication and to see a specialist.

We'd have to be like a day trip into town. Just to see the doctor and then drive back again. That's if you have a ride and they don't usually have a medical van that they can transport you. They used to have a bus that used to take people, but they stopped that bus route. So that made it harder for us to go anywhere. And the train well there's only a train that goes only I think twice a week or something. And if you don't make those trains you gotta stay overnight over there before you can come back. Again, it's hard to get to doctors and nurses. Like I said, they only come once or twice a week. If that.

Four participants said that even when they were able to access services, they had negative experiences with those providers. These adverse experiences are all staff related. They range from not feeling welcomed to staff being unfriendly to the participants.

One of the significant concerns five participants had about accessing services and treatment was in relation to confidentiality. Sammy detailed an experience around confidentiality when first diagnosed:

I found out through a nurse practitioner that worked in the health department in my community, in the First Nations community. And when she had told me, when she did the testing, she didn't actually tell me at first, she told my parents, so when she told my parents she didn't say it very kindly. She said it like; I want [participant's name] to come into the office so I can see the expression on [participant's name] face when I tell her. That's what they told my parents. So

when they came back what was said I kind of felt really uncomfortable because it's like who would say something like that? It's supposed to be professional. Don't mention stuff like that. So anyway when I finally did go to speak to her, I was in like I said I was probably scared.

This is similar to Irene who discussed how a lack of confidentiality prevents them from going back to their community:

I never went back. I haven't been back. I guess in a way it's, a lot of it has to do with ya know, you've got your gossip and all that. Not being able to access ya know our doctors and mentally. Like sure they have counselling but a lot of it's, a lot of confidentiality is broken and ya know like a lot of people don't like to say that but it's the truth. Ya know unfortunately that's how it is. It's probably like that in many communities.

When issues of confidentiality arise, it leads to experiences similar to those of Elizabeth who detailed concerns about the diagnosis:

I was scared she'd tell people even though it was confidentiality I was scared she was gonna tell everybody. It was so much fear after that. Somebody telling on me, scared of my family members, scared to even – scared I was gonna die or I thought I was. So I continued to use and hide. To deal with that pain. Knowing now I had to deal with something else in my life.

When participants did not feel confident in the confidentiality of services they were seeking, they merely detailed not accessing those services.

## Community

*Table 8: Coding for Community*

Nodes	Aggregate number of coding references	Aggregate number of items coded
<b>Community</b>	70	24
Left	19	14
Running Away from Home	2	2
Not wanting to go back	12	10
No Treatment in Home Community	15	13
Hasn't gone home	2	2
Returned Home	4	4
Would return if they could	3	3
Safe - In the city	4	4

\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

There were 24 participants who discussed their 'community' (see Table 8). No specific communities are named within this section, however, participant insights about issues they faced in their communities are important, nonetheless. Fourteen participants discussed leaving their communities because of their HIV-status. Sammy stated: "I wasn't accepted. Nobody liked me. When they heard HIV it was like oh no. It's coming to our community, what do we do? We're all going to get it, we're all going to die". Likewise, Mukada Mukaa detailed how life was hard because of having to leave the community: "My life with HIV has been a heck of a journey. Having to leave my community to go to [major cities] to learn the skills to be a survivor, with the stigma and discrimination that's out there around HIV/AIDS, it was hard". All participants in this theme had to leave their community because of issues related to acceptance, fear, or access to treatment and services they needed to survive. Participants (n=10) also noted that they did not want to return to their communities. This is highlighted by Elizabeth who said: "It's

not remote but it's isolated. If you don't have a car because there's nothing there. So no, I would never go back there. Plus, they don't have the medical and the healthcare, they don't have it". Blessing Otter discussed how it's unsafe because of a lack of healthcare access: "The current state of, no it isn't safe. Until the First Nations health catches up [...] I wouldn't consider moving back to a reservation. They're 25 years behind, minimum". This also highlights participant statements (n=13) that there is no treatment within their home communities. All 13 participants stated that there was no treatment for HIV/AIDS in their home communities, and this made it impossible for them to return home.

There were fewer participants (n=4) who said they returned home to their communities. However, even the decision to return home was not an easy one for participants, as they faced many challenges moving back to their communities while living with HIV. Dominique noted the reception upon moving home:

I made the decision to move back home to my home community, which was [community name]. When I did move back there, I made the choice that I was gonna be open and honest about my HIV status. That was one of the hardest things I had to do but I think I was well when I know when I left [the city] I was very confident when I did leave there that if anyone asked me a question or be ignorant towards me I would know how to respond in a positive way and I did do that. I did find people were labelling me right away. 'oh I wonder if he's gay, I wonder if he was gay all along?' Like those kinds of things. I really, I never answered them for a long time.

Ray of Sun also talked about how being home produces a feeling of safety, but about how the community struggles with the knowledge of HIV:

I feel safe in my community. Even though they struggle, some people struggle with HIV. It's still hard to face my community. I guess it's because I feel shame ya know but coming home was what I needed to do. That's what I did. My mom coming on

me always felt messy. They come and got me and straightened me up [laughter] because I'm grateful to be here today ya know.

There were also three participants who said they would return home if they could. However, the decision not to was about having limited access to care and services that prevented them from actually being able to return to their home community.

## Family

*Table 9: Coding for Family*

Nodes	Aggregate number of coding references	Aggregate number of items coded
<b>Family</b>	44	21
Not a good parent	7	6
Partner or Spouse	6	4
Supportive	4	3
Story of Family Member	2	2

\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

There were 21 participants who talk about their family during their stories (see Table 9). Substantially, these were negative in nature. There were overarching issues of trauma during childhood, stigma, rejection, and abuse that were experienced by both participants and by their families. This theme is highlighted by participants discussing how they did not have a good parent growing up. Charles Hill discussed how her mother was a drunk:

My mother is still alive but she's a drunk. She has a job and stuff. She's not a very good mother. I don't know, I love her still. She's got a lot of her own issues. She grew up in CAS [Children's Aid Society]. I'm not sure if she was in a residential school or not.

This is a familiar story; however Little Wolf highlighted the paternal abuse experienced as a child, leading to many of the issues faced today:

For me, I was a product of incest. My real father molested me from the time I was 4 till I was 14. I got pregnant by my real dad when I turned 14. My dad and his friends I should say, because my dad and his friends took turns on me all of the time. Me and my youngest brother. My youngest brother hung himself when he was 16. And that's what started me on the drugs anyways. I used to take them because they would take me away. I wouldn't have to think about what I was going through and my dad at the time, I was 10 years old. My dad was getting me high on heroin. So ya know and in his eyes, he used to tell me that it wasn't happening. I was imagining it. I was high on heroin – it wasn't happening I was imagining it.

Substantially, participants said their parents – many of whom had attended residential schools or had some other legacy of trauma happen to them in their lifetime – were addicted to drugs or alcohol.

However, not all comments in this theme are negative. Participants also spoke of their partners or spouses (n=6), with all six noting that they were supportive and helped them handle their HIV diagnosis. Family support was also mentioned by three participants in relation to other family members they had. This is shown in Irene's story:

I remember the doctor telling me that it was positive, I just remember feeling lonely it just seemed like my, right from my head to my toes I just felt empty and scared. I even thought about suicide. But it was my little boy because I was sitting there crying and it was him that come up to me and he was wiping my tears away. And he said, "I love you" and that's what changed my mind. I knew I had to, I had to be here for that little boy and so I just remember holding him and they had brought my aunt in to see me. And I had to tell her and she ugh, she was very supportive. I thank God every day for her. Because she helped me throughout what I had to do. By telling my family, my partner, she was basically the one that had to tell them because I was so emotional. And so when we got home to my place, I had to tell my partner and he knew I was getting tested because I had been sexually assaulted a year prior. And this is why I had gone to get tested. So, my partner, I remember sitting there crying and he didn't know what to say, but he had his head down and I thought it was gonna get up and walk out. But instead he



came and got up gave me a hug. And told me that he loved me and that we were gonna deal with this together. And I felt a little bit better. I didn't feel so afraid and alone.

In addition to support participants received from their family and friends, two participants discussed the loss of their immediate family members from AIDS-related causes. This had a significant impact on both participants as they tried to cope with their loss, while also coming to the realisation that they may also lose their own life to HIV.

## Culture

*Table 10: Coding for Culture*

Nodes	Aggregate number of coding references	Aggregate number of items coded
<b>Culture</b>	51	20
Creator	5	4
Elders	4	4
Language	1	1

\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

A discussion of culture took place in the majority of participants' stories (n=20). This theme talked about the importance of culture, the loss of culture, and how participants want to re-engage with their culture. Four participants also discussed the creator in relation to their HIV, while another four detailed the importance of elders to their life (see Table 10).

Participants talked about how there was a lack of disease and how we (as Indigenous Peoples) were one with nature, as highlighted by Many:

We didn't have no disease before. Now we look at these colonizers. And then they brought the disease and now we have to live with it. And our cultures, were not gonna exist in 500, us natives. Because they all want us to convert to their cultures. The world does not understand us natives. We're one with nature. Our mother

earth and we should not have all these diseases. I don't know. I feel sorry for our people.

Mukada Mukaa discusses the importance of teachings and culture in relation to understanding

HIV and becoming healthy again:

I think it's [HIV education] important because it's not being talked about as much as it is. We have a different way of educating people around teachings. I even had to learn about certain medicines to take. I had to learn about, a little bit more about the culture. I had to know who I was before I can help other people move forward. I also had to know what territory I was in and how they did their traditional teachings. Or shared their traditional knowledge. I never had a drum before. I was gifted a drum. And then there's a whole teaching process that happens so it was about teaching, it's about educating, it's not about taking possession or ownership over knowledge. But being able to share the knowledge that we obtain. Because the knowledge that we have is not ours. It's somewhere along the equator. And people have to realize about the teaching. But the respect, the love, being humble, the humility, courage. I think a lot of people are forgetting the teachings of the grandfathers about the difference. The tools that they left us. Ya know. And it's just that they forgot. Or they put them down and got distracted over years. And so it's time for people to start picking those teachings back up and sharing about HIV. Sharing about how did you end up being resilient? How did you move forward? What tools do you have? Because they're not ours.

This is again echoed by Elizabeth who said:

I didn't tell my elder that gave me my spirit name. I didn't tell him right away. I was ashamed to tell him. But I did eventually. I did go to sweats, and fasted in the bush by myself, went to a lot of ceremonies. My children were exposed to that too. I raised them that way. So yeah. Having all these agencies and support groups really helped me dealing with the HIV. The ceremonies even more.

Singing Medicine Water highlighted that Indigenous Peoples need to be proud of who they are and their culture. Through being proud of ourselves, we will be more resilient:

Be proud of your culture. Never hide it. Because the prouder you are, the more other people will be proud of it as well, ya know? They'll be able to identify and just embrace it. Embrace your culture, embrace your life. Ya we put such a thumb on people ya know. My niece who is aboriginal is darker skinned and I see her going through stigma, being treated differently and I always encourage her to find her culture and be proud of it. And she's like but nobody else is. I'm just like well

you don't have the right friends. And people grow up in stressful environments and some people can't deal with it, some people can, some people are proud, some people are not. I just tell my niece, love yourself that's what come first. And if you love yourself, you'll make excellent choices in life. Yeah. I'm as open and honest as I can be with people. I hope it helps them in some way. To know that they're not alone. Because I think that's the worst. People think that they're alone and when you find out all of these things are available it's just, they need a little coaxing and take the bull by the horns and go.

Participants believed that culture is essential to the well-being and healing process, but as noted above, most cannot access culturally competent services in relation to their HIV care.

This is compounded by the fact they have had to leave their communities. Leaving their community also affects negatively participants' ability to practice and learn their culture.

Overall, participants want to learn and practice their culture in a meaningful way.

## Education

*Table 11: Coding for HIV Education*

Nodes	Aggregate number of coding references	Aggregate number of items coded
<b>HIV Education</b>	64	25
Lack of HIV Knowledge	35	22
In community	14	12
Going to or speaking at Conferences	10	8

\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

There was a substantive discussion within participant stories about HIV education. This theme focused on education in participants' communities and more generally within the population. Twenty-five participants discussed issues around HIV education, with 22 noting there is a general lack of education around HIV (see Table 11). A lack of education extended to

understanding modes of transmission, risk factors, what HIV is, general prognosis, and treatment. This theme substantially tied in with stigma faced by many participants (to be discussed later in this section). Twelve participants detailed a lack of HIV education within their home communities, which led to issues of stigma. However, there were eight participants who said they had taken part in speaking engagements or conferences to help educate people about HIV and it also allowed them to share their stories of living with HIV. Ahiga highlighted how a lack of community education has led people to equate HIV status with being gay, rather than being an injection drug user:

They don't know nothing about it [HIV]. The kids are pretty dangerous about that. Not accepted over there. It's totally different on the reserve over there. They take you a different way. They don't think just about the drug, they think about a gay person and they think a lot of people know me and my wife have been together for 22 years and I never go. I got nothing against gay people anyway. I never go with gay people. I know it was drugs. I was injected. I know it's that. And they probably know about it and some of them they got all different, ya know. They think different. Some people they think whatever he's gay or. Some of them know I was doing drugs.

Further, Rick said that younger people in the home community lack an understanding of the different modes of transmission:

It's ok but I mean it's just maybe the young people won't understand. They'll have a lot of hate or scared eh. And they'll think that could catch it any way. Just by touching a door knob or something like that. Or even sharing a smoke or something. I don't know. They just don't have no clue.

Even when it came to people understanding their own risk of acquiring HIV, this appeared to be limited. Gray Wolf described it thus:

With my half-brother he tried at that time while he was using to bleach his needles and stuff and trying to keep clean, saying it won't spread or nothing but to this day I'm not really sure that did the trick. They say the clean needles is the safest way not cleaning them.

Elizabeth discussed how a lack of knowledge affected family life, detailing the subtle ways of trying to educate family about HIV so as to be accepted:

I was the one that was the drug addict, unfortunately lost my children, even before I was diagnosed. I was an alcoholic, drug addict, I lived in, I was homeless for a while, living in shelters for a while. Just a pretty bad life. So that's something I was dealing with. And I said now, now that I've got HIV that was the icing on the cake. I really topped off what I was already living, that life. So it was hard for me to tell someone that – they just didn't know what to say and their reaction was not allowing me to touch anything or throwing stuff away. They didn't know how to talk about it. It was hard for some. Because they didn't understand. I was told to put pamphlets around the house – I couldn't do that. I didn't want to keep reminding them I was positive and co-infected. I didn't want to. Some of the reactions would be they wouldn't like it. But I thought well if I put pamphlets out and just give them some awareness, because they were very ignorant. They didn't know what HIV was. They knew what it was, but they just assumed, well I was an IV drug user, but I could have gotten it from blood transfusion or my partner. But automatically it was because I was a drug addict. My own family had stereotypical things about me. Even though they were First Nation too. I'm sure – like I said their reaction was well it wasn't they made their judgment against me and well it's her life and she lived that life most of her life. So it was it was really hard.

Finally, Blessing Otter discussed how HIV education is not done correctly for Indigenous Peoples. The HIV education received was not done in a culturally competent way:

Umm done properly? There's plenty of education out there by white middle-aged healthy women, right? Which was basically doing the education at the time I contacted it, so it was probably 3 layers away from the world I live in. and I'd say that still holds true.

Many of the participants (n=8) discussed how they take part in speaking engagements or conferences about HIV education, where they can share their stories. Singing Medicine Water detailed how being able to share personal stories publicly has led a journey of healing:

So some people find it it's weird when I say I'm thankful I got HIV because I really am. It changed my life for the better because I was definitely on a down spiral at that point. And just knowing that you can help other people just through a conversation, and education, and information. And it's good to have family that are proud of you. My parents came to a speak for the first time; oh this was only

December, just the first week of December. It was AIDS awareness week and I happen to do a speak at the friendship centre. And I just said to my mom and dad would you guys like to go because it's close by and little tears they were just so thrilled that I had asked them. And then they were so taken aback afterwards because they never heard my story. They never heard my pain and my fears and stuff with HIV. So it opened their eyes. Because I never liked to share, I always say oh I'm doing fine. With them being older I never wanted to burden them with it. That's what I always thought I was: a burden.

Overall, participants in this theme are concerned about a lack of HIV education, especially for young people in their communities. They are concerned about the violence and stigma they faced as a result of a lack of education. Participants (n=8) also thought being able to share their stories was a fantastic way to educate others about HIV and the impact it has on their lives.

## Addictions

*Table 12: Coding for Addictions and Mental Health*

Nodes	Aggregate number of coding references	Aggregate number of items coded
<b>Addictions</b>	74	27
Drugs	51	23
Drinking	14	10
Drugs - types	5	5

\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

The theme of addictions came up in the vast majority (n=27) of participant stories (see Table 12). There were 27 participants who specifically discussed drugs in their stories. This ranged from their own personal use, through the use of drugs by others around them, to how drugs have had an impact upon them. Ten participants noted drinking excessively within their stories. This is highlighted by Bee Dabum who said: "My grandmother was a residential school

survivor. I saw a lot of drinking growing up. My mother was a speed freak in the 70s. She was doing injections. She smoked [drugs]. I think that's why I chose the coping mechanisms I did". Others noted how hard it was for them while they were on drugs: "I was hooked on medications pretty bad. And I was also into cocaine. So what happen is I got out of that for 11 years and now just trying to focus on myself. But it's been really hard". Other participants discussed how being diagnosed with HIV led to their drug use:

But in my eye's HIV was a death sentence to me so I kind of fell off the rails mentally. I got into addictions with drugs a lot more. And yeah, I just felt out of control. Like kind of lost. Once I got into the drug addictions I kind of lost everything. My self-worth, went through domestic violence with my partner, and restraining orders, and the whole kit and caboodle. (Singing Medicine Water)

Similarly, Brant noted:

I was on the right track, I found out I was HIV-positive, and everything was – I gave up. I was partying thinking I was gonna die right away. So I partied. I thought if I'm gonna die I'm gonna have fun before I die. Because I didn't know what HIV was. I come from a reserve and we don't talk – maybe we have like STDs and talk about it and school and everything, but I didn't know what HIV was.

Overall, the use of drugs and alcohol had a significant impact on participants' lives. This impact was felt from exposure at childhood to eventually developing dependences themselves later in life. All 27 participants discussed the use of drugs and alcohol as a coping mechanism from experiencing trauma or how they used them as a way to deal with their diagnosis.

## Sex and Sexuality \ Sex-Work

Table 13: Sex and Sexuality \ Sex-Work

Nodes	Aggregate number of coding references	Aggregate number of items coded
Sex and Sexuality\Sex-work	5	2

\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

There were five participants who discussed their involvement in sex work (see Table 13).

Many times, this experience was a violent one for the participants. Sammy discusses their time working in the sex trade:

I used to be a sex trade worker for 8 years. Downtown here in [city]. How I got into that was I was in a relationship and the relationship I got into with a gentleman who I thought loved me and I loved him, turned sour, turned into violence, like violence and physical. I let go of him because when I first seen him using, I said to him, well if you're gonna use how come I can't. That was how my attitude was. How come you can, and I can't. So, he gave me that first needle and first needle felt like heaven at first. Felt good but then you get sick and you want another one and then when the other one isn't there, I realize I have to go out and get money for that. Do some work because the boyfriend wasn't gonna cover that, so I used the sex trade. And then the sex trade went on for quite a few years. And I was supporting my habit, my drug addiction, my money from Johns and favours. I never had a pimp though, I always managed on my own and the other girls that were with me we managed to do it on our own and get out there.

It was also discussed how sex work posed health risks to individuals' health and how it can be viewed in a negative way by a sexual partner. Red Thunder Bid Man was disgusted after finding out their sexual partner had been involved in sex work:

Then I lost myself, got into trouble, had a girlfriend for a while before her. And then, you know, at the time she played it so well when she was around me, she wasn't smoking crack or sucking dick. Sorry. Being a prostitute. And then when I found out she broke my heart she was a crack smoking prostitute while dating me. You know how disgusting



that is? Then I started thinking I was kissing a 1000 dicks!? That's disgusting! So, and then some guy came up acting like he was her man and pushed me and I beat him to a pulp because he was supposed to be my best friend and he knew that it was my girl. And so, he called the cops on me because I broke his nose and I cracked his rib. And I went to jail. All because of a girl.

Sex work was a difficult topic for these participant that was filled with themes of violence and substance use. Many felt they had no choice but to enter into sex work or experience violence or as a way to help numb their pain to support their substance use.

## Homelessness

*Table 14: Homelessness*

Nodes	Aggregate number of coding references	Aggregate number of items coded
Homelessness	8	8

\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

There were eight participants who noted that they had experienced homelessness at some point in their life. Many of the stories around homelessness dealt with issues of stigma, as noted by Little Wolf: "When I became positive, I told my mom and dad, they kicked me out. They didn't want me in the house because they were scared to touch me, scared to use a dish, scared to go anywhere near me". Homelessness was felt in varying degrees, with six participants experiencing long-term homelessness and living on the streets or squatting. Two participants were able to couch-surf and for only a short period of time.

## Incarceration

Table 15: Incarceration

Nodes	Aggregate number of coding references	Aggregate number of items coded
Incarceration	5	4

\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

Four participants discussed incarceration within their stories. Three participants noted spending a significant amount of time in jail (over a year) and one participant had their partner discover their HIV status while incarcerated. Little Wolf's story about incarceration is shared in full at the participant's request:

I got out on parole, the last parole I got out. My real father got out of prison and I go back to the reserve and he's there. And he's the one I killed. I killed my real dad. I went to prison for one thing and the reason I went to the penitentiary in the first place is for smuggling cocaine [...]. I got a 3-year sentence for that. So, I was almost done my sentence, but I had 6 weeks left of my parole. So I come home to the native reserve, my mom said she had a surprise for me. So I said ok, I'll be home in 2 days. So, um, yeah, I got home and he's there [her real father]. So I took him for a walk in the back woods and I killed him. After I killed him, I called the police and told them exactly what I did, how I did it, I had no problem. Because of the proof that was there and everything that happened. Instead of me getting a life sentence I got 15 years. They charged me with involuntary manslaughter. But ya know what I mean. They couldn't, I guess, the way they looked at it that I waited too long. I guess in the eyes of the justice I waited too long. I said to them, at the time that it happened I was 14 when the last time he touched me, that's when I got pregnant and then the community found out about it. And he had to leave the reserve because there were men that were gonna kill him for it. So he ended up leaving the reserve and then when, after that my mind was never the same. I was never right after that. That's when I got involved with the drugs. [... when I was] in the penitentiary there was no problem there. You have native sisters in there, so I became [a member] of native sisterhood. And I started educating other women coming in and other women who had HIV and it didn't matter if you were a native

or non-native. It was all women that had HIV so I also got involved with another organisation that would come to the penitentiary and talk to me. Ya know. I became actually a big leader inside. The native movement of women with HIV. I got, I published a couple articles in the newspaper about it. I started working towards just different things. And then I got the 15 years. And that's when I really tuckered down. I ended up in prison again, I got my education, I got my high school diploma in prison. I got – there was a lot of different things I did in there. I got a hairdressing license in jail. I got a lot of different things. I didn't just sit around doing nothing. Because there's a lot of different things you can do in there. But it seemed when I was in there, I ended up gaining massive weight from one of the medications they had me on. And there was a guard in there that used to pick on me all the time about my HIV status and about my weight at the same time. Head of apes as they called her. And after doing 5 years, I snapped, so I tried to kill her. Now sitting in segregation I've been sitting in there 6 months in Ontario. I'm going through court now for attempted murder on a corrections officer. Ya know. I had a lot of backup. A lot of the guards knew what was going on in there and they had to testify on my behalf. So the judge, how ironic it happened to be. She was a large woman, 400lb woman in Kitchener, and she was reading the synopsis and all the stuff that was going on and she wouldn't give me anymore time. But I will give her a 15-year sentence which will run concurrently with her sentence now. So that means on my record it shows that I did 30 years instead of 15. And then they shipped me to [location]. Because now I couldn't be in the same prison as her because it was a conflict of interest. So they shipped me all the way to [name of prison] out there. That was a hard piece of time. There's a lot of big native women out there. And my skin is a lot lighter than a lot of the native women even though I'm full native and they don't accept that out there. So I took some severe beatings out there. I almost died out there once. But it made me a lot stronger of a person. I come back now, and I've got 2 years left on my sentence right now. And now I've been drug free for 5 years. Drug free. I'm still everyday working on it. But I'm clean now for 5 years. I've got my HIV under control. Taking my meds every day and I've got a doctor that actually gives a fuck. Ya know what I mean.

Incarceration as a theme was difficult to highlight given only four participants discussed it, however, the stories that come out of the theme are powerful. The stories tell of a system that the participants find to be stacked against them.

## Life- It's been hard

*Table 16: Life: It's been Hard*

Nodes	Aggregate number of coding references	Aggregate number of items coded
Life - It's been hard	10	5

\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

There are five participants who specifically mention that life has been hard for them. This theme isn't specific to any one issue. However, it is important to highlight that participants saw their lives as hard to live and detailed the challenges they face. Ray of Sun couldn't even express how life was hard, but just said it was "Ya know. All this time. Since I was diagnosed. It's been really hard. And I don't know how ya know. How other people, I don't want that for ya know. Because it's really coming fast". However, Many stated that: "Life has been hard. I lost my fiancé. I lost everything. But she knew I was already affected". For Yvonne, life has been hard due to finances:

Lots because I don't have like they said my life has been it's hard I can't buy groceries as much as I used to. Like I used to buy \$400 worth of groceries so I could live for the month. Now I only buy like \$15-20 and then I have to go and eat at the soup kitchens and sometimes soup kitchens are not all that great. So I don't eat some days. So whatever I have at home. A can of soup or something, I basically live off whatever I have if it's just plain macaroni with ketchup. So for me survival right now is um hard.

Given the other themes described in this research, having additional issues and hardships can be insurmountable for some participants. The level of frustration expressed during the stories are indicative of not being able to fully express the hardships participants actually experience.

## Death

*Table 17: Death*

Nodes	Aggregate number of coding references	Aggregate number of items coded
Death	11	6

\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

Participants (n=6) also described the death of loved ones and the impact that had on their lives. Five of the participants described having loved ones die due to HIV-related complications. Two participants also discussed how loved ones also lost their lives to drug use. Participants detailed the struggles they experienced as a result of these losses and how losing someone to HIV made them scared of dying themselves.

## Discrimination

*Table 18: Coding for Discrimination*

Nodes	Aggregate number of coding references	Aggregate number of items coded
<b>Discrimination</b>	80	25
Stigma	67	25
Stigma - Violence	6	4
Homophobia	3	3
Racism	10	9

\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

As themes have already revealed, discrimination played a large part in many participants' stories. There were 25 participants who described 67 instances of stigma they faced, all because of living with HIV (see Table 18). Four of those participants described violent acts committed against them as a result of their status. Gray Wolf detailed how stigma can turn into violence:

On the reserve there is still discrimination today and our pal just passed last month in July. These young guys [...] decided to get drunk and drive away the pow wow sacred drum. They left and no more than 10 minutes later they decided to do a second round and revved the heck out of their motor and muffler sound and now that really intimidated a lot of the campers [...]. They started to drive towards the exit, but I guess the one young guy that was driving noticed me. He backed up and started to drive towards me. I got off the road because I knew they were drinking obviously and there was another big guy who was a friend of mine, stood right on the road and this young guy looked at me and he says what the fuck do you want? I said I don't want nothing. I said what are you doing driving around the powwow grounds and he just told me to shut the F up again. He told me to get the F off the road and I wasn't even on the road. There was a guy standing right in front of the truck and he's telling me to get off the road. And then he just tried to give me a swat. I had a smoke in my mouth. He tried to swat my face, tried to hit me in the face. He knocked my smoke out of my mouth and he opened his door like he wanted to get out, he didn't. Then he just yelled at me, we don't want your AIDS in this community! So I guess he thought that was gonna hurt me in some way or something. I'm guessing he must've picked that up from his family, which is in the council today. Which is sad to see. I don't let them bother me. I do know there are some on the reserve who are educated, and they know how healthy I am today.

All 25 participants noted that stigma focused on a lack of education about how HIV is spread and the risks around it, as previously discussed. This stigma led participants to be rejected and threatened, often with violence. This was especially true if people found out from others that a participant was HIV-positive.

There was also a discussion around homophobia in three of the stories. The most prominent aspect was how being HIV-positive meant that a man must be gay. This came out in

the story of Ahiga (part of which appeared earlier in section 13: Education to illustrate a different point):

What's going on I was living in [community], and they don't know I have nothing about it over there. And my common law she doesn't know she had it too. She was incarcerated and they wanted to go test her in jail and she find out that. And the community they really don't accept me because they know my common law don't do drugs at all. They know I do drugs. And that's how come we had to move back. Went back to [community] and had to move back to [the city] because it's got nothing on the reserve for us. Yeah, we have to move here. To stay here in the community. They don't know nothing about it. The kids are pretty dangerous about that [being HIV+]. Not accepted over there. It's totally different on the reserve over there. They take you a different way. They don't think just about the drug, they think about a gay person and they think a lot of people know me and my wife have been together for 22 years and I never go. I got nothing against gay people anyway. I never go with gay people. I know it was drugs I was injected. I know it's that. And they probably know about it and some of them they got all different, ya know. They think different. Some people they think whatever he's gay or. Some of them know I was doing drugs. Yeah, that's what they think over there. That they not gay that's what they think. I was talking about my friend in [city] to go do some, some help people over there on the reserve. Up north I'm talking about. To educate the people and tell them. A lot of people they don't know nothing about it. A lot don't think it's, they don't know nothing. They just think about gay people, ya know. It would be nice if people know about HIV. Well I wasn't comfortable to live there because the people, some of them are pretty dangerous and for my safety ya know. Well my safety for me and my wife. I decided to come to [the city].

Nine participants also spoke about their experience with racism. This mainly focused on participants (n=7) discussing how they felt their medical professionals discriminated against them because they were Indigenous. Amaya stated:

I'd want them to know there's stigma. There's stigma even when you're native. There's a lot of stigma. So you're judged right away. So I'd like to say not in all places, but I can see even the doctors that know me, feel that I'm just sliding back to whatever their stereotypical Indian ways are. So that's kind of disappointing and disheartening. But I don't feel there's enough support. And I don't feel there's enough of a community that I know of that's really out there to support us and advocate for us and fight for us.

Overall, participants felt as though their race played a factor in the care they received or didn't receive. They felt as though they were second-class citizens in accessing care as a result of their race.

## Trauma

*Table 19: Coding for Trauma*

Nodes	Aggregate number of coding references	Aggregate number of items coded
<b>Trauma</b>	57	23
Residential Schools	12	9
Taken from community	11	8
Colonisation	7	5
Colonisation - Christianity	6	4
Violence	14	8

\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

Participants (n=29) described, throughout their stories, various forms of trauma that they and their loved ones experienced (see Table 19). There were nine participants who either directly attended a residential school or had a parent who attended a residential school. All of these stories detailed instances of abuse and the coping mechanisms that resulted. This included previously discussed themes such as bad parenting, alcohol, or drug abuse. Ray of Sun noted that residential schooling made her family angry and harsh: "My grandmother went through. I guess my father. My father too. But that was just being passed down? It made my



family harsh. I guess angry or something ya know". For Singing Medicine Water, it was dealing with the PTSD of watching the violence between father and mother:

I know my dad was a residential school survivor and was a very angry man. But now that I know that I can understand where he came from because my dad was very abusive to my mom. Even as a baby I have witnessed my dad beating my mom and all I remember is this curdling scream and blood everywhere. And to this day I still have PTSD from that. It's only diagnosed 4 years, yeah about 4 years ago when I started seeking therapy because I was asking her. I always have to either turn the TV off, walk out of a movie, if there's violence towards women. If I see a woman, even a hand going up, I just I can't take it. And then I went through the therapy and it ended up being that I had witnessed my dad licking the tar out of my mom and this is what caused my issues.

Nora noted the personal toll residential schools took:

Right after residential school. I grew up in Winnipeg. I was apprehended from my home after coming out from residential school. In Winnipeg it was very easy for me to get pills. I was dead; valiums, pain pills, I was – at an early age. I even got into the huffing too. Because I ran out of pills, so I need something. And then the drinking came. So that was my way of forgetting. I wanted to forget everything. I – the way – the residential school they've done a lot of damage to me. I can feel it it's gonna come up, but it won't come up right now. I can feel it right here coming.

However, for Dominique it was a subtle difference and the indoctrination of Christianity that affected them and their mother:

My mom went to residential school so that – I think that for me was a big one. Because I never really understood why my mom was the way she was. My mom had 15 kids and I was the 14th. [...] in the family and then there's a sister below me. But I never understood why my mom was the way she was. Because we were raised with my dad and my dad was a Frenchman from Quebec and we were raised in a non-native community, but we spend a lot of time with native people. But in the sense that it – the way it kind of plays out in my head – is that it was a lot of alcohol was involved when we were interacting with those people. And my dad was a musician so he was really popular at parties because he could play the violin; my dad played everything. And I guess he was the life of the party and whenever I was a little boy and spending time with this aboriginal family and I never knew they were aboriginal. I didn't find out until I was an adult that they were aboriginal. But I said, boy we used to spend a lot of time there and we never used to see our

parents it was just us kids off on our own away. And then we'd get back in the car, probably my parents were drunk, we never even knew but they would drive us, we would go back home. So yeah that part I come from I guess the traumatic part that happened was the alcohol because right up until I was 6 or 7 then my mom would find the Lord and I'd call it Christianity. Because it was just another form of alcoholism. Because even though my parents had become Christians, again we were submersed to the point where we were neglected because it all became all about God and there wasn't as much focus on us and again, we were neglected. So for me that whole transition from having alcohol parents to Christian parents really did a number on. And I never understood why my mom wasn't the greatest parent and neither was my dad. But it wouldn't be until years later that I learned my mom went to residential school and why that was because I didn't realize herself didn't have the parenting skills because she was taken away from her mom and in residential school for 8 years I know for sure, it may have been 10. But 8 years I know for sure because I've looked in the books at the TRC [Truth and Reconciliation Commission] has. They have the books and I looked in the records and I found my mom's name in there along with my aunts, and I looked how long they were in residents' school. So I know 8 years for sure, but it may have been 10, as many as 10. But in that time, my mom never got to see her mom a whole lot. Never got to spend time with her, but she had managed to maintain her language. Her and my aunt because she tells us that when she was in residential school, they had what they called the secret language club and so on recess or when they got breaks, they would go off away and they would always make a point of speaking our language. They got caught a couple of time she said. She said they got a hand slapped and that she said. For the most part that's how she managed to maintain her language because I know a lot of people that lost it and she was lucky enough to kept it. And she did learn a lot from my grandma because I know my mom talks when she does stuff, she would always tell us your grandma that's what she used to do, that's what she taught us. My mom is very traditional even though she says she's not. She's against anything like practicing sweat lodge or doing smudging or anything like that. My mom is really against that because of her being a Christian but I always thought it was because she became a Christian from being an alcoholic becoming a Christian, I thought it was from that but when I started hearing stories of other survivors, I realized my mom was saying the exact same message that the other survivors were saying. Exactly. Almost to the point. And a lot of it came from residential school telling them those are evil ways. And a friend of mine told me of this image, and my mom described something similar to it. This image of they used to see on the principal's wall of its kind of looked like snakes and there were white people going to heaven and native people were going towards hell. And my mom described something like that my friend describes it almost in detail. And I said, I remember my mom talking something

she used to see in her principal's office she said. And they would make references, "do you want to go here? Or do you want to go there? And if you want to go there, if you continue doing what you're doing, that the way you're gonna go. But you need to listen, listen to what we're teaching you. So you can go there." And my mom used to talk about that fear she had, and it really was ingrained in her because every time it came to talking about traditional things, it was almost like a fear like I don't want to hear it. Don't talk about it. I don't want to hear it anymore. And my mom – I respected her for that. I never pushed her back. It wasn't until I found out that she went to residential school, which wasn't until about 2005 or 2006 they had a 100-year anniversary. And while I was there, they had all of the books from across Canada out because they were doing this memorial and they said, ya know they said feel free to go through the books, so I started looking through them and that's where I found my mom's name in there. I thought wow I said wonder why mom never talked about her experience of being in residential school? And a woman approached me she said, did you just find out that your mother went to residential school? And I said yeah. She said well there's lots of people that are finding this out. She said because this is the first time, we're making these things public. And I said but I – I'm kind of in shock I said part of me understands why my mom is – it's helped me to understand but at the same time I'm feeling in shock because I'm trying to make sense of all this stuff because it helps me better understand why my mom was the way she was. And she said when you go back and speak to your mom don't tell her that you know. Try to bring it up in a conversation because you might just re-traumatize, maybe the reason she never told you is because she had bad experiences there. And so I just happened to talking about [community name] which is where she went and that's when she said oh that's where I went to school. And I said well how many years ago was that and she said well just when we were just little kids. And she said, she just talked about, she started talking about it very general, generalizing it, but as I started to hear her stories I began, sharing some of the stories with my mom. That's when my mom started sharing stories about what happened to her. The one thing that they did when they did the pay-out was, they were giving people the option to tell more or diving deep in the story and I had asked my mom. My mom actually didn't want to take the money when she got the pay-out, she was actually going to give it back to the church because her church was telling her that you're punishing God, if you take that money, you're punishing God. They said why don't you just sign it over to us. Like give us all the money and we'll take care of it. And my mom was about to do that I said, mom that's not what that's for. They're trying to exploit you. I said that it's not a punishment to God they're just trying to make restitution and there's no amount of money that will never be able to do that right? I said, but I said, giving it to them is not the way to go. I said, of course it's entirely up to her but I said but you can't let these people take

advantage of you. And so she didn't want to take it and she ended up taking it and then they asked her if she wanted to dive deeper into and talk to a lawyer and she'd get paid for whatever different things in her story. And she chose not to. She just didn't want to go there. And I don't blame her because I think – when I've heard some of the things, she's said she generalizes about them, but I often wonder if it didn't happen to her cuz she's always talking in the third person, this happened to so and so. She told this one experience where these boys had tried running away and they got caught. She said they were all brought into a room and put in a circle and they were put in the middle and they had their legs broken in front of them. And my mom never made any light of it, but I said mom that's trauma I said that would be traumatic for you to see it. They're making an example of these 2 boys and I said it's just not right. I said those are the kind of things they'll never be able to pay enough for all of those experiences that happened to you. But she also talked about the good things that happened to her. My mom is a very good quilter, she's a very good seamstress and she learnt those things when she was there. But again, the one thing I always say to her is I tell her you know, mom, whether you want to believe it or not you're very traditional. And I said because everything you do whether it's cooking, which she's always cooking wild meat, and her and my aunt when they used to get together, they used to, around hunting seasons, they'd gather up all this wild meat and have a cooking fest. And my mom and them would speak the language and my dad would be sitting in a room and my dad would get so frustrated with them because they'd be speaking the language and once in a while, he'd hear his name and he'd say what are you saying about me!? And they'd laugh. And she's said oh I'm just telling her a funny joke and your name just happened to come up and we can't translate it into English because it wouldn't be as funny. Those kinds of things really helped me get to know my mom. And my mom actually shared with me my mom was – my grandmother was a medicine woman. So that really got my curiosity. I'm actually trying to find out more about that because I do - I speak a lot with this woman from my First Nation she's an elder there and she knows my mom really well. And she knew my grandmother I guess, and I tried to ya know learn more about who she is because they actually have her in the history books because she had a lot of kids. My grandmother had a lot of kids. And they have pictures where she was one of the – our family was one of the families that the Queen – we got to meet with the Queen. So my mom was just a little girl at the time. But they got to meet with the Queen, and they took our picture with them. So she's kind of in the history books. And I look at that and I'm like wow, my grandmother must have been a really important woman in the community, because I know my grandfather was. He was a famous person they actually have some of the things he made in the (name of town) museum. And it's you know those kinds of things I look back on and I think wow, we've got to be proud of who we are as aboriginal people and

learn more about those things. Yes, we had all these terrible things happen but there's so many things I'm sure we could go back and be proud of who we are. And I think that's where I want to – I guess the work that I do is about advocating for First Nation people on reserves and off but more of a focus on reserve is I want to look at those things we had and return to those values. Including we never would've banished people with HIV we never would've if anything we would've taken care of them. Because of colonisation, residential schools, these kinds of things that happened to us we just forgot those things. We gotta make a return back and bring those teaching back. And bring those teaching back, there's where we need to go.

The impact residential schools had on participants was immense, whether they experienced it directly or inter-generationally. It had a definite impact on how participants were able to cope with living with HIV.

A total of eight participants noted being taken away from their families and communities while growing up. Mikey stated: "I was taken from my community. I was taken when I was 10 or 11. Um ever since then I've been involved in Children's Aid Society. And then from there to the streets, I guess". Charles Hill discussed a turn to alcohol because of childhood experiences and being taken by the Children's Aid Society:

My parents were ex-alcoholics my mom and dad well my father they met in a group home I guess they fooled around one night and yeah, I guess that's how I got conceived. And then yeah. I don't know. I never met my father until I was 20 and then he passed away shortly after I met him, he was sick I guess from yeah know not taking care of himself. Then my mother is still alive but she's a drunk. She's alright. She has a job and stuff. But yeah, she's I don't know. She's not a very good mother. I don't know I love her still. But I don't know. She's got a lot of her own issues. I think she. Yeah, she grew up in CAS. I'm not sure if she was in a residential school or not.

Being taken from family and community had a clear impact on the eight participants, all of whom struggled with addiction issues throughout their lives.

Eight participants also detailed significant violence experienced. This violence mainly came in the form of domestic violence (n=6). Singing Medicine Water stated: “Once I got into the drug addictions I kind of lost everything. My self-worth, went through domestic violence with my partner, and restraining orders, and the whole kit and caboodle”. Sammy detailed how life went from domestic violence to drug addiction and then to sex-work:

How I got into that was I was in a relationship and the relationship I got into with a gentleman who I thought loved me and I loved him, turned sour, turned into violence, like violence and physical. I let go of him because when I first seen him using, I said to him, well if you’re gonna use how come I can’t? That was how my attitude was. How come you can, and I can’t? So he gave me that first needle and first needle felt like heaven at first. Felt good but then you get sick and you want another one and then when the other one isn’t there, I realize I have to go out and get money for that. Do some work because the boyfriend wasn’t gonna cover that, so I used the sex trade. And then the sex trade went on for quite a few years. And I was supporting my habit, my drug addiction, my money from Johns and favours. I never had a pimp though, I always managed on my own and the other girls that were with me we managed to do it on our own and get out there.

Violence played a significant role in these participants’ drug addiction and relapse into addiction.

There was the common theme of feeling worthless as a result of the violence.

## Criminalisation

*Table 20: Coding for Criminalisation*

Nodes	Aggregate number of coding references	Aggregate number of items coded
<b>Criminalisation</b>	16	9
Non-Disclosure of HIV status	10	7

\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

Nine participants discussed, in varying ways, the criminalisation of HIV and the impact that had on them (see Table 20). Many's ex-partner said that the participant should be in jail because of failing to disclose HIV status, even though that status was unknown at the time. As a result of rumours by the ex-partner, the participant lost everything. Blessing Otter indicated personal confusion about responsibilities when first diagnosed saying: "Confidentiality around your sexual choices and behaviours. Possible criminalisation. Loss of opportunities, loss of friends, loss of quality of life, to name a few". Participants also noted fear of having to disclose to professionals and the stigma attached to it:

I was really scared to tell them. And I knew that I had to. I had to tell the dentist. I had to tell those people. At least I felt I had to. Because I thought if I don't, I could be charged for ya know. I could be charged for attempt murder or something like that. I could have criminal charges. It was difficult for me to tell even the professional people in my life. So all I did is walk around with fear in my heart and my mind. I was just always scared (Elizabeth).

There were seven participants who, as a result of stigma and lack of knowledge of their requirement to disclose, failed to tell people their HIV-status. In hindsight all participants now believe they should have disclosed their status.

## Participant Recommendations

*Table 21: Participant Recommendations*

Nodes	Aggregate number of coding references	Aggregate number of items coded
<b>Recommendation</b>	<b>111</b>	<b>26</b>
Education	25	17
More cultural Programs	16	13
More access to treatment care	11	9
More funding for Programs and Services	9	7
More funding from ODSP	9	7
More Programming	7	6
Harm Reduction	6	6
Do as people ask	5	5
Get Treatment	4	4
Deal with Crisis in the North	3	3
More programming for women	3	2
Prep for people coming home to die	2	2
Homelessness	2	2
Jail	2	2
Jurisdictional Boundaries	2	2
Picking up needles	2	2
Advise	1	1
Safe Place	1	1



Prevention	1	1
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\* major theme (dark-gray), sub-themes (light-gray), and the nodes which inform them (white).

Participants were asked to provide recommendations in relation to improving access to services or treatment or anything else they felt they was lacking. Twenty-six participants provided feedback on recommendations (see Table 21) they believe would best serve them and others living with HIV/AIDS. More than half of participants discussed the need for education in relation to HIV in communities and for their people. Bee Dabum stated: “And we need to also educate and give them the tools to not get infected”. Others talk about how we must conduct education from a cultural perspective: “it would benefit the culture and other communities to get the knowledge and access out here” (Many). There was a pressure from participants to urgently develop education to inform the younger generation: “I think it’s important to share so the younger ones can hear. Yeah. It’s just to share so the at-risk can hear and even out of 100 if sharing 1 person will hear and that 1 will tell another” (Brenda). There is an evident desire from participants for greater awareness and education around HIV in communities and beyond.

Participants asked for more cultural programming within HIV service organisations. Nora said “More native. Strictly for native people.” When they were asked what more they want to see when it comes to programming, Bee Dabum said “think there needs to be, if we could incorporate healing with more culture it doesn’t just have to be about taking your HIV meds”. This was further developed by Amaya who said “I would like to see our whole body included in our medical whatever treatment. And have it right there”. There was a clear desire from 16 participants, to see the whole body being treated with access to cultural programming.

There were 13 participants who said there needed to be greater access to treatment and care for Indigenous Peoples living with HIV. This is especially true in the north because, as Red Thunder Bird Man noted, the government needs to fund services beyond Toronto, and they should not be forced to go there for essential access and care. Little Wolf noted: “More clinics. More accessible HIV clinics. Easier testing, the testing that they have now, you can prick your finger and dot, more rapid testing for each clinic”. This also fed into the need for more funding for programs and services. Skywalker said: “So the services, they’re there, but there’s not as much money as there used to be”. This is also highlighted by Brenda who said:

Because see the funding runs out and that’s what we hear all the time. Oh we don’t have the funding. What is it is they run it into the frickin’ ground. No one is consistent enough or wants to follow through on it. So after a while you don’t want to play with them no more.

Funding was a concern with many participants, who also brought up the issue of a lack of funding through ODSP (n=7). Participants discussed a lack of ODSP funding, which translates into ODSP not providing participants with enough of an income to meet their needs. This lack of income placed many participants in tight financial position with all seven having to make choices about paying for basic necessities they required on a month-to-month basis.

Participants also stated that they would like to see more programming, generally (n=6). This would include more HIV services and programs in the north. There were six participants who also discussed the need for harm reduction. Skywalker said: “What they shouldn’t do to protect themselves. Like strategies. Harm reduction. Like certain strategies like always have, even though you don’t plan on using, always have some clean, adequate supplies”. As Copper Bic said, the lack of safe injection sites places people at risk: “Safe needle injection places. Yeah.

I think that's one of the biggest things because when we're in the riverbanks or in the alleyways we do it fast we don't know if we're mixing up peoples' needles". Harm reduction was seen as an important step in trying to combat the spread of HIV in participants' communities.

### Freedom of Information Requests

The request for information was submitted to Health Canada in December 2016 and answered in September 2017. The responses provide insight into the numbers of people accessing treatment and therefore in need of services in the province of Ontario. The responses also allow for an understanding of what funding the government is providing to communities and other First nations organisations within the province.

### Access to HIV Treatment in ON by First Nations people

In December 2016, a request for the following information was made: "Requesting information from the past five (5) years for the following: How many 'status Indians' who fall under Non-Insured Health Benefits program have been diagnosed or are accessing treatment/service for HIV/AIDS within Ontario?" This request was answered in September 2017. Based on the response, a relatively accurate picture of the HIV epidemic within First Nations communities in ON can be drawn. There were a total of 427 status First Nations people receiving treatment for HIV within the province (see Table 22). This number comprises 316 people who are registered to a First Nation in Ontario, with the remaining 111 being from First Nations outside the province of Ontario but accessing treatment within the province.

This number while lower than estimated epidemiological figures posted by both the provincial and federal governments, only accounts for status First Nations people. In 2008 (the

last date data are available) Indigenous Peoples in Ontario accounted for 853 of the people living with HIV. Therefore, half of this number is already made up of status First Nations people, this does not include non-status, Inuit, or Metis peoples. Additionally, this number is going to be larger given persons who may not be accessing treatment, those who may be accessing treatment via provincial or private insurance plans, and those who are unaware of their HIV status.

*Table 22: Number of First Nations accessing Antiretrovirals in ON, 2012-2016 inclusive*

Description	Total
Total Ontario First Nations Band Members	316
Total Non-Ontario First Nation Band Members	111
Total all First Nations receiving Antiretrovirals in Ontario	427

#### Funding allocation for Indigenous HIV Treatment, services, and programs in First Nations in ON

At the same time, a request was made for the following: Requesting information from the past five (5) years for the following:

- 1) What funding has been provided for ALL First Nations people in ONTARIO (Excluding Inuit and Métis peoples) for services and programs for people living with HIV/AIDS? This should include direct health care needs: (a) payments made for HIV medications (HIV antiretroviral HAART), (b) visits to specialists (infectious disease experts, counselling), (c) HIV diagnostic and ongoing routine testing, and (d) programs for people with HIV/AIDS (i.e., education, prevention, intervention), including any other services related to providing this care (i.e., transportation costs).

- 2) What funding has been provided to First Nations Reserves for people residing on Reserve in ONTARIO for services and programs for people living with HIV/AIDS? This should include direct health care needs: (a) payments made for HIV medications (HIV antiretroviral HAART), (b) visits to specialists (infectious disease experts, counselling), (c) HIV diagnostic and ongoing routine testing, and (d) programs for people with HIV/AIDS (i.e., education, prevention, intervention), including any other services related to providing this care (i.e., transportation costs).
- 3) What funding has been provided DIRECTLY to First Nations Reserves in Ontario for treatment, services and programs for testing and people living with HIV/AIDS (i.e., what money has been allocated to each of these communities for preventing and treating HIV/AIDS)?

This request was partially answered in the response. Substantially, it shows that approximately 250 individual clients accessed antiretroviral treatment each year from 2012-2016, at an annual cost of approximately \$1.4 million (see Table 2 for a breakdown of clients and total payment). The department noted that it paid for 426 unique individual cases across the five-year period<sup>19</sup> with a total monetary contribution of \$7.26 million. Based on these provided numbers, the Federal Government is paying, on average, \$5,863.29 per year for an individual's ART. Outside of funding considerations, these client numbers could also demonstrate that people who may

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<sup>19</sup> There is a one-person discrepancy that cannot be explained by the data provided. However, since it is revealed in the answers to two different questions (the first being about receiving treatment; the second being about the payment for treatment) the most likely explanation is that somebody may have a different funding source.

require ongoing treatment are no longer receiving it given the five-year distinct client total but substantially lower distinct client total each year.

*Table 23: Utilisation of Antiretroviral Access in ON by cost between 2012-2016*

Year	Number of Clients	Paid Annually
2012	239	\$ 1,403,876.47
2013	249	\$ 1,408,828.71
2014	250	\$ 1,460,509.62
2015	252	\$ 1,517,907.77
2016	249	\$ 1,473,500.23
	Distinct Client	Total Paid
5 Year Total	426	\$ 7,264,622.80

The request also dealt with all funding for services and programming related to HIV in First Nations communities, as per question 3 noted above. This funding could have been provided directly to a community or larger organisation that provides education, services, or programming to community members. The response detailed funding to three different groups, the first being directly to bands and council<sup>20</sup>, the second to tribal councils<sup>21</sup>, and the third to

<sup>20</sup> Band Council refers to the council of a band as defined in the *Indian Act*. There are 126 Bands in Ontario.

<sup>21</sup> Tribal Councils are central, advisory bodies that represent First Nation communities in specific geographic regions of Ontario. Councils are comprised of a Board of Directors, which generally includes the First Nation Chief and one additional representative from each member community. Member communities of a tribal council generally have common interests and band together to provide enhanced services to their citizens. There are 15 Tribal Councils in Ontario (Ontario Library Service - North, 2018).

political territorial organisations<sup>22</sup>. There were significant funding increases between 2011 and 2014 (see Table 24), especially when it came to funding directed to First Nations bands themselves. However, between 2014 and 2016, there has been funding stagnation. Between the years 2013/2014 and 2014/2015 there was just a 0.79% increase in funding. More substantially, between the years 2014/2015 and 2015/2016 there was a 0.46% decrease in funding for HIV services and programming, with just over \$4,000 removed from the direct-to-First Nations band envelope. Given that there are 126 bands in Ontario, if this funding were allocated equally across all bands (which it is not), it would amount to \$7,920.27 in funding being available directly for communities to deliver HIV services and programming in their community.

*Table 24: Funding provided for all First Nations people in ON for services and programs for people living with HIV/AIDS, including direct health care needs between 2012-2016*

Payment Route	Years				
	11/12	12/13	13/14	14/15	15/16
Direct to FN Band	\$163,100.00	\$293,778.00	\$ 403,129.00	\$ 411,000.00	\$406,451.00
Tribal Council	\$ 19,550.00	\$ 3,733.00	\$ 3,733.00	\$ 3,733.00	\$ 3,733.00
Political Territorial Org	\$587,771.00	\$578,605.00	\$ 587,771.00	\$ 587,776.00	\$587,771.00
Total	\$770,421.00	\$876,116.00	\$ 994,633.00	\$1,002,509.00	\$997,955.00

<sup>22</sup> Political Territorial Organisations (PTO) are secretariat bodies that represent large groups of First Nation communities in Ontario. Each PTO serves its member communities in various capacities, mainly through political leadership and advocacy, education, jurisdiction and negotiation, lands and resources, intergovernmental affairs, health, etc. There are four PTOs in Ontario, servicing more than 100 First Nation communities. The governing body of each PTO is made up of an elected leadership, including Elders, youth and regional advisory councils, as well as a Board of Directors. The four PTOs are the Anishinabek Nation - Union of Ontario Indians; Association of Iroquois & Allied Indians; Grand Council of Treaty #3; and Nishnawbe Aski Nation (Ontario Library Service - North, 2018).

## Conclusion

Through the use of storytelling, 17 major themes were developed to help create new knowledge about the HIV epidemic facing Indigenous Peoples in Ontario. Substantially, they reinforce previous findings of the impact of colonisation on Indigenous Peoples health and well-being. This research clearly shows a connection between traumas experienced by First Nations peoples and greater incidences of high-risk behaviours, particularly IDU, thus leading to higher rates of transmission of HIV and Hep-C. These findings will help to further our understandings and expand on already-completed research. This research highlights a clear lack of funding being provided to First Nations communities to support education, programming, and care around HIV/AIDS. This can be framed within an ever-evolving attitude by the Canadian government as not wanting to deal with the Indian problem and also by ignoring the exceptional nature of HIV and the impact it has within this high-risk population. Indigenous Peoples in Canada have historically been, and continue to be, an afterthought of the federal government, whereby inaction is the main mode of continued colonisation. This has contributed to a higher rate of transmission, especially through a lack of knowledge around HIV transmission risks. This research also informs new discussions about the quality of HIV programming for Indigenous Peoples, how funding can be a silent impact on how people receive care, and will provide clear participant-driven recommendations about how the government, AIDS service organisations, and communities can work to better support and treat people living with HIV in Ontario. These recommendations relate significantly to both macro, meso, and micro policy creation. Participants highlighted the impacts of macro colonial policy



through their experiences in residential school and the 60s scoop, but also how their lives were and are shaped through living on reserves and the low standard of living and healthcare provided on those reserves. Participants also discuss how healthcare policy ignores their needs and wants, often imposing a western understanding of healing and healthcare onto them. Participants mention acts of racism and discrimination while accessing the healthcare system, all of which are symptoms of meso level policies failing to ensure equitable access and care for this high-risk population. Finally, participants across the study discuss a lack of micro policies which would help them overcome many of the challenges they face, including access to holistic, culturally based healthcare offered in and by their communities.

## Chapter VII: Discussion

### Introduction

The use of Indigenous worldviews and ways of knowing has been vital in developing this research project, as it has allowed for the use of Indigenous methods to create new knowledge within the HIV/AIDS field while also contributing to our understanding of policy formation and application in this area. The wide-ranging freedom provided by the use of Indigenous ways of knowing has allowed for great flexibility in how this discussion section has come together to answer the questions posed within this dissertation. This research is Indigenized by the use of ceremony within its methodology, that is, through its primary role of engaging with participants by having them become the storytellers. As the storytellers, they created the knowledge that allows this chapter to be formed. This discussion section is Indigenized by having the stories ground it, while having the stories be re-told by an Indigenous researcher applying a policy lens. I have brought together my own worldviews and ways of knowing to interpret the research findings in order to organize and intertwine the experiences of those storytellers with the literature and other methods discussed throughout this paper.

The key findings in this research study mostly align with, where relevant, the current literature in the area of Indigenous HIV/AIDS. However, there were a number of significant gaps in the literature found, as discussed in chapter three. The findings of this research will help to fill those gaps and to assist in identifying other needed areas of research.

In an attempt to answer the research questions within this dissertation it was necessary to conduct participant-based research. Participants in this study have come from a variety of backgrounds and lived experiences. The make-up of the study pool is uncharacteristic, in the

sense that the participant pool is a marked departure from the general statistics of people living with HIV/AIDS in the province of Ontario. First, this is evident with an equal number of male and female participants in the study. This is interesting given that the ongoing rate of infection in women in the province of Ontario is at 20.2% whereas the diagnosis rate for men is 79.8% (The Ontario HIV Epidemiology and Surveillance Initiative, 2016). However, the same report also acknowledges “Between 2011 and 2016, there was a doubling in the percent of female diagnoses who were Indigenous and/or people who use injection drugs” (The Ontario HIV Epidemiology and Surveillance Initiative, 2016, p. 7), this would hold consistent with the self-reported incidence of IDU within the female population who participated in this research and is therefore in line with emerging research. However, equal female participation is significant and noteworthy in and of itself, given the issue of the exclusion of Indigenous women as participants within many research studies (Smith, 2012). Traditional AIDS research has been openly criticised as insufficiently attentive to women, with some claiming that rates of female infection were not entirely accurate as a result of mis-diagnoses and other factors. This research will add to their voice and attempt to overcome their exclusion from HIV research.

Another marked departure is the lower percentage of two-spirited and LGBT participants within the study. The lack of two-spirited involvement was unexpected at the start of this study, mainly because one of the two community organisations who assisted in recruiting for this project is a two-spirited HIV/AIDS organisation. There were only four participants who identified as two-spirited or gay/not-straight. However when looking at incidence rates for Indigenous Peoples in Ontario, nearly 50% of Indigenous men diagnosed with HIV report having sex with other men as a risk factor of HIV (The Ontario HIV Epidemiology

and Surveillance Initiative, 2016). It is important to note that two-spirited individuals are generally underrepresented in research studies, but this outcome may have a great deal to do with the way researchers ask defining questions of their participants, such as asking people to identify as 'gay' or 'straight', thus not allowing for the capturing of those who identify outside of those terms. This is nonetheless a significant departure in terms of the sample versus what the epidemiological data would suggest. Given a lack of accurate demographic tracking by the province, this may not be such an anomaly. Additionally, given that IDU risk factors are more prevalent across the north, this could also speak to why there is a marked departure within the sample size. It is also worth noting that straight Indigenous men are substantially absent from research studies and the general discussion of HIV/AIDS. This was highlighted by participants who underscore there is a lack of services directed toward straight Indigenous men, but instead, services are focused on men who have sex with men and women. Of particular interest, participants who identified as two-spirited were the highest income earners within the research study, which may be correlated to the fact that each of them had some level of post-secondary education.

Overall, the research was community-based, and all recruitment initiatives were led by the community partners. The make-up of the participants gives strength to the recommendations and highlights voices generally excluded from research. Given a lack of overall understanding of the demographic make-up of the Indigenous HIV community, the marked difference in demographic make-up from what is expected only adds depth and a new lens to the literature in this area.

This chapter will provide an overarching analysis of the central themes presented in this research. The goal is to provide clear and detailed answers to the questions posed in the methods chapter. This section will primarily be broken out to provide answers the sub-questions posed. The answers to these sub-questions will then connect to answer the central question posed in this research: how and to what extent does policy have an impact upon funding and/or service delivery for people living with HIV/AIDS in remote First Nations communities in Ontario, Canada? Therefore, in each of the following sections, the answer(s) to each of the sub-questions will be provided either in whole or will be connected with other sections to answer the question.

### Trauma, Colonialisation, and Risk

Colonialisation runs deep through everything Indigenous Peoples have come to know and be. It has framed the way they are able to live their lives and practice their culture. Canada is presented on a world stage as a country which is innocent of racism. Canada is a country of peacekeeping and one that is open to immigrants and refugees, however, we have a troubling and long history of colonisation – one that consists of white settlement policies that acted to wipe out Indigenous Peoples in Canada (Dua, Razack, & Nyasha, 2005). Again, Canada is a settler colonial nation-state, formed upon the basis of white supremacy and heteropatriarchy (Arvin et al., 2013). Since contact, Western law has functioned as a core tenet of the practices of European settler colonialism that has sought to silence, ignore, and dismiss Indigenous rights (Morgensen, 2011). As such, we see Indigenous Peoples conditioned by these actions within all aspects of political, economic, and cultural of life (Morgensen, 2011). The literature and stories presented within this research clearly exemplify issues already discussed in the context of

settler colonialism. Prior to going on, we will discuss the concept of settler colonialism and its various processes that will inform the rest of our discussion.

Settler colonialism at its core is based on the territorial possession by some and the dispossession of others, whereby the occupier will never leave (Simpson, 2011). For Arvin et al. (2013), the concept is also about the structure of society, not one of the past, but the one that continues to function today. For him, settler colonialism and patriarchy are both consistent within our present structures – whereby newcomers come to a place and claim it as their own and do whatever it takes to remove those who were already there (Arvin et al., 2013). Tuck and Wayne Yang (2012) argue the structure of settler colonialism is about a triad structure of settler-native-slave. Additionally, at its core, it is about wealth and material accumulation, whereby the land is extracted and destroyed - giving settlers more reason to destroy, remove or make ghosts of Indigenous Peoples (Arvin et al., 2013; Simpson, 2016).

The more pressing aspect of settler colonialism, which must be explored in this dissertation is the intersection and interaction of the realities of coloniality, racism, gender, class, sexuality and desire, capitalism, and ableism (Snelgrove et al., 2014) and the effects this has on this analysis. Heteropatriarchy themes are clearly evident throughout participant stories, exemplified by a lack of access, abuse and violence, and doctor mistreatment. Stories of the indoctrination of catholic practices on young girls and loss of community participants describe along with the imposition a western ideals of family and a lack of communal child raising. Heteropatriarchy arrived as a result of changing social systems to hold up ideals of heterosexuality and patriarchy as normal and natural – while others are abnormal and “othered” (Arvin et al., 2013). This led to the loss of culture and connection for two-spirited

participants who experienced systemic forms of homophobia, transphobia, and discrimination within their communities as a result of societal structures that have changed communities' understanding of gender. Additionally, the *Indian Act* sought to regulate marriage, which affected lines of descent, property, and the ability to hold land – having a an impact on many Indigenous women and their children today (Arvin et al., 2013).

We know that at the heart of colonisation is policy (Jackson, 2009). Policy is the tool that has been used to suppress Indigenous Peoples, whether it be through the creation of residential schools, the direction to remove Indigenous children from their communities and place them in foster care or up for adoption, or through the forced assimilation and enfranchisement of tens of thousands of Indigenous Peoples (Armitage, 1995; Jasen, 1997). Canada has a long history of colonial policy leading to adverse health effects among Indigenous Peoples. These macro-level policies also extend to a lack of action by the government in dealing with urgent health needs, as is the case with Indigenous Peoples living with HIV/AIDS. The act of choosing not to act at the micro-level is the conscious creation of policy. This lack of policy can be seen as the creation of policy outside of the formal structures of legislation and regulation. “This conception of ‘soft policy-soft option’ moves the debate out of the realm of governance alone and identifies it as a social construct designed to mediate public and economic interests” (Kennedy, Kin-sang Chan, & Kwan Fok, 2011, p. 44). This lack of policy creation can be construed as a form of policy creation and therefore a further act of colonisation, when the outcome causes harm to the group.

However, beyond the argument of policy creation and colonial policy, we know that policy has led to the colonisation of Indigenous Peoples in Canada. That colonisation has had

negative impacts on the people who experienced it and their loved ones, even generations later, which is called intergenerational trauma. This was discussed at length by many participants in the section titled “Trauma”. There were 23 participants who discuss the trauma they experienced throughout their lives, including being in residential school, taken from their community, or experiencing violence within their life. Through the process of colonisation, racism, which can be deeply ingrained throughout society, has developed as a result of many untrue preconceived notions of what Indigenous People in Canada are (Bourassa, McKay-McNabb, & Hampton, 2004). This aligns with participant stories related to experiencing racism in accessing healthcare services and within society more broadly. Smylie et al. (2006) argue systemic racism creates a barrier to ideal health in Canada. Racism can be experienced in a multi-layered approach, at the structural level as well as at the patient care level (Juutilainen et al., 2014), both of which were experienced and articulated by participants. This racism led participants to be less inclined to access services, which led to further issues of rejection and stigma. This has been a focus of ongoing research, Allan and Smylie (2015) note that racism within the Canadian healthcare system is a pervasive issue and leads to people avoiding care and treatment.

Throughout the research, there were a number of repetitive and concerning themes identified by participants. These themes or list of behaviours have become commonplace within Indigenous populations, mainly related to issues surrounding the effects of trauma and intergenerational trauma. In general, participants talked about how they had parents who were not good to them. Many identified their parents as people who used drugs, who neglected to take care of them, or who ultimately abused them, both physically and sexually. Muir and Bohr



(2014) argue that “Aboriginal child rearing practices may have been modified because of historical events such as colonialism, residential schools and foster care, and traditional parenting may have been corrupted by this history” (p. 76). Substantially, the role of family and parenting has been, in many ways, lost because of colonisation and the removal of children at young ages from their communities. This has led to issues of continued neglect and the repetition of negative parenting skills and coping mechanism moving through multiple generations.

The literature describes how this trauma can be manifested in negative coping mechanisms. These negative coping mechanisms are also based on being exposed to them at a young age, thereby normalizing their actions (Czyzewski, 2011). These negative coping mechanisms mainly take the form of drug and alcohol dependency. “As a result of a history of colonisation, isolation, poverty and language barriers, abuse of substances — especially alcohol and solvents — is more common in northern and remote communities. These communities are also more vulnerable to suicide, violence and poor performance in schools.” (Canadian Centre in Substance Use and Addition, 2018, p. 1) This is reflected in the fact that 23 participants discussed the use and impact of drugs on their lives. Similarly, when it came to alcohol, another 10 participants discussed the use and impact of that on their life. This aligns with the statistics within the broader national Indigenous population. In the national survey conducted between 2008 and 2010, 82% of the respondents from First Nations communities participating in a survey reported that alcohol and drug abuse were the number one challenge for community wellness faced by on-reserve communities (Canadian Centre in Substance Use and Addition, 2018). Given the high risk that comes with IDU, this is of particular concern for Indigenous

Peoples. We know that Indigenous Peoples are disproportionately affected by IDU-related diagnoses, in addition to Hep-C.

Beyond the risk of drug use, trauma has had a significant impact on how participants live their lives. Participants in the research study experienced homelessness, incarceration, and were sex-workers. These were wrapped up in an understanding, for some participants, that life has been hard for them. Many connected their negative experiences to a history of trauma and coping. Many became addicted to drugs and alcohol, leading to homelessness, and the need to perform sex-work, often both together which would ultimately contribute to their rate of incarceration. These themes wrap into one another and create an instance of high-risk activities that dramatically increase a person's risk of acquiring HIV. Therefore, there must be engagement with ways to reduce and break the cycle of intergenerational trauma experienced by Indigenous People. Through breaking that cycle, we can work on creating healthy relationships which can lead to limiting the use of negative coping mechanisms and eventually the many problems people face later in life.

### Jurisdictional Difficulties

This section will provide answers to sub-question one: what policies are in place that affect First Nations HIV healthcare? There is an apparent absence of specific micro-level policy in relation to Indigenous HIV/AIDS in Canada. As detailed in chapter four, the absence of policy is based on a conscious decision by policymakers to afford, or not afford, direction to any specific subject. While there may be internal ministry/departmental micro policies in place in relation to the dissemination of funding to communities and other organisations, this is of

limited scope with no particular focus on HIV/AIDS. Instead, there is a patchwork of overarching meso-level health care policies that piece together responsibility, jurisdiction, and funding responsibility for Indigenous HIV/AIDS health care in Canada generally and in Ontario more specifically. These policies however do not view the exceptional nature of HIV/AIDS within healthcare and treat it as just another health issue. Consequently, this sub-question is thoroughly answered through the inclusion of chapter four on Indigenous healthcare policy in Canada. The one aspect that is critical to analyse now, in order to provide a greater understanding of the question posed, is to look at the issue of 'jurisdictional confusion'.

Given the complex frameworks and policies discussed herein, there is a significant concern of jurisdictional confusion leading to problems that make it difficult for individuals who are living with HIV/AIDS to access services and care. Therefore, we must ask why this is. First Nations people continue to be left questioning who truly has jurisdiction over their health. Is this an 'Indian' issue that must be viewed as a federal issue alone, is it merely a health issue that the province must deal with, or is this a federal matter that must override provincial jurisdiction? Throughout the research, participants noted problems with accessing services, medications, treatment, and ODSP payments. Generally, Canadians assume there is an abundance of health care services available to Indigenous People, however, "this complicated multijurisdictional health care system for Aboriginal people makes it difficult for them to access appropriate health care services and receive health care coverage which they are entitled to." (Kurtz, 2011, p. 97) Health disparities can also be attributed in many ways to jurisdictional confusions and a lack of responsibility taken by either level of government to deal with First Nations people living with HIV/AIDS or to recognize the exceptional nature of what they are

dealing with. This jurisdictional confusion is likely to be exacerbated when taking place at the lowest levels of service delivery, that is by service providers and communities, who are responsible for trying to navigate this confusion to secure access to funding for treatment and services. Lavoie et al. (2010) argue that while jurisdiction may be “somewhat coherent in theory, jurisdiction and rules of implementation create considerable complexities” (p.89). This jurisdictional confusion has been reported by the Auditor General of Canada in the 2015 report which states:

The responsibility for providing health services to First Nations individuals is shared among federal departments, other levels of government, First Nations organisations and communities, and third-party service providers. According to various reports on First Nations individuals’ access to health services, the failure to clearly delineate the roles and responsibilities of stakeholders has resulted in service gaps, and access problems continued to exist for both federally and provincially funded health services (2015, p. 24).

There remains an apparent problem with understanding the jurisdictional requirements across this country in relation to Indigenous health. The current healthcare system is a mix of “many interrelated elements that are the responsibility of the federal, territorial, provincial, and municipal governments, Aboriginal authorities, or the private sector” (Lavoie & Gervais, 2010, p. 121). This results in evident gaps and ambiguities in service delivery and responsibility, especially for the end user who is looking to access services. The system is further complicated because it not only derives from a mix of jurisdictional concerns but is also made up of legal interpretations, non-public facing internal policies, and established practices within government ministries and departments, and within communities themselves (Minore & Katt, 2007). As a result, we see jurisdictional issues creating a policy vacuum in which Indigenous

Peoples become lost and are utterly unable to find the services and treatment they require when they require them.

The inability to streamline and understand jurisdiction is also having a significant impact on funding capabilities. Intertwined with this is the uncoordinated response between provincial and federal governments in trying to address the spread of HIV/AIDS. “Jurisdictional gaps have also been documented for First Nation adults seeking care in a variety of settings, leading to delays in access and negative outcomes” (Boyer et al., 2016, p. 4). While the provincial government(s) generally take the lead on the response to HIV/AIDS, resulting mainly from determined jurisdictional divisions that are entrenched in the Constitution, this division is posing a clear and present barrier to Indigenous Peoples in Canada. They are left with a federal government that has no established policy to provide funding for access to HIV/AIDS treatment and services while at the same time they fall outside of purview of the provincial government (Matiation, 1999). Having a coordinated system and responsive healthcare system that responds to the needs of Indigenous Peoples has been advocated by many for decades with little response. The Royal Commission on Aboriginal Peoples called for “cooperative, coordinated action by the government of Canada, the provinces and territories, and Aboriginal nations,” to establish a collaborative framework by which to resolve jurisdictional problems (The Royal Commission on Aboriginal Peoples, 1996, p. 84). Since the late 1990s, the government has continued to allow a fractured relationship to exist whereby jurisdictional confusion and fragmented services are the results. As a consequence of this inaction, it has been determined that “the high rates of morbidity and mortality among Aboriginal Peoples have been attributed in part to an uncoordinated, fragmented system of healthcare service

delivery” (Kelly, 2011, p. 1). MacIntosh (2006) sums up the situation like this: “In a nutshell, the issue is whether Aboriginal health governance is properly characterized as (1) an ‘Indian’ matter, and so within federal jurisdiction, (2) a ‘health’ matter, and so within provincial jurisdiction, or (3) a federal incursion into provincial jurisdiction which must be legitimated on a case-by-case basis” (p.196). More than a decade later, this uncertainty continues and has contributed to many of the problems and negative outcomes experienced by participants within this research study. To date, “the federal government continues to define its obligations to First Nations as limited to complementing what the provinces offer and as a ‘payor of last resort’” (Boyer et al., 2016, p. 4). However, I would contend the issue of jurisdiction needs to become a moot one, insofar as the continued conflict surrounding jurisdiction between the varying levels of government allows for the actual problem to remain and persist. In reality, the jurisdiction problem could be easily solved. Instead, what is actually taking place is the apparent avoidance by any level of government of policy initiatives necessary to deal with, and pay for, the urgent healthcare needs of Indigenous Peoples in Canada.

### [Incidence of HIV in First Nations People in Ontario](#)

The next two sections are set out to answer sub-question two: how much funding for HIV/AIDS treatment/policy/services do communities receive? Where does this funding come from? In order to answer these related questions, it is essential to understand how many First Nations people in Ontario are living with HIV/AIDS. The reason this is vital to answering the question is that all First Nations healthcare funding is generally linked to the prevalence rate of a specific health issue. Therefore, to fully understand the issue of funding and to place it in a

context relevant to how much funding communities receive, it is necessary to first identify the incidence of HIV/AIDS in this group.

As has been discussed throughout this dissertation, there is no clear understanding of HIV/AIDS incidence within First Nations or the larger grouping of Indigenous Peoples in the province of Ontario. This is the result of a lack of ethnicity tracking before 2009. Additionally, current tracking is based on voluntary self-identification at the time of testing or diagnosis. This poses significant problems for Indigenous-specific HIV/AIDS organisations, who receive funding based on estimated population incidence and self-tracked statistics of clients served. The core issue faced by client-focused organisations is the fact that their base funding comes from population incidence. Therefore, their services and the reach they can have will all be limited by that number, which will then determine their overall funding, thereby hampering their ability to serve the clients they currently have and limiting their ability to attract or support additional clients. When organisations cannot support or provide services above their funding allotment, this perpetuates the cycle of showing a lack of clients served and thus suppresses their self-tracked statistics. In Ontario, there is not a clear and verifiable answer to the question of how many Indigenous or First Nations people are living with HIV/AIDS, which I would suggest is a clear policy failure that contributes to a lack of access and funding, since funding is based substantially on incidence.

In 2008, the Public Health Agency of Canada (PHAC) independently modelled the number of people living with HIV Ontario and estimated that 625 Indigenous persons were HIV-positive, inclusive of First Nations, Inuit, and Métis people living in urban and reserve communities. At the same time, the province of Ontario estimated that Indigenous Peoples,

who made up 2.4% of the province's population at the time, accounted for 3.2% (853) of the 26,628 people living with HIV in Ontario— or prevalence of 0.42%. Although significantly different, these are the most accurate published and up-to-date statistics currently available in relation to Indigenous HIV/AIDS prevalence in the province on Ontario.

However, we can couple these statistics with further studies that show that, in Ontario from 2009 to 2011, 43 (2.7%) of 1,573 new HIV diagnoses were in Indigenous Peoples. Of the 43 diagnoses in Indigenous Peoples from 2009 to 2011, 26 (60%) were in males, and 17 (40%) were in females. From 2009 to 2011, most HIV diagnoses in Indigenous Peoples were concentrated in three regions of the province. Fourteen (33%) of the 43 HIV diagnoses were from the Northern region, 13 (31%) were from Toronto (31%), and 6 (14%) were from the Southwest region.

In 2016, there were 236,685 First Nations People living in Ontario. Of those, 53,795 First Nations people resided on reserve (Government of Canada, 2016b). A 2016 report from Ontario HIV Epidemiology and Surveillance Initiative estimated there were 132 new HIV diagnoses in Indigenous Peoples in Ontario between 2011 and 2016 (Wilton J., Liu J., Sullivan A., Sider D., & Kroch A., 2016). Therefore, we have a wholly unclear picture of the actual incidence rate within the province, especially regarding ethnicity. However, if we calculate the PHAC number of 625 in 2008, add in the prevalence between 2009-2011 of 43, and finally add in the new prevalence from 2011-2016 of 132, we could estimate a current prevalence of approximately 800 (at the low end) to about 1028 (at the high end) of Indigenous Peoples living with HIV in Province of Ontario.



It is clear based on the freedom of information requests that there are currently at least 427 status First Nations people residing in the province who are accessing ART. This gives us the most direct and clear number of incidences within this population. However, there are apparent issues with tracking people who may not be accessing treatment during this period (including those who have been diagnosed through anonymous testing and did not seek out treatment) or those who are mobile between this province and other neighbouring provinces. Additionally, this number will not catch newly diagnosed cases or those who are currently unaware of their status. It also does not take into account those who do not have status, or Inuit or Métis peoples. Therefore, there seems to be a clear need for additional, exceptional policy that will address these gaps in incidence tracking.

## Funding

There is no clear funding structure provided by the federal government for HIV/AIDS prevention, treatment, programs, or services for First Nations Peoples in Ontario. This has limited the ability to provide detailed answers related to the costs associated with an individual's HIV status within the province of Ontario. Based on freedom of information requests, it could be determined that the federal government, through non-insured health benefits is covering approximately \$1.5 million dollars a year (\$5,863.29 per person) for the past three years towards antiretroviral treatment access in Ontario. However, because it is not possible to determine the other specific costs associated with care and treatment, it is not possible to determine a more accurate number as to how much the federal government is spending per HIV incidence in the province. There is also no other available comparable data related to the cost of providing ART in the province. However, Kingston-Riechers (2011) found

that the direct annual costs<sup>23</sup> of a person who is asymptomatic is \$14,453, while a person who is symptomatic will have annual costs up to \$16,846. Over the course of a person's lifetime, they will have direct healthcare costs totalling \$250,000 (Kingston-Riechers, 2011). It should be noted that these costs increased by 22% from the year 2001 through to 2011. Therefore, it can reasonably be expected these numbers in the present day would be significantly higher. The Ontario AIDS Network (2015) reported that the cost of each HIV infection was estimated between \$253,000 and \$402,000 (USD). We should expect the direct medical costs of a First Nations person to be even higher given the already high costs to deliver care in the north. This is in addition to the higher rates of co-morbidities, including Hep-C, and a higher rate of being diagnosed at a later stage of infection.

The federal government has provided a general funding breakdown for First Nations programs and services, including prevention, related to HIV/AIDS in the province of Ontario. This breakdown shows that the federal government has provided approximately \$1 million per year for each of the past three years. This amount is totally inadequate, considering there are 126 individual First Nations bands across the province. Divided equally (which it is not), that funding level would work out to just \$7,920.27 for each community to be able to deliver HIV services and programming (minus treatment costs) to its people. Breaking this number down further, in 2015/16, there were 53,795 First Nations people residing on reserves in Ontario. This would equate to the federal government paying \$18.55 per person under its responsibility for

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<sup>23</sup> The direct costs of a medical condition include the resources used to treat that illness. Direct costs include prescribed medications, in-patient and out-patient care, and the patient's out-of-pocket expenses. The patient's out-of-pocket expenses may include the cost of over-the-counter medications, co-payments for prescription medications and nutritional supplements, which are not covered by government or private health care plans (Kingston-Riechers, 2011, p. 9)

HIV prevention and service provision. This funding is clearly inadequate, given participant responses discussing access to care, where 19 participants noted there are no HIV/AIDS services for them within their reserve communities. Additionally, a further six participants said they lacked services in general, even after leaving their communities – meaning 25 participants detailed lacking access to services they deemed necessary for their health.

The funding for the fiscal year 2013/14 (\$994,633) saw a significant increase from the year 2012/2013 when the funding was set at \$876,116. However, what appears problematic is that after three years of funding increases, between the years 2014/15 and 2015/16 there was a decrease of 0.46% in funding for HIV services and programming in First Nations communities. This is concerning given the fact funding has not kept pace with the increasing diagnosis rate of HIV within this population. There has been, on average, an increase in HIV infections in the Indigenous population of 2.54% each year since the year 2011. However, we have not seen the funding envelope keep pace with this increase (plus inflation) when it comes to providing prevention, care, or services, despite much of this funding being tied to rates of incidence.

A lack of funding to First Nation communities, Tribal Councils, and larger Territorial Organisations has only hampered the work of HIV prevention and education, and access to treatment and services for those needing it. This is also clearly demonstrated within participant stories. They discuss a lack of access to services and treatment within their communities and in urban centres. They specifically discuss how their communities lack access to prevention and education programs, which are used to inform their people of HIV risks and to assist in reducing stigma. A study conducted by Choi et al. (2015) notes investment in prevention programs have significant savings long term. The study found that between 1987 and 2011, community-based

programs within the province of Ontario were able to avert 16,672 new infections which saved the healthcare system some \$6.5 billion Canadian dollars. The authors also argue that between 2005 and 2011, each dollar that was spent on prevention saved \$5 in return (Choi et al., 2015). Given the increasing incidence of HIV infection within this population in the province, we should see a funding increase, year after year, not a decrease. This lack of funding is additionally problematic because, since the Canadian government launched its AIDS strategy in 2004, there has been more than \$104 million, which was committed under the strategy, that has been diverted or withheld from being spent on programming and services (Canadian HIV-AIDS Legal Network, 2018). That report notes “numerous HIV and AIDS organisations across Canada are being pushed to the brink, with some preparing to close permanently. It is against this worrisome backdrop that [we ... release] an important analysis of how the federal government presided over the steady erosion of funding, leading to this unfortunate turning point in the history of the HIV response in Canada” (Canadian HIV-AIDS Legal Network, 2018, p. 1). This poses great concern when participants have discussed a lack of access to prevention and education services in addition to treatment and programming within their communities. Why is it that funding is decreasing or remaining stagnant when there has been money earmarked for this very type of programming going unspent? There are evident problems with funding envelopes not being dedicated appropriately for use.

Canada has created a policy and legislative framework based on genocide. There is a chronic need to fund essential services and address the mass over-representation of Indigenous Peoples in prison and children in the care of social services in this country (Palmater, 2014). The issue of systematic and chronic underfunding is not new to First Nations communities. Milloy

(2008) argues that the near-total collapse of First Nations is the direct result of persistent underfunding in every sector while, at the same time, forcing communities to deal with issues of systemic abuse through residential schooling, the 60s scoop, and mass incarceration. The government, through its capacity to regulate the amount of money that flows to First Nations has found new ways to target and starve Indigenous communities (Simpson, 2016). For Simpson (2016) the government today can “kill an Indian and get away with it. But the murder now is fiscal, is reputational, not necessarily, or some might say, exclusively, corporeal” (pg.441). The government through its regulations and requirements for First Nations reporting, has all but put nation against nation for the same pot of money. Today, accounting and accountability mechanisms help colonial powers translate their oppressive and assimilative objectives into practice (Neu, 2000). Further, Neu (2000) argues “while not all of these translations had genocide as a consequence, in a number of instances genocide was associated with the deployment of accounting and accountability mechanisms” (pg.268). The government has a clear objective to bog nations down with reporting and accounting for every dollar it spends, resulting in less community-facing programming, as money is redirected to reporting mechanisms. Additionally, as reported by participants, the onerous task of reporting and navigating the bureaucracy is cause enough to not seek out care, treatment, or services, leaving Indigenous Peoples with no access and waiting to die.

### Access to care and treatment

The following sections will work in collaboration to answer sub-question three: how and to what extent does funding and/or service delivery affect people living with HIV/AIDS? Given the details highlighted above in relation to a lack of HIV/AIDS funding for communities and

organisations, this section will analyse how that lack of funding has affected First Nations people living with HIV/AIDS. Participants highlight a lack of access to care and treatment for their HIV status. In the results chapter, the theme of access was discussed. In this section, there were 24 participants who discuss the impact that a lack of access to healthcare services had on their lives. Given the lack of funding, having a lack of access to care is unsurprising, especially across the north. Participants detailed a lack of essential services such as testing and follow-up care being available in their communities. This is a standard issue across the north in Indigenous communities for a range of health services (Diaczuk, 2015). As a result of a lack of access, participants were required to leave their communities in order to access services within urban centres such as Thunder Bay, Sudbury, North Bay, Toronto, Ottawa, or Hamilton. This, in turn, creates problems for urban centres that are now receiving clients from across the north who are looking to access services. This places centres under further stress. A majority of HIV/AIDS service providers are already working at or above capacity with access to limited resources to deliver services and supports (Cram, 2016). Having people forced out of their community due to a lack of services, only further strains the system across the rest of the province.

A significant concern raised by participants, especially in relation to accessing care in their community, was around the confidentiality of their HIV status. Five participants discussed issues of confidentiality within their communities that resulted in additional issues and problems for them to deal with. Participants did not feel confident, if they were tested in their community, that their test results would be kept confidential or that if they accessed services in their communities, that this access would be kept confidential by people who work within the healthcare system and also live in the community. In the section on Treatment in Chapter four,

a participant discussed lacking access to necessary drugs because no level of government was willing to pay for it. This forced disclosure of HIV status to different groups including Band and council, the Chiefs of Ontario, and ODSP, in order to try and advocate for getting access to necessary treatment drugs. This is not a new issue, as Verde and Li (2003) identified confidentiality in small northern First Nations communities as a reason people did not access services and care. However, this went beyond just trying to access services and treatment, Participants noted a lack of confidentiality as a reason they felt they had to leave their community. This has meant that participants are no longer connected to their families and communities as a result of needing to access care out of their community.

Participants discussed a lack of immediate post-diagnoses follow-up and care in relation to their emotional state and mental health. This led to six participants discussing, within the theme of diagnosis, that they wanted to die after being told of their diagnosis. There is no available literature that discusses suicide within Indigenous Peoples living with HIV. This lack of data can be associated with a “justifiable mistrust of historically oppressive educational systems, educational disparities, role burdens within academe, the devaluation and marginalisation of their research interests, and outright discrimination” that Indigenous Peoples living with HIV/AIDS face (Walters & Simoni, 2009, p. 1). However, it is clear— based on the themes of feeling scared, traumatized, depressed, and being lonely – that after a patient is diagnosed with HIV, there is a gap in immediate access or referral to mental health and support resources to prevent possible suicidal behaviours and follow through.

The problem of suicide and self-harm is exacerbated by a general lack of mental health care across the north in Canada (Dyck & Hardy, 2013; Lin, 2017). When looking across Ontario,

“In 2004, the average number of psychiatrists practicing per 100,000 people in Ontario was 13.1; however, in north-west Ontario, the rate was only 3.3 psychiatrists per 100,000 population.” (Webb et al., 2017, p. 4) This is concerning given the rate and use of mental health issues experienced in the north. “In 2004/2005, use of emergency rooms for psychiatric reasons in northern Ontario was more than double the Ontario average” (Webb et al., 2017, p. 6). Not only do people have to deal with coping with the initial diagnosis of HIV, but they must also deal with the significant stigma associated with their diagnosis. Stigma was a concern for all participants within the study, and a lack of access to care only increases the role HIV stigma plays in their lives. Therefore, a lack of available mental health service and treatment poses a great risk for Indigenous Peoples who have been diagnosed with HIV/AIDS. A lack of policy dealing with HIV/AIDS as an exceptional illness had a direct consequence of a lack of appropriate and timely healthcare access.

There were barriers experienced by participants who expressed frustration with the repeated negative experiences they had when accessing their healthcare and service providers. This led participants to state that they were less likely to seek follow-up appointments or any further medical treatment at all. It is well documented within the literature that Indigenous People experience discrimination and stereotyping when accessing healthcare, especially in the north (Browne, 2003; Browne et al., 2011; Nestel, 2012). This is particularly concerning given that four study participants noted they were non-adherent to their ART prescriptions. Indigenous Peoples experience racism and poor experiences when accessing health care in Canada at an alarming rate. In 2015, a patient reported to the CBC that her “doctor wrote her a prescription, and told her she was good to go. When she got home, she discovered all the



doctor had scribbled on the prescription form was a crude drawing of a beer bottle, circled with a slash through it” (McCue, 2015, p. 1). Indigenous Peoples face issues of racism and systemic discrimination at disproportionate rates when trying to access services in Canada (Allan & Smylie, 2015). These adverse experiences are concerning when they are interlinked within historically low rate of ART uptake by Indigenous populations in Canada (Wood et al., 2006). The creation of national HIV/AIDS policy that would direct resources specifically to Indigenous People living with HIV/AIDS would assist in overcoming some of these adverse experiences and resulting negative consequences. Overall, negative associations with accessing services are likely to affect further perceived and actual access to care and treatment by Indigenous Peoples living with HIV/AIDS.

Access to services was a significant concern for participants across a variety of fronts. Participants discussed access issues in three straightforward and distinct ways. They stated there were issues in accessing culturally-based services, and programs or services for women and straight men, and also noted that access to services was impeded by a lack of transportation services. There is significant research on the lack of culturally-based, relevant, and competent healthcare being offered within Canada, especially in the north (O’Sullivan, 2013; The Truth and Reconciliation Commission of Canada, 2015). A lack of culturally-competent healthcare was noted as a reason why participants may not access services or treatment. Participants overall wanted to be able to access services and care that took into account their ways of knowing, being, and healing. There were concerns that physicians did not understand traditional medicines and the effects this could have on what they are prescribed, or that physicians are openly telling participants that their traditional medicines would do

nothing for them. Again, being able to access services and treatment that take into account Indigenous Peoples' ways of healing allows them to heal holistically (taking into account the 'body' or physically, but also mentally, emotionally, and spiritually) (Clifford, McCalman, Bainbridge, & Tsey, 2015). Therefore, as this research continues to demonstrate, access and treatment are clearly hindered by a lack of culturally-based interventions across access to care, programs, and services.

There were also concerns raised by women and straight male participants, noting they lacked specific services and programs to meet their needs. The research shows that "women living with HIV experience more social rejection, shame, discrimination, violence and perceived stigma than their male counterparts. These feelings may be heightened in rural areas, where there are fewer women living with HIV, more isolation and less socialisation" (Rapid Response Service, 2013, p. 3). There continue to be calls made to evoke women-specific HIV services both domestically and internationally, to respond to the unique and specific healthcare issues they face (Carter et al., 2013). Participants discussed themes present within the literature. Specifically, they were unable to access information related to risks associated with motherhood and additionally they felt unsafe taking part in programming around men.

Similarly, an interesting sub-theme that emerged under the theme of access was that of straight male participants noting they lack any specific services geared towards them. It was argued that services in the north almost always cater to men who have sex with men and to women. This left straight male participants with no access to programming specific to them, including mental health and support groups. There is limited literature on this issue and nothing within a Canadian context. However, a lack of programming is not surprising given that straight

men have, statistically, an extremely low risk of contracting HIV via vaginal sex (Patel et al., 2014). However, in the case of HIV exposure across northern Canada, the primary risk factor is IDU (Ontario HIV Treatment Network, 2014). Given that half of the study participants identified as straight males, it is important to recognize that when people do not see themselves reflected in services and programming, they may be less likely to access those services. Three participants specifically said they, as straight men, had no access to information related to reproductive rights and risks, as they all were interested in becoming fathers. There was also concern about a lack of information related to the criminalisation of HIV in Canada and what their responsibilities were in having sex with women (especially given the changing legal discourse through the evaluation of case law in this area). Therefore, ensuring straight males living with HIV/AIDS have access to specific services that meet their needs around IDU but that must also be offered around issues of parenthood and responsibilities under the law.

A lack of access to transportation services also poses significant problems for Indigenous Peoples and all those who live across northern Ontario and Canada. This was clearly identified within the research as a rationale for not being able to access treatment, services, and programs. A lack of access to transportation was also identified as a reason for leaving one's community to move south to more populated urban centres to access services and care (Goraya, 2016). This has been an issue across Canada's north for many decades. A report from the Ontario HIV Treatment network notes:

Transportation can be a barrier to accessing HIV-related services in rural areas. For example, many rural residents do not get tested because of difficulties getting to testing centres. Due to a scarce number of health care providers in rural and remote areas, people living with HIV may need to travel long distances to access HIV-related services.

Residents who lack accessible transportation are less able to participate in face-to-face support groups or access the medical care they need. (Rapid Response Service, 2013, p. 3)

This supports the comments made by eight participants who said that they were unable to access HIV testing within their community and did not seek out testing because of a lack of ability to leave their community to do so. While HIV point-of-care testing is a feasible, preferred, and accepted mode of testing, and has been embraced by diverse populations in Canada, there are currently no rapid anonymous HIV testing sites located in the north (Minichiello et al., 2017). This lack of access poses a significant problem for those looking to access testing resources in their community since they currently are required to leave to access such services. Additionally, the federal government provides no or limited funding for transportation services to access programming. The federal government typically only funds transportation for medical care-based services. Participants note they were declined transportation assistance in order to leave their community to seek out HIV testing. A lack of transport has a definite impact on participants' ability to access care, services, and programming. Additionally, it is clear that as a result of these limits, people will eventually be forced to leave their community, in order to seek these things out in urban centres.

Finally, a lack of access to HIV education and prevention programs in remote communities had a significant impact on participants and the larger communities they come from. There were 25 participants who discussed how a lack of HIV education had an impact on them. Specifically, many noted the impact a lack of educational programming had on their knowledge the risk factors associated with HIV and how they could acquire HIV. Participants noted a lack of HIV education led to significant stigma directed toward them by their families

and the broader community. “In many rural areas, religious conservatism and lack of knowledge about HIV mean the disease is rarely discussed and can be invisible” (Rapid Response Service, 2013, p. 2). HIV education has been lacking for more than a decade in most northern First Nations communities (Smith, 2016), which can be connected to the lack of funding afforded to First Nations communities across the province of Ontario. Not only does a lack of access affect stigma, but a recent study in rural communities found that, because rural clinicians have limited experience with HIV, they are unable to provide comprehensive information for their patients, leaving them to educate themselves as well as their doctors (Veinot, Harris, Bella, & Challacombe, 2012). Additionally, the use of HIV programming has been proven to be one of the most effective prevention tools available (Aggleton et al., 2018), and therefore there should be a move toward providing education services as a mode of prevention within rural and remote First Nations communities. Overall, it is vital that communities have access to HIV education materials in order to prevent further transmission but also to combat the stigma associated with it.

In its totality, a lack of access to care, treatment, services, and programming for HIV has led to adverse health outcomes, be they mental, physical, or spiritual. The lack of access has left people in the north unable to stay in their communities and has forced many to move to urban centres to seek out the resources they require to survive. All of these access issues have resulted in Indigenous Peoples living with HIV/AIDS being forced not only to leave their community but ultimately to not want, or to not be able, to return to them. This will result in the continued colonisation of Indigenous Peoples through the loss of culture, connection with family and kinship, and a loss of spirituality. Ultimately a lack of access, mainly resulting

from a lack of funding for programs and services, is the continued effort to marginalize and colonize people living across the north.

## Recommendations

This section will answer sub-question four: what processes/actions can be taken by the federal/provincial governments and First Nations communities to re-evaluate current practices of funding and service delivery to improve any inefficiencies that may be found? The recommendations being provided are encompassing of the data noted throughout this research. There is particular emphasis placed on the recommendations made by participants. Therefore, each of the recommendations starts with the word “we”, in order to reflect the understanding that the recommendation is formed through the stories and experiences of the participants. Further, the recommendations were made in consultation with the community organisations and are endorsed by them. The aim was to ensure that these recommendations captured the voice of Indigenous Peoples living with HIV/AIDS and to incorporate their recommendations with the larger body of knowledge and literature to inform their overall depth.

This section must be viewed in the context of the colonial structures that continue to affect every aspect of Indigenous life, especially that of participants in this research who are defined by legislative status and fall within colonial federal jurisdiction. Many times we see recommendations related to Indigenous Peoples being presented as an act of reconciliation – or a new way forward. I reject this approach. As Tuck and Wayne Yang (2012) argue, decolonisation cannot be just a metaphor. For them “the metaphorisation of decolonisation

makes possible a set of evasions, or 'settler moves to innocence', that problematically attempt to reconcile settler guilt and complicity, and rescue settler futurity" (pg. 1). The problem with reconciliation is that it implies that Indigenous Peoples were once whole, experienced a rift and are now trying to be made whole again (Stanton, 2011). However, this is not the process of colonisation in Canada. As Indigenous Peoples we were not approached as equal nations but instead we were gradually oppressed and marginalized by others (Stanton, 2011). While the Canadian government continues to deny Indigenous nations and people their sovereignty there is no way in which we as a people can be reconciled with. Instead, this section will offer a set of recommendations to improve the lives of Indigenous People living with HIV/AIDS – nothing more. This is not a path to reconciliation or a way to undo the injustices Indigenous Peoples have faced, and continue to face. I hope this can be a starting point for the resurgence of Indigenous voices – giving stories and people agency to have their voice heard and to take part in healing. Snelgrove et al. (2014) argue that resurgence is a way to restore and regenerate Indigenous nationhood. I hope through these recommendations; Indigenous voices can be heard and the restoration of nationhood for them may start or continue.

This section is broken down into five sets of recommendations. First, recommendations directed toward the federal government for the overall improvement of funding and access for HIV/AIDS treatment, care, and services in First Nations communities. Second, recommendations directed toward the provincial government – this is important because many of the services and programs accessed by participants were provincially supported off-reserves. Third, Indigenous communities and political organisations can undertake work to improve the conditions and education of their people in relation to stigma and access to services within

their communities. Fourth, a set of recommendations are provided for non-Indigenous HIV/AIDS community organisations – this being a main resource for many Indigenous Peoples who are unable to access any other Indigenous-specific resources. Fifth, these recommendations lay out work Indigenous HIV/AIDS organisations can undertake to further improve their service delivery to their clients. Finally, there is one recommendation directed toward those Indigenous People living with HIV/AIDS.

#### Federal Government

1. We call upon the federal government to resolve jurisdictional confusion surrounding Indigenous HIV/AIDS funding by creating a clear policy that details its responsibility for funding HIV/AIDS care and services for First Nations people living on reserves in Canada. This policy can take the form of a ministerial directive that will clearly provide direction to the bureaucracy as to how funding should be determined for programs and services to First Nations communities for delivery of programs and services related to HIV/AIDS. This will provide clear guidance so First Nation communities can understand what funding they can access and where they can access it.
2. We call on the federal government to provide sustainable and adequate funding for HIV/AIDS care, treatment, programming, and services in First Nations communities. This funding should be stable and long-term, so as to avoid creating unnecessary work for communities in having to apply and re-apply for funding on an annual or semi-annual basis.
3. We call on the federal government to continue its commitment to addressing the significant issues affecting Indigenous Peoples across the north including poverty, lack of



education, lack of adequate housing, lack of clean drinking water, addressing youth suicide, and the continued trauma experienced by Indigenous Peoples. Without tackling such underlying issues, the incidence of negative coping mechanisms will continue to drive up the incidence of HIV/AIDS within the Indigenous population.

4. We call on the federal government to provide a funding envelope that provides access to culturally-based healing treatment for Indigenous Peoples living with HIV/AIDS. This should include funding for culturally-based programming and services for the same group that can be accessed by both Indigenous and non-Indigenous organisations.
5. We call on the federal government to provide a dedicated funding envelope for services and programming, both culturally-based and not, to meet the unique needs of Indigenous women living with HIV/AIDS. This recognizes that Indigenous women face high rates of violence by males in our society and being provided dedicated space and service is urgently needed to address the high incidence rates of HIV faced by this sub-population.
6. We call on the federal government to provide a funding envelope for services and programming, both culturally-based and not, to meet the needs of straight Indigenous males living with HIV/AIDS. HIV/AIDS is affecting Indigenous straight males at higher rates than the general public, and we must recognize that services and programming have typically been directed toward men who have sex with men and women.
7. We call on the federal government to provide a funding envelope for HIV education in First Nations communities, with a focus on youth. We must remember that HIV prevention is a cost saving endeavour for everyone. This funding should seek out

culturally based education programs that focus on the unique challenges and risks faced by Indigenous Peoples living in remote and non-remote communities.

8. We call on the federal government to work with provinces to increase access to HIV and sexually transmitted and blood borne infections (STBBIs) testing (including rapid and anonymous testing) along with access to specialists and treatment within First Nations communities. This should include more stringent accountability measures to ensure patient confidentiality.
9. We call on the federal government to provide a funding envelope to increase access to harm reduction measures within First Nations communities across the north. This includes having spaces such as safe injection sites for individuals to access.
10. We call on the federal government to do as people ask. Indigenous People living with HIV/AIDS are struggling through the bureaucracy to access care, treatment, programming, and services they feel they require to live their life. This includes access to culturally-based care and programming. People wish to access what they need in a timely fashion without having to make daunting requests that take time, resources, and significant effort, many times only to be declined. Having a clear policy that lays out what can and cannot be funded and where to access that funding, can assist in solving this problem.

#### Provincial Government

11. We call on the provincial government to increase its funding of the Ontario Disability Support Program (ODPS) for people living with HIV/AIDS. Indigenous People already

struggle with homelessness; many think their benefits are too little to survive on, and this leaves them facing issues that only exacerbate their health problems.

12. We call on the provincial government to provide a funding envelope to provincially funded AIDS service organisations (ASOs) to provide access to culturally-based healing treatment for Indigenous People living with HIV/AIDS. This should include funding for culturally-based programming and services that can be accessed by both Indigenous and non-Indigenous organisations. This is in recognition of the fact that many, if not most, Indigenous Peoples are forced to leave their communities and access treatment and care off-reserve by provincially funded ASOs.
13. We call on the provincial government to implement Indigenous cultural sensitivity training for all physicians and medical care professionals within the province. This is a recognition of the treatment participants have received by provincially-mandated and supervised physicians. This recommendation supports the call by the Truth and Reconciliation Commission to create an environment where culturally-appropriate medical care is the standard and whereby all people are treated with respect, and their cultural beliefs are understood and taken into account.

#### Indigenous Communities and Political Organisations

14. We call on Indigenous Communities and Political Organisations to be receptive to HIV/AIDS education and harm reduction initiatives undertaken by other levels of government and ASOs. This includes actively seeking out funding and opportunities to support such work within their communities.

15. We call on Indigenous Communities and Political Organisations to undertake initiatives to educate members of their council and respective health care teams about HIV/AIDS, issues of confidentiality, stigma, and the supports or services they can provide.
16. We call on Indigenous Communities and Political Organisations to work with their communities to address the issue of HIV/AIDS stigma within their communities. Only by breaking the cycle of stigma and rejection can we honestly be open to eradicating HIV within our communities.
17. We call on Indigenous Communities and Political Organisations to work with ASOs and prepare to accept your community members back after they have passed on to the spirit world. Communities should be prepared to receive their member and allow them a dignified burial within their home community.

#### Non-Indigenous HIV/AIDS Community Organisations

18. We call on Non-Indigenous HIV/AIDS Community Organisations to undertake initiatives to educate members of their staff about colonisation and the unique issues faced by Indigenous Peoples in Canada and in particular those living with HIV/AIDS.
19. We call on Non-Indigenous HIV/AIDS Community Organisations to work with Indigenous groups and ASOs to develop and implement culturally-based and competent programming and services for Indigenous People.
20. We call on Non-Indigenous HIV/AIDS Community Organisations to ensure that they develop and implement culturally-based and competent programming and services for Indigenous women in particular. This may include dedicated space and time for

women's only programming – in recognition of the disproportionate violence Indigenous women face.

21. We call on Non-Indigenous HIV/AIDS Community Organisations, especially those in the north, to ensure that they develop and implement programming and services for straight Indigenous males. This is in recognition of their growing incidence of HIV in this group and a lack of resources available to them.

#### Indigenous HIV/AIDS Organisations

22. We call on Indigenous HIV/AIDS Organisations to seek out funding to implement and increase programming and services for Indigenous Peoples they serve. This should include being a leader in understanding the cultural healing practices of their clients and to assist them in advocating for culturally-based health care experience if they wish for that.
23. We call on Indigenous HIV/AIDS Organisations to develop and implement culturally-relevant and competent HIV education in First Nations communities and urban areas with a particular focus on our youth.
24. We call on Indigenous HIV/AIDS Organisations to develop and implement culturally-relevant and competent HIV harm reduction practices that can be deployed in remote or hard to access First Nations communities alongside urban centres.
25. We call on Indigenous HIV/AIDS Organisations to partner with non-Indigenous ASOs to assist them to develop and implement culturally-based and competent programming and services for Indigenous People.

26. We call on Indigenous HIV/AIDS Organisations to ensure that there is dedicated programming and services for women. This may include dedicated space and time for women's only programming – in recognition of the disproportionate violence Indigenous women face

27. We call on Indigenous HIV/AIDS Organisations to ensure that there is programming and services for straight males, especially across the north. This is in recognition of their growing incidence of HIV in this group and a lack of resources available to them.

28. We call on Indigenous HIV/AIDS Organisations to work with First Nations communities to help prepare these communities to receive their members for burial.

#### Indigenous People living with HIV/AIDS

29. We call on all Indigenous People living with HIV/AIDS to seek out testing, treatment, services, and programs. We call on them to remain on their treatment so as to achieve and maintain an undetectable viral load.

#### Conclusion

Through answering the four sub-questions above, a clear connection has been drawn to answering the central question which is posed in this research: how and to what extent does policy have an impact upon funding and/or service delivery for people living with HIV/AIDS in remote First Nations communities in Ontario, Canada? The simple answer is that a lack of exceptional HIV/AIDS policy targeted towards First Nations Peoples living with HIV/AIDS is directly tied to a lack of funding for treatment, care, services, and programming for Indigenous Peoples living with HIV/AIDS in the province of Ontario. This clear lack of policy creates no incentive to deal with the problem at hand – in fact it creates an environment where

governments would not want to intervene and have to spend more money. Overall, there is a clear lack of policy coordination and funding, which leaves First Nations people across the north experiencing a lack of access to HIV testing, education, and harm reduction. This has directly contributed to the ongoing HIV crisis across the north and within rural and remote First Nations Communities. A lack of funding being provided to communities is resulting in people living with HIV/AIDS not being able to access the services they need and also in facing stigma and discrimination. This lack of support leads people to leave their community to access their healthcare needs in larger urban centres, and many of them never intend to return home. Unfortunately, some of these people will become homeless, addicted to drugs and/or alcohol, sex-workers, or incarcerated. All of these issues have ties back to a lack of policy and more so a lack of responsibility being taken by the federal government to deal with this crisis across the north. Until such time as the federal government chooses to recognize its responsibility and properly deal with the issues of colonisation and the impacts it has on Indigenous health, the problems experienced by participants will continue to happen.

Throughout this section, there is clear connection in showing that everything happening within HIV/AIDS policy in Canada is set in a context of macro-level policies. These macro-level policies are at the heart of perpetuating colonialism (among other things) and further isolating Indigenous Peoples living with HIV/AIDS. The meso-level policies that serve to deliver care are unfocussed, jurisdictionally-confused, and underfunded. This contribute to the dislocation and forced migration of First Nations people from their communities into urban centres to access 'adequate' care. Finally, micro-level policies are all but absent (non-existent) or are so unfocussed and unfunded as to be virtually absent. This all leads to significant confusion and a

lack of delivery which has harmful implications for First Nations peoples living with HIV/AIDS in Ontario.



## Chapter VIII: Conclusion

### Overview

Colonialism has had a significant impact on Indigenous Peoples' health in Canada. The violence, displacement, and loss of culture experienced by Indigenous People in Canada can be directly linked to a history of traumatic policies which sought to destroy the 'Indian' in Canada. Through direct policy interventions, children were removed from their families and communities, cultural practices and speaking of traditional languages were forbidden, and a legacy of poverty and silence began. At the macro-level today, colonial policy, or the silence of policy allows for substandard healthcare to be delivered to Indigenous Peoples right across this country, and this is especially true of First Nations people living with HIV/AIDS. At the micro-level Canada has no direct policy to combat an HIV/AIDS crisis taking place within Indigenous communities (both urban and rural) in Ontario and beyond. At the meso level, there are many general policies that have neither the focus nor the funding to deal effectively with an exceptional health crisis such as HIV/AIDS. This lack of policy and direction has left First Nations communities with a lack of funds to support the high needs of their community members living with HIV/AIDS. As this research has shown, this has resulted in many being forced to leave their communities to seek out access to care, treatment, programming, and services in urban centres.

The key findings in this research study generally align, where relevant, with the current literature in the area of Indigenous HIV/AIDS. The central conclusions of this study are that a lack of specific policy direction by the federal government has result in significant funding gaps to address the HIV epidemic facing First Nations communities in Ontario. A lack of funding has a

direct impact on how First Nations people living with HIV/AIDS are able to remain healthy and stay in their communities. This lack of funding direction extends to areas of prevention, education, treatment, and access to services and programming. A lack of funding direction is indicative of a continued effort by the Government of Canada to avoid its duty to Indigenous Peoples in Canada and it continues with its proven history of creating traumatic policy that is meant to be rid of the 'Indian problem'.

The recommendations provided herein were taken directly from First Nations people living with HIV/AIDS and provide concrete ways for the government and ASOs to respond to help correct the issues facing this sub- group. Direct and immediate action is needed on the recommendations provided, as failure to do so will result in increased HIV transmission within a population that is already overrepresented in many negative health outcomes.

### Research Questions Answered

This research sought to answer one central question: how and to what extent does policy have an impact upon funding and/or programming, care, treatment, and service delivery for people living with HIV/AIDS in First Nations communities in Ontario, Canada?

In order to answer this central question, there were four sub-questions developed to provide context and information to give to detail and specificity to this answer. The research sub-questions explored are as follows:

1. What policies are in place that affect First Nations health care?

In relation to this sub-question, there is an absence of specific policy in relation to Indigenous HIV/AIDS in Canada. This absence is of importance to note due to the exceptionalism of HIV/AIDS as an illness. As has been discussed, there are other federal and

provincial policies that designate HIV/AIDS as exceptional within healthcare service provision, but there is no such exceptional policy at the federal level to assist in addressing the rising incidence of HIV/AIDS within First Nations Peoples and communities. This is also clear inaction by the federal government, thus avoiding its responsibility to fund the necessary services and programs for communities. While internal ministry/departmental micro policies may be in place in relation to the dissemination of funding to communities and other organisations, this is of a limited scope and with no particular focus on HIV/AIDS. Instead, there is a patchwork of inter-jurisdiction health care policies at the meso-level that piece together responsibility and funding for Indigenous HIV/AIDS health care in Canada generally and in Ontario more specifically. Consequently, this sub-question is answered through the descriptors found in chapter four on Indigenous healthcare policy in Canada.

2. How much funding for HIV/AIDS treatment/policy/services do communities receive?

Where does this funding come from?

In order to answer this sub-question, it is essential to recap how many First Nations people in Ontario are living with HIV/AIDS, as almost all First Nations healthcare funding is generally linked to prevalence rates of a specific health issue. It is clear, based on the freedom of information requests, that there are currently at least 427 status First Nations people residing in the province who are accessing ART. However, there are apparent issues with tracking people who may not be accessing treatment during this period or who are mobile between this province and other neighbouring provinces. Additionally, this number will not include newly-diagnosed cases or those who are currently unaware of their status.

There is no clear funding structure provided by the federal government for HIV/AIDS prevention, treatment, programs, or services for First Nations Peoples in Ontario. This has limited the ability to provide detailed answers related to the costs associated with an individual's HIV status within the province of Ontario. Based on freedom of information requests, it could be determined that the federal government, through non-insured health benefits is covering approximately \$5,863.29 per person per year towards antiretroviral treatment access in Ontario. The federal government has provided a general funding breakdown for First Nations programs and services, including prevention, related to HIV/AIDS in the province of Ontario. This funding details the federal government has provided approximately \$1 million per year for each of the past three years. This amount is dramatically low when considering there are 126 individual First Nations bands across the province. That funding level would work out to just \$7,920.27 for each community to be able to deliver HIV services and programming to their people.

3. How and to what extent does funding and/or service delivery affect people living with HIV/AIDS?

Participant stories form the basis of answering sub-question three. Participants highlighted a lack of access to care and treatment for their HIV status. In the results chapter, the theme of access was discussed. In this section, there were 24 participants who discussed the impact that a lack of access to healthcare services had on their lives. Given the lack of funding, having a lack of access to care is unsurprising, especially across the north. Participants detailed a lack of essential services such as testing and follow-up care being available in their communities. As a result of a lack of access, participants were required to leave their communities in order to

access services within urban centres such as Thunder Bay, Sudbury, North Bay, Toronto, Ottawa, or Hamilton. Having people forced out of their community due to a lack of services, only further strains the system across the rest of the province.

4. What processes/actions can be taken by the federal/provincial governments and First Nations communities to re-evaluate current practices of funding and service delivery to improve any inefficiencies that may be found?

Finally, sub-question four can be answered through use of the recommendations being provided through this research. These are broken down into five sets of recommendations. First, recommendations directed toward the federal government for the overall improvement of funding and access for HIV/AIDS treatment, care, and services in First Nations communities. Second, recommendations directed toward the provincial government – this is important because many of the services and programs accessed by participants were provincially supported off-reserves. Third, Indigenous communities and political organisations can undertake work to improve the conditions and education of their people in relation to stigma and access to services within their communities. Fourth, a set of recommendations are provided for non-Indigenous HIV/AIDS community organisations – this being a main resource for many Indigenous Peoples who are unable to access any other Indigenous-specific resources. Fifth, these recommendations lay out work Indigenous HIV/AIDS organisations can undertake to further improve their service delivery to their clients. Finally, there is one recommendation directed toward those Indigenous People living with HIV/AIDS.

Overall, the question of how, and to what extent, does policy have an impact upon funding and/or programming, care, treatment, and service delivery for people living with

HIV/AIDS in First Nations communities in Ontario, Canada is answered by a comprehensive analysis of the data gathered. At the macro level, Canada's continued colonial policy system strives to marginalise First Nations people by failing to provide the basic necessities they need for survival. Instead, there is a complex and complicated framework of policies and arrangements in place at the meso level which is supposed to deliver healthcare to First Nations people. This system is failing. There is a clear lack of funding being provided for HIV/AIDS education, prevention, services, and care. This lack of funding has contributed toward serious harms for First Nations people caught up in this system. Substantially, a lack of policy at the micro level has forced First Nations people out of their communities and into urban centres, off reserve, to access basic care they need to support their life. This results in the continued colonisation of First Nations people as a result of inaction by the government to deal with the pressing matter of healthcare and to designate HIV/AIDS as an exceptional healthcare issue needing dedicated resources and efforts.

### Research Contributions

This dissertation fills a clear void in the literature by finding there are no policies which specifically direct funding or services to First Nations people living with HIV/AIDS. This research has created a policy framework to specifically analyse how Indigenous policy can be understood by placing policies within the framework of policies of assimilation and colonisation at a macro level, policies of accommodation at the meso level, and policies that could be decolonial at a micro level. Through this framework, this dissertation conducted a detailed review of policies which form a structure which allows for the piecemeal HIV/AIDS funding and service delivery today.

The findings of this research will also inform new discussions about the quality of HIV programming for Indigenous Peoples, and how funding can have a silent impact on how people receive care. It will also provide clear participant-driven recommendations about how the government, AIDS service organisations, and communities can work to better support and treat people living with HIV in Ontario

The overall contribution of this dissertation is that it details, for the first time, that policy, or a lack thereof, is directly tied to a lack of funding for treatment, care, services, and programming for Indigenous Peoples living with HIV/AIDS in the province of Ontario. Significantly, while the federal and provincial governments choose to recognize the exceptional nature of HIV/AIDS as an illness in other frameworks, the federal government refuses to address the exceptional nature of the illness for First Nations and Inuit people for which it has responsibility. I therefore conclude this lack of a policy directed towards First Nations Peoples living with HIV/AIDS creates no incentive for the government to deal with the problem at hand. Through a lack of coordination and funding, First Nations people across the north experience a lack of access to HIV testing, education, and harm reduction that has thus directly contributed to the ongoing HIV crisis across the north and within rural and remote First Nations Communities.

## De/Limitations and Future Research

### Delimitations

There are a number of delimitations related to this research. Given the scope of work and detailed inquiry required, it would not be possible, given the timeframe and resources (including cost), to conduct a pan-Indigenous study related to this topic within or outside of the

province. Therefore, this research had a sole focus on the First Nations peoples and subsequently recruited only members of communities who have status under the Indian Act. This was in part due to community requests, with the community organisations wanting to understand why First Nations People living in communities were leaving and seeking services in urban centres. Another reason for such a restricted view is that there already exists aggregated information on HIV/AIDS for the broader Indigenous population; however, there is no literature that focuses on HIV/AIDS policy for First Nations people specifically. Additionally, the status First Nations population has centrally-controlled health data through their use of Non-Insured Health Benefits, making access to data more accessible.

This research was also limited to First Nations within the province of Ontario. This was to ensure that policy implications were focused on jurisdictional issues between the federal and just one provincial government. Additionally, the delivery of prevention, treatment, and programming would change between provinces when First Nations people access services off-reserve due to different funding priorities and initiatives. Given that this research is being conducted only in Ontario and there is no Inuit territory in this region, the Inuit people were excluded from this study. This was also in keeping with a Tri-Council policy regarding community consultation, as there are no major Inuit HIV/AIDS organisations outside the city of Ottawa in Ontario, and that was not a practical study location for this research given its distance. Similarly, Métis do not fall within the above-mentioned policies, and therefore were not included in the research.

In consultation with my community partners, this research does take on an overtly critical stance of settler colonial policy and colonisation. The scope of this research was



intended, in many parts, to be broad and descriptive in nature. There are significant contributions to the critical literature in relation to settle colonial policies and the continued imposition of these policies on Indigenous Peoples today. This document was intended to assist the community partners in gathering evidence to further their case for expanded funding and programming, we therefore did not find it useful to take an overtly critical position within this work, and risk a negative reception to the overall research findings and recommendations.

### Limitations

A number of limitations are reflected within this research study. Given the timeframe and availability of resources, it was only possible to conduct storytelling with 29 participants. It was difficult to recruit participants who fit all the criteria, especially finding individuals who either have used medical services within their community or left their community as a result of, or based on, factors related to their HIV-positive status. However, I believe this is a significant sample size given the small size of the overall target population and limited resources for travel to conduct on-site research.

There were community engagement issues throughout the study. Both 2-spirits and OAHAS experienced significant staff changes and internal governance challenges at multiple times throughout the study duration. This included the loss of multiple executive directors from both organisations. However, this was partially overcome by continued engagement with the new Executive Directors or the organisation's board of directors. However, this meant that this dissertation could not be reviewed in whole by either community partner, however individual chapters were reviewed at different points. The lack of full review has been at the request of

the community partners who have noted a lack of capacity to review. However, detailed discussions and presentation of findings have been given to both organisations.

The limited number of participants used in this research study in combination with community engagement issues resulted in a lack of representation from queer/2-spirited individuals. At the outset, there was an expectation of having a more significant number of queer/2-spirited participants, however, almost all recruitment took place in partnership with OAHAS and occurred in the north. Throughout the research, there were details surrounding the fact that queer/2-spirited individuals were forced to leave their communities and small cities in due to stigma and discrimination in relation to their sexual orientation/gender identity. Thus, many queer/2-spirited individuals end up migrating to larger urban centres where they may find a greater sense of community and thus were not located in my main areas of recruitment.

There were also limits placed on this research related to accessing government documents. Policy reviewed was limited to what was publicly available. Internal policy related to funding decisions was not found nor provided when requested for this research. Research conducted through Freedom of Information requests was also wholly reliant on the government's willingness to release all the data it had and therefore can only reflect what was returned from those requests.

My study offers suggestive evidence for the direct implication of how a lack of policy that would direct funding for HIV/AIDS to First Nations communities has negative impacts on First Nations people and their communities. Overall, there is a lack of funding being given to First Nations in order to deal with the HIV/AIDS epidemic that they are facing, and which continues to grow. This research shows that, due to a lack of programming and services in First

Nations communities, people are forced out and into urban centres where they can access appropriate care. This has wide ranging implications including a loss of culture, connection to their family, homelessness, and overall increases their vulnerability. The study appears to support the argument for a change in how the federal government directs funds for healthcare services, with a clear need to target funding and policy towards combating HIV/AIDS within First Nations communities.

#### Future Research

Further research needs to be conducted in the area of epidemiological surveillance related to the number of Indigenous People in Ontario are living with HIV/AIDS and also those who may be at a disproportionate risk. This information is vital in order to create sound research around the needs of the community and the requirements for funding. There also needs to be a comprehensive program review of services offered within and across the province of Ontario for Indigenous communities and people living with HIV/AIDS, including resources to which they have access for prevention, treatment, services, and supports. There must be research related to culturally-appropriate and safe HIV prevention tools that are geared towards the unique factors Indigenous Peoples face, including a legacy of trauma. Finally, further research must examine the stories of 2-spirited/queer people living with HIV/AIDS, as this research was relatively void of this data.

## Conclusion

In trying to Indigenize this research through modes that move beyond western ways of knowing, I reached out to an artist friend, Patrick Hunter<sup>24</sup> to take the themes and stories presented here and to represent them in a visual way. I end this dissertation with that painting and the explanation that informs it.

Titled, “TALKING STICK” – “The concept for this painting was inspired by the First Nations people that were sharing their stories of becoming HIV-positive. When I was given the briefing behind the research for this dissertation, the findings were not what I expected to read about HIV/AIDS. As a 2Spirit man, I realized that this isn’t just a LGBTQ2 issue, it’s a human issue that requires much more thought and empathy. The image features a hand holding the talking stick that for generations, First Nation cultures had used when discussing serious issues. When you said all you needed to say, you passed the stick along. On it are 7 Eagle Feathers for the 7 Grandfather teachings that I believe were needed for people to actively share their stories. Below that sacred medicines are burning, creating a good space for the stories to be

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<sup>24</sup> Patrick Hunter is a 2Spirit Ojibway Woodland artist from the gold mining community of Red Lake, Ontario. Hunter paints what he sees through a spiritual lens which is inspired by his homeland and growing up seeing the original works of Woodland painter Norval Morrisseau. Patrick attended Sault College in Sault Ste. Marie, ON for graphic design and graduated in 2011, the same year he made the move to Toronto. Creating has always been his passion and the focus of his life from an early age. A transformative year for Hunter was 2014. Unable to find meaningful employment in his field, he launched his own company, “Patrick Hunter Art & Design”, with the intent to create artwork that makes people feel good. Since then, a small clothing and housewares line has been born and sold to folks around Canada and the world. Hunter still resides in Toronto, but makes regular journeys home to stay inspired, be with family and teach art classes to the next generation of Woodland artists.

shared. Encircling the imagery is my interpretation of the AIDS ribbon that is worn to bring public awareness but painted as a sweet grass braid” (Hunter, 2018).



## Appendix 1: Research Ethics Board Approval



To: Sean Hillier  
Policy Studies  
Re: REB 2015-343: How Policy Affects Funding and Service Delivery For HIV/AIDS in Remote  
First Nations Communities in Ontario, Canada  
Date: November 9, 2015

Dear Sean Hillier,

The review of your protocol REB File REB 2015-343 is now complete. The project has been approved for a one year period. Please note that before proceeding with your project, compliance with other required University approvals/certifications, institutional requirements, or governmental authorizations may be required.

This approval may be extended after one year upon request. Please be advised that if the project is not renewed, approval will expire and no more research involving humans may take place. If this is a funded project, access to research funds may also be affected.

Please note that REB approval policies require that you adhere strictly to the protocol as last reviewed by the REB and that any modifications must be approved by the Board before they can be implemented. Adverse or unexpected events must be reported to the REB as soon as possible with an indication from the Principal Investigator as to how, in the view of the Principal Investigator, these events affect the continuation of the protocol.

Finally, if research subjects are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and approvals of those facilities or institutions are obtained and filed with the REB prior to the initiation of any research.

Please quote your REB file number (REB 2015-343) on future correspondence.

Congratulations and best of luck in conducting your research.

A handwritten signature in black ink, appearing to read "L. Lavallée".

Lynn Lavallée, Ph.D.  
Chair, Research Ethics Board



## Appendix 2: Memorandum of Partnership with Communities



### Memorandum of Partnership

**Project Title:** How Policy Affects Funding and Service Delivery For HIV/AIDS in Remote First Nations Communities in Ontario, Canada (the “Research Project”)

This Memorandum of Partnership is made this 1<sup>st</sup> day of October, 2015.

BETWEEN:

Art Zoccole, Executive Director,  
2-Spirited People of the 1st Nations

and

Tony Nobis, Executive Director  
Ontario Aboriginal HIV/AIDS Strategy

the “Community Partners”

And

Sean Hillier, PhD Candidate  
Ryerson University  
Ph: 416 979 5000 x 6220

the “Researcher”

The Researcher and the Community Partners agree to conduct the named Research Project in accordance with the guidelines and conditions described in this document.



## **Purpose of the Research Project**

The purpose of the Research Project is to examine how policy affects funding and service delivery for HIV/AIDS in remote First Nations communities in Ontario, Canada

## **Research Project Description**

This research will examine how policy (e.g., Indian Act, Canada Health Act, Indian Transfer payments, Constitution Acts 1867 to 1982) affects funding distribution and the accessibility of HIV/AIDS funding/programs for status First Nations (FN) people within remote reserves in Ontario, Canada. Grounded in Indigenous theory, this research will utilize a variety of western and Indigenous research approaches and methods to examine how the aforementioned policies affect funding and resources for HIV/AIDS within FNs. This study will explore the policies and funding arrangements for HIV/AIDS prevention and treatment, with particular attention given to the origin of funding/services, how they are utilized, and the role each level of government (federal/provincial) plays in the delivery of HIV/AIDS services.

Using qualitative methods and an Indigenous theoretical framework, this research will examine the current funding arrangements and delivery of healthcare care services related to HIV/AIDS to FN communities in Ontario. First, participants in Toronto will take part in a storytelling method wherein they will discuss their views on the availability and access to needed services, their experiences with the services, and changes they would suggest; Second, based on these findings, sharing circles will be conducted in four remote FN communities to allow for an open discussion regarding any challenges faced in accessing healthcare funding and how communities deal with the prevention and care of people living with HIV/AIDS.

This research will seek to expose the availability and sufficiency of funding and services within communities while analysing the policies that have created systemic barriers, with an objective of ascertaining how federal policy affects the funding and service delivery of HIV/AIDS services (and how they are perceived by clients and practitioners. Further, the processes or actions that can be taken by the federal/provincial governments and FN communities to re-evaluate current practices of funding and service delivery to improve any inefficiencies will be explored. The goal of this research is to offer a better understanding of services available to people and communities affected by the HIV/AIDS epidemic and to make recommendations of ways policy can help to prevent the spread of HIV/AIDS within these communities. A comprehensive dissemination plan will share the results with policymakers, participating FN communities, and academic communities. The results will provide concrete policy recommendations for real change with a lasting impact upon the epidemic of HIV/AIDS within FNs communities.

## **Governing of the Research Project**

The research will be conducted by a PhD Candidate from Ryerson University under the Supervision of Dr. Lynn Lavallée. The research project will be governed under the direction of

Mr. Hillier's PhD dissertation Committee, with input and consultation with the community partners (2-Spirited People of the 1st Nations and the Ontario Aboriginal HIV/AIDS Strategy).

Conflicts will be resolved through collaboration with the PhD dissertation Committee and the community.

### **Ethics and Values**

The research project will abide by Tri-Council Policy Statement (TCPS) regarding research involving First Nations, Inuit and Métis Peoples of Canada (Chapter 9). In particular, the researcher will seek to understand and respect community customs and codes of practice, as required in TCPS Article 9.8. The researcher will do this through constant inquiry and participation in traditional practices (i.e., throughout the consent process of offering tobacco), the use of Indigenous methodologies, and detailed reviews of the literature. This project will seek input at all stages of the research from the community partners, especially if any problems arise during the data collection or data analysis.

### **Analysis and Dissemination of Research Findings**

Preliminary research findings will be reviewed with the community partners before writing and publication. This will allow for appropriate interpretation of data as well as helping the researcher to position the analysis in the context of the community. Through the community partnerships, a final research report will be disseminated to the appropriate community stakeholders.

### **Transparency of Funding**

The research project is funded by the Canadian Institutes of Health Research in the amount of \$15,000. The researcher is conducting the project as a member of the Ryerson University community (PhD student). Expenses, such as travel and incentives, will be paid from the researchers' research funds.

### **Data Ownership and Intellectual Property Rights**

The researcher will be the steward or caretaker of the data for the duration of the project. The documents collected, and notes taken during interviews, will be stored on secure computers (password protected, encrypted files) and stored in locked office facilities at Ryerson University. At the end of the project (and after a period of 5 years) the documents and notes (de-identified) will either be given to the community partners (2-Spirited People of the 1st Nations and/or the Ontario Aboriginal HIV/AIDS Strategy) or if they do not wish to have them, they will be destroyed.

Any publication of the research will acknowledge participation of all parties and that support for the research has been provided by both the Community Partners and CIHR.

## **Communication**

Regular updates will be provided from the Researcher to the Community Partners, through telephone discussions, email and formal reports.

## **Dispute Resolution**

Disputes will be resolved through communications between the Researcher and the Community Partnerships. In the event that a solution to a dispute cannot be resolved, the supervisory community will have final say on the direction of the project.

## **Term and Termination**

This agreement may be terminated by the written notification of either party. Termination of this agreement will not affect the Community partners standing with the Researcher, his Supervisor or Ryerson University.

## **Principles of the Partnership**

The following principles will be reviewed and confirmed by both parties.

- To do no harm to the community.
- To do no harm to the relationship between the community and the researcher.
- To place the needs of the community as a first priority in any decision.
- To undertake research that will contribute something of value to the community.
- To involve the community in active participation of the research process and to promote it as a community-owned activity.
- To ensure the research design, implementation, analysis, interpretation, reporting, publication, and distribution of its results are culturally relevant and involve the community.
- To ensure that research carried out is done in accordance with the highest standards, both methodologically and from Aboriginal cultural perspectives.
- To promote the sharing of knowledge gained through this project to society at large
- To abide by any local laws, regulations, and protocols in effect in the community or region, and to become familiar with the culture and traditions of the community.
- To ensure that the community is fully informed in all parts of the research process, including its outcomes through publications and presentations, and to promptly answer questions that may emerge regarding the project and its findings.
- To communicate equally with the other partners in all issues arising in the project.
- To abide by university research ethics guidelines.

- To provide a link between the Researcher and other community members, and provide relevant, timely information on the Research Project.
- Within their respective roles as researcher and community representatives, to advocate and address together any health, social, or other issues that may emerge as a result of the research.

### **Signatories**

This agreement shall have an effective date of October 1, 2015 and shall terminate on January 1, 2017.

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Art Zoccole, Executive Director,  
2-Spirited People of the 1st Nations

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Tony Nobis, Executive Director  
Ontario Aboriginal HIV/AIDS Strategy

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Sean Hillier, PhD Candidate  
Ryerson University

## Appendix 3: Consent Form



### Ryerson University Consent Agreement

#### **How Policy Affects Funding and Service Delivery For HIV/AIDS in Remote First Nations Communities in Ontario, Canada**

You are being invited to participate in a research study. Please read this consent form so that you understand what your participation will involve. Before you consent to participate, please ask any questions to be sure you understand what your participation will involve.

**INVESTIGATORS:** This research study is being conducted by:

Sean Hillier, PhD Candidate

Policy Studies, Ryerson University

350 Victoria Street, Toronto, ON M5B 2K3

(416) 979 5000 x 6220

[shillier@ryerson.ca](mailto:shillier@ryerson.ca)

**Supervisor:**

Lynn Lavallée, Ph.D. Associate Professor

School of Social Work, Ryerson University

350 Victoria Street, Toronto, ON M5B 2K3

(416) 979 5000 x 4791

[lavallee@ryerson.ca](mailto:lavallee@ryerson.ca)

This study is funded by the Canadian Institutes of Health Research.

**PURPOSE OF THE STUDY:** This research will look at federal policy and funding for HIV/AIDS programs and services for First Nations people within remote reserves in Ontario, Canada. The goal of this research is to offer a better understanding of services available to people and communities affected by the HIV/AIDS epidemic and to make recommendations of ways policy can help improve services within these communities.

**WHAT YOU WILL BE ASKED TO:** If you volunteer to participate in this study, you will be asked to do the following things:

- Take part in a 1-3 hour one-on-one sharing session with me, Sean Hillier. The questions will focus on your life and experiences of living with HIV/AIDS and how you have accessed treatment during your time living in your community.
- Review the transcript of the sharing session to make sure it is accurate and give you the chance to remove anything that you are not comfortable in sharing.
- I would like to audio-record the session. The audio recording will be transcribed; however, your name will not be used. If you are uncomfortable with this I will take detailed notes, and/or the audio recorder can be turned off if you want to share something specific without being recorded.

**POTENTIAL BENEFITS:** I cannot guarantee that you will receive any benefits from participating in this study. However, there is a possibility that you will feel a sense of belonging by participating in the research and by sharing your story. The research will also contribute to the knowledge about HIV/AIDS service delivery in First Nations, Métis and Inuit communities.

**WHAT ARE THE POTENTIAL RISKS TO YOU AS A PARTICIPANT:** The risks associated with your participation are minimal. This project may involve you sharing something that makes you uncomfortable or causes you stress. If this happens you can stop participating either temporarily or permanently. I will also provide you with a list of Traditional People/Elders and counsellors/psychologist you can speak to, attached at the back of this form. There is also a risk that by participating your identity may be revealed. In make sure this does not happen I will not use your real name in the transcript and you can sign this consent form with an alias name. Also, nothing with be put in the transcript that can potentially identify you, like places you may have worked, your community, etc. Also, you will have the opportunity to review your transcript to remove anything you are not comfortable in sharing. I can send you a copy of your transcript by email or you can pick it up from me in two weeks' time if you do not want to share your email address.

**CONFIDENTIALITY:** Your participation will remain confidential. I will be the only one who knows you participated. My supervisor will be able to review the finalized transcript but will not know your name. As mentioned above, your name will not be included in any written documentation. I will be hiring a transcriptionist to type out the audio recording. The transcriptionist will sign a confidentiality agreement. If you are concerned with this, I can share the name of the transcriptionist with you or you can choose to not have your interview audio recorded.

All records, documents and audio-recordings will be kept in a locked file cabinet at Ryerson University and only I will have access to this information. All computers and memory sticks used for this research will be password protected and encrypted to protect your information.

Once the audio recording is transcribed, the audio recording will be erased. The rest of the data will be kept until December 2020 because further reports may be written and require us to look back at aspects of the project. After 2020 all data will be destroyed/shredded and/or erased.

Confidentiality will be maintained to the extent allowed by law. For instance, if you share information related to self-harm or harming others, or information related to child abuse/neglect I am required by law to report this activity.

**INCENTIVES FOR PARTICIPATION:** For sharing your knowledge and experiences you will be provided with \$50 for your time. If you stop participating or have to leave early you will still be given the \$50. The payment will be given at the start of the session.

**VOLUNTARY PARTICIPATION AND WITHDRAWAL:** Participation in this study is completely voluntary. You can choose whether to be in this study or not. If any question makes you uncomfortable, you can skip that question. You may stop participating at any time and you will still be given the incentives and reimbursements described above. Your choice of whether or not to participate will not influence your future relations with Ryerson University or the investigators Sean Hillier and Lynn Lavallée involved in the research.

**REMOVAL OF YOUR DATA FROM STUDY**

If you choose to stop participating, you may also choose to not have your data included in the study. If you have completed your participation and you wish to no longer have your data used within the study, you may contact me (my contact information is located on the first page of this document) within six (6) months of this date to have your data deleted.

**QUESTIONS ABOUT THE STUDY:** If you have any questions about the research now, please ask. If you have questions later about the research, you may contact me at the information contact at the start of this form.

This study has been reviewed by the Ryerson University Research Ethics Board. If you have questions regarding your rights as a participant in this study please contact:

Research Ethics Board

c/o Office of the Vice President, Research and Innovation

Ryerson University

350 Victoria Street

Toronto, ON M5B 2K3

416-979-5042

[rebchair@ryerson.ca](mailto:rebchair@ryerson.ca)



**How Policy Affects Funding and Service Delivery For HIV/AIDS in Remote First Nations  
Communities in Ontario, Canada**

**AGREEMENT:**

You have two options to demonstrate your willingness to participate. You can sign this agreement (with your real name or an alias) or in place of signing you can accept this gift of tobacco, if that is part of your cultural practice.

In accepting this tobacco or signing the agreement you understand the project, have asked questions about the study and agree to participate. You have been told that you can change your mind and withdraw your consent to participate at any time. You have been given a copy of this agreement.

You have been told that by accepting this tobacco or signing this consent agreement you are not giving up any of your legal rights.

- ☐ I agree to the session being audio-recorded
- ☐ I do not agree with the session being audio-recorded

\_\_\_\_\_ I accepted tobacco in place of signed consent

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

## **Counselling Resources**

### **How Policy Affects Funding and Service Delivery For HIV/AIDS in Remote First Nations Communities in Ontario, Canada**

#### **Toronto:**

Centre for Addiction and Mental Health (CAMH)

60 White Squirrel Way, 2nd Floor

Toronto, ON

General Phone: (416) 535-8501, ext. 3988

Aboriginal Services Program: (416) 535-8501, ext. 3988

Rainbow Services (LGBTTIQQ2S): 1 (800) 463-2338

[http://www.camh.ca/en/hospital/care\\_program\\_and\\_services/addiction\\_programs/Pages/guide\\_aboriginal\\_service.aspx](http://www.camh.ca/en/hospital/care_program_and_services/addiction_programs/Pages/guide_aboriginal_service.aspx)

Anishinaabe Health Toronto

**179 Gerrard Street East**

**Toronto, ON**

**Phone: (416) 920-2605**

[www.aht.ca](http://www.aht.ca)

**519 Community Centre**

**519 Church Street**

**Toronto, ON**

**Phone: (416) 392 6874**

<http://www.the519.org/programs/community-counselling>

## Appendix 4: Research Information



Hello,

My name is Sean Hillier. I am a First Nations Ph.D. Candidate at Ryerson University in Toronto, Canada, in the Policy Studies Program. Could you please share this email through your networks.

I am emailing you today to ask if you would like to voluntarily participate in my doctoral research study, entitled “How Policy Affects Funding and Service Delivery for HIV/AIDS in Remote First Nations Communities in Ontario, Canada”. The project is funded through the Canadian Institutes of Health Research – Doctoral Award. My doctoral supervisor is Dr. Lynn Lavallée.

In order to participate you must:

- 1) be at least 16 years of age;
- 2) have been diagnosed with HIV/AIDS;
- 3) have left your remote Ontario reserve community (you can determine for yourself if you feel your reserve was/is remote) to get treatment or support for your HIV/AIDS status.

This research will look at how available and sufficient the services are within your First Nations community from your perspective. The goal is to merge the experiences you’ve had in accessing services while connecting them to the policies that may have created barriers to getting the best possible service. The objective of the research is to determine how federal policy affects the funding and service delivery of HIV/AIDS services (and how they are perceived by clients and practitioners). The goal of this research is to offer a better understanding of services available to people and communities affected by the HIV/AIDS epidemic and to make recommendations of ways policy can help to prevent the spread of HIV/AIDS within these communities.

The study will have up to 50 participants taking part in the research. If you agree to participate in this study, you will be asked to answer a series of general questions about your experiences with accessing services in your community or outside your community and how you felt about the services you accessed. This whole process may take between 1-3 hours, depending how much or how little you wish to share. You will receive an honorarium for your participation.

If you are interested in finding out more information or if you would like to participate please contact me via email: [shillier@ryerson.ca](mailto:shillier@ryerson.ca) or Ph: 1 (647) 988 3448

**This research has been approved by the Ryerson Research Ethics Board. I have worked with the Ontario Aboriginal HIV/AIDS Strategy and Two Spirited People of the First Nations to develop this research project. The community partners will not have access to your personal information.**

Kind regards,

Sean Hillier, PhD(c)

## Appendix 5: Recruitment Email and Screening Script



Hello,

My name is Sean Hillier. I am a First Nations Ph.D. Candidate at Ryerson University in Toronto, Canada, in the Policy Studies Program. Could you please share this email through your networks.

I am emailing you today to ask if you would like to voluntarily participate in my doctoral research study, entitled "How Policy Affects Funding and Service Delivery for HIV/AIDS in Remote First Nations Communities in Ontario, Canada". The project is funded through the Canadian Institutes of Health Research – Doctoral Award. My doctoral supervisor is Dr. Lynn Lavallée.

In order to participate you must:

- 1) be at least 16 years of age;
- 2) have been diagnosed with HIV/AIDS;
- 3) have left your remote Ontario reserve community (you can determine for yourself if you feel your reserve was/is remote) to get treatment or support for your HIV/AIDS status.

This research will look at how available and sufficient the services are within your First Nations community from your perspective. The goal is to merge the experiences you've had in accessing services while connecting them to the policies that may have created barriers to getting the best possible service. The objective of the research is to determine how federal policy affects the funding and service delivery of HIV/AIDS services (and how they are perceived by clients and practitioners). The goal of this research is to offer a better understanding of services available to people and communities affected by the HIV/AIDS epidemic and to make recommendations of ways policy can help to prevent the spread of HIV/AIDS within these communities.

The study will have up to 50 participants taking part in the research. If you agree to participate in this study, you will be asked to answer a series of general questions about your experiences with accessing services in your community or outside your community and how you felt about the services you accessed. This whole process may take between 1-3 hours, depending how much or how little you wish to share. You will receive an honorarium for your participation.

If you are interested in finding out more information or if you would like to participate, please contact me via email or phone.

416-979-5000 ext. 6220

[shillier@ryerson.ca](mailto:shillier@ryerson.ca)

**This research has been approved by the Ryerson Research Ethics Board. I have worked with the Ontario Aboriginal HIV/AIDS Strategy and Two Spirited People of the First Nations to develop this research project. The community partners will not have access to your personal information.**

Kind regards,

Sean Hillier

Hello,

My name is Sean Hillier, I am a doctoral student at Ryerson University, I am contacting you because you have expressed interest in participating in my research study. In order to determine your eligibility to participate I have to ask you a few questions, is that okay?

Just as a note, any answers you provide to these question will be kept confidential and any notes I take during this call will be destroyed once your eligibility has been determined.

First, are you at least 16 years of age? Answer: \_\_\_\_\_

Second, have been diagnosed with HIV/AIDS? Answer: \_\_\_\_\_

For the next question, you can determine for yourself if you feel your home reserve is remote.

Is your community remote and if so, what is the name of that community?

Answer: \_\_\_\_\_

Community: \_\_\_\_\_

Finally, have left your community to get treatment or support for your HIV/AIDS status?

Answer: \_\_\_\_\_

If a participant does not meet the eligibility requirements, I will thank them for taking the time to speak with me but inform them that they do not meet the requirements to participant in the study.

If they do meet the eligibility requirements, I will thank them for taking the time to speak with me and inform them they meet the requirements to participate and that I would like to schedule a time to meet with them to conduct the Story Telling method.

Additionally, I will ask to collect successful participants' emails, so I can send them the consent form for their review before the meeting date. Also noting that a hard copy will be provided to them on the day of.

Email address: \_\_\_\_\_

## Appendix 6: Recruitment Flyer



Policy Studies  
Faculty of Arts

### SEEKING FIRST NATIONS PARTICIPANTS FOR RESEARCH IN HIV/AIDS FUNDING

We are looking for volunteers who are:

- 1) 16 years of age or older,
- 2) have been diagnosed with HIV/AIDS,
- 3) be from an Ontario reserve



You will be asked to share your experiences with accessing health and community services in relation to your HIV/AIDS status. This one-on-one interview will take approximately 1-3 hours (depending on how much you want to share).

You will receive an honorarium for participating in this study.

For more information about this study please contact:

Sean Hillier, PhD Candidate. Email: [shillier@ryerson.ca](mailto:shillier@ryerson.ca) Ph: 1 (647) 203 3448

This research has been approved by the Ryerson Research Ethics Board. I have worked with the Ontario Aboriginal HIV/AIDS Strategy and Two Spirited People of the First Nations to develop this research project. The community partners will not have access to your personal information. This project is funded by the Canadian Institutes of Health Research. My doctoral supervisor is Dr. Lynn Lavallée.

shillier@ryerson.ca

shillier@ryerson.ca

shillier@ryerson.ca

shillier@ryerson.ca

shillier@ryerson.ca

shillier@ryerson.ca

shillier@ryerson.ca

shillier@ryerson.ca

shillier@ryerson.ca

shillier@ryerson.ca



## Appendix 7: Freedom of Information Request

Requesting information from the past five (5) years for the following:

- 1) What funding has been provided for ALL First Nations people in ONTARIO (Excluding Inuit and Métis peoples) for services and programs for people living with HIV/AIDS. This should include direct health care needs: (a) payments made for HIV medications [HIV antiretroviral HAART], (b) visits to specialists [infectious disease experts, counselling], (c) HIV diagnostic and ongoing routine testing, and (d) programs for people with HIV/AIDS [ie. education, prevention, intervention]. Including any other services related to providing this care (ie. transportation costs).
- 2) What funding has been provided to First Nations Reserves for people residing on Reserve in ONTARIO for services and programs for people living with HIV/AIDS. This should include direct health care needs: (a) payments made for HIV medications [HIV antiretroviral HAART], (b) visits to specialists [infectious disease experts, counselling], (c) HIV diagnostic and ongoing routine testing, and (d) programs for people with HIV/AIDS [i.e., education, prevention, intervention]. Including any other services related to providing this care (i.e., transportation costs).
- 3) What funding has been provided DIRECTLY to First Nations Reserves in Ontario (list broken down by First Nations) for treatment, services and programs for testing and people living with HIV/AIDS (i.e., what money has been allocated to each of these communities for preventing and treating HIV/AIDS).

## Appendix 8: Freedom of Information Request

Requesting information from the past five (5) years for the following:

- 1) (a) How many 'status Indians' who fall under Non-Insured Health Benefits (NIHB) program have been diagnosed or are accessing treatment / service for HIV/AIDS within Ontario?
- (b) What is the total number of persons who access NIHB in Ontario currently accessing the below listed medications for their HIV status?
- (c) What is the total costs paid out for the medications listed below for persons residing in Ontario and covered by NIHB.

**\*Table of medications pertaining to questions (b) and (c):**

### **Brand name (generic name)**

1. Atripla (efavirenz + emtricitabine + tenofovir disoproxil fumarate)
2. Complera (tenofovir disoproxil fumarate + emtricitabine + rilpivirine)
3. Genvoya (elvitegravir + cobicistat + tenofovir alefanamide + emtricitabine)
4. Stribild (elvitegravir + cobicistat + tenofovir disoproxil fumarate + emtricitabine)
5. Triumeq (dolutegravir + abacavir + 3TC)
6. Trizivir (AZT + 3TC + abacavir)
7. Combivir (AZT + 3TC)
8. Auro-lamivudine/ zidovudine (AZT + 3TC)
9. Teva-lamivudine/ zidovudine (AZT + 3TC)
10. Kivexa (3TC + abacavir)
11. Prezcobix (darunavir + cobicistat)
12. Truvada (emtricitabine + tenofovir disoproxil fumarate)
13. Celsentri (maraviroc)
14. Fuzeon (enfuvirtide for injection)
15. Isentress (raltegravir)
16. Tivicay (dolutegravir)
17. Edurant (rilpivirine)
18. Intelence (etravirine)

19. Rescriptor (delavirdine)
20. Sustiva (efavirenz)
21. Auro-efavirenz (efavirenz)
22. Viramune (nevirapine)
23. ViramuneXR (nevirapine extended release)
24. Auro-nevirapine (nevirapine)
25. 3TC (lamivudine)
26. Auro-lamivudine (3TC )
27. Retrovir (AZT, zidovudine)
28. Viread (tenofoviridisoproxil fumarate)
29. Ziagen (abacavir, ABC)
30. Aptivus (tipranavir)
31. Crixivan (indinavir)
32. Kaletra (lopinavir-ritonavir)
33. Norvir (ritonavir)
34. Prezista (darunavir)
35. Reyataz (atazanavir)
36. Telzir (fosamprenavir)
37. Viracept (nelfinavir)

## Appendix 9: Demographic Survey

### Interview Guide – S. Hillier PhD Research

To be filled in by researcher at start of interview after consent has been received.

(note: Demographic data is voluntary and will only be used to describe the sample population. The specific demographic data will not accompany the person's transcript or be aligned in any written documents).

Participant ID code: \_\_\_\_\_

Age: \_\_\_\_\_

Educational Level: \_\_\_\_\_

First Nation Community: \_\_\_\_\_

Sex: \_\_\_\_\_

Income: \_\_\_\_\_

## Appendix 10: Interview Guide

Interview Guide – S. Hillier PhD Research

Participant ID code: \_\_\_\_\_ Pseudonym: \_\_\_\_\_

Thank you for joining me today. Before we begin, I would like to go over the consent process with you (review consent form and allow for questions).

Thank you for agreeing to take part in this research. I will now start the audio-recorder (if participant agreed). Again, please share as much or as little as you feel comfortable. You can pass a question or stop at any time or you can ask that the recorder be turned off and I will take detailed notes instead.

- 1) Can you tell me a bit about your experiences with being diagnosed with HIV?
  - When were you diagnosed?
- 2) Tell me about accessing services and treatment for HIV in your First Nation?
  - Are there specific HIV services located there?
  - Was there any education for HIV/AIDS within your community?
- 3) Can you tell me a little about your choice to leave your First Nation?
- 4) How has accessing treatment been since you have come to Toronto?
  - Have you been using any culturally specific services for treatment or support? Tell me about your experiences with those services?
- 5) Is there anything else you wish to share about your experiences as a First Nations person living with HIV and how you have accessed services or funding for treatment?
- 6) Are there any recommendations or improvements you would suggest to improve treatment, especially within your community?

## Annex A: Participant Stories

### Participant 001: Mikey

Although I don't remember the exact day I was diagnosed with HIV, I remember that I contracted it while living in [city name]. I was taken from my community when I was about 10 or 11 years old by the Children's Aid Society. I was running away from home all the time and since then I've been on the streets. The streets are a part of me now. That is where my livelihood is, where the friends that I hang out with are as well as most of the people I know.

All I could do was laugh when I was told I had HIV. I was in shock and I almost couldn't believe it. Me? With HIV? It took about two days before reality hit me and I realized that this would be my life.

I've been living in [city name] since 1994 and have only accessed treatment here. Accessing services in [city name] has not been a great deal of an issue for me as I usually go to drop-in centres, two of which are culturally specific treatment services. Any centre I go to, I end up getting kicked out of and most of the time I'm not sure why. I've liked most of the services I've gone to here, even though I haven't felt a great deal of comfort towards one. In terms of the community that I come from, I'm not aware of any accessible treatments there or of how good they are. I haven't been back home since being taken away.

As a First Nations person living with HIV, when sharing my experience with people, there are times where I talk to someone who isn't HIV-positive, and they don't speak to me in a rude way or suggest that they would speak about me in a rude way to others. Sometimes when

those people talk to others, I hear remarks such as, “Oh, he has HIV,” or, “Don’t touch him, he has HIV.” I could never do that to someone and it is something that I cannot tolerate. I can’t say if racism plays a part in it, but regardless, who is anyone to tell me anything about myself?

There are some improvements that I would recommend be made to services for both Aboriginal and non-Aboriginal people living with HIV. One change that needs to be made is creating more programs for youth and children. If there ever becomes a cure for HIV, everyone should have access to it.

## Participant 002: Ahiga

My name is [name]. It means “he fights”. I have been living with HIV for the past 30 years, which I believe I contracted through drug use. I was diagnosed only 15 years ago when I moved to [city name] from where I grew up - a reserve called [name of community] in Northern Ontario.

During my time living on the reserve, I was a street guy. I was a heavy drinker and I lived on the streets. I lived on the reserve with my wife of seven years and afterwards with my current common-law partner of 22 years. While living there, I was not aware of my HIV status as I was not showing any symptoms and also because there was no open dialogue on the reserve about HIV. It was not until I developed pneumonia that I started noticing my symptoms. Unfortunately, there was no support available on the reserve. There is no education, discussion or help concerning HIV or AIDS. My partner and I had to travel to [city name] so that I could be properly diagnosed and access medical support. It was there that I was not only diagnosed with HIV, but also learned that I had been living with HIV for 15 years prior to my diagnosis. I was completely in shock when I found out and the discovery made me depressed.

When my partner and I travelled back to the reserve, things only got worse. After getting back, my partner was incarcerated. While in jail, she was tested for HIV and discovered that she had contracted the virus as well. When the community on the reserve found out, they started looking at me differently. They no longer accepted me as they knew that my partner was not a drug-user and that I am the one who uses drugs. People started to spread rumours that I contracted HIV because I was gay, though I have never been with another man in my life.



Whenever I went to drink with friends, they would worry that I might try to share drinks even though I am careful of my illness and always pour my own.

The youngest people on the reserve are the most ignorant and also the most dangerous. There have been times when they have come up to me, called me disgusting and ran away. I started to fear mine and my partner's safety and I wasn't sure what to do until I was told about a man who specialized in support for people with HIV and AIDS in [city name]. People had suggested that I moved there for proper support for my illness, and although it took me a while to accept that I needed the help and that my partner and I needed to be in a safer community, I finally decided to move to [city name]. In [city name] I received aid and got involved with a support group that really helped me. Without that support, I'm not sure I would have made it. On top of the support I felt from this amazing group of people, I decided to seek help from an Elder and got involved with Traditional Healers. I would enter sweat lodges with the Traditional Healers and talk with them, some of which even had HIV too. The Elder helped me to overcome my depression by offering space to speak and practice healing. Communication is key in the healing process and has helped me a lot in my journey. I sought other services that [city name] has to offer after spending time with the Elder and Traditional Healers, however I had issues with one of the services which almost had me stop trying to seek support. Luckily, I changed my mind and got more involved with group therapy.

Although there is adequate support in [city name], there are not many good doctors. All the doctors that I have visited do the same thing: they see me for about five minutes, give me a short check-up, ask me to sign papers for blood work, I go and have the blood work done and then nothing happens. Every time I follow up with a doctor regarding my blood work, I receive

no answer which can get really frustrating. I have been waiting over six months for the results of my most recent blood work.

I heard that [different city name] has many great doctors who specialize in HIV healthcare and that is where I am located now. Regardless of doctors and the healthcare system, public communication and education can really help with HIV/AIDs healing. I am currently taking a course on how to educate others properly on HIV because I would like to see a change in public mind-sets surrounding HIV/AIDs. I hope to see more education on my reserve and up in other northern communities surrounding HIV/AIDs, especially among young people who are the upcoming generation. It's crucial that there is accessible education on general information about the disease, transmission, sexual intercourse, drugs and contraction. Most importantly, society - especially those on the reserve - needs to be educated about the harmfulness of the stereotype that HIV/AIDs is just a disease that gay people experience. HIV/AIDs is not only alive in the LGBTQ+ community. It exists far beyond the gay community and people need to be made well aware of this.

My experience with HIV started out rough. I'm not sure how I contracted HIV – it could have been from a lot of things. Back in the '90s, my husband and I used drugs and I was using intravenous drugs at the time. I learned that a couple of the people I was doing drugs with had HIV, so I figured it was likely from them that I contracted it, but I'm not sure if that's true. At the time, my husband had also been seeing another woman. He didn't have HIV though. I'm not sure how he didn't have it since I did.

When I was diagnosed, I felt all kinds of emotions and had thoughts of suicide. I continued to use drugs for a couple of years, but finally stopped and decided to start looking after my health. After that, I moved provinces to see my family and then moved to my husband's home First Nations community. My husband's sister lives there and she wanted him to meet her kids. He didn't know his family very well and was excited to spend time with them.

My husband's family in the First Nations community treated me badly - his brother-in-law especially. One time he told his son-in-law, an OPP officer, to wait on the highway when there was a courier coming in with my medication. When the courier pulled into the driveway, his son-in-law followed the courier driver in and asked to see what was in the box. I took everything out for him and he looked at me and asked, "Are those your crazy pills?" "No," I said, "Those are the pills that are going to keep me alive." He didn't understand what HIV was and had the police stop my medication from being delivered. I couldn't believe it - the police are supposed to be educated people. It's still hard to believe that my husband's family could treat me like that. I was really hurt by it all.

In the First Nations community there were no HIV specific or general medical available. There was no doctor or nurse. The only education provided on HIV is for the children. There is no education for adults and nobody talks about it. The closest doctor is located in a town an hour away and in order to access treatment I would have had to travel an hour and a half.

One day, the Chief from the community took my husband and I to that nearby town to go shopping and left us behind there. We didn't know what to do so we started drinking and that night I got hit by a truck. I went to the hospital and was released the next day with a

broken tibia. The doctor told me it was okay to walk on it, but it quickly became swollen and painful. When I got back to the First Nations community, I started asking the Chief to take me back to town to see a doctor again, but he kept saying he had to wait for more passengers. Finally, after walking on it for two weeks, the Chief took me to town. Before the doctor could put a cast on it, we had to wait a while for the swelling to go down.

I knew we had to leave the community because of everything that had happened, plus I was immobile - getting around in a cast and wheelchair and therefore unable to hitchhike in and out of town. We went to see a man that my husband went to school with to see if he could help us leave. He made a few calls and got us on a plane to [city name] that night. When we got off the plane, I felt totally lost and helpless. The only things I had with me were my medication and a set of clothes. We didn't even have enough money to get a taxi from the airport. It was a good thing that I had been in contact with an HIV worker in [city name]. He left us \$20 at the airport so that we would be able to make it from there to a shelter house.

We lived at the shelter for a month, but it was hard to get around in my wheelchair and I really wanted to get out. I didn't care if I had to sleep on the floor somewhere. Thankfully, we found a place to live through the help of workers at the shelter. That was all 16 years ago and I've been in [city name] ever since. Since coming to [city name], I've been doing much better. I haven't had any issues accessing medical services or getting my medication. I haven't been taking my medications now for a couple of months but that's because I missed important appointments with my doctor and other specialists due to being sick. I have called on multiple occasions to get my medications but wasn't able to by phone, so I have been without my medications since.

### Participant 003: Nora

I don't really care for my HIV doctor. My family doctor said that she will soon be able to prescribe me HIV medication, so it might be nice to go to her instead. My HIV doctor is rough with women. He doesn't like when we miss appointments and I can tell he really doesn't like when we are not doing well with our blood counts. Most of the patients are survivors of both HIV and residential schools. I was in residential school until I was 12 and when I got out, I was forbidden from my home in [name of hometown]. Being in residential school is what lead me to drug use and drinking and I still struggle with the memories. It was very easy for me to get pills in [name of hometown]. I was taking Valium, pain pills, and huffing at a young age. When I ran out of pills, I needed something to help to forget the traumatic memories, so I started drinking. Residential schools have done a lot of damage to me and I wish I could forget everything. For example, I've had a hard time with women since residential school, especially lesbian and bisexual women as I was molested by a lesbian woman there.

I wish there were more services available for Native people to begin healing. Some of us have HIV because we turned to drugs or sex to cope with the trauma we have experienced. Having a centre for HIV positive Native people to get together would be really helpful. I've found that connecting with my cultural traditions has helped me move through my experience with HIV. Recently, I started going to drumming circles. First, I started singing and this year I made two drums – one big and one small. I've also been working with an Elder which has been really impactful. Having a place where we could access services like these would be great.

The discrimination I have experienced having HIV has been incredibly painful. Even my own family shunned me. I've asked my son to visit me and he tells me that he won't because I'm sick. He doesn't believe that I have stopped using drugs and says he's afraid of accidentally sitting on a needle at my house and getting HIV. The same sorts of things are starting to happen with my grandchildren. My grandson recently started talking to me on Facebook and gave me a phone number where I could reach him at certain times. When I phoned him, his stepfather came on the phone and said, "What are you phoning here for? I'm the one who looks after this house." The way he said it suggested that his family is his and not mine. That's what hurts the most. I want to see my grandchildren but if they are going to be ignorant then I won't go there. The lack of education and understanding where they are makes things really difficult.

For my personal healing, I've started drinking sage tea and going to sweats to get rid of the grief and cleanse myself. I try to live a positive life now. I won't be able to go on if I am filled with negative thoughts. If I could make any suggestions on a broader scale, I would suggest that access to services and education about HIV be improved. There needs to be more access to doctors and spaces for healing. We have to go through so much and we need healing to help us.

#### Participant 004: Yvonne

My name is [name] and I was diagnosed with HIV in 1996. I believe I contracted HIV while I was cleaning my room and was poked by a needle in the doorway. I didn't think anything of it until two weeks later when I got really sick and was so weak that I couldn't move. A friend picked me up off the sidewalk and took me to his house where I slept on his floor and lay there vomiting for three days. Initially, I thought it was just the flu. I wasn't able to eat or drink anything and my friend wondered if it could be HIV. He suggested I go to a nurse's station to get tested. Although I wasn't aware of what HIV was at the time, I took his advice.

When I was tested, there was a mix up with my diagnosis. I received another woman's test results and she received mine. This wasn't resolved for 30 days, so for 30 days I was unsure of my HIV status. I didn't feel that I could talk to anybody about this. I felt hurt, angry and alone. I cried all the time and worried about my children who didn't know what was going on with me. The day I finally got my correct test results I wanted to die. I got drunk every day after that for a really long time. I was mad at the world and everybody in it. Part of the reason it was such a difficult time for me to be diagnosed was because at the time I didn't have anywhere to live. I had been kicked out of the hotel room I was staying in even though I had paid my rent. I had to haul all of my belongings with me and walk along the streets. A few years later I decided to return to my home community. Before going, I called the HIV services there to find out what I would be able to access when I arrived. I found there was nothing back home for me. After a while, I went to a doctor and was put on medication. I have since had many different

medications, but I have always had difficulty taking them consistently because of partying, or because the places I spend my nights often change and I don't always keep them with me.

I first left my community because I didn't feel that there was anybody to talk to there. The only people who know about my HIV status are my sister and brother. My family doesn't want to talk about it with me. My sister won't even allow me to tell anyone, probably because the family doesn't know anything about HIV and she thinks they would be afraid of me. I don't know if her family would allow me in their home if they knew. I wish there was someone who would talk with me about my HIV.

People sometimes ask me why I look so skinny or comment on how I used to look healthier. In those situations, I just try to shrug it off and make an excuse. When I'm drinking or sharing cigarettes with people, I often wonder what would happen if they found out that I was HIV-positive. They would probably think they could get HIV from sharing with me. If they found out, they would probably get mad that I didn't tell them myself. The only times that I'll tell someone about my HIV status is if I feel they need to know or if they are at risk of contracting it. I've had some really bad reactions in the past. There was an incident once where a lady ran around telling everybody on the street that I had HIV. People questioned me about it, but I told them that if there was a situation where they needed to know that I had HIV I would have told them. A lot of this stems from a lack of education in many communities about HIV.

There are very few medical resources available in my home community - not even a pharmacy. Once a week or so, a nurse or doctor comes to a hall for a day at a time, but they are always really busy so it's difficult to get a chance to see them. Otherwise, to see a doctor



requires a day-trip into town, which you can only access if you have means of transportation. There used to be a bus to take people between towns but that's no longer available because there aren't enough people to pay for the gas. There's a train that comes twice a week, but if you miss it, you have to stay overnight before you can return home. In order to get my medication, I have to go outside of my community.

Where I live now, I have a support system. There are doctors and hospitals I can reach in case of an emergency. I have a healthy relationship with my doctor and have been seeing him for 10 years now. He makes my appointments and sets me up with my medications. His office provides transportation for me to get to my appointments and bus tickets to get home. I used to attend night groups once a week where patients would all get together, talk, have dinner and sometimes go for field trips here and there. I also have access to [name of local mental health service] which offers a lot of programs. They help me with my laundry and provide lunches, so I have a place to eat. I also travel with them sometimes and am invited to conferences. Most importantly, these programs enable me to interact with other people who have HIV - people who have become new friends and elders who check up on me. The staff here also helps me when they can, but they can only help me when I ask them for it.

I would love for there to be more culturally specific services available where I live so that I could get more involved with my culture. Through leaving my home community and having to go back and forth, I have lost a lot of friends and family and it has been really challenging. If there were more culturally specific services, I think I would be more peaceful than I am now. Occasionally, I participate in traditional practices like smudging and going to pow wows. I often take nice long nature walks and I enjoy going camping though that is difficult

to do because I don't have vehicle. I also have some friends and family here that can offer me support, though there are many people that I love who still don't know about my HIV status. My sister has me over to sleep at her house when I need it even though she isn't doing well herself - she has epilepsy and is in a wheelchair. We've had a challenging relationship with respect to my HIV. When she found out about my diagnosis, she told everybody without asking me and those people avoided me after that. It still makes me feel really alienated when my sisters tell other people. Since my diagnosis, I have thought about my children a lot. I still cannot accept that one day I will have to tell them that I am HIV-positive. I hope to tell them soon; however I am unsure how to do this, especially since I am not closely connected to all six of them.

I struggle with basic survival - high rent prices with very low income leaves for very little money for food or transportation. I have to walk everywhere I go, and my right leg isn't strong enough for walking and my back pain is unbearable. Everything hurts, and I feel like I'm falling apart. I often have to eat at soup kitchens and some days I don't eat at all. I basically live off whatever I can find – sometimes just plain macaroni with ketchup. I live day-to-day just trying to survive. Above all, social stigma and racism are my greatest struggles as a First Nations woman living with HIV. There is an obvious lack of knowledge and understanding surrounding HIV. If there was more public education about it, the public would stop looking at people like me differently and there would also be less risk of contraction. I often see needles laying on the street that never get picked up. I have a container that I sometimes carry with me to put them in, but if I don't have it with me then I don't know how to safely collect them.

If there was one piece of advice I would give to another person in a similar situation to me, it would be to not give up and believe in yourself. It has been a long, hard journey for me with many ups and downs, but considering all I have been through I'm still here fighting for my life. I have my children to think about so I'm not ready to quit yet. Find your inner strength and keep strong.

## Participant 005: Dominique

At the time I contracted HIV, nobody knew much about it. That was 25 years ago. I had heard of the term AIDs, but people rarely mentioned the HIV virus. Prior to being diagnosed, I was really struggling to come to terms with who I was. I was struggling to understand my sexual identity and orientation and I hadn't been open about it with anyone. I didn't even feel comfortable thinking about it. After I learned my HIV status, I realized that neglecting to understand my sexual identity put me at risk for HIV because I wasn't protecting myself adequately. I think I had internalized homophobia, so much so that when I was diagnosed I didn't tell my family. I thought that my family would think I was gay and being gay was a concept that I was considering at the time.

After two years of searching for my identity, I discovered the term two-spirited – a term that I could identify with and allowed me to feel comfortable with who I was. When I learned I was HIV-positive, I wanted to learn as much as I could about it. I sought out information and read a lot about it. At this time, the movies “Philadelphia” and “And the Band Played On” were just coming out. They were big movies at the time and started to open up the conversation around HIV. Doing things like watching these movies, putting myself into alcohol treatment and having conversations helped me to come to terms with my HIV and gain the courage to tell my family.

There was a young man that I met way back in the beginning that had a huge impact on the process of accepting myself enough to be honest with my family. We would meet at the bar where we would sit and talk for hours. He told me he had AIDs and shared his whole story with

me. He had been kicked out of his First Nations community and his one wish was that one day he would be able to move back and die in the community he was born. He wanted to die somewhere familiar surrounded by family - not in an empty hospital room in a strange city. When he tried to go back to his community, they kicked him out and sent him back to the city. He told me about how he was feeling and his struggle to find himself and a supportive community that he would belong in. I think that was one of the main sources of his pain and why he was constantly searching for ways to self-medicate. We didn't talk much about drinking or drugs though, just about our lives. His friends asked me to encourage him to self-medicate in the ways he was and eventually I did talk to him and about his friends' concern about his substance abuse. He said that he knew he had a problem but when he lost the choice to die at home, his spirit was broken. He explained that he loved his friends here and they were a great support system but they weren't the same as having acceptance in his First Nations community. He couldn't come to terms with the fact that he was in a strange city and would never be able to fulfil his last wish. He became sicker and sicker.

I tried to imagine what it would have been like for him. It made me so angry to think about how his family rejected him. At the time, my family still didn't know about my HIV. He inspired me to tell my family and not stand for it if they tried to reject me in similar ways to how his family rejected him. I didn't know it at the time, but a lot changed for me from the first time I met that young man to where I am today. The last time I met with him, I didn't realize it would be the last time I would see him in that setting that we had been meeting each other for years. Two weeks later, I brought my son downtown and happened to bump into one of his friends and they said that he was very sick in the hospital and didn't have much longer to live

and had been requesting to see me. I went to the hospital with my son. I went up and had my son wait outside the door so that I could go in first. He was hooked up to a bunch of tubes and had an oxygen mask on over his mouth. He had lost all of his hair aside from one patch of his long, black hair. He had also lost a lot of weight. His hospital gown hung off him like a coat hanger. He could see in my face that I was concerned and he reassured me that I was not going to end up like him. "Don't even think it because you're not gonna be this way," he said. I went up, gave him a hug and told him I had a surprise for him. I called my son in and for the first time ever, I saw a person's eyes literally dance. They lit up. All this time, I had been telling him stories about being a dad and about my son. He was finally able to see the love between my son and I and in that moment I felt why I loved my son so much.

I had my son sit away from us, so we could talk some more. He told me that "God brought us together for a reason." He told me that he believed I was a warrior because he saw a warrior spirit in me. "You're gonna go back and tell my story to communities so that this doesn't happen to somebody else," he said. He felt strongly about that and needed to know that I was going to be a fighter. When I left, I felt a sense of renewed passion and purpose.

A month or so later, I was in a program. There was an alcohol and drug counsellor there who told me that while I'm going through my journey of learning about HIV, I need to take it in bits and morsels at a time and stop trying to swallow the whole thing. She saw that I was reading books and watching movies and I would often cry from overloading myself with HIV-related content. She told me that if I slowed down, I would be able to find my way. I realized in that moment that I had to recognize that being HIV-positive doesn't define me. I had been so immersed in learning about HIV because I thought it was who I was, but I am not HIV. Learning

this has helped me to take steps toward healing and trying to find a sense of empowerment to be able to move forward in a healthy way. After that, I made sure to keep informed about HIV but not overdo it or let it consume me.

About two years later, I made the decision to move back to my home community. When I moved back, I made the choice to be open and honest about my HIV status. That was one of the hardest things I had to do but I was ready. I was at the point in my journey where if anyone asked me a question or was ignorant towards me, I would be confident in my response and that's what I did. There were some people who would label me right away and said things like "I wonder if he was gay all along." For a long time I didn't answer them, however, two years ago I had the opportunity to speak at an LGBT talk for the community's annual parade. In my speech, I addressed rumours and was honest with everyone about who I am. I didn't feel like I had to prove myself to anybody, but I wanted to say who I was and how I got to be where I was that day.

Over the past 20 years, I have spent lots of time in First Nations communities working to improve support for people with HIV. When I have asked people in leadership roles how they support First Nations people with HIV, they haven't had a clue how to answer. They don't see HIV as a priority, but in my view it should be a priority since so many of us don't have anywhere to turn to. There are some services in the nearby city, but it's not the same as having a place in your own community. I can't imagine how hard it is for some people who have no support at all. Every time I meet someone newly diagnosed with HIV, I think about that young man I knew and the struggle he had being rejected from his community.

As I have learned more about my family history and reflected on my childhood, I have realized the impacts of intergenerational trauma I have experienced. Only recently have I come to understand why my mom was the way she was. My mom had 15 children and I am 14<sup>th</sup> and youngest boy. We were raised by her and my dad who was a Frenchman from Quebec in a non-Native community. From what I can remember, when my parents would spend time with other Native people, there was always a lot of alcohol involved. My dad was a musician and was really popular at parties because he could play the violin. He was the life of the party. At these gatherings, our parents would leave us and all of the kids were off on our own. At the end of the night, our parents would drive home drunk with us in the car. This happened until I was about seven years old. After that, my mom found the Lord and my parents became Christians. My parents became so immersed in religion that we became neglected again, just like we were when they were drinking. It was all about God. God replaced alcohol and there was never a focus on us kids.

Whether it was alcoholism or Christianity, I never understood why my parents were the way they were. It wasn't until years later that I learned my mom went to residential schools and that explained a lot. She was there for about 10 years and hardly ever got to see her mom. I also discovered that her mom and aunts went to residential schools and none of them ever learned how to be a healthy parent. Somehow, my mom and aunt managed to maintain their traditional language while at residential schools. My mom would tell us that when she was at residential schools, they had what they called "the secret language club" and at recess or on breaks they would go off and make a point of speaking our language. They got caught a couple



of times and would get slapped on the hand. She was lucky to have been able to keep her language alive because I know a lot of people that lost it.

My mom is a very traditional Christian even though she says she isn't. She is against things like practicing sweat lodge or smudging because of being a Christian. I always thought that she became a Christian merely to replace her alcoholism, but I later realized that it likely came from being in residential schooling. Other residential school survivors I have met say the same things - almost to the exact wording - that my mom would say. A lot of this came from the teachers and staff in residential schools telling the students that their traditional ways were evil. My mom described to me an image on the principal's wall in the residential school that had white people going towards heaven and Native people going towards hell. My mom told me the teachers and principal would say, "Do you want to go here or do you want to go there?" while gesturing at heaven and hell. "If you want to go to heaven, you have to continue doing what you're doing and that's the way you're gonna go," she said to my mom. "But you need to listen to what we're teaching you so you can go there." This fear was really ingrained in my mother so much so that if I ever mention traditional knowledge to her, it triggers the fear in her and she will tell me not to talk about it to her.

I initially found out about my mom going to residential school about 10 years ago when I unknowingly went to a 100-year anniversary. The Native community where it was being held was where my mom had gone to residential school. At the memorial, they had books laid out with people's names that went to residential schools all across Canada. I was looking through the books and found my mom's name. I was really shocked to learn that my mom went to residential school for approximately 10 years. A woman approached me and said that the same

thing was happening to a lot of other people whose parents went to residential school as it was the first time that this information was being released to the public. She advised that I didn't tell my mom I knew because there was probably a reason she didn't tell me. She probably had bad experiences there and by bringing them up, I may re-traumatize her. Later, when I was talking about the town, my mom told me that was where she went to school. That was when I explained to my mom what I knew and she began telling me stories about it.

When there was a payout given to Indigenous Peoples who were sent to residential schools, my mom wanted to give her money to the church. Her church was telling her that she was punishing God by accepting the money. They told her that if she gave the money over to the church, they would take care of it. I told my mom that they were trying to exploit her and that it wasn't punishment to God - the government was just trying to reconcile. I told her that even though no amount of money could ever be enough, giving it away to the church and letting them take advantage of her was not the solution. She was also asked if she wanted to talk to a lawyer to tell her story and be paid for that, but she refused. It would have been too difficult for her to revisit her past and tell her stories. Sometimes she will tell stories to me but they are always very generalized and in third-person. She told me about one experience where these boys had tried to run away but got caught. All of the kids at the school were brought into a room and the two boys were put in the middle and had their legs broken in front of everyone. Sometimes my mom talks about the good things that happened to her at residential schools, like how she learned about quilting and sewing there.

I'm really curious to learn more about my family history. My mom shared with me that my grandmother was a medicine woman. I often speak with an elder from my First Nation who

knows my mom and knew my grandmother really well, so I try to learn more about my grandmother from her. My grandmother is in history books at my First Nations community because she had a lot of children and our family was one of the families that got to meet the Queen, so there is a picture of that in the book. That makes me think that my grandmother must have been a really important woman in the community. My grandfather was also well known and some pieces he has made are featured in a museum. These kinds of things really make me think that we have to be proud of who we are as Aboriginal people and learn more about the practices of our people. Yes, we have had a lot of terrible things happen to us but there are so many things we have to be proud of.

The work I do is about advocating for First Nations people on and off of reserves but my focus is on people on-reserve. Indigenous Peoples wouldn't have banished people with HIV in the past - we would have taken care of them. Because of colonisation, residential schools and these traumas that have happened to us we have forgotten those values. We need to make a return and bring back those teachings.

Accessing HIV services and treatment can be very challenging. One of the greatest struggles I faced in accessing HIV treatment was about 10-15 years ago when my virus was starting to show immunity to all medications. I had come to the end of my treatment and there were no other feasible options available for me. There was one treatment option left where I would have had to be injected twice daily. The treatment wasn't covered, however, so I had no way of accessing it. I was on a disability support program but the province still wouldn't cover the medication. They asked me to look into if my band would cover it. They refused. I had to write a letter to the Chiefs of Ontario to get them to lobby for me to have it covered. During

this period of three months while I waited to hear the decision, I had no medication or treatment. Finally, I ended up getting confirmation that the treatment would be covered. I suspected that the coverage came from my band. I wasn't comfortable with this decision and I explained this to them but I didn't have a choice. What would a person who doesn't have status do in a situation like this? What about someone who identifies as Métis or Inuit?

In the current system, it is easy for a person with HIV, especially an Aboriginal person, to fall through the cracks. My doctor told me if I wasn't able to have the medication covered, I likely would have died and that he would have used my story to lobby for a policy change. It shouldn't take a person dying for someone to take action. I made it through and I am here today, so I decided that I should do something about it myself. I have tried to be proactive since and have been able to get my medications covered, but I'm not sure if everyone else has the same access and if they did they would likely have to work as hard as I did. Aboriginal people face a greater challenge in accessing treatment and are at a greater risk of falling through the cracks regardless of being on or off of reserve. A conversation needs to be had around accessing medications for HIV and HIV-related side effects or comorbidities.

I originally to [city name] because I wanted to compare the experience of living with HIV there against living with the virus in my home community. My initial experiences when I moved here were bad. When I lived in a smaller community, I experienced less stigma because people knew me for me. I used my status in the community as an opportunity to educate other people about HIV as they got to know me. It was easier to get access to treatment because I had a relationship with my doctors, nurses, pharmacists and any other healthcare professionals from spending a lot of time in the hospital. When I moved to [city name], I couldn't even find a

doctor. I eventually found myself at the end of my prescription for a pain medication for AIDs-related symptoms and no doctor to prescribe me more. Out of desperation, I went to the hospital and explained what had happened to me, that I had been on this medication for ten years and that I needed a new prescription. The doctor questioned me. “Are you sure you’re not going to leave here and sell it?” she said. I asked her, “What are you basing that on? Is it because I’m Aboriginal?” I explained I was being truthful and that I really needed the medication. I left the hospital crying and upset without a prescription. I phoned a lawyer that I met years before who specializes in HIV and AIDs law. She instructed me to go back and repeat three words to the doctor. So, I went back to the doctor and said them. “Do no harm,” I said. “You took an oath. You can do no harm to me.” She eventually gave me the prescription and told me I could come back every 30 days, but it was unlikely another doctor would give me the prescription. After that, I went to an HIV specialist who reluctantly gave me my prescription and I saw him frequently until I finally found a doctor who I’ve had for about a year and a half now. I struggled for ten years until I was able to find a doctor. When I compare these experiences against living in a small community where I had a relationship with my healthcare providers, I would say it has been much more challenging here.

While HIV services and treatments have been better in smaller towns in my experience, I can’t say the same for First Nations communities where it can be very limited. Despite this, there is some funding that is provided to each First Nations communities for HIV. Access varies between communities and can be dependent on who their health representative is in the community. In my home community, there was a woman who delivered HIV workshops every year for a period of time. When I go to reserves, I lead education and promotion initiatives with

youth on HIV and AIDS. Over the past six years I have also shifted my focus to community members who already test positive for HIV. I want to ensure there are proper services in place to support people with HIV moving back to their First Nation. Usually, there are not adequate services or testing available within a First Nations community.

People living in fly-in communities face additional challenges in accessing healthcare. According to my doctor, for fly-in communities, people rely on Telehealth and are flown to the city every six months for appointments depending on their health conditions. Another big challenge they face is accessing regular blood tests that are time-sensitive. I imagine they'd probably have to fly a healthcare provider to the community, though I'm unsure. It is our right as people living with HIV to have the same access as any other Canadian. Indigenous Peoples ought to stop accepting things as they are and challenge the system.

I am currently planning on moving back to my First Nation community because I feel I will be able to make a greater impact that way. Around four years ago, I helped to pass a resolution for all First Nations in Ontario. Since then, it has been sitting idle because none of the Chiefs know how to implement it. I've been asked to take leadership and go to all the Chiefs of Ontario to do a presentation on how to take action with the resolution. We are currently working on having the resolution posted in all band offices, though I'm not sure that this will have any impact. We need to do something bigger to help people recognize how important this resolution is for our First Nations. If I move back to my First Nation, I would be able to step forward and take the leap as a voice for First Nations people. Right now, we don't have one. HIV affects First Nations communities more than people know and the stigma surrounding the virus can be severe and ostracizing. I know of a man with HIV who moved back to his home

community and had rocks thrown at him, “AIDS” painted on his house and people would sometimes even clear a store when he entered. This is deeply saddening to me and I know that we must work to eliminate the stigma.

We need to be better at actually providing actionable workshops to our communities so that they can better understand how the stigma attached to HIV can seriously hurt people. It’s beneficial to have somebody who is actually living with HIV telling their story and explaining how HIV impacts them, how it feels to be a community member with HIV and how they would like to be recognized in order to not be ostracized or othered. If we can begin to address these issues, we will be able to improve the lives of so many Indigenous Peoples with HIV.

Another thing that is really important to me is access to culturally specific services for HIV in addition to mainstream medicine. While I was raised as a Christian, I do consider myself someone with a traditional background and I’ve always felt a sense of familiarity with traditional teachings. It’s almost like I’ve already experienced them even though I’m just learning about them now. Sometimes I hear things and I think, “How come I already know all this stuff?” Or, “How come I feel like I’ve been here before?” Elders have told me that feeling is called blood memory and it is me remembering things from my ancestors. It’s really important to me to take part in my traditional spiritual activities and I would like to have equal access to both traditional and mainstream medicine. Here in the city, we have [name of culturally specific service] right next to a pharmacy and a clinic. In one First Nation community I went to, I saw a walk-in clinic, a pharmacy and a traditional medicine centre all in the same building. In this case, if somebody is receiving traditional medicine and they are worried about something interacting with western medicinal practices, they can easily ask questions. I would like to see

something like that here because we have a large Aboriginal population. Medicine men or traditional counsellors and mainstream doctors could and should be used to complement one another.

In navigating my journey living with HIV as an Aboriginal person, I always try to broaden my lens. When working with the non-Indigenous Peoples, it's important to think about how much they understand about our culture and how much our culture understands the mainstream ways. Colonialism had such a major impact on us as Aboriginal people, potentially in more ways than we even recognize. Sometimes it can be challenging to decipher if something I know is from my Indigenous heritage or something I learned from growing up in the mainstream. I sometimes get the two mixed up and have to sit back and reflect to understand where my fear is coming from. Is it something that I learned from my experiences in colonial society or is it something that has come out of our culture? These are really important questions to ask as I am learning more about my culture while doing work in settler communities. In my work, I am often asked to act as the bridge between the traditional and the mainstream and sometimes this is really hard. More often, though, the challenge is getting non-Indigenous Peoples to understand our ways and be respectful and patient. They often reject the way we do things and won't accept that we do things differently.

The greatest advice I can give to someone with HIV - especially an Aboriginal person - is to adopt a holistic perspective. By that, I mean recognizing that there are many different aspects that determine who you are as a person. I hope that anybody who is living with HIV will come to understand that HIV doesn't define you. It may be a part of your identity - it's in your body - but it doesn't define who you are. It's important to identify the core of who you are and



understand the traumas that may have happened to you. It isn't so important to understand how you got HIV but why you did and accept the losses from that. Once you learn these things, you can use your experience to teach others. For me that has been the most important thing: teaching. When I lead workshops with youth, I try to have them learn from my experiences and ask those questions that they might be afraid to ask no matter what. If I were to have that opportunity when I was younger, maybe I wouldn't be in the situation that I am in today.

I would like to see better communication between non-Indigenous and Indigenous health organisations. More of the work being shared between the two communities could be really beneficial for everyone. While there are some really great programs in the mainstream, they need to be adapted to fit within the Indigenous worldview as well. On the other hand, some of the mainstream teachings are positive but are not always a good fit with Indigenous Peoples and better communication between the two could address this. I would also like to see better support for First Nations people transitioning from living on-reserve to off-reserve. While there are programs for people off-reserve, which is a huge draw for people to leave their remote communities, there are currently none on-reserve. An on-reserve organisation could incorporate many programs in addition to for those with HIV such as Hepatitis C and sexually transmitted and blood-borne infections.

## Participant 006: Rick

Hello, my name is [name] and I am HIV-positive. I believe that I contracted HIV through engaging in high-risk sexual behaviour. Four years ago, when I learned about my diagnosis, I felt shocked and afraid. I remember trying to understand what I had done wrong and I couldn't figure it out. I never thought something like this would ever happen to me — I guess I must have felt invincible.

I am First Nations and I grew up on a reserve in Ontario. I had a rough upbringing. My father was an alcoholic for a while and my parents split up early. We also moved around from place to place which made it difficult for me to feel secure in school. I think I developed a skewed understanding of parenting and the idea of family because of my childhood experiences. I started engaging in unprotected sex as a young person and in retrospect I think to myself, "What was I thinking?" I can't pinpoint why I took the risks I did but perhaps I simply wasn't given the right support at the time.

Coming out to my family about my diagnosis was extremely difficult. I sat down with a few relatives to explain my situation and they simply nodded their heads and responded, "okay." I'm not sure if they didn't know how to handle the news or if they didn't have a clue what HIV was. Following that, a lot of misunderstandings and blaming took place and I haven't been back home since I received my diagnosis. I have been residing in [city name] where I receive support services for HIV through an agency.

I am grateful to have access to this agency here in [city name]. They are welcoming and caring and have opened many doors for me. If I ever need to talk to somebody, they'll offer the

space and support for me to do so. I see a doctor here regularly - every three months - for blood work and also access support services such as supportive health programs and groups for people with HIV. The meetings are a great way to get comfortable with the HIV lifestyle, receive support and meet new people. As well, the groups provide me with a sense of empowerment as I am encouraged to get back into school or a workplace and am reminded not to give up. I also have access to First Nations services here. For instance, I regularly meet with a medicine healer and an Elder and I also attend sweat lodges. These practices are important for my recovery as they support me in working towards bettering myself, healing and remaining strong.

Participating in First Nation services allows me to practice my culture and be sure of who I am and where I am from. I must always remember that I am an Aboriginal-Canadian first and foremost and that my diagnosis doesn't define me. I miss my home and I often think of going back. I also miss the wilderness and the fishing, but I feel reluctant to return due to a fear of being further stigmatized. Sometimes I get scared that people back home will act afraid of me or believe they could contract the virus through any type of physical contact. I also worry that if I were to go back, people will talk and I would somehow ruin my family's name. Where I am from family reputation is very important.

Living with HIV is not easy. Deep down I often hurt inside, but I like to encourage myself to practice acceptance. This condition is something I need to accept and I can't run away from it. Being diagnosed with HIV has truly changed my world and the way I view the meaning of life. I take life more seriously now and realize the importance of taking care of myself. I am grateful for the services I have access to and my experiences with the services I have accessed have

been quite positive. At times, however, I run into difficulty when trying to fill my prescriptions. It's challenging handling costs and transferring over my prescriptions when changing pharmacies. The last time I had this issue, I spent a long time on the phone with the insurance company trying to access my prescription at a new pharmacy. I ended up handling the matter on my own without any assistance.

Sometimes I feel concerned that the options available to me may be limited and I wonder whether I am missing out on getting access to the most recent and advanced forms of HIV medication because I am Aboriginal. If I could make recommendations in regard to services for Aboriginal communities and HIV, I would like to see more educational programs brought into communities, such as sexual education in schools. I think that if sexual education was taught earlier in schools, Aboriginal adolescents may become aware of the dangers of unprotected sex which would likely increase their motivation to practice safe sex. These sexual awareness programs could prevent the spread of sexually transmitted infections, like HIV and Hepatitis C, in Aboriginal communities and better the health of the Aboriginal population as a whole.

## Participant 007: Bee Dabum

My name is [name] and I was diagnosed with HIV in June of 1999 in [city name]. I had recently gotten married to my partner and my daughter was two at the time. In my live, I have experienced sexual abuse which has led me down a pretty destructive path. I was using anything from drinking to popping pills to injection drug use to cocaine on the street as coping mechanisms.

My first visit to my doctor was in grade 12 when my girlfriend noticed that my breathing was worsening and my lips and fingernails were blue. When I went to the doctor, I had a coughing fit, passed out and was sent to the [city name] General Hospital. There, they diagnosed me with Acquired Immune Deficiency Syndrome and pneumocystis pneumonia, which affects many people with HIV. At that point, I had 16 T-cells left in my body and my viral load, which counts the number of HIV particles in a millilitre of blood, was 240,000. The scariest moment was when I was told I had HIV in the hospital's intensive care unit all by myself.

Before my partner and I got together, we shared the fact that we were both former injection drug users with each other. In lieu of this, we decided together to get tested before we were sexually active. Our results came back negative but showed that we were both positive for Hepatitis C. I guess I was in the window period of HIV [where your status isn't reflected in a test] and I never went back to get retested. When I found out I had HIV, my first thoughts were of my husband and daughter. They both got tested and by the grace of the Creator, they both tested negative. Accepting the illness was a huge challenge. It took me almost two years to get acquainted with it. When I was first diagnosed, I followed an intense

medicine regiment taking two or three doses five times daily. Today, I'm grateful to say that I'm on a one-pill-a-day regiment and that's all I need.

When I was first diagnosed, I didn't have a lot of information about the virus. With the help of places like [name of culturally specific HIV/AIDs prevention not-for-profit organisation], I gained knowledge to help myself and others. When I have shared my knowledge with youth and other communities, it has helped me heal. I have also been healed and strengthened by the support of my family.

In my First Nation's community, I did not feel a lot of support while going through this process. In the first few years after being diagnosed, I was told I could ask my First Nation's band to pay for an HIV conference. Their response was, "Well, if we have to sponsor you then we have to do it for everybody." Because of their negativity, I never asked again. Even my family hasn't treated me like a burden in that same way. They've accepted it, they still love me and they have all said that they don't want me to be treated like a leopard. I feel like there was more support for me in [name of current city]. I have family, [name of HIV/AIDs not-for-profit previously mentioned], a Native Friendship Centre and a health centre that offers drumming and other great services that I can access. In the Friendship Centre, there are weekly circle meetings for women that are culturally based, so we use tobacco, eat strawberries, help with the water, drum, sing and share whatever we want to share.

I felt a great connection when I did a 30-day program that offers men's and women's circles out in [place name] on the way to [city name]. It's all rooted in Indigenous worldview. We would start everyday by smudging, learning about the four medicines and sharing stories of

abuse with one another. I also experienced cedar baths, learned how to make my own drum and took part in women's sweat lodges. The cultural connection gave me a great peace of mind and healing. When I came out of that first sweat, I felt pure and loved and like all of the negativity that was weighing on my shoulders for years was gone. I never wanted to leave that safe haven.

[Culturally specific not-for-profit previously mentioned] and [other HIV/AIDs not-for-profit] are integral parts of my life and I'm grateful that they exist. I do, however, feel more comfortable accessing programs that hold Indigenous values and offer Indigenous services. [Culturally specific not-for-profit] is better because I have that native connection with them. If I want a smudge, if I'm angry about the way somebody treated me or if I just want to cry and vent, [culturally specific not-for-profit] is really great. They've never shut the door on me. They have never said I couldn't come back. I feel like I'm number one priority there and they've also set me up with communities and audiences so that I can share my knowledge.

I feel that some of what I have experienced has been intertwined with intergenerational trauma. My grandmother was a residential school survivor so I saw a lot of drinking while growing up. My mother was a speed freak in the '70s - injecting drugs and smoking. I think these things contribute to why I chose the coping mechanisms I did.

For me, healing means incorporating our culture. It shouldn't just be about taking our HIV medication but also about doing things like going to sweat lodges, drumming circles and taking a language class. There needs to be holistic and therapeutic touch like reiki and massages incorporated. I realize that these things cost money and that some of these services are still

offered, but I would like to see a lot more of these holistic services because they've made a major impact on my life. The same thing applies with having a program for maintaining a healthy diet. Some of us can't always afford to eat healthy. We want to, but sometimes it's cheaper to eat junk food than it is to eat healthy food. I get \$250 towards food through [name of disability support program], but at the end of the day that's gone pretty quick.

I've been HIV-positive for 17 years now and I have been going to Indigenous communities and speaking to youth about what it's like to live with HIV. I believe in doing this to prevent risk and to try to stop the spread of the virus, but I also talk about Hepatitis C because they often go hand in hand. My greatest belief is that no matter what the Creator brings you, the Creator will get you through it. An illness is an illness and you just have to learn how to cope and live with it.



## Participant 008: Many

Hello, my name is [name] and this is my story of living with HIV for the past 16 years. Although I am Indigenous, I didn't grow up on reserves. When my twin and I were just kids, my mother dropped us off on a doorstep and we never saw her again. I have only ever experienced living in towns and cities. I now consider myself a city boy.

Unfortunately, I was forcefully placed into a residential school at a very young age and have experienced, as well as witnessed, many traumas since then. My residential school, run by Mennonites, was very strict and I lost my culture because of it. I was also forced to speak a language that I had never heard of - one that was very different from what my family spoke. I was forcefully integrated into white society, losing my Indigenous identity and becoming familiar only with the dominant language and white culture.

Throughout my life I have seen people get run over, hang themselves and be shot because of their experiences. Even with all of this trauma, I was not phased. My life did change, however, when I was diagnosed with HIV. My diagnosis was quite shocking to me. I sensed that I had contracted something, but I would have never guessed that it was HIV. I believe I caught it from a woman that I was seeing who didn't tell me about it. I knew she had something because she was constantly scratching her hands. She had an infection on them. I urged her to get them checked, but she never listened to me and unfortunately passed away from AIDS.

I caught HIV when I was just 24. Around 2001 or 2002, I was in the psych ward when I was approached by a doctor who told me that I had HIV and that I was dying. The doctor also handed me a medication that I would have to take constantly to avoid developing AIDS. I'm on

a good medication now that works well and has a less intense regiment than the one I was initially prescribed, but this cannot compensate for the repercussions I have faced because of my diagnosis. I have developed an accompanying virus, most likely because of being on too many medications. I have lost my fiancé who thinks I should be jailed. I have lost everything.

I went to [name of First Nation], the [group of Indigenous Peoples]'s land in Ontario and they had no knowledge surrounding HIV, yet I know that HIV and AIDS exists in [name of First Nation]. I believe the disease came to the community from settlers and people outside of the community.

I find that people who are not Indigenous do not understand our peoples and our culture. We are one with nature and Mother Earth and should not be facing such diseases. I left my community, but it was not my choice. Due to my upbringing in a white society, I have been unable to communicate and connect with my community. I ended up accessing treatments in [city name] and everything fell into place for me. I was introduced to multiple people, including my counsellor who I have told everything about my life to. After a while, I was placed in [service name], even though I did not want to be there. Following my time at [service name], I was moved to the hospital where I was introduced to many organisations, counsellors and traditional healers who are there for me if I ever want to visit or talk. I hope to see more Indigenous services becoming accessible in the future, as many communities can benefit since they lack knowledge about HIV and AIDs.

I feel that all Indigenous Peoples are scared to enter and integrate into white society because of fear of all of the bad things that are happening and because they may lose their

culture. I hope to let all Indigenous Peoples know that treatment for HIV is very beneficial and gaining knowledge and access from other communities and white society can actually be more helpful than harmful. Most importantly, people need to make sure they are getting checked for HIV and AIDs, as it is an epidemic that does exist within and outside of our communities. I want to see change occur within Indigenous communities - like seeing speakers who live with HIV or AIDs giving talks and sharing their stories to encourage people to not be afraid to step outside of their comfort zone and look outside of the community for support. I also hope that everyone learns that HIV and/or AIDs does not define you or your life, as it does not define mine. I am a survivor. I am a warrior.

## Participant 009: Ray of Sun

### “A Ray of Sun in Dark Times: Travelling Back Home/HIV-positive”

There is no place in Canada that I have not seen. I’ve travelled everywhere across Ontario, Saskatchewan, British Columbia...I have been all over Canada. My mom calls me “the gypsy”, but my name actually means “the ray of sun”, the light giving life to people. Being First Nations, my community is everything to me. I am a descendant of residential school survivors. I am surrounded by loved ones: a son, a husband, a mom and my community. This support is important because I am HIV-positive.

I was diagnosed at the age of 17 in May of 1993. I didn’t think I was going to test positive because I was so young. I was sexually assaulted twice and one of my assaulters had AIDs. I didn’t know that until he died. I remember I was so afraid and felt very alone. I was afraid to tell my family and friends because I feared they might not accept me. I was lucky though. They did, even though they were afraid. They were afraid because I am an addict. I also have anxiety and PTSD, which has made my diagnosis even harder to accept, but my community, friends and family have all supported me. They brought me home to help with my addiction and I went through a month of withdrawals. It was really rough on all of us.

I was 17 when I initially left my home community. I was really messed up and I wanted to run away. It was hard for me to leave home because everything happened to me all at once. I was so young, was just sexually assaulted and there were no services provided in my community that could help me. There are no HIV services or treatment in my community at all, which makes me afraid because there is such a high number of Aboriginal people, women and

children living with HIV. When I left, I went back and forth from having medication to not having medication and from having a doctor to not seeing a doctor. I saw a specialist, but we did not get along because he assumed that I got HIV because I was a drug addict. That really hurt my feelings. Eventually, I dried out and went back home. I had to leave to be rejuvenated and it's been great being back. I decided I wanted to straighten myself and become healthy again. I wanted a healthy mind, body and spirit. I feel safe in my community, though I know there are people like me here who struggle with HIV and it's still hard to face that.

I have had two major complications as a result of my status. One day, my T-4 counts went up and my CD4s went down to the low 200s. I became so sick that I couldn't move. It was my son who noticed and laid down beside me. I knew he was scared. All of this has greatly affected my son. I know a lot of people talk cruelly about people with AIDs which is hard for him because both his mom and dad have HIV. My cousins arrived, propped me up and helped me. When my mom came over to me was when I knew I had to use all my strength left. I had to get better.

Since I've been back home, my chief and counsellor have started to better prepare the community for supporting people with HIV/AIDs. I am able to see a counsellor who listens to me. In addition, I go to church with my mom. We bring my smudging bowl and she makes me carry my bible around.

There are only two HIV treatment centres in Ontario. It's hard to get into these programs when you are an addict and are taking methadone. The [city name] treatment centre

will accept me if I go through a 21-day addiction program. I've decided to do this and I am going to get better.

HIV and Hepatitis C education begins with our Chiefs, counsellors and our people. We need more education about HIV in our schools and we also need to take the time to listen because it's hard to talk about. We need to learn about HIV because it's not going away. We need to learn to listen because there are a lot of people with HIV and nobody knows.

I am called the gypsy, the ray of sun, though my light has been the support of my community and my family. My strong mom who has taken care of me at my lowest. My husband of 11 years who has supported me. I have plans: I want to be here for my family, get a job and be healthy. After 21 days, I am looking forward to treatment - time spent taking care of me - and then I'll be travelling back home.

## Participant 010: Gray Wolf

My name is [name] and I was diagnosed with HIV when I was 18 or 19 years old. I believe I contracted HIV using intravenous drugs. I grew up in Northern Ontario and moved back to my First Nation when I was 17 or 18 years old to live with my mother. My parents separated when I was young due to alcohol use. I lived with my father, but the alcohol use continued and there was violence in the home. As a result, my siblings and I cycled through foster homes which made school and life hard.

When I moved back to my home community, I began experimenting with drugs and alcohol. Shortly after, I was introduced to intravenous drugs. When I was 18 or 19 years old, I started noticing that something was wrong with my body. I contacted my doctor and asked to have an HIV test done because I knew the risks around using intravenous drugs. The HIV test came back positive, so I started seeing a doctor in a town in Northern Ontario. After more tests and blood work, I found out that I was co-infected with HIV and Hepatitis C. This impacted my family greatly and I was traumatized.

When I returned to my First Nation, I faced a lot of stigma and discrimination that is associated with AIDs. There was a lack of education on my reserve, so many people did not understand HIV. There wasn't a lot of medication available so that people could live healthily. I felt like I had no choice but to run away from my own community.

While in treatment, I struggled to maintain consistent results because I felt isolated and continued to use drugs and alcohol. I tried to incorporate traditional models of healing while using European medicine. For example, I started seeing a medicine man and joined a drum

group on my reserve. I spent a lot of time travelling between town for treatment and the reserve to see my family. Ultimately, my treatment has been a positive experience. Today, I am undetectable which means that my counts are back to normal. I continue to struggle with drugs and alcohol, but I am part of a program downtown that helps me abstain from use.

Currently, I am in a relationship and have hopes of starting a family. I want to be cautious and consult with my doctor first to be sure that I do not infect my girlfriend or a baby with HIV. This is important to me because HIV has not only impacted me, but also my brother, sister and others on my reserve. To this day, I still experience stigma and discrimination from members of my reserve. I can say, however, that access to services has changed since I was first diagnosed with HIV. More people are accessing the services off-reserve that I was, but I wish that there were more services specific to Aboriginal people and traditional ways of healing, like sharing circles and drum ceremonies.

There are still no services on my First Nation as well as little education available at the clinic. I would like to see information given on the importance of being safe if people are going to use intravenous drugs. I have learned that it is not enough to just clean needles. People need to stay clean and safe. I am aware that the Band Office is interested in learning more about HIV to keep up to date and help those in the community. This makes me hopeful in case I decide to move back onto the reserve. Because of the lack of housing there, my HIV status and the inability to access services there, this might not be possible. I would move back if I could.



## Participant 011: Charles Hill

My mom and dad met in a group home. They were alcoholics. One night, they fooled around and I think that's how I was conceived. I never met my father until I was 20 and he passed away shortly after. My mother is still alive but she's a drunk. She's alright - she has a job, but she's not a very good mother. I love her regardless. She grew up in the Children's Aid Society and I'm not sure if she went to residential schools or not. She doesn't talk to any of her family, so I haven't either outside of her and my brothers. I've never been to my First Nation's community and I don't practice anything cultural, although maybe down the road I will. I would probably be interested in Native teachings and sweat lodges. Right now, however, I don't have much connection to my community.

When I first started doing drugs, it was just pot. I was just getting high with my buddies. I think I got drunk for the first time when I was 15. I liked it and I started drinking regularly after that. As a teenager, I started doing odd jobs in the summer and would smoke pot every day. One day, I started to notice that I wasn't buying weed anymore, I was only buying booze. Back then, I didn't want to be like my mom and be a drunk, so I forced myself to stop buying booze. I noticed I liked getting drunk a lot though. When I was 17, I started drinking again and it became a problem for me. It's been a problem for me for a long time since - even today.

I've been using needles since 2008 and started using them heavily back in 2010. Before then, I would just drink a lot. There was a girl I met that had Oxys and I didn't know what they were. Everyone was shooting them up so I tried it too and then started doing them all the time. Eventually, I got addicted.

I found out I had HIV in August 2012 when one of my friends was sick. She went to the hospital and I guess she was there for about two weeks. The doctors didn't know what was wrong because she wasn't getting better. They tested her for HIV and the test came out positive. Her boyfriend came downtown and told our little circle of friends about it because we all used needles together. Some of my buddies got tested too and we all ended up having HIV. When I found out I had it, I felt terrible and depressed. I didn't really know much about HIV at the time other than that if you got it, you're going to get AIDS and die. I started going to this place called [service name]. I talked to the staff there and they got me in to see an HIV specialist. I started getting medication for it and my viral load went down. Since then, it has been undetectable, and I've had no major health issues.

It's pretty easy going to [service name]. All I do is show up there and they take care of me. They offer an incentive for people to go, where every two weeks or so they give out free groceries and a \$10 gift card to a grocery store. They also give us two bus tickets anytime we're there. I noticed my friends were getting these things from them, so that's what initially made me go. I love going there. Everyone is really nice and I've never felt discriminated against because of having HIV there or at any place in town here.

I was going out with a girl before I found out that I was sick. I was with her for a long time and we had a child together who is 11 now. When I found out I was sick, she was pregnant again. We decided to have an abortion because I was ignorant. I thought the baby would be sick too. I didn't understand that the baby could be healthy, so she had the abortion. After she had the abortion, we found out that my girlfriend wasn't infected. I thought that maybe I didn't have HIV for very long before we found out she was pregnant.

I'm now with a different girlfriend who knows I'm sick. One day, she said, "I want to have a baby with you." I didn't want to because I was scared. I didn't want to get her sick and I wasn't sure if it was even possible to get pregnant, but we tried. She got pregnant and everything was fine. I think it was because I was on medication. We now have a healthy 12-month-old daughter and [name of girlfriend] is healthy too. She's even pregnant again. She's five months along now and we recently found out it's a boy. [Name of girlfriend] still doesn't have HIV so hopefully the baby's going to be healthy too, just like his sister.

There are many people like me and [name of girlfriend] who know that one of the people in the relationship is sick but still want to have a family. It wasn't something I talked about with other people, not even the doctors at [service name]. It was just something we did because we wanted to. We took a chance and it turned out good.

## Participant 012: Sammy

When I first found out I was HIV-positive it was a very scary experience. I had been having symptoms and knew it was HIV before I was even tested. I was tested by a nurse practitioner in my First Nations community who didn't let me know the news in a way that I felt was kind. She told my parents first. "I want to see Sammy, tell her to come into my office so I can see her face when I tell her," she said. I felt really uncomfortable because it was unprofessional of her to say something like that. When she told me I had HIV, I admitted that I kind of knew already. I had started losing a lot of weight, had sores and felt really fatigued. When I looked up the symptoms of HIV online I suspected it was what I had. I explained what I was going through to the nurse and that I had been using drugs with a lot of other drug addicts. I explained that I was mixed up in that circle and I suspected I contracted HIV that way.

I was also a sex worker for eight years. I was in a relationship with a gentleman and we thought we loved each other but it turned sour and violent. When I first saw him using I said, "Well if you're gonna use, how come I can't?" He gave me my first needle and it felt like heaven at first. It felt good, but then I got sick and wanted another one and another one. When the next one wasn't there, I realized I would have to work to get money. I had to work myself because my boyfriend wasn't going to cover my habit. I went on working in the sex trade for quite a few years in order to support my drug use. I never had a pimp. I always managed on my own affairs alongside the other girls that were with me. I worked with a transgender fellow for many years. He was my sweetheart. He used to go with me on the streets and look after me which was comforting. He would go with a client and say, "Stay there. I'll be right back. If you're

going to be alone tell somebody so I know.” I would always let him know how long I’d be gone so he could look out for me if I was gone too long. We did that for each other. When I found out he was HIV-positive, it hurt but I stayed by his side. He was also using drugs and said he came in contact with HIV by sharing needles. When I first started using, I didn’t know that I could catch HIV by sharing needles. He told me to be careful and take precautions or it could accidentally happen to me too.

I believe I came into contact with HIV shortly after my friend warned me about sharing needles. When we would all use drugs together, we would forget to keep ourselves safe. When you’re high, you aren’t really thinking and end up mixing up everyone’s needles. I was also a sex trade worker at the time, so I could have contracted it from the sexual activities I was engaging in.

Before contracting HIV, I dated a younger gentleman who was 23 when I was 35. He told me he had Hep C and explained to me that there was a possibility I could get it. He said it was my choice if we used protection and asked if I wanted to. I wasn’t sure and asked him what would be more comfortable. He said that sometimes condoms can be uncomfortable, so I agreed to not use one. I don’t know what I was thinking at the time. That is how I came in contact with Hep C. When I told my mom I had Hep C, she was concerned and told me to be careful or else I could get something worse. I told her I would be careful, but then I went off and got HIV.

The nurse who diagnosed me with HIV asked if I wanted to seek help and I said I would figure that out myself. She told me about the health unit here and about the [name of program]

in the hospital for people in my situation. When I first started the program, I was really nervous because it was a new environment with new people and I felt out of place. After about an hour or so at the program, I felt more comfortable and they told me they were going to help. Through [name of program] I found out about [name of culturally specific program], which is an agency that has been really good with me and my family. I haven't used their services lately because I have been clean for 11 years now, but I worked with them consistently from the point of my diagnosis.

Before I was diagnosed, I was in a car accident. I was hit by a car downtown and suffered a back injury as a result. When I was diagnosed with HIV, I told my doctor about my bad back and he said that it would make my back worse. He said HIV eats at your cells and that he would have to keep an eye on me through my family physician. The car accident is what led to my use of medications. My opiate use became really bad. I started off taking one, then two, then four, then eight. It just kept increasing. I wasn't watching myself carefully and I kept taking more and more of the opiates that were prescribed to me.

I owe a lot of my success to my mom. She's the one who helped me to get off the streets, get clean and seek help. I thank her and the Creator for that. She brought me back to reality from where I was in the beginning. When I first came home I was a wreck. I weighed less than 100 lbs and I was full of sores all over my face from the drugs. I was hooked on medications, cocaine, and all kinds of other drugs. I was letting myself go. I was incoherent and numb in my brain. When my mom noticed, she said we should go seek help. I said I didn't want help at first and that it was just pills. I thought I didn't have a problem at first, but when it came down to it, it did bother me. I had almost burned my house down. I was lying in my bed and a

cigarette fell out of my fingers and burned a big hole through half my bed. Since then, I've been clean. When I came home, my mom finally helped me out and took me to many different agencies to get help. I accepted all the help she gave me and went with her. We went everywhere and anywhere services for people with HIV were being offered. My mom found out about a methadone program and asked if I wanted to go. I agreed to going even though I was terrified. Both my mom and dad came with me to the first appointment and I held my mom's hand because I was so scared. I have been on the program for 11 years now and my dosage of methadone is almost down to nil. I started at 180 mg and now I'm down to 10 mg. The methadone has worked its wonders. Don't get me wrong - in some aspects, it didn't. It was quite the experience being an addict. I have my mom to thank for helping me get this far. She passed away two weeks ago and it's been really hard without her.

My three-year-old grandson has also played an important part in getting me this far. I really love being a grandma. He's been my inspiration to stay clean and to be a great mom and grandma. I also live with my 22-year-old son. We've had a somewhat rocky relationship and for the last 11 years, my mom was living with us as well. Now that she is gone, I try to be grateful that she was there when I needed her most to keep me strong. I was really weak, but I'm stronger now and I can feel it. I'm in the midst of losing my father and that's just another part of life I have to live with.

Something I'm really scared about when I lose both of my parents is the stigma and discrimination I'm going to face. It's going to stick to me like glue. When I came home to my First Nations community, I wasn't accepted and nobody liked me. When they heard I had HIV, they rejected me. People thought that if I was in their community, they were all going to get it

and die. Of course, it's not like that, but people didn't really understand HIV. I opened up a lot of peoples' eyes to what HIV is, but a lot of others walked out on me. There is just such a lack of education and knowledge in the community these days. It's making me sick. I've been living on the First Nation for almost 12 years now so I see the ignorance every day. One child told me she was told HIV was a sore. I try to explain the truth to them and they just look at me funny and are often surprised at what it really is. When I first returned to my community, I spoke at an HIV youth conference. I explained to everyone what HIV was, how you can come in contact with it and what help you can seek if you do. I cleared a lot of misconceptions with the kids on what kinds of activities can transfer HIV and they were really surprised. After I left, I faced all kinds of stigma and discrimination. I try to be strong and not let these people chase me away from my community. I'm stronger than that. Sometimes I may break, but I know I am strong.

I have two other brothers that are also HIV-positive. My oldest brother - also my biggest idol - passed away 12 years ago. I'm the second oldest now. I have a big brother that's struggling with addiction to this day while trying to deal with HIV. He still dates and he does fine, but he doesn't disclose his HIV status in his relationships. This makes me upset and I try to tell him how important it is to disclose his status. If he doesn't, he could hurt his partner or even be charged.

Over the years I have been amazed with how healthy someone with HIV can be if they take care of themselves. It's amazing how many years a person can live. I see it everyday. There are a couple of people in my community who are HIV-positive, use drugs and live an unhealthy lifestyle. When I compare myself to them I think, "Wow. My god. Look at me! I feel so healthy." I also have a cousin who is in bad shape. She's has AIDs and still works as a sex trade worker.



She doesn't have a care in the world or any respect for herself. It's a heart-breaking story. The drugs and the streets will take her and that's that.

Once, a woman with AIDs and I went out as a team for a man who wanted two women when we were working as sex trade workers. I knew she had AIDs, but I still didn't know how to act in that situation. I had to back away at one point because I was scared I was going to catch her virus. She hadn't disclosed to the two men and I was wondering if I should tell them. If we told them, we would lose their business, but if we didn't, then they could get HIV and continue to spread it themselves. I took one of the gentlemen aside and explained to him that she had AIDs. He didn't believe me and thought that I was just trying to cause trouble. I told him he could believe what he wanted. I told the girl that I had to back out and she didn't understand why. She said if we used protection, I couldn't contract HIV. I explained to her that condoms do break and if that happens the gentlemen are going to want to keep going and not want to ruin the mood by going to get another condom. I felt really bad when I left her.

Two weeks later, I saw her downtown while I was working on the same corner. Her face was all beat up and swollen and she had a black eye and a fat lip. She told me that after I left, the guys found out she had AIDs. They beat her up and threw her out of the car. I told her the truth - that I was the one who told them and said it was their choice to stay or not. I told her that I thought they would have left her, not beaten her up. I cried and told her that I didn't mean to do that to her. I told her she should have disclosed herself ahead of time to avoid dangerous situations like this.

I haven't been in a relationship in 12 years due to fear. I know there are people with HIV who still date, but I am not comfortable with that right now. The fact is that relationships are tricky. There could be someone out there who would accept you for who you are no matter what, but there are also people who wouldn't. As soon as they find out you have something wrong with you, they discriminate right away. I'm okay though. I have a grandson, a son and a daughter and they all keep me busy. They tease me and say, "Oh mom, we're gonna buy you a dildo! It will be your company. At least you won't be alone!" I laugh so hard when they say that. At least when I'm alone, I know I'm safe.

When I was speaking at a youth conference, a boy came up to me and told me he saw needles unsafely disposed of around his community. He explained that he went to the dump and found needles lying on the ground. He wanted to know if there was anything that should be done. I went to the band office and explained this situation. After that, we held a band meeting with the police, the counsel and the Chief. I spoke up and said that this is not right. This tells us that there are addicts in our community and that we have to watch out for them. Not only that, but there will be some coming home that are sick and need to be cared for. We have to open our arms and not shoo them away. We need to give them support, love and care and not treat them how I was treated when I came home and felt unwanted. My brother was also treated badly when he came home HIV-positive. The Chief kicked him off the reserve and said to him that he was not welcome here anymore. When he wouldn't leave, the counsel and the Chief of counsel got together and wanted to offer money to my brother so that he would leave. They told my brother he could take the money to pay to live somewhere else, but he wouldn't do it. He stayed home and fought for his place in the reserve. I was so proud of him.

That was when he became my idol because he gave me the strength to stay put and not run. I still feel the stigma every day because it's here, but I don't run.

I face stigma everywhere in my community. I have neighbours on both sides of my house that know I'm HIV-positive. On one side, the husband gives me a really hard time but the wife is fine. On the other side, the whole family including the mother and her husband talk about me. I try to give it a blind eye and a deaf ear. I try not to hold on to the things they say and let them affect how I think and feel about myself. I just let it go. I have worked really hard to this day to become undetected and stay strong. We all break down sometimes, but I try really hard to pick myself back up.

Since my mom left things have been really hard. My dad, who is my stepdad, has picked up where my mom left off in some senses. He has been there to help take care of me and I'm there to help take care of him. We had a strong bond between my mom, stepfather and I. We were all close and bonded like glue. I'm still broken in many ways since losing my mom. I was asked to be a speaker on a panel at a news conference, but I can't do it. It's going to take some time, at least a year, before I'm able to speak on panels again. I am a good panel speaker and I have no problem answering any questions people have for me, but I'm not ready yet. My mom used to go with me to conferences and I always felt comfortable when she was there. She was a good mom and knew how to comfort all three of us children. She was so sweet and it felt so nice to have her close. Now that she's not here, it's going to be difficult to go to events without her support and encouragement.

I've been HIV-positive now going on 12 years. I have since lost a lot of teeth and had to fix them all. It's uncomfortable and I am currently missing one. I want to try to get something for my back pain, but I don't want to go back on opiates. I want to stay away from all of that. I wonder if I can find some other alternatives that I could go on to help with the pain. I also travel to see a traditional healer who is a medicine man outside of our community. He gives me homeopathic medicines that I take regularly. He gives me cedar tea, raspberry root and change. I stopped taking the change and started taking cherry tree root instead. All I have to do is make the tea and drink it.

There are no HIV specific services in my community, so I have to go to the city. There is only a nurse practitioner who has limited knowledge about HIV on the reserve. We have brought people in to run youth conferences and workshops quite a few times over the years. However, I'm not sure that they have had any real impact or if they got any information across to community members. I remember we had a couple HIV, Hep C and AIDS conferences where nobody showed up. There was only one person sitting amongst all the empty tables and chairs. I've had to explain to people that there are services in the city that they can go to, like [service name], if they need it. [Service name] provides support in many different ways. There's an LGBT worker who is really great and will work one-on-one with you if you want them to. He will drive out to where you are or you can go to him. I've been dealing with the service for 12 years now, ever since I was diagnosed. There are also HIV/AIDs workshops and seminars every Wednesday, a needle exchange, peer support workers, counselling and more services available.

Our Chief prevents any HIV specific services and treatment from coming to our community. It would be really helpful to have a service like [service name] in our own

community, but I don't think it will happen. It really hurts and is a shame. I've mentioned to the chief that I'm HIV-positive and that there are other people who are sick and living off-reserve who would likely want to come home to their community to be with their families if there was support available for them. I had to fight him in order to have [service name] come to offer conferences and workshops. I'm the one who has to fight for them and I feel like I shouldn't have this responsibility on my shoulders all the time. The Chief should accept the realities of HIV and welcome people into our community who are going to offer education about it. It's really unfortunate that we have to go to the city to get access to services when we have our own health department at the band office. We have one doctor who comes into the community regularly, but he doesn't know anything about HIV whatsoever. We have been trying to get someone to come to our community to offer HIV treatment, but the Chief will not approve of it.

Travelling to the city to get treatment is a huge pain. I find it particularly challenging because I have a young grandson who I take with me virtually everywhere I go. It's impossible because he's at the age where he's starting to get into everything. There have been times when I've had to cancel my appointments because I don't have a sitter for him and can't bring him to the city with me. One time I had to come to the city to see the doctor at [service name], but my grandson got sick, so I had to cancel to look after him. It's tricky getting in and out of the city especially when you're coming from First Nations communities. It takes me 15 minutes to travel there, but there are other First Nations that are much further from me and harder to travel from. For example, there are people that have to drive for two hours. There is nothing available for them in their communities, like mine, and it is a shame.

I have also had challenges with accessing my medications. In the beginning, I had a prescription from my family physician. He put a hold on my prescription when someone told him I was selling my medication. I had the authorities checking in on me and they were going to charge me. They didn't in the end. I started paying for medication out of my own pocket or by asking my family for help. It was getting ridiculous. My family was enabling me by helping me financially and when they realized, they had to stop. They called it tough love. There is no pharmacy on-reserve, so I have to go to a pharmacy that is off-reserve about seven minutes away.

Another great agency I have used for about 12 years is [service name]. The support and information they have to offer has been really good for me. They also offer connections to other agencies if I need a referral for something that they don't offer. I feel at home when I'm at [service name] and [service name]. I access another program for people with HIV/AIDs called the [name of HIV/AIDs clinic]. They are located at the hospital and provide access to HIV specialists. I access my doctor through them. When I want to see him, I go through three different nurses first. The first nurse takes my vitals, blood pressure, weight and height. The next one asks about my CD4 counts and wellbeing. The third nurse works with the doctor and takes all of the information down throughout the appointment. The doctor gives me a check-up and asks questions about how I'm doing and informs me about my updated CD4 count and viral load.

I don't like my doctor at all and a lot of other people have complaints about him. He doesn't believe in homeopathic medicine, so when I told him I live in a First Nations community and that I see a traditional healer, he said "What's that? You don't need that. You have me - I'm

your doctor!" I told him that I see my healer because he helps me and that I believe in the Creator. He asked what the Creator was, so I explained that it's like God in our traditional thinking. I got a dirty look in response and he sat me down and explained that I don't need that stuff. I tried to explain that I do and that it's working. He said that it's going to screw up my CD4 count and viral load. I find that he's a little racist against Aboriginal people. My dad is a white man who is Scottish and Irish, and he told me he sees that my doctor is racist too. One day, I was in the waiting room at the doctor's office with my dad and there were three other Aboriginal people waiting to be seen. They were joking and laughing and the doctor came out and said, "What's so funny out here? Why don't you share it with me?" They explained that it was nothing serious and was just a joke. He said, "Well I'm not in the mood today to hear any of your crap. I'm going to my office and when the secretary sends you to me, don't come in there with that attitude." I turned to my dad and he said that maybe he was just having a bad day. I didn't think so.

Accessing cultural services is very important to me. I go to sweats and sacred ceremonies often. You don't necessarily need to sweat at a sweat lodge, you can just sit around the sacred fire and if you're comfortable you can open up. If you're not comfortable opening up, you can just sit. They hand the feather around the circle and when the feather gets to you, you can speak if you're comfortable doing so. If not, you just pass the feather to the next person and it keeps going. Right now, I'm fully traditional in my practices. I grew up that way and learned from watching my mom. It's important to have these ceremonies. Where else would we go if we didn't? If these types of spaces didn't exist, wouldn't we be lost? We'd be searching for help forever. I have gotten to where I am today because of the information I have

learned through ceremony and culturally specific services for HIV. If I didn't have these services, I would have to get information from the streets and it wouldn't be right.

I worry about the next generation that's coming. Preparing for the next generation should be a central focus right now because of the lack of education and knowledge that exists for them. When the next generation arrives home, there will be nothing built for them. Right now, we have to go to the city to access information and it shouldn't be that way. We should have services right in our communities where we can access them easily and quickly. Not everybody has the ability to leave their home. Not everyone is healthy enough to leave their home to get access to healthcare. It can be really tough.

We need better healthcare in Canada for everybody, and especially people with HIV/AIDs. This epidemic is getting ridiculous and can't go on the way it is. It's like a plague - everybody is getting infected without anything being done to stop it. I see people sick and dying from HIV because they're scared to access services. There aren't enough beds in hospitals to take care of people with HIV. We only have one doctor here in the whole city that is an HIV specialist and we need more. The care that this one doctor provides isn't enough. I was going to go all the way to [city name] to see a doctor because the one here wasn't providing adequate care. It isn't easy to get a travel grant or to accumulate the money in order to be able to travel that far. Even if you do get the grant, it's not enough to cover gas, food and hotel if you need it. There are other added costs, like parking, and it can become very costly.

Overall, getting access to treatment and services for HIV can be really challenging. You have to fight hard to access to services like [name of disability support program]. I had to go



through [name of free legal service] in order to receive support from [name of disability support program]. It took a whole year and I should have been able to get it a lot sooner. I was turned down after I submitted my first application. I explained to them I had HIV and they thought I was lying and just trying to get money. The second time, my mom helped me with my application and we got turned down again. About a year and a half later, we finally got it.

It is not an easy journey - being diagnosed with HIV, especially as an Indigenous person. However, with the right attitude and a drive to fight hard and advocate for yourself, it is possible to live a long, healthy life.

### Participant 013: Mukada Mikaa

I faced immense discrimination after I was diagnosed as HIV-positive. One place I've always felt safe and heard is within the medical community, where everyone has an understanding of my condition. This is something that I've relied on and trusted over the 25 years that I've been diagnosed. I don't really know how I contracted HIV, but I believe it was sometime before 1993.

Things have been difficult for me. I was forced to leave my community and had to jump from city to city and face all sorts of stigma and discrimination along the way. On top of these external factors, there was an element of internal struggle. I would ask myself questions like: How do I go about life? Am I going to die? What do other people with HIV do? Where do I belong? With everything I was going through, I had to develop tools and communication skills that could better assist others in my community who are also HIV-positive. I wanted to help.

The biggest obstacle was being part of an organisation called [organisation name] which is an AIDs committee. During this time, the committee had terrible support workers. Though I had all the skills fit for employment, I was denied consideration for jobs. That was when I decided, alongside a few other people, that we would create our own group. This group consisted of spiritual advisors, Elders and had mostly male members. We would sit together and discuss how we could move forward, survive and support each of our individual journeys. It was basically like a group of friends getting together from different regions to discuss various topics and coping strategies.

Services and treatment for First Nations people with HIV living in their communities are pretty much non-existent. In order to receive treatment or care, you need to travel quite a distance. For example, to reach my own care provider, I need to travel at least three and a half hours. The commute and travel expenses can become a burden after a while. A benefit of our group is that we could find someone to accompany us to appointments which can be much more comfortable than traveling and seeing a doctor alone. Sometimes when people go alone to the doctors, they are either intimidated by them or don't understand what's being said to them entirely. Something I truly believe is that there needs to be more research and studies that include the Native community since much of the information given to us stems from non-Native research. I participated in a research study that didn't go too well once and after that I promised myself that if I ever did any other study, I would specifically request to be represented as Native. I wanted to be documented and identified as First Nations in the report.

It's devastating that we don't have sufficient education within the First Nations community on AIDs and HIV. There are workshops and conferences, but I am not aware of any actual education beyond that. We would be educated on conditions like diabetes and cancer, but not so much on HIV and AIDs. As an educator, I believe it's important to spread knowledge as much as possible. The only way people are going to be aware of a subject is if there is a constant spread of information. As well, often those with HIV will battle other illnesses either subsequently or from their previous health history. For example, alongside HIV, I have also been struggling with diabetes and have lost a limb to because of it. There are some medications that do not mix well with HIV medication and this is not common knowledge. You need to be

diagnosed, told and taught this and having someone by your side during these difficult times is important. It can really make a difference.

I have never lived on the reserve, but I have spoken to a number of Elders there about my HIV status, but they would tell me that there weren't any medications they could provide me with. The Elders would suggest that people with HIV take up their condition with doctors or pharmacists instead. With all the shame and stigma, it's possible that people don't want to confide in their family and friends and ask for support during these processes. It is possible that they may think that they will be ostracized and removed from the community if they were to reveal their condition.

The treatment and services that I've received are different from others in the community. This is because I have a voice and am educated on this topic so I have knowledge, skills and tools. I am one of the lucky ones. I have a partner, Jack, who is very supportive of me and my lifestyle. Some people are so ashamed that they go to their appointments alone and deal with their struggle alone entirely. No one should have to go through that. I believe that one of the most important aspects of living with HIV/AIDs is that people should know about your condition. You should be in an environment safe enough to be able to confide in people and if the environment is one of compassion and the people around you are educated, the feelings you have about your condition will be much more positive.

In terms of the medicine I've been provided with, I've always felt that much of the precautionary information was not properly relayed. The types of side effects and how negative they are haven't been clearly presented. No one tells you that you'll be vomiting and later

develop leg pains. Knowing that your chances of dying or infection is a lot higher than that of normal people is an extremely scary concept, but it's important to know. It can transform from an emotional matter to a psychological one. The fear of asking yourself, "When am I going to die?" is paralyzing.

I am a member of the [name of HIV/AIDS organisation] and typically I don't like policies and boards, but I somehow found myself sitting on the board as an Aboriginal representative for Ontario. This is something that I am proud of - being able to represent my people from [city name] through to [city name] both on and off of reserve. Although organisations are taking steps in a positive direction, there is still an immense amount of stigma surrounding HIV. It's interesting to see even doctors carrying out stigma as well. An older friend of mine experienced that with his doctor and behaviour like that is the reason why people don't feel safe around medical professionals. If you are someone who is meant to take care of my body and give me medical advice, how can you be anything other than compassionate and understanding? Doctors who are disrespectful cause people to not want to be tested in the first place, let alone seek treatment.

Combining culture and medicine is something that I see as important. It's beneficial to have culturally specific services as it helps strengthen community relationships and bridge gaps between western medicine and cultural healing. In cultural services like these, it's important to have Elder participation and leadership. Our people have much respect for them and they create a sense of security. The problem is that some of the Elders aren't well informed on HIV. There are many types of elders and each one can contribute a different kind of advice or healing.

All in all, this whole journey isn't just been about being diagnosed with HIV. It is about how you will continue living your life with it and how you will continue to live the best version of your life. I believe that can be best done when you have people who care about you and you're living in an environment that is allowing you to grow and to love. Strengthening a good attitude and developing a sense of humour can also be a great remedy in the process. Lastly, health is an essential aspect of living with HIV. I want the Minister of Health to be more responsive to the HIV/AIDS community. There are stories to be told, things to be said, and issues and concerns that need to be assessed. It's time that people of power take the time to address these. They need to take a second to see through an Indigenous person's eyes.

## Participant 014: Singing Medicine Water

Some people find it weird when I say I'm thankful I contracted HIV, but I really am. It changed my life for the better. I was diagnosed with HIV fifteen years ago. It was very confusing at first. I was on a downward spiral at that point of my life and through the process, I have learned that I can help other people simply through conversation, with education and by offering information.

I was diagnosed at a walk-in clinic in the [neighbourhood] of [city name]. There was absolutely no gentleness coming from the doctor when they gave me my diagnosis and that kind of caught me off guard. I was thankful that Health Canada contacted me a couple days afterwards with more information. I felt really lost as soon as the words "HIV-positive" came out of the doctor's mouth that day. Instead of doctors sending you off not knowing what to do, there should be some sort of system. Maybe you could be advised to have a friend with you at the clinic, like an organized buddy system where you were set up with someone from an agency. That would make things easier. My experience was a bit of a circus.

I was diagnosed in the early 2000s, so it wasn't a death sentence. HIV was being treated back then, but in my eyes, HIV equalled death. This made me fall off the rails mentally. I got into drugs a lot more and went through domestic violence with my partner that resulted in restraining orders. I felt totally out of control once I got deeper into drug addiction, I kind of lost everything, especially my self-worth.

It wasn't until four years ago that I felt my self-worth again. I did the [name of AIDs not-for-profit organisation] leadership program and it really turned my life around. That's when I

felt who I was as an individual. I thank the people at the [name of AIDs not-for-profit organisation] endlessly. They saved my life. I suggest to anybody that would like to learn about themselves and who they are to do a leadership program. The results were amazing and I came out a different person.

It's only been in the last 15 years that we've really overcome systemic barriers. The [name of Indigenous HIV/AIDs organisation] is incredible in what they do for communities all across Canada. They've really made a movement. I've had the opportunity to go to their meetings once a year to give my input and be a part of the community. HIV is the number one issue for this organisation and everyone who is a part of it is committed to advocating for other people, whether or not we have HIV/AIDs ourselves. Going to meetings like these gives me makes me feel secure. I'm aboriginal. I can be proud to be aboriginal and I can be proud of having HIV too. I put my identity to better use now when I advocate for my community. I met a lot of people through [name of Indigenous HIV/AIDs organisation]. I was able to travel to a lot of places and tell personal stories. I've been picking up my culture when I go to these different conferences - learning new ceremonies, what each ceremony represents and why ceremonies are held for so many different things. It's beautiful because I didn't grow up with that, so to learn it and to see the Elders giving a piece of themselves every time is like watching history come straight out of their mouths.

I've learned that in the Native culture, our elders are sacred, and we take care of them. That's what I do right now. I'm a caregiver for my dad who is 90 and in a wheelchair. I see my folks pretty much daily to make sure they're alright. I plan their dinners, take care of their appointments and I love it. I wouldn't trade it for the world. I adore my parents and I'm so



thankful for being adopted by them. I was part of the Sixties Scoop. I was literally taken and scooped out of my home. There's currently a class-action lawsuit happening and I'm part of that as well. That's been an eye-opener for me because I'm now coming to understand a lot of my own fears. While growing up, I was afraid of all kinds of things.

My biological mom died of ovarian cancer and my dad had lost his arm and his left eye in a truck accident. All seven of my brothers and sisters were taken from our home and put up for adoption. I haven't been back to my reserve since I was adopted and last year was probably the first time I seriously thought about where I came from and who my parents were. I was at a pow wow recently and while I was watching a group of ladies doing the round dance, I thought of my mom.

I grew up in a white family, so I lost all of my culture and cultural identity. They were a very loving family and for that, I was so fortunate. My dad was a minister and my parents had a bunch of their own biological kids, so I fit into the family pretty well. My parents always told me I was adopted, right from the beginning. They never hid anything from me. They told me, "If you wanted to find your roots or meet your family, we would be honoured to make the connection." Growing up in the [family name] family, however, I never felt the need to find my roots. I don't like change and I was very comfortable where I was with my family. I was never told not to keep my culture. My mom always tried to get me involved with Native things, but if you live on that side of the tracks growing up, you're characterized as a worthless drunk, and if you live on this side, you're not Native. I would tell people I was Portuguese, so I wouldn't have to deal with the stigma. I was light-skinned so I got away with it for years. When I would interact with Native people, the kids would say, "You're too white, you shouldn't be here." My

mom asked me about five years ago, “Are you proud of yourself? Are you proud of your heritage? Where are you at in life with that?” I just said, “Yeah, I’m proud of all the experiences that I’ve had to come through.” I believe that. Hopefully I can be a rock for other people to see and say to themselves, “Hey, if [name] can make it through, maybe I’ll give it a try.” Encouraging other people in the community is my goal.

I got HIV when I was raped. One night at the bar, I was drunk and high and within seven minutes of taking one drug in particular, everything was a lot different. I basically blacked out. What I wanted to do was hide in a bathroom stall and let it pass. I thought I’d be able to lock myself in and stay safe, but that was not the case. The bouncer, a big fellow named [name], found me in the washroom being raped by six guys, hardly breathing. It was pretty traumatic. [Name of bouncer] told me a couple months later that he had to pull me out of the bathroom, pull my pants back up and throw me over his shoulder like the firefighters do. He ran down two flights of stairs and right out the front door. It was February. I do remember coming back to consciousness in a snowbank and all I could hear was, “Come on buddy, just breathe!” Somebody put some snow around my neck and that was when I took my first breath. I would never experience an experience like that on anybody, because it took something from me.

Once I found out about having HIV, I felt ashamed and fell into an ongoing self-destruct mode. I didn’t have much of a sense of family at that point in my life. I am so thankful to organisations like [name of different HIV/AIDs organisation] who picked me up and dusted me off. They introduced me to First Nations two-spirited people who I felt connected to in ways I’ve never felt with anyone before. I also got involved in the men’s lunch program and put my cooking skills to use with the community and got a lot out of it. I absolutely loved it. I wish I was

still living in [city name]. Another really important step in my healing journey was reaching out for mental help for the first time. I knew I had experienced issues in the past, but having affirmation from a counsellor that everybody has issues allowed me to feel able to talk about mine in an open group at the leadership program. I'm very thankful that I reached out for help when I did, because I don't think I'd be here if I didn't. My first counsellor from the two-spirited community was [name of counsellor]. She gave me a real sense of what an honour it is to be two-spirited. She gave me some information on how two-spirited people were acknowledged healers back in the day. Today, our society has made being gay or two-spirited out to be a negative thing, so a lot of people that were two-spirited lost their identity.

I would like to go back to my reserve this summer. I find that you get to a certain age after you've passed your stages of partying where it's time to mature and make plans to fix what is broken. I started looking for my family after the pow wow where I imagined my mom dancing with those ladies. The first thing I googled was my last name and my dad's first name. I found out he had just passed away the year before, so I missed it. I want to go up to the reserve to find their gravesites and pay my homage and respects to them - to thank them for giving me life and giving me up. Any apprehension I have about going back to the reserve is just because it's a new thing. I'll be opening up a lot of emotions if I meet my biological brothers, sisters and other family members I've never met.

I knew about AIDs when I was young. That knowledge was something I grew up with. My sister was in commercials for HIV awareness in the '80s and '90s. Since I was educated about HIV/AIDs, it really took me for a spin that I ended up getting it, but I think things happen for a reason. There have been a lot of struggles with HIV but there have also been a lot of moments

of encouragement. I have new family, new friends and a community I can care for and be cared for by wholeheartedly and not have to worry about stigma and discrimination. I'm a strong advocate with family and friends on just discussing the issues of HIV and getting the information out there. I always tell my nieces and nephews, "Don't ever say it's never gonna happen to you, because you never know." It's was only recently that I reached out and made a connection with my family again. Once I got HIV, I cut everybody off and kept them at a distance because I was feeling ashamed. Now, I have the opportunity to help to fix things and let people see the virus with a different eye. I visited my brother's church recently and I was taken aback when a couple of the ladies pointed at me, saying "That's [brother's name]'s brother, [name]. That's the power of medicine - He had AIDs!" It was HIV, but still, medicine is incredible. While providing a little education to that group of ladies, it was great feeling that I didn't need to be ashamed.

My family talks about me and prays for me in their prayer groups. "Pray for [name]. Pray for his HIV," they say. I like to show them that prayers do work, but healing is also done through taking care of yourself: eating healthy, exercising and meditating. These are things that I did not do before I had HIV. I was an out of control party animal. Sometimes I think about life as a stone pathway. Each stone is different and they all represent something, whether you go forward or go backwards. Making it from one end of the path to the other is the important part. Don't stop halfway and say, "I can't do it."

In my speeches, my messages are often about hope. I like to tell people, "You really have to have hope. Never lose that sense of hope, because once you lose it, it's so hard to grasp at anything." I find a lot of members in my community don't have hope and they're suffering

with addictions and mental health issues. I'm often the one that brings smiles and gets people laughing at themselves again. Enjoy life, because life is so short.

I've buried far too many friends. For the past ten years, I've really been committed to friends that are dying. They seem to come into my life in the last 3 months of their lives and it's a pretty amazing experience, bumping into old friends on the street that I haven't seen in years when they are in such dire circumstances. I am a caregiver. It's in my nature to help people walk to the spirit world knowing that they had a great life and accepting all the challenges life has given to them. This is a time for forgiving people, forgiving themselves and offering anything that can make the transition easier for them. Going out with an open heart, knowing that you're good with God and are on good terms with yourself makes a huge difference. To watch people take their last breath is devastating, but to know that they took their last breath going out with good spirits, not alone, is probably the best part.

My friend [name] was sick with HIV, cancer, addictions and mental health issues. On one of his last few days, I asked him, "[Name], when was the last time a nurse took you outside to enjoy the sunshine? It's summertime." He said, "Oh, a couple weeks ago." I picked him up and carried him outside. He was a stick, weighing only about 80 pounds. It was one of the best things for him because he was able to pay his homage with tobacco in the four directions and say thank you to the Creator. The next day, he passed. I see myself eventually becoming a full-time case worker. I want to actually commit my life to taking care of people. It's one of my goals in life to open a private hospice of my own so that the community has their own people around them at all times.

When I was in [different city name], I was at the [name of hospital department]. It was an old Victorian house that they had converted into a health care centre with elevators and a chef's dream kitchen. They would have lunch programs, meal programs and invite newly diagnosed people with HIV people for a Sunday dinner. The Sunday dinners were a full-course roast beef dinner with Yorkshire pudding. People who had recently been diagnosed were able to meet people and create friendships without being so afraid of their diagnosis. I find food that food is so unifying. It brings everybody together from all walks of life. The [name of hospital department] is an absolutely beautiful thing unlike anything we have here in Ontario. In [name of municipality near home city], we've tried to create our own food program for some clients. We do a monthly dinner, but it's nothing like the weekly meal at the [name of hospital department] where you could plan your whole week around it knowing you'd get healthy meals every time. On top of dinner, they had counsellors on site, you could do your homework, use the internet, play the piano or sit in their gardens. Since I've come back from [different city name], I haven't found an agency like that. It's definitely needed for newly diagnosed people and for building the community in general.

The reason why I like [city name] is because of the HIV specialists there. I had [name of doctor] as my HIV specialist and family doctor and he has always made me feel so welcomed. He gives hugs and, and says things like like, "Hi, doll. How are you, doll?" He'll give you his personal cell phone number and say, "If you need to call me, this is my direct cell phone number." I've never experienced a doctor that caring before. It made a world of a difference to me. Basically, it made me feel encouraged to access healthcare in a way that I wouldn't have if I didn't have a good doctor. The fact that he is also HIV-positive made me feel like he understood

my journey. He could understand my feelings, what's going on in my head, the fear and the unknowing.

I'm not living in [city name] right now, but another city nearby called [different city name] where everything is so divided. My family doctor and HIV specialist have to be completely separate, even in terms of sharing test results. I find that [different city name] has very few specialists in the area. You have to travel to [hospital name] in [nearby city name] to do any blood work or see a specialist which can be stressful because you have to travel so far and depend on a ride program, which is absolutely garbage. It's often the case that they're either late, don't show up or it's a filthy, disgusting car that nobody would want to be in. It's important that we have stability for each person because hospital visits are stressful for everybody. You just want it to be as smooth and easy as possible. One of the main things I miss about living in [city name] was the easy access. I was able to walk to my doctor's office and could call him 10 minutes before to say I'm on my way and he'd say, "Okay, doll, just come on up!"

As well, I never felt ashamed of using a food bank in [city name] - they were everywhere. Here in [different city name], I felt ashamed. There's different stigma here. You're either very wealthy or you're not and they make you feel it. I dread going to the food bank because they look down on you in a time of need. I also find that in [different city name] there's not much of an HIV community. It's very small and a lot of people don't get along with one another. We had our men's program close down because of people being mean to one another. The men's program was a social outlet for men. It was a great place to vent. Sometimes they'd play games, sometimes they'd eat, but because of one bad apple, now it's gone. I asked the

executive director if they were going to replace it with something, because you can't take something that important away and not offer something else. If was one bad apple who was causing trouble, it would be reasonable to give him a two week suspension or something. Let him know that his behaviour is unacceptable for the agency, but if he needs the services, he needs the services. They won't do that there. They cut you off completely and then you're left with nothing.

I can see that mental health and addiction are becoming huge problems in [different city name]. [Local AIDs organisation] has done a lot for accessibility since the new executive director started four years ago. [Executive director's name] has made a lot of positive changes to fix what was broken with the agency. We just lost one of the caseworkers - the only male caseworker we had. A lot of people are dishevelled about that. They don't have their men's group and now they don't have a male counsellor to talk to. For some of the men, that's all they want and all they need: to have a one-on-one with a male figure. Some of them are dead set against the female staff and I tell them they're missing out because of their attitudes.

I've watched my community essentially implode on itself. We've got about eight people that come out to things these days . We've tried many things from movie night, to bowling, to horseback riding. If people were interested in something, we'd try to get it off the ground, but it's depressing volunteering at an agency where nobody wants to come out. You get sign-up sheets and ask everyone, "What do you guys want? How can we make this better for you? What are your needs and wants?" I want to keep the community moving because right now, it's kind of stagnant. That's part of the reason why I want to go back to school and become a caseworker. The less these people move, the quicker they will die.



My niece who is Aboriginal is darker-skinned and I see her experiencing stigma and being treated differently. I consistently encourage her to find her culture and be proud of it. She'll say, "But nobody else is proud of it." I tell she doesn't have the right friends then. People grow up in stressful environments and some people can't deal with it. Some people can. Some people are proud and some people are not. I just tell her, "Love yourself. That's what comes first and if you love yourself, you'll make excellent choices in life." I'm as open and honest as I can be with people. I hope it helps them in some way to know that they're not alone. I think it's the worst when people think that they're alone. When you find out that all of these things are available and actually go for it, everything can change.

Self-esteem is a big issue right now. We've got northern communities that are going through crisis with youth taking their lives and we've had chiefs say on the news that they lack hope and self-esteem. I think that once we've dealt with trauma from residential schools and healing both the people that went through it and their families, that's when we can start helping our youth. We have to fix it one stage at a time and it really has to be fixed. We can't just have words. There needs to be action. Mr. Trudeau, never back down on your words. If you make a promise, please fulfil it. The act of putting people on reservations may have been thought of as a good thing back in the day, but our treaties have put us in such a tiny box. We need to rewrite our treaties and come up with current ones. We need to change with the times.

I have seen a lot of changes in the past 10 years. I've seen so many Aboriginal people become lawyers, doctors and scientists - it's incredible. It must be an incredible feeling knowing that they've come from hopelessness and poverty all the way to trying to fit in so they can make a difference for their communities. I feel so proud every time I see somebody with a

challenging past succeeding. It makes you feel proud of being Aboriginal and embracing change. We can't step back. We need to keep advocating for people and going to marches.

When I did a public speech here in [different city name] where I shared my story and experiences, I was welcomed with open arms. I was even honoured by an Elder. She gave me her eagle feather with a beautiful casing and beadwork that she did herself. She said to me, "Your story was beautiful. It touched my heart. My brother was two-spirited and he passed away. I want you to know I lost my mom last year." She made the casing 30 years ago for her own mom and when her mom passed, she figured she had to find somebody in the community who needed it. She came up and offered it to me and we both shed a tear. She was a beautiful lady and it was beautiful for me to see how moved she was just with this simple story of my life and my experiences. Some were good, some were bad, but they have all amounted to who I am today. We need more Elders that are accepting of HIV and are aware of all the information out there, because they are the ones who teach. They are the ones who pass on the knowledge. They are the ones who are taking care of our grandchildren while we are out working long hours. It's the Elders that we really need to connect with because when they understand the importance of something, they'll pass it on to their grandkids and hopefully improve self-esteem by doing so.

To this day, I still have PTSD from my childhood experiences, like seeing my dad beat my mom. I was only diagnosed four years ago when I started seeking therapy. If there's violence towards women in a movie or television show, I have to turn it off. If I see a woman and even just a hand going up near her, I can't take it. When I went through therapy, I realized that what initially caused my issues was seeing what my dad would do to my mom. As I mentioned earlier,

I experienced high levels of domestic violence in one of my recent relationships. He was a criminal and an addict. I thought if I loved him, I could help him change and find himself. I hoped I could help him do the right things and acknowledge what's gone on in his past so that he could move forward, but I realized that everybody has to do it on their own. They have to make that commitment on their own and do their own work. Though this was terrible, if I wasn't with him, I wouldn't be where I am today.

Going through domestic violence pushed me to realize that I've got a lot to work on in my life. It identified so many things in my own past and showed me that I had to take care of myself. I had to pack a bag. I left everything - my home and everything that I owned. I came to a community that was so opposite of [city name], where I was living when I was in that relationship. Here in [different city name], everything closes at 8 p.m. There's nowhere to create a social life and certainly no gay bars. It was a big cultural adjustment that was hard to do, especially since it was the first time I had ever lived on my own. I never thought I could be on my own, but now that I've been on my own for four years, I've been learning to love, respect and be myself. Now, I just want to help other people find themselves and make a happier community for everybody.

I want to tell all the Indigenous men out there to be proud of your culture. Never hide it. The prouder you are, the more other people will be proud of it as well. They'll be able to embrace it. Embrace your culture. Embrace your life.

### Participant 015: Elizabeth

My name is [name] and I was diagnosed with HIV sometime between 2006 and 2007. At the time of the diagnosis, I was not living in my First Nations community. To me, finding out that I was positive sounded like a good thing. When I realized that this was not the case, I was devastated. I was raised in a Catholic household and I feared the consequence of sin. I was scared of telling my family and for my life. I was afraid of being alienated and I thought that people would want nothing to do with me. I was right. My family did not want me around. I was the black sheep, but these problems started long before I was diagnosed with HIV.

Before the diagnosis, I was experiencing drug and alcohol addiction as well as homelessness. This resulted in losing my children to the child welfare system. HIV was not something that was ever talked about. My friends and family did not understand it or know how to handle the situation; therefore, I experienced many stereotypes because I was an intravenous drug user. Given the fact that I thought HIV was a death sentence, I did not immediately seek out help or support. I went back home and continued using. This was how I coped because I did not have any other resources. For years before I was diagnosed with HIV, I had Hepatitis C. I was fortunate enough to receive a liver transplant, however, I became addicted to the opiates that were prescribed to me. I felt extremely guilty that someone had just died and I was given the gift of life with their liver, yet I continued to use. I was alone and it was hard to continue living this way.

Eventually, I reached out and started seeing a doctor in [city name]. I continued to use drugs, but I also began taking medication to treat HIV as well as methadone to quit opiates. As I

got healthier, I started to realize that HIV can be managed. I became active in support programs and my fear of dying lessened. When I was diagnosed, there were not any services or treatment for HIV in my community. I moved to [city name] because there is more support there and I have access to better healthcare. There are none of these services in my community, so I would never move back there. In [city name], I have access to a doctor, a psychiatrist and a women's support group. I also frequently access harm reduction sites that focus on education and prevention of HIV. This is important in the process of learning how to reduce stigma and raise awareness.

Additionally, outside of the formal healthcare system, I participate in sweat lodges with community Elders, participate in fasting and attend various traditional ceremonies. I would even say that the ceremonies are just as important to my overall health and wellbeing as accessing the formal healthcare system. I could see this after I stopped dancing in pow wows, as I was at my worst then.

As a First Nations woman living with HIV, I would like people to know that it is like any other illness and it is important to reach out to the organisations that can offer you help. I would also say that it is even more important to continue living life by not living in fear. My one recommendation to the government would be to improve services for HIV by providing more education. This could involve going to communities and reaching out to individuals like me who are too ashamed to ask for help. Through this journey, I have learned that there is no shame in being diagnosed with HIV and providing more education will help others realize the same.

## Participant 016: Brant

It's been really a rough road. I've had a lot of mental issues during my time living with HIV, like anxiety when I'm around other people and being suicidal. I was diagnosed in 2014 and was very healthy beforehand. I've been really isolated since and have never fully accepted my HIV status, partly because I was deceived by my partner. My partner had HIV and I didn't know about his status. I met him in a detox centre and he told me that he was in detox for alcoholism, but didn't mention his status. You're supposed to tell the person you're in a relationship with, even if it's only one night of casual sex. You have to be honest and he wasn't honest with me. I didn't know he was using intravenous drugs. He just recently died, and it was because he wasn't taking care of himself.

I didn't know what HIV was when I was diagnosed. I come from a reserve and we don't talk about these things. Maybe we talked about some STDs in school, but not HIV. When I first contracted it, I had no idea where to go. The doctor said they'd send me to a specialist so I went. They asked me to take pills and I said I wouldn't take them. I went to visit one of my cousins in a nearby city, and we spent two weeks drinking. All of a sudden, I got pneumonia. I had never had pneumonia in my life. I hadn't been taking my HIV medication and I didn't even know I had it for about a week. I was wondering why I was coughing, thinking I may have caught a slight cold or something. I had no idea that pneumonia was a symptom of HIV. It felt like there was somebody standing on my chest. I told my auntie and cousin to take me back to the city so I could go to the hospital. Right when I got to the hospital, I collapsed. I don't remember what happened for two days after that, but I know I was there alone without family

support. I stayed in there for like four weeks with absolutely no visitors, and my family was right there in a nearby city. It was tragic. I had quit my job because I thought there was no hope here. I lost hope, and still today, some hope is lost. After all these years living with HIV, I still struggle everyday just to take my medication.

I come from a really strong family. All of my sisters and brothers have good jobs, and for me, it's like I'm scared of life. Before I came to [city name], I was living in [province name] for 15 years. They didn't have enough resources for people living with HIV there. I was afraid of being stereotyped when accessing healthcare, especially because I didn't find that the nurses and doctors took very good care of me in the hospital. It's like they're always three feet away from you, and that really made me feel like a monster. These people are professionals. They're supposed to be helping you. I was constantly attempting suicide at this time, but I guess it wasn't my time. The suicide attempts happened like 20 times in [province name], doing things like trying to jump off bridges and slice my wrists and hang myself. Another reason why being at home was so hard was because I was afraid of being stereotyped by my friends. I was scared to tell them the truth. Even after all these years, I've never told my friends that I'm HIV positive - especially the people that I associate with there who are professionals and go to school. I was scared they would treat me differently. I didn't want to be treated like I was treated at the hospital, when it felt like I was a nobody and a monster all at once. After enduring this and lacking access to resources, I had to go somewhere different.

I had a dream where all of a sudden I was surrounded by buildings and high-rises, and I watched the sun reflecting off those buildings as I walked towards them. It still gives me goosebumps to think of it. I decided to follow my dream, so I packed up everything to head to

[city name]: a place I had never been in my life. I started giving all my stuff away. I gave away my dressers, my beds, and everything else I had to my friends who lived in my building until all I was left with was my two duffle bags and enough medication to last me for two months. I took the bus here and it took two and a half days. I didn't know it would take that long before it was already happening. I was so sore after that! When I got off in [name of city between hometown and destination], they thought I was drunk because I was holding my two bags and my legs were so wobbly. It took a whole other day and half to get from there to [name of destination city]. There are a lot of stops on the way. When I reached [city name], I started feeling more at ease. I had to stay in a shelter at first, but that was alright. It's a beautiful city with beautiful people and lots of opportunity.

I feel content here now. I don't feel lonely even though my family is in [province name] and [other province name]. They washed their hands of me because they think my HIV status is my mistake. Today, I talk to them long distance. Even my parents treat me differently, which can be really hard and lonesome. Today, I talked to my sisters on the phone and they asked me about why I don't come back to [province name]. Every time they ask me that, I feel sick in the pit of my stomach. I don't want to go back there. I know the things that have been done to me there. I want to start a new chapter of my life - do things like go back to school and find employment. I haven't achieved my goals because I've been worried about my disease. Someday I'll overcome this, but the first thing is to get myself back to being healthy.

I haven't had any problems accessing resources since living here. The first time I went into the shelter on [street name] here, they got me an outreach worker. I worked with this one woman, [name], and she had a huge heart. She helped me in so many ways. She helped me to



make connections with different housing services, like with the one I'm living in now. I'm living at [name of HIV/AIDs housing service], which is a shelter for people who have HIV and AIDs. It's staffed 24 hours which makes me feel comfortable. I'm taking antidepressants and my HIV medication everyday. I work with a case manager who's helping me to access all available resources, reminds me about my appointments and helps get me to them too. My case manager also helps me find affordable housing so that I don't go back on the streets. [Name of HIV/AIDs housing service] is only a temporary place, but I'm really grateful that there are people out there who are really supportive and that I'm not living alone with HIV. I also have an HIV specialist, a counselor, an addictions counselor and a physician through [hospital name] who support me.

I've attempted suicide four times since being in Toronto, but for some reason I think I have a guardian angel beside me. Everyday I question myself and ask, "Why did this happen to me?" I question God, too. "Why did you put me on this earth to suffer?" I ask, and then I break down and cry. I suffered as a child. I've suffered with a disease. I'm trying to be strong, but every time I talk to somebody about HIV, my childhood and my trauma, it hurts. Most of the time, I don't want to bring up any of these things because I don't want to get emotional. Sometimes I'm better off not talking about my HIV status at all. At the end of the day, I have to go home, and if I was talking about it, I'll be thinking about it. I like to be stress-free. I do a lot of meditation to help with stress. I light candles, sit there and just listen. I also write a lot about my frustrations and my stress to try to improve my life. I'm really grateful I'm alive today, that I'm not sick and that I'm living in [city name] with access to all these resources. I want to get on with my life and start achieving my goals. I want to be somebody someday. Right now, I'm lost.

I'm really nervous and I'm not in the right headspace. I have to learn to accept my HIV and I'm not really accepting it right now. Maybe I wasn't always smart, but I have come a long way and I'm a survivor. I survived. I'm trying to deal with my addiction and alcoholism at the same time. It's hard, but I think I'll get through this. I recently saw my specialist and they told me that my virus is undetected, so that's a good thing. I've never felt healthier than I do today.

## Participant 017: Skywalker

My name is [name] and I was diagnosed with HIV in December of 1990. I was always told to get my affairs in order because I was going to get really sick within five years. That began 27 years ago and I'm still here. I used to live in my First Nations community as a kid and we would cross the bay by driving across the ice in the winter and in the summertime, we would have to take a ferry. I had a couple of friends there when I was a kid, but there isn't much there, especially in terms of accessible treatment. Some resources such as smudging and ceremonies are very accessible. It is important to have access to Aboriginal services when living with HIV because of the spiritual experiences that can be so helpful, like meditation.

I contracted HIV by using intravenous drugs at the age of 19. Prior to injecting cocaine, I was smoking crack at the age of 18. I was sitting in the living room, having a few beers and my wife, as she often did, went into the bedroom to get high. That day, I tried the drugs that she was using and I've been hooked since then. Another time, some friends came over to my house and injected powder cocaine to get high. That's how I got started with cocaine.

When I was diagnosed with HIV, I didn't want to tell anybody - not even my mother. People found out in the end and I experienced the stigma that comes along with being HIV-positive. In the 1990s, it was an automatic assumption that if you were HIV-positive, you were gay. I ended up having to give up my business due to this and it has caused many rough times in my relationships. I have one good doctor who has offered me access to services like [service name] and [service name], which has been good. I didn't like the counsellor that I had so I don't see her anymore. As well, my housing worker has booked appointments with my specialist for

me that I was unaware of, so my specialist doesn't want to see me anymore. I have a family doctor in [neighbourhood name] for all my health needs. Today, I use the food bank, [service name] and [HIV/AIDs care service], which does a lot of good. The pharmacy that I go to is the same pharmacy that I've been going to for the last 14 years. Every day, I go to the pharmacy to pick up my medication. I am quite fortunate, as I am only on one pill a day and have been on this medication for the past couple of years. In the past years, I have also struggled with pneumonia and shingles. Pneumonia is the most common because I smoke crack once in a while which leads to breathing issues.

I think there is such great misinformation and skepticism around being HIV-positive. Many people are afraid. In jail one time, I was separated into protective custody because when people found out, they were uncomfortable having me around them. There is a lot of misinformation in regard to how people can contract the virus. Once, I was at a treatment centre and an AIDs patient was talking about how a nurse told him that HIV can be contracted from a teardrop or something like that. I thought that was so stupid that I left the treatment centre right after that.

In my opinion, education is very important. There needs to be awareness regarding how people can and cannot contract HIV and what they can do to effectively protect themselves. I also think that harm reduction strategies such as having some clean and adequate supplies available can be really effective. In particular, needle exchange programs are very important. I remember going to [street name] looking for a needle that was two dollars per piece. It took me two hours to get there and even if it was used, it would not have mattered. I would have still used it because I needed the hit. To try to sanitize used needles, I would use bleach,

although I was unsure if that would be effective for Hepatitis C as well. I have also been infected with the Hepatitis C virus recently and the medication was ridiculously expensive. The pharmaceutical industry is taking advantage of these patients because the prices are completely outrageous.

As a First Nations man living with HIV, I would like everyone to know that we're all people. We all have basic human emotions and feelings. People are basically all good no matter where they came from and we need to look after each other a little bit more. I would like to see more harm reduction as discussed earlier and some support in place for people on reserves to improve their education and ways of life.

## Participant 018: Blessing Otter

I go by the name [name], but sometimes I feel the opposite of what my name suggests. There was a time in my life where my skies were dark and I felt confused and lost. I was hurting. I felt alone, despite having a family. I was married with two children, but things did not feel right.

In 1993, I found myself in circumstantial turmoil. I was diagnosed with HIV - a virus that I contracted sexually that would soon unravel trivial times in my life. While juggling to maintain a marriage and raise two beautiful children, I began to see everything I loved being ripped away from me. How was it that I suddenly could be told that I won't survive this? How was it possible that I would have to find ways to say goodbye? How could it be that my entire existence would just end?

Things were confusing to me and I felt that doctors weren't explaining things to me properly. People who I was meant to trust and lean on for guidance were more concerned with collecting data from my diagnosis than finding ways to improve my quality of life. Scientific researchers would talk to me in the language of business and research - a language that was unfamiliar to me and better tailored to them. They should have done this better. They could have informed me better on how research studies were conducted. There was no one to communicate with me in plain terms what was expected of me or what I could expect from them. When it came to research studies, I felt intimidated by the way they ran their system and I was spoken to in jargon which hindered my ability to grasp the entire picture.

Typical to any other problem solving situation, my reaction to being diagnosed with HIV was to find treatment. This was especially hard given that I felt like there were barriers in places that should be wide open with support and encouragement. These medical services were so isolated from our community that I felt as if they didn't even exist. I did not believe that I had complete access to any form of help, let alone feeling comfortable or being able to trust that medical help. If you blindly trust researchers, you may find yourself confused on your rights to confidentiality or the possibility of being criminalized. When it came to medical support and guidance, I felt that medical organisations were more interested in keeping people at bay, only giving tiny pieces of help when they felt it was fit.

My community and I were taught basics on health and wellbeing from medical professionals. It was nothing extensive and it certainly didn't touch our hearts. It wasn't authentic care and was merely someone reading off a script. It was hard trusting and paying attention to a perfectly healthy Caucasian female with little to no real experience or hopes to connect with us. It was difficult to relate to these people and organisations. As a man, it was difficult to relate to a woman teaching me about HIV as well. I needed something that could mirror me and my experiences. This gap leads to people not being able to obtain proper education and information on subjects that can inevitably change their life.

Community is important, but mine is falling apart. Safety is a great concern during these times and I don't feel safe anymore. On any given day, I felt afraid to leave my house and come back to find my property damaged or vandalized because of the hate that people have for me because of HIV. The reserve is falling behind while the rest of the world is steadily moving forward. If I were to guess the amount of years it is behind, I'd say 25 years deep in the past.

That isn't right. How can we progress as a community and a nation if there are people still staggering so far behind? Communities grow on acceptance, tolerance, inclusion, safety and education, all of which are lacking, and members of the community hurt because of it. The real concern is how to bring ourselves out of this ditch. Education can be thought of as the building blocks to that ladder that will eventually help us to climb out. Education must be given in a manner that reaches individuals and is delivered properly. The person doing the teaching needs to make a connection with the audience. For example, someone with HIV could better depict life, struggles, treatment and mental wellbeing than someone without.

One of the biggest influences that pushed me through this difficult time was Ceremony. This is something that has helped rebuild a connection to who we truly are. It has encouraged our culture and related us back to our cultural roots. This was a safe place where I was able to freely communicate, spend time with people and release my energy while also helping someone else with their energy. Ceremony is selfless. It has no agenda and no devious or empty promises. Ceremony should be available and promoted much more so that people can find suitable outlets to let their frustrations and issues air out and so that they can peel away the layers of each issue until they are left in a vulnerable yet safe place. Ceremony helps you understand who you are and know that the issues you're going through do not define you unless you allow them to. HIV isn't me. HIV doesn't run my entity, my identity and my entire existence. I am much more than that and Ceremony made sure I knew it.

Difference of location is the only thing separating us from the rest of Ontario in terms of the quality of medical care we receive. If there could be an elimination of jurisdictional boundaries, we could all access equal and efficient health care. The end goal of health care is to



ensure better health and safety for the general public, isn't it? It's about giving medical care as a basic human right and changing the lives of people for the better, right? If so, then it's about time we actually focus on that.

## Participant 019: Amaya

My name is [name] and I was diagnosed with HIV in 1985. When I was diagnosed, I was given five years to live. Here I am - 30 years later. I was living in [city name] at the time when I got infected by my partner and had to come home to [different city name]. Being back in a small community, I found there were no doctors. I had no support at all. I had to hitchhike back and forth between home and [city name] where I would meet with a representative from [name of HIV/AIDs not-for-profit]. The service was so small back then, run by two people on top of a store, so there was literally no information available. I had a daughter then, but my ex-husband decided to use my diagnosis to get custody of her. The custody battle moved all the way up to the Supreme Court of Canada. It was disgusting and unheard of. They had me take my daughter out of school and she was forced to be tested for HIV. With her negative test results, she could go back to school but the whole thing was completely devastating at the time.

Things today are so much better than they were before. Back then it was terrible and there was a lot more stigma. There is still stigma, especially for women and people running the family, but it's not nearly as bad. There are still very few places to go to access Indigenous services and support. It's such a small community I don't feel comfortable accessing them. My family knows I'm HIV-positive, but they don't want anyone to know. It's a big secret and I don't like living this secret life.

I've been positive for so long. I feel like a pioneer. I've set the foundation for myself and my standards of the care I receive, so I'm a pretty demanding person. I demand the type of

healthcare I want and if the doctor isn't understanding, I'll go somewhere else. Even some of the doctors that know me address me as whatever their stereotypical idea of an Indian person is. That's kind of disappointing and disheartening. Right now, I have a really good doctor and team which has taken almost 30 years to put together. I use the [name of HIV, AIDs and Hep C clinic] at [name of hospital], [name of community centre] for my family doctor and a medicine man or medicine woman. I also get traditional medicines and teachings from [service name]. I like traditional teachings because they keep me grounded, centred, and more wholesome overall. I use our medicines to complement Western medicines because I don't completely trust Western medications. I have been really sick before and I've been really healthy at times as well. Now, I have a happy kind of balance. I like teachings, so when ceremony is available, I try to show up. I smudge a lot, use cedar, go to sweats and other things.

There isn't much of a community that's really out there to support us, advocate for us and fight for Indigenous Peoples with HIV and AIDs. Doctors often think our traditional medicine is hokey because there's no scientific data to support it. It's all anecdotal and as a woman, there's no gender-specific research either about how traditional practices help. I live and base everything on anecdotal information. In order to improve the quality of services Native people receive, our whole body should be included in our medical treatments. At positive care clinics, for example, they should have a Native person offering support with teachings included. I am not asking doctors or health care providers to start advocating or encompassing the whole spirituality of being Native in their practice, but it is something that most Indigenous Peoples are out of touch with. There's no roots.

I'm also too scared to go back to my community. I don't even drive anymore so I don't know how I'd get around there. If I went back, it would mean that I would have to come back to [city name] to see my doctors. Services are not accessible in my community. I have such a great team of doctors here now. There's no way I would ever leave them. Other than my family, I have no reason or desire to go back to the community. There is a lot of stigma there because there of a complete lack of education and support around HIV/AIDs. They don't have the resources - the doctors and the people just aren't there. It requires leaving the community to get support, education and whatever else you need. I don't know of any HIV-specific services there except [name of service].

My mother was an alcoholic and that's why my siblings and I were sent to foster care homes. Because I was taken away from my family at a young age and moved around so often, I grew up thinking I was white because I was embarrassed of my own people. It's wrong, but I think a lot of us feel like that, so we drink, we get lost, we do drugs and get totally lost in it. I wish there was more help for all of us. Foster care was really traumatic for me and I hated it from the beginning. I ran away from the family I was placed with when I was six years old. I hitchhiked 14 miles away from home with a bag of chips and a bottle of pop. Later, I ran away from home around 11 or 12. I came to downtown [city name] and was on the streets. I couldn't be in those homes anymore, so I just kept running and got married really young.

I think my family would've been fine if we had stayed together. I didn't want to separate from my brothers or sister. I tried to take all of us to Children's Aid to see if they would take all of us together, but she said it was impossible. Thankfully, she was an honest woman, so I protected all of us. I had a lot of responsibility. I had to ward off the bill collector, the cops and

others from coming to our house and finding out what was happening behind closed doors. There was a lot of abuse. I still haven't dealt with a lot of it and I don't know where to go for help for that. It's personal, deep and I've blacked a lot of it out. That's why we self-medicate. You do drugs and party just to forget it ever happened. There's so many of us like that. It's sad and I don't think that it's just with Indigenous Peoples - it's across the board.

It was hard leaving my community because my family is there. I wasn't even HIV-positive when I first chose to come to [city name]. I came for the health of my daughter. I wanted my family to be there for my baby's growth, but I didn't have that option. I go back to my community sometimes because my daughter is there now. Because of the stigma, she doesn't want me to be open about my HIV status in the community. She just had a premature baby - almost 3 months early - and she also experienced racism within the healthcare system during this process. She was kicked out of the Neonatal Intensive Care Unit at [hospital name]. They weren't equipped to deal with the baby back home and after two days of being home, she was transported by emergency helicopter back to [city name]. She's coming along now, but she stays in the community because she is scared of experiences like these.

## Participant 020: Brenda

My name is [name]. I was diagnosed with HIV seven years ago, likely due to intravenous drug use and possibly because of a transplant surgery in the 1980s. A few years back, I went back home to northern Ontario and was quite surprised to see that the people there seemed to be okay. I first came to the city because there was no access to methadone in the north. I think it is great for younger people to live at home, but access to care is the main reason why I choose to stay in [city name]. I also fear change and my family doesn't live there anymore.

My children live all over Canada, in [city name], [city name] and [city outside of Canada]. They all have their own lives, though my daughter wants me to move in with her. I'm afraid because I'm unaware of what she has told people in her small town about my HIV. It's not that I'm ashamed and I am sure there are a lot of HIV-positive people there, but I wish to talk to people about my HIV myself. Many HIV-positive people refuse to speak about it because of the stigma around it. My experiences were similar when I was diagnosed with Hepatitis C years ago. It was a bad thing to speak about because people would actually move away from me and to the other side of the table. I believe that the stigma of HIV is just as bad as Hepatitis C now, which is why many people continue to keep it discreet.

After waking up from a coma, I caught pneumonia and that was when I was diagnosed with HIV. I had been around HIV for a long time before that since my brother has HIV. I also had a boyfriend who had HIV before me, so I was having check-ups every three months. In regard to my intravenous drug use, I was running out of supplies and had been using drugs for 44 years. Using drugs just seemed normal to me - it is part of my lifestyle and might be in my genes too. It

seemed normal because I was taken out of school at a young age and what became normal for me was chaos.

I think I'm quite lucky because when I get sick, there are many agencies to help me access food and supplies. My experiences with [service name] and other programs focus on services for Native people. I used to access treatment and services at [service name], where I can see a doctor. I can also see a doctor through the [name of clinic]. I have also had access to [names of three other services]. I have recently gotten access to more culturally specific services for two-spirited women and am often involved with teaching and support for Aboriginal people. I also feel that I am able to continue pushing for survival and recovery because I know the traditional teachings and healing practices of my culture that relate to HIV.

I think it is important to share my story so that young people can hear it, especially those who are at risk. Even if sharing my story only means I can reach one person out of a hundred, I will continue. I am always pushing for access to services at [service name] for men and women, for older women and for more programs in general. When funding runs out, no one is dedicated enough to commit to following through with certain programs, so putting pressure on organisations is important. Without getting too much into politics, I would recommend that politicians follow through with their promises to the people to improve treatment, services and things that I need as an HIV-positive person.

## Participant 021: Bear

My name is [name] and I've been living with HIV for about ten years. Participating in sweat lodges and ceremonies are very important for my healing. Recently, I went to a sweat lodge and purified my insides. It feels good because you're sweating out all of the bad stuff that's inside. It's important for my health. It boosts me up and, for me, it's important for my inner soul.

I go to a centre over on [street name] where I always have access to their traditional medicines and cultural events. I went on a retreat with a group of HIV-positive Indigenous women through the centre and it was great. I'm glad I'm not alone because when we're all together, we discuss living with HIV and living on or off of the reserve. We also end up talking a lot about the stigma that exists around HIV.

We do what we can to help people become more informed about living with HIV. Lately, I'm always trying to get myself involved. Right now, I'm involved with an organisation that deals with the stigma that Aboriginal women living with HIV experience. They're trying to get Indigenous women across Canada together to fight against that stigma, discrimination against Indigenous women and collect answers for why Indigenous women are being murdered. With this organisation, we used to do skits about the stigma around HIV. Through these, we show the things that happen when police arrest you and you go to jail, when you're in a lawyer's office, when you're in front of a judge and other moments when you would commonly experience stigma and discrimination. We did these little plays in a lot of different places and it would deepen the understanding of those watching us. People who see it can come to understand



why things are the way they are. They can see what it's like to battle jail time or deal with the police when they're giving you a hard time. I wish we could do those skits ongoingly.

People could become more aware of HIV if there was somewhere they could go to get more information. More people need to be thinking about how to get their knowledge out there into the public. We need to workshop ideas about how to hold assemblies where we can tell people what HIV is about. If I knew about HIV a long time ago, I wouldn't have done injections, but I knew nothing about HIV back then. I didn't even know you could get it from needles. I was also wrongly under the impression that that if you used bleach, you could clean the needles properly. It doesn't work that way though. You can still get HIV.

Originally, I started doing drugs just out of curiosity. I was a marijuana smoker, so I was going to go buy marijuana down the street. There was a guy was there who I ended up getting romantically involved with afterwards. It was a big mistake because he got me involved with smoking crack cocaine and I loved it. I was with him for a year and crack cocaine was just always there, so I was really addicted then. One thing led to another, and curiosity led me to a needle. Before that day, I had never used a needle before. I was with a guy who was injecting himself and I was watching him. He said to me, "[name], this actually feels different." He was using needles to inject other drugs mixed with the cocaine. I wanted to try, so I did. That's how I got HIV.

It was a horrible experience when I was first diagnosed. I was in my thirties then and I initially went to a clinic for my diabetes. They took my blood and I went about my day. I never went back to the doctor, so in order to communicate with me they posted a note at the place

where I went to school, not too far from the doctor's office. They told the school my diagnosis and posted it on the wall. A lady who wrote the note approached me and said, "There's a note there for you. I think you'd better see it." The minute I looked at it, I noticed that she was standing on the other side of the room as if I was going to pass the virus to her by breathing near her face. It was a really awful way to find out. When you misunderstand or don't know how you can catch HIV, you shouldn't draw your own conclusions and talk about people who are HIV-positive behind their backs. The lady who wrote that note was working in a place where you shouldn't talk about people like that. She must feel bad now about how she treated me. If I went around spreading misconceptions about HIV or humiliating someone and later found out the truth about how HIV is contracted, I would feel awful about acting like that.

My niece also acted out of being misinformed when she found out I had HIV. I went to her home one day because I was traveling through and it happened to be when I had my period. One of her kids had the chickenpox and my niece was worried that by having me sit on her couch while I had my period, the HIV could spread to her kid. She sent all the kids away because she thought they would all catch my disease. That was pretty sad.

Though my friends and family know I have HIV, they don't really discuss it to me directly. My family first found out I had HIV when I got out of jail. They all live in [name of other province] so they had to come to [city name] to see me. My sister showed up first, worried because I was really sick at the time and I wasn't taking my medications. I wasn't even seeing an HIV doctor. My sister came thinking I was going to die from this. My mother and other sister showed up thinking the same thing. They were all crying at the doorway because they all thought I was about to die. It was a little sad. They didn't know anything about how HIV

progresses, so it was a traumatic for them to see me like that. At the time, I thought I somewhat knew what I was doing, but really, I was sick, not taking any meds and didn't have a doctor. Nowadays if I've got medications, I take them regularly.

Here in [city name], I have lots of support. There are so many clinics and doctors that I have access to. My HIV doctor is actually very supportive. I know where I can go if I need to talk to somebody about HIV. I can go to her, a clinic or a traditional doctor. I also have a doctor who prescribes me medicinal marijuana and another doctor if I want to talk to about other medications for my own use. I also use traditional medicines to prevent getting sick or if something is not right.

I originally come from [name of different city]. I left because they're clueless there. That city doesn't evolve fast enough for me. I didn't have HIV yet when I was living there, but because I'm sick now, I can't move back. I wouldn't know what to do if there was a health-related incident while I was there. If I were to end up without a place to stay or if somebody was to disrespect me and say, "Oh, you're sick, [name]? I don't want you here," I wouldn't know what to do. That kind of situation plays out in my head when I go home. Another reason I don't like to go back to [city name] is because when I do, I have to worry about my medication. The only way I can have medication when I visit is if I get them from [city name] and travel with them. A few years ago, I lost my medication while traveling and had to figure out how to get more. It was a problem and I was so frustrated. I had to go through the whole prescription process again over the phone with my own pharmacist back in [city name]. I tried to get my medication in this little town that knew nothing about HIV, but I didn't know if there was a clinic for this kind of thing or if they even had doctors. When I gave it to the pharmacist in this

little town, they didn't even know what these medications were. They had never seen HIV medications in a little town like that. I felt like they were so clueless.

It took a month to finally get back on my proper medications. It took them that long to ship them to this tiny town. A month is a long time without medication. When I went to jail, it was the same way. The doctor there didn't know what kind of medications I should have. I told her that my medications were in my purse and she could have gone and looked at them, but they won't go into your belongings in jail. They ended up giving me whatever medications they had even though they were the wrong ones.

I think the government should fix the jail system so that it doesn't have to be like this when people with HIV are in there. If I happen to land in jail, there should at least be a proper doctor who will give me the right kind of medication. I don't want to be stigmatized or told that I'm dirty because I have HIV. I hear people complain a lot about how they get mistreated, especially trans women and Native women. An example of this happened one day when I was using nail clippers in jail and people mistreated me because I could have drawn blood and spread the virus. This is the stigma that people with HIV experience. It's everywhere - even in the jails.

In terms of safe injection sites, I don't really approve because we're trying to get people to get off of these drugs, not encourage them. I do support having clean needles available though. Injection is the worst thing because people can pass on anything that way. I used to volunteer and make safe injection kits, which I think is very important. People need to have

knowledge so that they know to not keep using the same needles over and over. We need more education.

## Participant 022: Rob

My name is [name]. I was diagnosed with HIV 25 years ago when I went to get checked by a doctor for using intravenous drugs - specifically cocaine. I was diagnosed after my girlfriend became pregnant with her third child. I was using cocaine a little bit then and there were not many options for harm reduction like there are nowadays. I completed the blood test and the results came back positive for HIV. My doctor called me and told me to get my affairs in order since I had less than two years to live. After that day, I was taking 60 medications a day and now I only take one. Without this drug, I would probably be dead and that is why I support all HIV-related studies.

Many people refuse to get checked because they are scared of finding out. I tell them that it is not a death sentence anymore and that it is best to find out. I told everyone that I was HIV-positive, and it was harder back then than it is now, especially since I was also co-infected with Hep C. HIV was considered the gay disease at the time which made things tough. I was even put in jail a couple of times for being HIV-positive. It was hard. Now, I tell everybody.

I did not get access from any First Nation programs, though I hear they have a great HIV centre in [city name]. From 2003 to 2008, I was in [different city name] where the service was horrible for me. The city was far behind, but I still decided not to return to my First Nation. I had little information and figured that in small towns, there would be less support than in cities. I often went back and forth between the city and the reserve growing up and it was hard when I went to the reserve.

Now, there are many treatments and services for Native people. I personally started a support group for straight males and females with HIV. For treatment, I go to [name of community health centre], but my doctor moved to [name of clinic]. Due to recent symptoms in my liver, I will be seeing a specialist for Hepatitis. I have also accessed services including [service name] and [service name] when possible. I am not accessing any services specifically for Aboriginal people right now, but I am interested in culturally specific services. I would like to get to know more about it because my dad is Native, but I have lost contact with him for more than 20 years now. I also don't want the Natives in his community to exclude me since I am not fully Native like my father is. My mother is French and Dutch.

I would like for people to get checked when they think it's even remotely possible that they would have HIV. There's more good than harm in doing so and it is not a death sentence. I have friends who live in cardboard boxes outside, thinking they have HIV and they refuse to be tested. More people are dying from drinking and drugs than from HIV these days, though. This new drug fentanyl is a big concern on the streets now. Every week, somebody is dead. I have never really gotten into drugs, which I am glad for. I have abstained from everything but marijuana.

My recommendation to others living with HIV would be to surround yourself with people who struggle with the same problems in life. I go to a centre every Monday morning to visit those who have also been in jail. 90% of them are also Aboriginals and every week I start my week with a smile.

### Participant 023: Irene

My name is [name] and I was diagnosed with HIV when I was 17 years old. I remember that day so clearly. I was getting tested because I was sexually assaulted, but I wasn't expecting for my test to be positive. My aunt and son were with me. I think I went into shock and I remember feeling so lonely. I felt empty and scared from my head to my toes. I even thought about suicide, but it was my little boy that changed my mind. I was sitting there, crying and he came to me and wiped my tears away. He said, "I love you," and that's what changed my mind. I thank God every day for my aunt because she was also very supportive. She told my family and partner for me because I was so emotional. As my partner held his head down, I thought he would leave me, but instead, he gave me a hug, told me he loved me and that we would get through it together. My mother and I are close, so I wasn't surprised that she was supportive. When I told my father, he got really defensive at first and told me to get tested again before telling me he loved me and supported whatever I had to do next. He was always giving tough love to the family and we weren't particularly close since my parents divorced when I was four years old. When I told my brother, he instantly started crying. I think that was the first time I ever really saw him hurt. He was also very supportive.

By that time, the word had somehow gotten back to my reserve. At this point, there was already a gentleman on our First Nation who had had been diagnosed with full-blown AIDs. I guess with both of us being diagnosed, our community came closer together. Our Chief and Council became educated and we had a community feast with 95% attendance. We even brought the kids out of school because everyone thought it was important for them to know.



Unfortunately, the other man with AIDs passed away which made the community scared. Everybody was afraid because they didn't have a full understanding of the condition. They thought that if they came near me or anyone else with HIV/AIDs, they would contract it. We also brought out the other neighbouring First Nations high school and public school children for education.

That was the first time I told the community myself that I was HIV-positive. I remember feeling so scared of what people were going to say. To my surprise, everybody was very supportive. I told them my story and at the end, everybody got up and gave me a hug. Thank God I got that support - a lot of First Nations people don't get that. I've heard of people being told to leave the community and offered money to "go and die somewhere else". After I opened up about my experiences to my own community, the Chief, CHR workers, my mom and I started to travel to different First Nations communities to share how we moved through our struggles with HIV as a community. To do this, we got money from the Ministry and the 10 of us travelled together.

Even today, people don't really care about HIV. I saw it when I was travelling. They think it's treatable and manageable and if it's no big deal, then why use a condom or take care of themselves? I can say for myself that HIV really changed my life. It wasn't until the eight years ago that I really grew up and started to take the time to heal. I was so young when my parents divorced, I had my son, was sexually abused, and was exposed to different things like drugs and alcohol. I didn't realize I wasn't taking care of myself mentally, spiritually and physically. I wasn't walking in balance because I didn't take the time to forgive that person who gave the virus to me and I didn't take the time to forgive myself either. I just shut myself off. I thank the

Lord for my family and my community support. Without them, I don't think I'd be here right now.

I've gotten so sick a couple of times where I've ended up in the hospital and people were coming to say goodbye. The first time I got sick, I remember being in there and my son being so afraid. He didn't know what to expect. He started to jump around and act out, but we let him because he needed to let it out somehow. He just knew that mommy was sick, but he didn't know why. I also remember my mom coming to see me when I was really weak- weighing about 90 lbs. When she saw me, she just started crying. That's when I knew I had to fight and give my family hope. It took everything inside me to pull myself through that. The doctors had told me that I'd live to be 30 years old, so when I turned 30, I think I had that in my head that the end was near and I ended up in the hospital for the second time. My cousins, who are very traditional people, told me it wasn't my time and that I needed to pull myself together for my family. I did. It took me a little while to get myself better but with the help of my family and my community, I was able to do it.

At that point, I was still imbalanced mentally and I started to abuse alcohol and drugs again. I did that for a few more years, which put me back in the hospital. I had my spiritual awakening there. I could hear drumming and I thought I was going crazy, but I knew my dad was having a sweat for me that with his close friends. I could hear them singing and drumming right in my chest. My husband started smudging me at the hospital and in those moments I thought to myself, "It's time to grow up now. You're 41 years old and you need to look at your life, figure out where you want go and how long you want to live." That was when I started going to church again, participating in traditional ceremonies and seeing a counsellor. I started

taking all of my medications and doing all of the right things instead of all of the wrong things. It's been a long journey but I'm here and my son is 26 years old now. It feels good that he can be safe in knowing that his mom has HIV but it's okay.

Years ago, when all of this started, people weren't as educated as they are now around HIV, but our communities are still lost and are in need of more education. There are no services in our community for HIV treatment at all. There never was and probably never will be. From my reserve, we have to go to [city name] or [city name] to see a specialist. We do have counselling on the reserve for alcohol and drugs and the occasional doctor comes through, but not specifically for HIV resources and education. HIV workshops are held once in a while, but we need more considering all of the drug use and potential needle sharing that is going on. There isn't a needle exchange program on the reserve because people think that needle exchanges promote drugs which makes them afraid of it. I think needle exchanges are important for communities. Just along the [name of highway], there are about five communities where the needle use is very high. Unfortunately, our Chief doesn't want to face the reality. We need to start becoming more educated about these issues and it starts with the Chief becoming educated. Our people aren't playing it safe with sexual activity, young pregnancies and addictions.

I left my First Nations community when I turned 19 and never went back. It has a lot to do with gossip in the community and not being able to access resources like doctors and mental health services. We have counselling there but confidentiality is often broken. When I first got sick, I wanted to be at home with my family but the services just weren't there. Moving to [city name] was a big culture shock for me, but I loved the big city because nobody was going to

judge me. You get to live in this big world and you can make it what you want it to be. A lot of things would need to change for me to go back home like housing, gossiping and resource access. Right now, I'm in the midst of accessing addiction counselling through [name of culturally specific service] and they have quite a bit to offer. I just want to live a stress-free and balanced life going forward instead of making everything so complicated.

Overall, there needs to be more education, counselling services, treatments and overall support for people with HIV, especially from Elders who understand HIV. I am happy to be where I am today, and I've gotten here by having a great community. If it's not HIV, it will be something else and a lot more of our communities need to come together to support each other.

## Participant 024: Copper Bic

My name is [name] and I was diagnosed with HIV two years ago, though I was living with it for a while before being diagnosed. At the time of my diagnosis, I was living under a bridge and was on drugs. I had lost a lot of weight and was feeling really weak. I am not entirely sure how I contracted it, but I suspect it was either from sharing needles, getting an unsanitary tattoo or from one of my girlfriends. After I got my tattoo three and a half years ago, I went from 260 to 170 lbs. Around that time, I got into crystal meth and any other drugs I could find. I was sharing needles and didn't think twice about it, so it is difficult for me to say exactly how I contracted HIV.

My parents got divorced when I was eight. My dad left after that and I haven't seen him since. This period of my life was full of changes. We went from living in a nice part of town to the downtown area. My mom began drinking and my uncles were drug dealers. My mom has 11 kids and I am her youngest. We lived our own lives, separate from hers, and didn't have to go to school. This went on for a while.

Getting diagnosed with HIV was a terrible and scary feeling. I was a drug addict at the time and felt like I was at the bottom of the barrel. I didn't think anyone cared about me. I was using crystal meth, which is the absolute worst drug in the world. It made me lose all of my morals and took my life away from me. In some way, I am glad that it did because it forced me to change and be the person I am today. Sometime after my diagnosis, I realized that I needed to clean up my life. Taking crystal meth was preventing me from ever getting better. Every time I took it, I felt horrible and was in a lot of pain. I started spending more time with my

grandchildren which helped me get out of this dark time. I started to hang around different people and realized that there is more to life than using drugs. Normal people don't go around sticking needles in their arms all the time.

I have been back to my home community over the past 20 years, but I have become accustomed to city life. I find it easier to live in the city than back in my community. It is more convenient to access food banks and different places to access help in the city. It's also easier to see my friends and neighbours compared to back in my community where I would have to walk for a long time to see a neighbour. Here, I am able to access programs and services for people with HIV. The home I am living in now for people with HIV/AIDs has really helped me to get better. I have watched others come in who have become much sicker and passed away. This has made me realize that I can't take my life for granted. I have to make sure I am doing things right, so I can live and see my grandchildren.

I have several other health problems in addition to HIV. I also have diabetes, Hepatitis C, and I may have prostate cancer - I'm still waiting for results. My doctors have been really great, however, and I have accessed many health services since living here. Needle exchange programs have been one of the most important services for me. Before these programs existed, we were using drugs in the riverbanks and alleyways. We had to be quick, so we were sharing needles and using anything we could. Safe needle injection sites allow us to take drugs in a safer environment where we aren't sharing needles. I think this service has the biggest impact on quality of life for people like me.

Education on HIV is also an important issue that needs to be improved for Indigenous Peoples. Children on reserves generally lack a proper upbringing and develop unhealthy lifestyles. Some children on the reserve begin having sex at the age of 10 or 11. They watch their parents and uncles using drugs and they begin doing it as well. Kids are spreading HIV at increasingly younger ages and pretty soon, this will wipe out all reserves. I know now that if I focus on my health, keep taking my medication correctly, eat and sleep well, then I will get better. The medications that are available now allow people to live much longer. However, there is a misconception that it isn't a serious issue if you get HIV anymore because of how advance the medication has become. People who are on drugs don't realize how bad things could be if they get HIV. They don't realize that it could quickly take your life, make you weak and make your muscles disappear. I do some volunteer work to try to get the word out there about this.

I think this HIV/AIDs will continue to be a problem on the reserves and HIV will continue to be an epidemic for years and years. HIV is prevalent in many bands across all generations and it continues to be spread. Children on reserves need more role models. We need to keep learning about HIV and emphasize education on reserves.

## Participant 025: Red Thunder Bird Woman

My name is [name]. I was diagnosed with HIV in 2011 and left my reserve a year later. Originally, I wasn't sure what was happening to my body. In fact, I believed it was a terribly persistent yeast infection, a vitamin deficiency or issues due to poor diet. I lived on a reserve and didn't have any means of personal transportation, so I often had to rely on the help of others if there was an emergency that required a car. When my symptoms got really bad, I contacted my community health representative so that she could take me to my doctor's appointment. I allowed her to come into the doctor's office with me because I didn't suspect that I would hear that I contracted HIV that day. The doctor told me that my "STDs had returned". When I asked the nurse which one I had, she replied simply, "The HIV one." My initial reaction was to not take it seriously - that it was okay and could be fixed. However, the community health representative, who happens to also be my daughter, began to cry in the background. Uncovering my condition was difficult for my family because I was supposed to be educated on the topic of HIV and AIDs. I preached the importance of understanding the virus and how to protect yourself against it. In fact, I worked with [name of political organisation] on raising awareness about the HIV virus and AIDs, yet here I was being diagnosed with HIV.

A social element of having the virus that really upset me was the lack of knowledge of how HIV/AIDs is spread and the overall stigma attached to it. There were people who were actually afraid to be around me, sit next to me or speak to me. This left me in shock. Obviously it's a virus in my blood - it isn't transmitted through conversation or breathing the same air as me. People were acting absurdly and I decided to leave the reserve. If people would treat me



this way, then I was better off without them. This was a difficult decision for me because I had always wanted to live on the reserve where I could build family relations and grow old in a community. After I was diagnosed, people stayed away from me and my mom's house where I was staying. This meant that my sense of community went down the drain.

I am a woman's pipe carrier, which means I have a drum, turtle shaker and water bowl. I was offered to start a journey to cure myself spiritually that incorporated sweats, prayers, ceremonies and a series of selected medication. When this was offered to me, I wasn't ready for it. I moved to [city name] in 2012 and no longer have access to Aboriginal groups to practice cultural activities although I would really like to. I'm currently accessing services from name of Indigenous treatment centre] where I'm dealing with my drug problem. I'm really hopeful that this time I recover entirely. I am living at the [name of Indigenous women's shelter] and am much closer to the organisations and facilities that I need. I have an HIV specialist now who I'm happy with. I have to travel by bus which takes longer than commuting with a car, but I felt that it was a better trade-off than sitting in a car with someone who was disgusted by and afraid of me every time I needed to get somewhere.

Besides, while I was living on the reserve it was generally much more difficult to access services and facilities. When I was diagnosed and required medication, I had to wait up to four months before I was able to start my medication because of how far I lived from the clinic. To make matters even more difficult, there weren't any HIV/AIDs specialists or support groups available to us. Even the public health unit in [name of town nearby to reserve] didn't have these services available to us. I was able to get access to pamphlets and hand them out to family and friends for work I was doing with [political organisation previously mentioned].

Knowing and understanding the information that I learnt through my job with them is what saved me. Had I not known anything about HIV/AIDs and how to go about living life with it, then I probably would have wanted to kill myself. Education really is key. There's an accessible clinic nearby in [city name] where I live now called [clinic name], where I and everyone I know go to get medication.

The Elders on the reserve would refer to HIV as the "dirty disease". It breaks my heart to be labelled as a dirty person. I made a mistake where I had a passionate night without protection and I fell ill. It's as simple as that. It's a virus that requires medication, similar to many other illnesses. The main difference is that rather than fully curing this disease, I can suppress it so that it doesn't travel to anyone else. It's a problem that many people don't know this, or they do but still choose to believe their previous assumptions. Many people also allow fear to motivate their actions and beliefs. I call that choice as it is: ignorance.

At first it was difficult to explain my condition to people. One of the hardest moments was having to explain everything to my boyfriend. I had to tell him about me hitting menopause and contracting HIV all at the same time. He got tested after our conversation and fortunately wasn't HIV-positive. After I told my friends in [city name], they started acting distant and behaving differently around me. Just last week when we were sharing a beer or a cup of coffee it wasn't the same. This experience gave me some perspective. They behaved this way with me because they weren't properly educated on the topic of HIV/AIDs and neither were the people back at the reserve. On the reserve, I knew of two people who were diagnosed with HIV and both committed suicide. If education was provided to help change perspectives, to make crucial information available and allow people the guidance they require, then people wouldn't feel so

trapped that they would think killing themselves was the only way out. On the reserve, we would get one or two educational seminars a year, but in order to motivate people to attend you had to create an incentive such as offering food.

Something positive that has come from this experience is how much perspective I've gained. In the past, I was the person teaching others about how to go about protecting themselves, how to tell people after being diagnosed and how to live with HIV. Now, the tables have turned and I am the individual who actually has HIV. I've learned that everything is easier said than done. Another positive that has come from this experience is that I've changed some of my previous habits. For example, I don't engage in one night stands anymore. Instead, I find myself trying to get to know the person for at least four months before taking the next step. It's only right, as the person should know what they might be getting themselves into. Through my experience, I've also really learned to value education. It isn't just about learning new things, but also changing mentalities, beliefs and encouraging change in behaviour for the better. Education doesn't have an age either. There should be greater education on HIV/AIDS for the younger crowd who are acting irresponsibly with drugs and their life decisions, as well as greater education for the older crowds who still believe in things like the HIV/AIDs being the "dirty disease".

Personally, I'm a social butterfly. I love to talk to people and get people organized to enjoy themselves. Just because you have HIV does not mean your life is over and you should sit at home alone all day. I think programs should be made that allow people to come together, talk about their lives or problems and enjoy each other's company. When I lived in [different city name], I was a member of [name of community-based HIV/AIDs not-for-profit] and now I'm

using [name of different HIV/AIDs organisation]. Both are excellent services. Similar to these, we need to expand these types of services, maybe even incorporating Aboriginal culture, spiritual healing and other cultural activities. Lastly, we should have a designated location that is safe and that we can call our own.

## Participant 026: Kalti

My name is [name] and I am here to share my story of living with HIV with the world. I am an Indigenous man, but I did not grow up on reserves. When I was only an infant, I was in a horrible car accident that killed everyone in my family except for my brother and I. My aunt took custody of us and we were placed in foster homes at just 14 months old. I was placed with a family from Barbados and have spent almost all of my life with them. Having been separated from my reserve and growing up in [city name] for most of my life, I do not carry many aspects of my heritage with me. I lived a normal life there. I met my wife, worked at [company name], had a home and was happily married. On August 30th of 2010, I went to the hospital because my organs were slowly shutting down. When the doctors conducted blood work, I discovered that I had HIV and Hepatitis C. I fell into a coma for 121 days, during which I experienced multiple heart attacks and lung failures.

I am not a typical HIV case. I am not gay, did not have sex with many women, and did not contract the virus from intravenous drug use. I am here to show others that HIV does not only apply to the LGBTQ+ community or drug users. I believe that I contracted HIV from blood I came into contact with on my face, hands, and teeth when engaging in physical fights with others.

After the coma, I was told by medical professionals at the [name of hospital] that I should prepare to die. My wife did not like the idea nor the pessimistic attitude. She set out to find any hospital that would be willing to help and came across [name of different hospital]. Specialists at [name of hospital] had me come to [city name] for treatment. They took

phenomenal care of me. The HIV specialist at [name of hospital] is great and believes in me. I focused on the Hepatitis C as well through a care group called [group name] which has helped me on this journey. I see my doctors, specialists and care team members almost every day. On top of all of that, I have eight amazing medical teams helping me along the way at every step. I will admit, when I first came to [city name], I was new, alone and frustrated. I felt like I was drowning, but then I discovered the team at [hospital]. This place became my anchor.

I have been living in [city name] for five years now. Some changes have occurred in [name of hospital] and talking to people who are HIV-positive has become a bit less accessible in the past while. This change has a big impact on me as I am still new to HIV and am no longer able to readily access first-hand information from others who are experiencing the same things as I am. In addition to my HIV and Hepatitis C care, I have accessed the Native Centre and Indian Affairs. Indian Affairs has treated me very well. On top of the care, Indian Affairs pays more for my medications, even though drugs are not a concept that Indian Affairs supports. [Hospital name] has been a great aid in this process. Indian Affairs is very important to me and I have utmost respect for them.

While this experience has been great for me, I do experience depression and loneliness being away from home and my wife. As much as I try to visit my wife, it can be difficult as once I go home, I do not want to leave. My wife and I are at different points in our lives right now and I do not want to make her put her life on hold. At the beginning, we thought I would be in treatment for six months, which would not be too long to be away from each other. Six months has turned into five years. Although we keep in touch through text, I am not there for her

physically or psychologically anymore. We are at the age where we need each other the most, but I am not with her because she decided I need to stay alive.

Although I never lived on a First Nations reserve, the reserve is still my home and the First Nations peoples are my people. I cannot forget that they are my people and I definitely want to be with my people. I want to be buried on the reserve to be with my people, my brother, my mother and my aunts, but first, I need to see a change for my people. There are not many services available for individuals diagnosed with HIV in the community. There is only one health centre that is run by a woman. Although the number of people with HIV on the reserve is small, HIV can have a significant impact on the community. If I engaged in sexual activity with one person on the reserve, HIV would spread through the whole reserve in a short time. For the survival of my people, we need to ensure that our people are involved and educated on the matter to prevent our community from being wiped out.

To make a change in the system, we need to start somewhere and I believe we can start with letting each other know that we are not alone in this world. There are many of us experiencing HIV and HIV is not a big deal in and of itself. The depression that comes along with HIV is one of the hardest things you have to experience. We need people to be there, to let us know that we are not alone and to be able to stop by to visit every couple of weeks. We have to let those who are suffering from HIV know that there is life beyond this virus and that people are there for them. We need to support individuals experiencing HIV before it becomes an epidemic on our reserves worse than the sniffing of gasoline.

Many people believe that HIV is a death sentence. The best thing you can do is continue to live your life the way that you have been living it and continue to maintain the same productivity you have grown accustomed to. HIV may slow you down along the way, but you cannot look at your disease as a deterrent to doing what you need to do every day. HIV is not that type of disease. It will affect you psychologically and force you to think that you are going to die. HIV cannot stop you from doing anything that you want and need to accomplish in your life. It will change your life, but you still have to live your life the best you can.



## Participant 027: Little Wolf

When I was first diagnosed with HIV eight years ago, there was a lot of animosity in my family. The reserve that I live on is very remote. I live far into the woods. We had heard about HIV on television and read about it in books, but people talked about it like it was this big enigma. People thought, "If you catch it, you're going to die." When you live in a remote community, especially on a reserve, there is a lot of stigma surrounding the HIV virus. When I became positive, I told my parents and they kicked me out. They didn't want me in the house because they were scared to touch me, to use a dish I used, and to go anywhere near me. They told the rest of the family and everyone else had the same perceptions of HIV and how it's contracted. I have a sister who is a little bit more educated than they are. She went to the University of British Columbia. After five years of being away, she brought pamphlets and educational materials back to my mom and dad, and she walked them through it and explained to them that they can't catch HIV by looking at me or touching me. It took those five years for my family to accept that I had HIV and that I was still the same person. When they saw me for the first time, I think they were expecting to see someone that was covered in sores and 100 pounds skinnier. My mom is now my biggest supporter. When I was kicked out of my house, I came to the city. I had nowhere to go on my reserve. Nobody would take me in, and there aren't a lot of places to stay on the reserve if you have nowhere to go. There are no shelter systems. I came to [city name] and I got into drugs that I had never heard of before. For the five years that I was down here, I became a crack addict and a harder heroin addict than I was when I was up north. On the reserve, drugs were a lot harder to get and much more expensive. Down here, they're much more accessible. I was in and out of jail for drug use and smuggling, and

ended up with a murder charge for killing someone. I'm on parole right now from a life sentence. I know that if that if my family had been more accepting of me and my condition, my life would've turned out differently. If there had been more education about HIV, my life would've probably went in a different direction. Up where my home is, there is no access to resources. I still don't have a family doctor up there and I was born on the reserve. I have to come to [city name] to see a doctor, or you can go into [different city name], but there you're dealing with a walk-in clinic doctor since it's a smaller community.

I was a product of incest. My father and his friends molested me from the age of four until I was 14, which was when I got pregnant. They took turns on me and my youngest brother all the time. My youngest brother hung himself when he was 16, and that's what got me started using drugs. I used them because they would distract me from the pain of what was happening with my family. The first time I tried drugs was at the age of 10. My dad would give me heroin as a technique to make me feel like I was imagining the abuse.

In the penitentiary, I became president of the native sisterhood and started educating native and non-native women about HIV. I mostly worked with women who had HIV, and I became a big leader inside. I published a couple of articles in the newspaper about it. When I got out on parole, I went back to my reserve. I only had six weeks left on my original sentence. My father had gotten out of prison and was back on the reserve too. He was forced off of the reserve when the community found out about what he had done to me. There were men there who were going to kill him. When I saw him for the first time, I took him for a walk in the back woods and killed him. After I killed him, I called the police and told them exactly what I did and

how I did it. Instead of getting a life sentence, I got 15 years in prison. They charged me with involuntary manslaughter.

I really tuckered down when I ended up in prison again. I got my high school diploma and a hairdressing license while in jail. I didn't just sit around doing nothing. I was gaining a lot of weight during those years from one of the HIV medications they had me on. There was a guard in there who used to pick on me about my HIV status and my weight. She was actually the head of security. After five years of the abuse, I snapped and tried to kill her. This meant that I had to go through the court for attempted murder on a corrections officer. A lot of the guards knew what was going on between the guard and I and they had to testify on my behalf. The judge didn't add any time to my sentence, but had to ship me to a prison in Saskatchewan since I couldn't be in the same prison as the guard. It would have been a conflict of interest. Even though I'm full native, my skin is a lot lighter than a lot of the native women there, so I took some severe beatings. I almost died once. The whole experience has made me into a stronger person, and now I only have two years left on my sentence. I've also been clean for five years and I have my HIV under control. I've been taking my medications everyday and I have a doctor who actually gives a fuck.

It's much simpler to access proper care in the city. I've had no trouble accessing treatment there. The problem is that I don't like [city name]. I'm not a big city girl. I'm from the country. I like to go out in the backyard, start my fire, talk to the Creator and throw my tobacco. You can't do that here. I can't start a bonfire in my backyard - I'll go to jail for that! There are no services or treatments available for HIV in my home community, however. I can't drive anymore due to a seizure disorder and it's almost impossible to live up on the reserve without

access to a vehicle. The closest general store to my home is almost 20 minutes down the road by car. By foot, it would take you about five hours to get there. When I went home, that was the one thing that I started campaigning for: getting a specialist on the reserve. A lot of family doctors don't feel comfortable prescribing HIV medication. They'd rather that you saw an HIV doctor. Alternatively, I got involved with the [hospital name], and the doctors there told me that I'd have to come to [city name] once a month to access their services and pick up my medications. I only get \$1000 per month from the government to live on and if I had to get to [city name] and pay for a stay overnight, it would get expensive. I recently found an organisation that helps me by paying for the necessary bus and taxi fare once a month. When I'm in the city, I access other services too, like [community service name]. They have a house for people that live with HIV and AIDs. They have a calendar of events, like Christmas dinners, movie nights, trips to the beach, and all sorts of other things. It's awesome! My husband and I are both involved with that as well. Back when I was first diagnosed, there was nothing. I'm being honest with you. Now that I and others work our asses off, there are a lot more resources available.

Remote reserves lack HIV education even more than mine does - reserves that you have to fly or snowmobile into. Those are the reserves that need help and education. [Name of home community] is more of a progressive reserve. Once we moved into the 2000s, the numbers of youth with HIV grew by a lot. I'd guess that  $\frac{1}{3}$  of the population on my reserve has HIV today. It's especially a problem with the youth. They are experimenting with the needles and unsafe sex much more than older folks are. The youth are the ones that are dying, and a lot of them are ignorant about it. I know a couple with an HIV positive child, and they believe that

sweat lodges and other traditional practices are going to save their child. I went and cried with the mom one day, and I said, “Listen. You may not believe in the white man’s medication, but right now, this is what you need to save your child’s life or he’s gonna die.” The child still hadn’t tried the antiretroviral yet. They were doing sweats and bringing in medicinal healers. She allowed me to take her son with me to [city name] one day, and we got him started on the antiretroviral. Today, he’s healthy and working on the reserve as a construction worker.

I’m trying to take steps towards educating the rest of my community about HIV. I work with [name of HIV support organisation]. I go to the office once a month, get all of the information I can, and take it back to the reserves. I have a friend with a car who drives me around to the different nations in the area and I drop resources off at the free clinics. I also try to make sure that the educational materials are in accessible language that the youth will understand. I rewrite it if I have to. A lot of them can’t read or write, so including pictures and artwork is good for keeping their attention. Right now, we’re trying to get funding from the government to help us pay for the costs needed to spread these resources around. This will help us educate community members beyond youth, like the elders who are in denial about rising HIV rates and new treatments. People are getting sicker and sicker, and the elders who don’t believe in the white man’s medicine don’t understand why their traditional medications aren’t working. The Creator promised this medicine would work for everything, but these are diseases that our people have never heard of. It wasn’t until the white man came that these diseases existed on our lands. The elders still rely on their old medicines, and that means that they’re dying. Elders are respected in the community, so if we can get the elders to understand that these medications aren’t bad, maybe HIV rates will become lower. So that way – because a

lot of the younger respect the elders. So if we can get the elders to tell the youngers listen this is a good thing, maybe the HIV will lower. The elders are where the young people get their stories from, that they pass down from generation to generation. If we can get the elders to get on board with us, it would make a big difference.

I also care for myself by practicing my cultural practices. I do sweats and have a healing woman that gives me herbs that I make tea from. Once a month, I go to a place in [city name] when I go down to pick up my medication to do a sweat and say my prayers. My cultural practices make my soul feel better. They are for my soul, just like talking to the Creator. After I've done my sweat and take my grandmother's herbs, my mind and soul feel free. I don't feel sick anymore. When I take the white man's medication, I'm sick for almost three days after. Especially when I start new ones. Now that my HIV is progressing, they doctor's are trying different medications on me to see what's going to bring my viral load down. My doctors are supportive of my cultural practices and holistic approach to medicating my condition. He says to me, "Whatever makes you feel better." He's not going to tell me what I can't do. I'm an adult.

As a First Nations woman living with HIV, I want to tell those who are enduring similar struggles to mine. Make sure that whatever you do, you try. You're going to find the fight, believe me, and you're going to find it more from the elders than you are from the youth. You have to stand tall and strong, and just let it bounce off of you when someone insults you, because they're only hurting you because they don't understand and aren't educated properly. Take it upon yourself to try to educate them. Try to make them understand that you're the

same person as you were before. Don't give up, because once you decide to give up, that's when your body is going to die, and then there goes your soul too. That's how I look at it.

We need more accessible HIV clinics on our reserves, and we need easier testing at these clinics. For example, twice a month or so a doctor could come to remote reserves with a team of nurses to offer services. There also needs to be more structured education. Women that have HIV are breastfeeding, and a lot of them don't understand that that's where the HIV process starts. Taking your antivirals while pregnant is a necessity, and so is refraining from breastfeeding. That decision determines whether your child is HIV positive or not. There are a lot of pregnancies on reserves - you can't go 10 miles without seeing a pregnant woman - so if the government could bring in some kind of specialist onto reserves once a month that would make a huge difference. You have to know what you can and can't do as a person with HIV, and it will take structured education by medical professionals to get us to a point where everyone is educated.

## Participant 028: Red Thunder Bird Man

The only problem with me is my ignorant mouth. It's why I can't get to where others already are. Because of my ignorance and anger, I sometimes don't know how to pull back. I'm so uneducated that my mind doesn't realize the potential outcome of getting angry.

If I still lived in [city name], I'd be in jail for life. Fifteen years ago, I had no criminal record, but when I came to [city name], I got one. I was in and out of the city but came back mainly because of work. I lost myself when I came back and got into trouble.

I'm a quiet guy and I keep to myself. I have friends and stuff, but when people come at me, I lose it. It used to take a bit to push my buttons, but one day, I lost it and started hurting people. I just don't like ignorance. If you're ignorant with me, I'm not going to pull back. I'm going to derail you. I'm East Coast French, Native and Irish - the three nastiest. Now, I have something like 87 convictions. Thank God there are no murder convictions or anything like that in case I was ever going to try to clean it up.

When there's more than one person in a house doing needles, you have to pay attention and make sure you have your own kit. Once when I went to the washroom, I left my needle there and I guess someone grabbed it because when I came out of the washroom, I saw someone else's blood on my needle. My blood was light, but I could also see a darker spot of blood that I knew wasn't mine. Someone else even said there was two kinds of blood in there. There were only four of us in that house, but one guy was really ignorant and didn't care. When I found out I had HIV, I beat him up.



I've been using drugs for 10 or 15 years. After I started using, I found out I had Hepatitis C. That was around the same time that one of my family members died. I got a little careless and I didn't pay attention to what was going on. Ever since I was a kid, I've said I was never going to catch a disease. I was always the cleanest man. I looked like John Cena back in the day. It has all been going downhill since I caught HIV. I'm no longer a healthy and clean person anymore. I really lost myself for a while after being diagnosed, but soon after, I found a place in the [name of neighbourhood] where I can talk to people. A lady there started helping me and she brought me to the Elder who gave me my name. I gave him tobacco and we sat together and smoked some. He told me my name, my colours and my clan. I told him I really needed to get deeper in this, so he told me about the sweat lodge.

When I get a little too far off course, I try to get to a sweat lodge. No matter if I'm not full blood, I just need to see the trees, breathe the air, and be with the birds and the animals. People say I get along better with animals than I do with humans and it's the truth. I'll sit there at my door and the animals come to me. I had a squirrel that would sit with me for a while. A cat even came in and didn't want to leave. I'm an animal person. That's why most people call me "the wolf".

I only found out I had HIV about five years ago. I got arrested, so a year later when I was in jail, I asked for a blood test. I must have gotten the results, but I was totally zonked out. I was in jail for 17 months, but they tell you not to be too obvious bringing information about your HIV into jail because that's when you'll have more problems, so I didn't. I couldn't see it in my face, so I kept forgetting. I only remembered every time a lady would come for a medical exam. She would ask me how I was doing. When I came out of jail, I still hadn't fully processed that I

had HIV. Even though I had the papers in my bag, it wasn't at the front of my mind. When I came out of jail, I disrespected my wife by having sex with her and not telling her I had HIV. My brain didn't collect it enough. The system in jail needs to be refined, because I'm pretty sure there are a ton of people in jail that have AIDs or HIV. I think they should make a specific area for people with HIV. As soon as you come in, you get divided based on if you're HIV-positive or not. Why should I take hate from 39 men because they don't like that I've got HIV? I've got to live in there and everyone is afraid of my "cooties".

My wife, [name], wanted a baby when I came out of jail. Every time she saw me, she'd say, "We're gonna have a kid. We're trying to make a kid." It turns out that she actually already knew that I had HIV and she just wanted to see if I would tell her about it myself. Someone called the public health line on us because my wife was trying to have a baby with me when they knew I had HIV. It was crazy. Anybody can have HIV and as long as they're taking their medications and they're just a carrier of the virus, they can have a baby. Look at Magic Johnson, he had so many kids after he had HIV. This pathetic doctor at public health told my wife, "Well, [name], you can just tell me you didn't know he had HIV and I'll put him in jail." My wife had already told her three times that she knew, so why was she forcing her to say something that she was never going to say?

Certain people know I have HIV. I'm excessively angry most of the time, so I try to keep the information in my circle because I know the outcome of my ignorance. People just don't understand. I always hear people put down people with AIDs. I can tell them about how my level is so low that it's undetectable, but people will still come at me saying, "Oh you're an AIDs victim," and put me down to the point where I get angry and want to hurt them. I've chosen to

just tell certain people - people who are more accepting, or more understanding - and hide it otherwise.

I had people who were there for me - some are hypocrites though. My nieces are. They say they're there for me and then when I would tell them what I needed and how I needed it, they were never really there. People said to me, "If you need me, call me. I'll come and get you," but then when the time came, they never did. They'd just ask, "Why are you being lazy?" and hang up.

I know there are a couple of good people in Queen's Park. The big building where everybody talks. I know they are too scared to speak up because they don't want to lose their jobs, but if you aren't speaking up, then what are you there for? You say you're there for us people but, yet you don't want to speak up for us when it's time. All they do is say, "I tried." You didn't try! If you tried, you would be fighting right beside us. The system is messed up. The system doesn't care. This means that we need to step up in unity as a community. We need to be in there where the cameras can see us. Even if the government can't get us in there without being rude, ignorant or being vulgar and aggressive, they still need to listen to us speak our minds and then let the system know what we have to say.

The municipal government should stop spending money things that aren't [city]-based. We need to be making more places for people to work and hiring more people. Our government wants to help a third world country but doesn't want to help their own. Money spent carelessly could've helped to build things like bigger buildings for people to live or more offices for doctors so that more people could be helped. The more doctors and space you have,

the more that people can stay at home in [city name]. That makes sense to me, but it's not about sense. It's about looking good and making money. These people don't know what [city name] needs. The new mayor is a fucking asshole. He said he's going to do a lot for us, but he hasn't even done one thing.

The system is hypocritical. The people in power are only there for rich people or people that have jobs and want more things. They don't care about people. For instance, I'm on disability support and people still look at people who are on disability like we're lazy. If I didn't have a problem with my head, I could get back to work, but I was always getting fired because my mind wasn't there. Tory just looks at us and doesn't offer assistance. Somebody told me they were trying to bring ODSP payments up to match the minimum wage, but he doesn't want to do that because we're just lazy people.

When I'm accessing services and treatment for HIV here in [city name], it's awesome. When you go outside of [city name] to the suburbs, it's so much harder. When you're in the Native reserves, it's so hard. Like on [name of First Nations community], half of the people who need services are still not being seen because the services are already full. Let's say there are 1,000 people who need to access health services and only enough space for 300. Where are the other 700 going to go? The other 700 have to go away or wait until someone leaves and then one person gets to replace them. It's pathetic. Why can't they have more than one or two places open to meet the demand? These people have to travel to [nearby city name] to get any services which is tiring. These trips are ripping a hole in my pocket. Why should I have to spend money to travel and get my HIV medications? It's my responsibility to take care of my HIV, but it shouldn't be my responsibility to travel in order to do so.

The white man only wants to be greedy and collect money. They don't even care about their own unless they're rich. If you're rich, they don't care what colour you are. There are a lot of black rich people and a lot of rich Native people who get respect only because of their money. It's just a bunch of rich people who have all of the power who are watching everybody die and making everybody work for them. The healthcare system is messed up - specifically the system up north. Even if they do have services, they don't have enough. The government needs to actually understand that not everything is about rich people. It's about all of the people and everybody needs to be treated the same. The gays and the lesbians finally got their rights after fighting for them and black people too. Natives have had to fight for our rights because the lands were stolen from us. Why don't we put everyone in jail who runs the broken system? I wonder how they would feel if they were properly disciplined for treating people terribly. They think that if you're rich and have HIV/AIDs, you deserve everything they can offer, but if you have less and are Indigenous, they'll throw you in the gutter.

We're not savages, we're people just like the white man. We have hearts. We bleed. We starve when we're hungry and cry when we're hurt. We have problems and sometimes we can even deal with them.

## Participant 029: Heather

I was diagnosed with HIV about 26 years ago. It was absolutely traumatizing because back then people were dying from AIDs. I was pregnant at the time and had been feeling sick, so my doctor asked if I wanted to get tested. At first, I was hesitant to take the test but decided I would. When the results came back, the doctor told me he had some bad news for me. I broke out into tears and was completely surprised. Right away, I followed up with specialists who gave me some confusing information. One doctor said I between five and 12 years left to live. I was especially worried about my baby but the doctors assured me that my baby would probably be okay if I started on medication immediately.

I'm not sure how I contracted HIV, however I suspect it was through sex. I was raised in a city with prostitutes, dealers and drug addicts so I fell into using drugs by being around the wrong crowd. Drug use was the way of life there. I have been using drugs on and off for almost my whole life. I am doing my best to stay sober and clean and it's been a few months now since I last used drugs. My daughter is also three months clean from crack cocaine right now and I am pretty proud of her.

I was never raised in a First Nations community, but I visited on occasion for summer holidays and vacations. I grew up with my mother and grandmother. My father also lived in the area and we would visit his side of the family in his First Nations community. My brother and I liked being there with the family, but because I wasn't raised there, we always feel like outsiders. It can be hard to be there because they treat us differently. I call them occasionally and try to share what's going on with me and my health, but they don't seem very interested.

Their children never did drugs like we did and so I think that is partly why they treat us the way they do.

In terms of accessing services for my HIV, I have two HIV workers and the [name of HIV/AIDs support organisation] where I live. I meet with the HIV workers once or twice a week to talk. They offer counselling services and we go out and do things together. Sometimes we go for coffee or a ride and chat. I've really enjoyed their service. In terms of culturally specific services, I sometimes receive smudging and cleansing and also attend meetings for Natives. I would like to learn more because I don't really know my own heritage since I wasn't raised on a reserve. I think it would be beneficial to learn more in order to find balance and understand what has happened in the past.

If I could give one piece of advice to someone going through a similar situation to me it would be to take care of yourself. Pay attention to whatever illness you have and whatever you do, go out and get medicine for it. I'm still alive after at least 26 years and I'm still doing very well. I pray every day that I stay this way.

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