Antiretroviral Therapy Access, Acceptance and Adherence among Urban Indigenous Peoples Living with HIV in Saskatchewan: The Indigenous Red Ribbon Storytelling Study

by

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Dalla Lana School of Public Health
University of Toronto

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Abstract

Human Immunodeficiency Virus (HIV) can be managed effectively with antiretroviral (ARV) therapy. However, Indigenous peoples living with HIV (IPLWH) in Canada are less likely than non-Indigenous peoples living with HIV to access and adhere to ARV therapy. To date, most studies examining this issue aim for statistical generalization and do not focus enough on contextual factors. To investigate this imbalance, a collaborative research effort called the Indigenous Red Ribbon Storytelling Study (IRRSS) was developed by the study investigator and 11 community partners. The purpose of the IRRSS was to examine how IPLWH construct and understand their experiences of ARV therapy use.

The study used an Indigenous qualitative research design, critical ethnography, and a community-based participatory research orientation. Study participants included adults from two cities in Saskatchewan. Informed consent was obtained from all study participants, who also accepted a traditional offering of tobacco. The study involved two Indigenous sharing circle interviews comprising a total of 15 key informants including IPLWH, 20 individual IPLWH interviews, six IPLWH participant observation sessions, and a survey of socio-demographic and health information.

Thematic data analysis was conducted using the Behavioral Model of Health Services Use and sensitizing concepts within the context of critical Indigenous qualitative research. Themes included holistic health care, culture, family and friends, and the value placed on respect and trust. The majority of IPLWH live with three interacting dimensions of social vulnerabilities. Their identity living with HIV is compounded by their substance use disorder and their social contexts as a culture-sharing group
impacted by relations with the Nation State of Canada. Nonetheless, they are able to adapt positively to adversity, especially when appropriate underlying socio-structural mechanisms are in place to support their resilience.

Recommendations were developed to improve the lives of IPLWH, most notably to involve IPLWH in anything that affects their lives, including needle exchange programs and holistic health care that is founded on Indigenous values, cultures and beliefs. Any consideration of access to, acceptance of and adherence to ARV therapy among IPLWH should view biomedical, behavioural and social aspects of care for IPLWH as an integrative system.
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Last, I would like to acknowledge my parents, Frederick Nowgesic of the Kiashke Zaaging Anishinaabek (Gull Bay First Nation) and Deana Nowgesic (née MacLaurin) of the Fort William First Nation, and my partner, Donald Boere, for inspiring me in so many ways.

All my relations.
About the Author

I am Anishinaabe from Kiashke Zaaging Anishinaabek. My parents are Anishinaabe or Ojibwe. Both attended Aboriginal residential schools and, despite the legacy of the Aboriginal Residential School System, they persevered in keeping true to their cultural traditions, ultimately passing these values down to me and my three sisters.

When I was a child, my father taught me what it meant to him to speak Ojibwe. His Ojibwe first language was his spirit. It was the way he thought, and his thoughts and beliefs were what made him uniquely Ojibwe. He told me that the Ojibwe language was an action language conveying thoughts that were dynamic, non-static and forever changing. Later in life, I realized that he was talking about the relational ontology and epistemology of Ojibwe people. For my father, his Ojibwe language was a cultural aspect of his being, feeding his spirit and determining the way he lived his life. This teaching, among many that I received from my father, impacts who I am today.

Sixteen years ago, by means of a newsletter article (Nowgesic, 1999), I explained to my colleagues what my beliefs were concerning my nursing profession as an Aboriginal person. In that article, I introduced the term Aboriginal health nursing. For me, Aboriginal health nursing was not about providing generic nursing services to Aboriginal communities. It was the way in which nursing services respected Aboriginal ontologies and epistemologies, such as incorporating Aboriginal cultural practices, theories and values into the nursing process. It was a process relevant to Aboriginal, or Indigenous, peoples and their way of life. The concept of Aboriginal health nursing was taken up by many Indigenous nurses across Canada. Last year, a national nursing body, the Canadian Nurses Association, prepared a policy document speaking to the concept of Aboriginal health nursing (Canadian Nurses Association, 2014).

Given my background as a health professional (e.g., nursing and epidemiology), I am aware of how the dominant discourses of clinical and positivist-oriented health practices affect the use of antiretroviral therapy among Indigenous peoples living with HIV (IPLWH). I suspect that hegemonic discourses, such as behavioural science models, are limited in their propositions concerning health services use among IPLWH. I challenge the propositions put forth by theoretical paradigms that are not Indigenous-centred in terms of their ontological and epistemological stances toward Indigenous peoples. In this regard, I see myself as a transformative intellectual.

I am committed to social justice for and self-determination of Indigenous peoples. I have advocated for the rights of Indigenous peoples. And I believe that research involving Indigenous peoples must lead to social change in their best interest.

All my relations, Earl Nowgesic.
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Chapter 1 Introduction

This dissertation is a research study investigating antiretroviral (ARV) therapy use among Aboriginal, or Indigenous, peoples living with the Human Immunodeficiency Virus (HIV). For the purpose of this dissertation, the term “Indigenous peoples” is synonymous with the term “Aboriginal peoples,” and refers to groups of peoples such as First Nations, Métis, Inuit, American Indian, Alaskan Native, Native Hawaiian and Maori. Throughout this dissertation, I may differentiate between certain Indigenous peoples within the context of legislation (e.g., status First Nation versus non-status First Nation), place of residence (e.g., on-reserve First Nation versus off-reserve First Nation) or specific groups of peoples (e.g., Maori or Native Hawaiian). After I collected the data, and while I was writing up the dissertation, I began using the term Indigenous Peoples Living with HIV (IPLWH) instead of the term Aboriginal persons living with HIV/Acquired Immunodeficiency Syndrome (AIDS) or APLWH. The rationale for this shift was to account for the different groups of Indigenous peoples (i.e., First Nations and Métis) involved in my study as well as to employ a term better aligned with the title of the study: the Indigenous Red Ribbon Storytelling Study (IRRSS). This dissertation reports findings from the IRRSS, a qualitative inquiry into the use of ARV therapy among IPLWH. I focused the research on one key factor—ARV therapy use among IPLWH. The main goals achieved in the qualitative study were to engage communities in community-based participatory research; to understand the use of ARV therapy among IPLWH; and to develop recommendations to improve the lives of IPLWH. My research focused on personal, interpersonal and socio-structural vulnerabilities and resilienties affecting ARV therapy use among IPLWH in central Canada. In Canada, IPLWH, in comparison to non-Indigenous peoples living with HIV (PLWH), are less likely to access and adhere to ARV therapy. Evidence for this is confirmed by quantitative studies that aim for statistical generalization. I am more interested in the contextual factors (i.e., structure) such as how (i.e., under what circumstances) and why decreased access, acceptance and adherence to ARV therapy use among IPLWH occur.

Worldwide, very few qualitative studies have investigated ARV therapy use among Indigenous populations. Those that have investigated it only addressed single discrete factors such as access and adherence to ARV therapy (Chongo, Lavoie, Hoffman, & Shubair, 2011; Ka'opua & Mueller, 2004; Milligan & Lavoie, 2012; Newman et al., 2007). My study did not limit its scope to a single factor but looked at access and adherence to ARV therapy and also acceptance of ARV therapy among IPLWH. Furthermore, unlike the Newman et al. (2007) study, which mainly explored and described ARV therapy among IPLWH, my study explored and described (as well as explained) the phenomena in question, taking into account the complex interactions of multi-level factors (i.e., individual, interpersonal and structural) affecting access to, acceptance of and adherence to ARV therapy.

The main research question for my study is as follows: How do IPLWH construct and understand their experiences of ARV therapy?
Decreased access, acceptance and adherence to ARV therapy use among PLWH is an important research problem that needs to be studied, particularly given the burden of HIV among Indigenous populations and also in light of the existence of an effective treatment that decreases HIV-specific mortality and morbidity. Other reasons for addressing this problem include the emergence of HIV drug-resistant strains due to non-adherence to ARV therapy among those currently receiving ARV therapy, and the claims that decreased HIV viral load effectively contributes to HIV prevention efforts.

1.1. Research Problem

The broad research problem I have addressed is access to, acceptance of and adherence to ARV therapy among PLWH in the Saskatoon and Prince Albert areas of Saskatchewan, Canada. Existing quantitative studies indicate that PLWH, in comparison to non-Indigenous PLWH, are less likely to access (Wood et al., 2003; Wood et al., 2006) and adhere (C. L. Miller et al., 2006a) to ARV therapy. However, these studies aim for empirical generalization (i.e., statistical inference) and are not focused on the contextual factors explaining how and why PLWH are not accessing and adhering to ARV therapy.

The phenomena of decreased access and adherence to ARV therapy among PLWH has been examined primarily using research based in a positivist paradigm. Positivist research relies on experimental design as its methodological criteria for achieving rigour (Denzin & Lincoln, 2005). Experimental design typically focuses on external validity (Denzin & Lincoln, 2005) vis-à-vis statistical inferences derived from probability sampling, where the “sampling units are chosen based on their representativeness of some wider population of units” (Schwandt, 2007, p. 269). Considering my substantive research topic, along with my experience being Anishinaabe (Ojibwe), status First Nation from Kiashke Zaaging Anishinaabek (Gull Bay First Nation) in Ontario, and my 20 years of experience working in the health sector as a senior administrator, assistant professor, epidemiologist and registered nurse in Ontario, as well as my being involved in the Indigenous HIV community movement in Canada, and my burgeoning commitment to the field of qualitative inquiry, I have come to believe that a focus on context and values will have better explanatory power than quantitative research for understanding ARV therapy use among Canadian PLWH.

Access to ARV therapy comes with its own set of complicating factors for PLWH. Acceptance of ARV therapy by PLWH has not been studied per se among this population. Adherence behaviour to ARV therapy is complex and should take into account the lived experience of persons accessing ARV therapy, including psychosocial issues and daily needs (Ickovics & Meade, 2002). HIV/AIDS research remains largely siloed in its approach to generating knowledge, and it does not take full advantage of interdisciplinary understanding incorporating social and behavioural sciences (Friedland, 2006). Access to, acceptance of and adherence to ARV therapy occur within a context beyond the disease itself and involves structural (e.g., social, economic, cultural, health care), behavioural (e.g., knowledge-base, motivation, skills, personal relations) and biomedical (e.g., drug regimen complexity, drug side effects,
HIV viral load, CD4 cell count) issues that intersect, creating a complex environment (Friedland, 2006). No studies to date fully explain the combined effect of these three issues on HIV drug therapy use specific to IPLWH in Canada.

1.2. Focus of the Research Problem

In order to generate a researchable study question and a research design, the study partners and I focused our research interest on one key factor—ARV therapy use among IPLWH. To this end, it is important to know what is included and what is left out in formulating my research problem.

Since the research problem was restricted to understanding the use of ARV therapy among IPLWH, the following areas were not addressed in the study: HIV prevention; HIV exposure; HIV transmission; HIV seroconversion; HIV/AIDS diagnosis; and HIV/AIDS care, treatment and support that is not related to ARV therapy. Regarding the biomedical factors pertaining to ARV therapy, only those factors which impinged on health behaviours related to ARV therapy use and which could be explored and understood from a qualitative perspective and within the larger context of socio-structural factors were addressed. For this reason, the effectiveness of ARV therapy or the effects of adherence to ARV therapy on HIV drug resistance were not addressed. That is, issues relating to ARV therapy that cannot be studied using qualitative inquiry were not addressed.

I addressed ARV therapy use among IPLWH by focusing the research problem using the key sensitizing concepts of structure, vulnerability, resilience, access to, acceptance of and adherence to ARV therapy, which are discussed in Chapter 3 (Conceptual Framework: Understanding Indigenous Peoples’ Use of ARV Therapy) of this dissertation. Sensitizing concepts provided a reference point from which to investigate empirical instances (Blumer, 1954; Hammersley & Atkinson, 2007).

1.3. Research Purpose

The main purpose of the study was to understand socio-structural vulnerabilities and resiliencies affecting ARV therapy use among IPLWH in Canada from a qualitative perspective. To my knowledge, no one in Canada had explicitly studied the concept of acceptance of ARV therapy among IPLWH. The concepts of access and adherence to ARV therapy among IPLWH had been investigated, and in comparison to non-Indigenous PLWH, IPLWH in Canada were less likely to access and adhere to ARV therapy. This study focused on the contextual factors (i.e., social structure) governing how (i.e., under what circumstances) and why decreased access, acceptance and adherence to ARV therapy among IPLWH occurred. Interdisciplinary research on this phenomena is limited, and no studies in Canada have examined the combined effects on IPLWH of access to, acceptance of and adherence to ARV therapy.

1.4. Research Question

The main research question for this study was as follows: How do IPLWH construct and understand their experiences of ARV therapy? In order to help conceptualize the research question, a
causal-loop diagram (CLD) of possible personal, interpersonal and socio-structural factors affecting access to, acceptance of and adherence to ARV therapy among IPLWH was developed. Figure 1 illustrates the dynamic interplay of a great many factors in a large and complex system.

**Figure 1: Possible Personal, Interpersonal and Socio-Structural Factors Affecting Access to, Acceptance of and Adherence to Antiretroviral Therapy among Indigenous Peoples Living With HIV**

“CLDs explain relationships between variables and primarily produce qualitative images of a situation” (Williams & Hummelbrunner, 2011, p. 41). The variables are connected by feedback loops, which can either facilitate or impede a specific variable. In the CLD, facilitation is denoted by a plus sign (+) and an impediment is denoted by a minus sign (-). “Negative feedback works by reversing the direction of change… [and] positive feedback increases the rate of change…” (Rickles, Hawe, & Shiell, 2007, p. 935). The interconnected variables included in my CLD were derived both from what I reviewed in the research literature and from my reflexive thought process. Based on the CLD, the use of ARV therapy occurs within a larger socio-structural environment. At the best of times, ARV therapy use is complex and at the worst of times, it can be chaotic. The variables depicted in the CLD may not be relevant to all
populations and settings. However, the intent was to develop a rudimentary understanding of what ARV therapy use might look like and how and why it might occur, in this case, targeting IPLWH in the cities of Saskatoon and Prince Albert in Saskatchewan, Canada.

1.4.1. Rationale.

The rationale for the selection of the main research question was five-fold. First, this question helped to delineate “patterns related to the phenomenon in question [and] to identify plausible relationships shaping the phenomenon” (C. M. Marshall & Rossman, 2011, p. 69), which will be explained in Chapters 5 (Accessing ARV Therapy), 6 (Accepting ARV Therapy), 7 (Adhering to ARV Therapy) and 8 (Discussion, Part One: An Integrative Summary) of this dissertation. This also helped to clearly set objectives 2 and 3 of the study, outlined in the immediate next subsection (Study objectives) of this chapter. Second, the research question helped to address gaps in the existing research literature by building upon those limited findings from existing studies conducted in Canada in order to explore, describe and explain the context in which access to, acceptance of and adherence to ARV therapy among IPLWH occurred. Third, the question helped create new knowledge that can be applied broadly by interested parties to develop effective health systems, services and policies to support IPLWH within the context of ARV therapy use. This will be explained in Chapter 9 (Discussion, Part Two: Implications, Limitations and Future Research). Fourth, the question and its subsequent research have implications for fostering ongoing interdisciplinary collaboration and multi-stakeholder engagement to ensure a comprehensive approach to addressing ARV therapy use among IPLWH. Fifth, researching the question helped to advance concepts and inform theories and methodologies, adding to the knowledge base for how to study complex systems in a manner that considers context. Such knowledge, as discussed in Chapter 9, has the potential to be utilized in different cultural settings, since the research question can be applied to other populations where issues of ARV therapy use may only differ in degree of severity.

As mentioned, very few qualitative studies have investigated ARV therapy among Indigenous populations and those that have were restricted to Australia (Newman et al., 2007), the United States (Ka'opua & Mueller, 2004) and Western Canada, namely in British Columbia (Chongo et al., 2011; Milligan & Lavoie, 2012). These studies have only addressed single discrete factors such as “HIV treatment uptake” (Newman et al., 2007) and adherence to ARV therapy (Chongo et al., 2011; Ka'opua & Mueller, 2004; Milligan & Lavoie, 2012). Beyond exploring and describing the research problem (Newman et al., 2007) or addressing a single concept such as adherence (Chongo et al., 2011; Ka'opua & Mueller, 2004; Milligan & Lavoie, 2012), this study began to explain the phenomena in question by taking into account the complex interaction of multi-level aspects of ARV therapy use. That is, this study examined contextual factors affecting access to, acceptance of and adherence to ARV therapy in an inordinately beleaguered subset of the Canadian population suffering from HIV (i.e., IPLWH) in central Canada.
1.4.2. Study objectives.

As mentioned, the main research question was: How do IPLWH construct and understand their experiences of ARV therapy? Within the context of the study design (Chapter 4 Methods), which is critical Indigenous qualitative research using a community-based participatory research orientation, an ethnographic methodology and Indigenous methods, my research objectives were as follows:

1. By means of a first Indigenous sharing circle, to engage community members in the design of a qualitative study (i.e., individual interview guide) to investigate ARV therapy use among IPLWH.
2. By means of individual interviews, to understand ARV therapy use among IPLWH in the Saskatoon and Prince Albert areas of Saskatchewan, Canada.
3. By means of participant observation, to contextualize individual interview data in terms of how the physical and social setting of health services contribute to the behaviour of IPLWH in order to further understand ARV therapy use among IPLWH.
4. By means of a second Indigenous sharing circle, to reflect upon the preliminary findings of the study while creating opportunities and the will for community members to engage in social action to improve the lives of IPLWH.

1.5. Background to the Study

The study was interested in understanding the use of ARV therapy among IPLWH and communicating an explanation in such a way that it could be applied by interested parties to develop effective health systems, services and policies to support IPLWH. This research problem was important for four main reasons.

1.5.1. Effective management of HIV by antiretroviral therapy.

The first reason for studying ARV therapy use among IPLWH was that, although there is no cure for HIV, this chronic disease can be effectively managed by ARV therapy, which decreases HIV-specific mortality (Hogg et al., 1997; Palella et al., 1998; Walensky et al., 2006), and increases life expectancy by up to 13 years beyond the survival rate of those infected with HIV who are not receiving ARV therapy (Walensky et al., 2006). ARV therapy is also known to decrease morbidities such as opportunistic infections experienced in clients with advanced HIV infection (Palella et al., 1998).

1.5.2. Burden of HIV infection among Indigenous populations.

Second, there is an increased burden of HIV infection among Indigenous populations. Although the first AIDS case was diagnosed in Canada in 1979, it was not until the 1990s that the HIV epidemic noticeably affected the Indigenous, or Aboriginal, population (Archibald, Sutherland, Geduld, Sutherland, & Yan, 2003). In 2008, Aboriginal people accounted for 8.5% of the estimated 64,000 people living with HIV in Canada (Public Health Agency of Canada, 2010b; Public Health Agency of Canada, 2012c; Yang et al., 2010). By 2011, Aboriginal people accounted for 8.9% of the estimated 71,300 people living with HIV in Canada (Public Health Agency of Canada, 2012c). Furthermore,
Aboriginal persons accounted for 12.6% of all incident HIV infections in Canada at a point estimate of 3,335 with a range of 2,370 to 4,300 in 2008 (Public Health Agency of Canada, 2010b; Public Health Agency of Canada, 2012c; Yang et al., 2010), and 12.2% of all incident HIV infections in Canada at a point estimate of 3,175 with a range of 2,250 to 4,100 in 2011 (Public Health Agency of Canada, 2012c). From 1998 to 2008, in comparison to the non-Aboriginal population, HIV exposure categories in the Aboriginal population were more likely to be people who inject drugs (PWID) (60% vs 23.4%), women (48.8% vs 20.6%), people under 40 years of age (69.5% vs 57%), and people between the age of 15 and 29 years (32.5% vs 20.6%) (Public Health Agency of Canada, 2010a). In comparing the Aboriginal subgroups, there was a difference among exposure categories, gender and age for reported AIDS cases between 1979 and 2008 (Public Health Agency of Canada, 2010a). AIDS cases among First Nations were mostly PWID (47.5%), and aged 30-39 years (45.5%) for both sexes combined. The main characteristics of Inuit AIDS cases were PWID (31.8%), heterosexual (31.8%), and aged 30-39 years (54.5%) for both sexes combined. The Métis AIDS cases were mainly men who have sex with men (MSM) at 43.1% and aged 30-39 years (34.6%) for both sexes combined. And finally, among unspecified Aboriginal AIDS cases, the main characteristics were MSM (34.9%), and those aged 30-39 years (46.5%) for both sexes combined. While Aboriginal persons represent 3.8% of the total population in Canada (Statistics Canada, 2010), the Aboriginal HIV incidence rate (32.6 per 100,000) was 3.6 times higher than non-Aboriginal persons (9.0 per 100,000) in 2008 (Public Health Agency of Canada, 2010b; Yang et al., 2010), and 3.5 times higher than non-Aboriginal persons in 2011 (Public Health Agency of Canada, 2012c). The disproportionately higher HIV infection rates among Aboriginal people have also been reported specifically in Ontario (Lachowsky, Dewey, & Summerlee, 2011), in British Columbia (BC) (Hogg, Stratdhe, Kerr, Wood, & Remis, 2005), and in Saskatchewan (Becker et al., 2012). In Saskatchewan, injection drug use (IDU) and Aboriginal ethnicity are significantly correlated (p < 0.001) (Konrad, Skinner, Bukassa Kazadi, Gartner, & Lim, 2013). Across Canada, in 22 sites, using perinatal surveillance data since 1997, the proportion of Aboriginal mothers in comparison to non-Aboriginal mothers was higher in terms of having IDU as the mode of HIV acquisition (67% vs. 27%, p < 0.001) (Sauve et al., 2013). It is clear from these figures that the Aboriginal population is over-represented in the HIV epidemic in Canada.

A study conducted by Tjepkema, Wilkins, Senecal, Guimond, and Penny (2010) reported that the mortality rate among urban Aboriginal adults was higher in comparison to non-Aboriginal adults living in urban centres, with HIV/AIDS being one of the most common causes of death for the period 1991 to 2001. Examining HIV-related mortality rates from 1999 to 2005 among IPLWH, Martin, Houston, Yasui, Wild, and Saunders (2011) found that ARV-naïve IPLWH receiving highly active antiretroviral therapy (HAART) had higher HIV-specific mortality rates in comparison to non-Indigenous PLWH after controlling for IDU (p = 0.0091). Martin et al. (2011) interpreted this finding as IPLWH having inferior
biomedical responses to HAART in comparison to non-Indigenous PLWH. Yet, the Martin et al. (2011) study did not address the context or circumstances surrounding the high HIV-specific mortality rate among IPLWH who were on HAART (e.g. adherence to HAART), rather suggesting that future research should “explore how Aboriginal HIV patients experience HAART treatment to understand if they encounter challenges that have not yet been well documented” (p. 96). The findings from Martin et al. study (2010) were consistent with an ARV therapy cohort collaboration conducted between 1998 and 2009, which reported that in comparison with “white Canadians, mortality in Canadian First Nations people (AHR, 1.48; 95% CI, .96-2.29) was higher, both for AIDS and non-AIDS mortality rates” (del Amo et al., 2013, p. 1800). The challenges that IPLWH may face surrounding ARV therapy can be explored from another perspective. Wood et al. (2003) found that many IPLWH died during the period 1995 to 2001 without ever receiving ARV therapy, and posited that Aboriginal ethnicity was negatively associated with receiving HIV drug treatment prior to death (p = 0.008).

1.5.3. Development of HIV drug resistance.
Third, there is a unique health risk contributing to the HIV epidemic. The development of HIV drug resistance is associated with sub-optimal ARV therapy use and non-adherence to ARV therapy (Little et al., 2002; Public Health Agency of Canada, 2012a; Wainberg & Friedland, 1998). In North America, the frequency of HIV drug-resistant strains has increased by 3.4% and 12.4% for the periods 1995 to 1998 and 1999 to 2000, respectively (Little et al., 2002). In Canada from 1999 to 2008, 9.8% of newly diagnosed, treatment-naïve people were HIV drug-resistant (Public Health Agency of Canada, 2012a). “Some of the increase observed for the time period 2004-2008 [in Canada] was likely due to an increase primarily in the province of Saskatchewan during each of those years” (Public Health Agency of Canada, 2012a, p. 18). Research is required to determine the etiology of HIV drug resistance in Saskatchewan. Non-adherence to ARV therapy causes incomplete suppression of HIV viral load in blood and genital secretions, contributing to HIV drug resistance in individuals as well as the public health risk of HIV drug-resistant strains being transmitted into the larger community (Wainberg & Friedland, 1998). Notwithstanding the variance in reports of what level of adherence is necessary to achieve sufficient virologic response to ARV therapy—from 95% (Paterson et al., 2000) down to 73% (Bangsberg, 2006; Shuter, Sarlo, Kanmaz, Rode, & Zingman, 2007) for example—achieving optimal adherence is an important goal. An additional challenge to adherence is prescription error. A study conducted in Vancouver between 1996 and 2003 revealed that PWID living with HIV were not being prescribed ARV therapy according to therapeutic guidelines that had been the standard of care since 1997, and they recommended the use of triple HIV drug therapy or HAART (Wood et al., 2007). Non-adherence to ARV therapy is a public health issue of the utmost importance because HIV drug resistance poses a threat to untreated HIV patients who are drug-naïve insofar as available ARV therapy could become ineffective in treating drug-resistant variants (Wainberg & Friedland, 1998). In Ontario, among
treatment-naïve patients, HIV drug resistance increased from 10.4% to 14.8% for the time period 2005-2007 to 2008-2011, respectively (Sullivan et al., 2012). In Saskatchewan, there was an increased trend of HIV drug resistance from 1999 to 2008 (p < 0.0001) and, for this same period, the overall transmitted drug resistance in Saskatchewan was estimated at 15.1% (Public Health Agency of Canada, 2012a). Patients who have been exposed to HIV drug-resistant strains and then begin ARV therapy have been shown to take a longer time to suppress HIV viral load, and once suppressed, the time to treatment failure was shorter (Little et al., 2002).

1.5.4. HIV prevention using antiretroviral therapy.

Fourth, studies using mathematical models indicate that immediate ARV therapy along with current prevention approaches can decrease HIV transmission (Blower, Gershengorn, & Grant, 2000; Fang et al., 2004; Granich, Gilks, Dye, De Cock, & Williams, 2009; Law, Prestage, Grulich, Van de Ven, & Kippax, 2001; V. D. Lima et al., 2008; Velasco-Hernandez, Gershengorn, & Blower, 2002). These theoretical studies have been confirmed by other studies using empirical data (Attia, Egger, Muller, Zwahlen, & Low, 2009; Castilla et al., 2005; Cohen et al., 2011; Das et al., 2010; Donnell et al., 2010; Montaner et al., 2010). The various mathematical modeling studies conducted in Canada (V. D. Lima et al., 2008), the United States (Blower et al., 2000; Velasco-Hernandez et al., 2002), Australia (Law et al., 2001), South Africa (Granich et al., 2009) and Taiwan (Fang et al., 2004), have all reported consistent findings indicating that treating HIV-infected persons with ARV therapy can decrease the HIV transmission rate with a median point estimate ranging from 25% (Law et al., 2001) to 54% (V. D. Lima et al., 2008), and up to 90% if ARV therapy is used with universal voluntary HIV testing (Granich et al., 2009). Empirical studies have demonstrated decreased HIV transmission at the individual level (Attia et al., 2009; Castilla et al., 2005; Donnell et al., 2010) and population level (Das et al., 2010; Montaner et al., 2010), thereby contributing to overall HIV prevention efforts with a reduction in HIV transmission rates of up to 92% (Attia et al., 2009; Donnell et al., 2010). In their study involving 1,763 HIV serodiscordant couples, Cohen et al. (2011) found “a relative reduction of 89% in the total number of HIV-1 transmissions resulting from the early initiation of [ARV] therapy, regardless of viral linkage with the infected partner” (p. 503). Although ARV therapy is financially costly at first, ARV therapy is cost-effective in the long run due to averted HIV-positive cases overall (V. D. Lima et al., 2008). For example, initiating ARV therapy in HIV-infected persons would save the Canadian province of BC up to approximately $95 million in direct treatment costs from 2006 to 2030 (V. D. Lima et al., 2008).

Although these theoretical and empirical studies are not without their limitations—they assume that universal voluntary HIV testing will occur, that treatment options will include a simple drug regimen, that behaviour change will take place once ARV therapy is initiated (Granich et al., 2009), and that for those who are medically eligible, immediate HIV diagnosis and use of ARV therapy will be undertaken (Law et al., 2001)—the argument for decreased HIV transmission is a compelling one. In an
earlier study differentiating HIV testing and ARV therapy uptake from behavioural changes in sexual practices, Fang et al. (2004) reported that ARV therapy use among HIV-infected persons can reduce the HIV transmission rate by 53%.

In summary, access, acceptance and adherence to ARV therapy among IPLWH are important because effective treatments exist to decrease HIV-specific mortality and morbidity; yet, the burden of HIV among Indigenous populations is high. This issue is important because drug-resistant strains of HIV associated with non-adherence to ARV therapy are emerging, and because there is evidence that deceased HIV viral load effectively contributes to HIV prevention. For these four reasons, the current study is interested in investigating the relationship between personal, interpersonal and socio-structural vulnerabilities and resiliencies affecting access to, acceptance of, and adherence to ARV therapy among IPLWH. However, it is important to ensure that such a study is focused and has manageable parameters.

1.6. Overview of the Dissertation

Before proceeding any further, a brief overview of this dissertation is helpful. Chapter 2 presents a literature review focusing on: Indigenous peoples, health disparities, and HIV; and on ARV therapy use among the general PLWH population as well as ARV use in relation to Indigenous cultures. Chapter 3 provides an overview of the conceptual framework of the study vis-à-vis social structure and critical Indigenous qualitative research. Chapter 4 outlines the methods for the study, provides a description of the study population, presents key features of the larger group the study pertains to, and presents key ethical considerations of the study.

Chapters 5 through 7 present the empirical findings from the study in relation to the main research question. Chapter 5 presents the study findings on access to ARV therapy among IPLWH. Chapter 6 presents the study findings on acceptance of ARV therapy among IPLWH. Chapter 7 presents the study findings on adherence to ARV therapy among IPLWH.

Chapter 8 of the dissertation provides an integrative summary of the study findings, interprets such findings and places them in the context of my research question and the literature I reviewed. Chapter 9 critically examines the implications and limitations of the research study, provides directions for future research and emphasizes the importance of a full understanding of the experiences of IPLWH with ARV therapy use.
Chapter 2 Literature Review

This chapter critically reviews the major empirical and other research literature relevant to the research topic on access to, acceptance of and adherence to AVR therapy among IPLWH. This review informs the foundation of the study.

Although the review of the major research literature was not restricted to a specific time parameter, the earliest recorded study included in this literature review was published in August 1996 and the latest study was published in May 2014.

The literature review was conducted using computerized databases and Google as well as conference abstracts. The review included topics related to ARV therapy among both general PLWH and IPLWH and relevant topics related to the health of Indigenous populations (i.e., health status, health care, and social determinants of health) which could potentially be applied to an understanding of ARV therapy access, acceptance and adherence issues among IPLWH. Although different in some fundamental ways, health status vis-à-vis co-morbidity, access to health care, and social determinants of health of Indigenous peoples shares some similarities with the structural factors affecting ARV therapy among IPLWH, and they too merited comparison and examination.

A search of internationally published works was conducted for literature pertaining to the use of ARV therapy among IPLWH. The content of the search focusing on Aboriginal health in general and on the general PLWH population was restricted to Canadian studies. The reason for this restriction was because this dissertation is specific to the Canadian context. However, since not much literature has been published in the area of ARV therapy use among IPLWH, works published outside of Canada were also reviewed. The literature search related to general PLWH and to Aboriginal health was conducted using two databases (i.e., Scopus and Scholars Portal) and the literature search related to ARV therapy use among IPLWH was conducted using four databases (i.e., Scopus, Medline, PsychInfo and Scholars Portal). Additionally, a search of abstracts from the conference of the Canadian Association of HIV/AIDS Research between the years 2010 to 2014 was conducted. Finally, some of the texts reviewed were *pearled references* or “piece[s] of literature found by studying the body or bibliography of another document” (Beahler, Sundheim, & Trapp, 2000, p. 7). ‘Pearls’ were selected based on journal articles that were considered to be key sources of information. The conceptual phase of this dissertation focused on those articles that used original and primary data. Sourcing of the research literature for inclusion in this review was based upon the following search terms: Indigenous, Aboriginal, First Nations, Métis, Inuit, Maori, HIV drug treatment, ARV therapy, access, acceptance, adherence and compliance. The literature review contextualized the research topic within the broader literature, helping to postulate new conditions of the research problem.
For this dissertation, three main aspects of the literature were critically reviewed: (1) Indigenous peoples, health disparities and HIV; (2) ARV therapy use among people living with HIV; and (3) ARV therapy use in relation to Indigenous culture.

2.1 Indigenous Peoples, Health Disparities and HIV

As articulated in the Canadian Constitution, Aboriginals are comprised of three distinct peoples: First Nations, Métis, and Inuit (Department of Justice Canada, 1982). These three groups have existing Aboriginal and treaty rights that are recognized and affirmed by the Canadian government (Department of Justice Canada, 1982). In 2006, the population distribution of First Nations, Métis, and Inuit living in Canada was 60%, 33% and 4%, respectively; the remaining 3% were reported as unspecified or as multiple Aboriginal responses in the Canadian census (Statistics Canada, 2010). These populations are growing much faster than the non-Aboriginal populations in Canada and are, consequently, younger. For the ten-year period of 1996 to 2006, the growth rate for the Aboriginal-identified population was 45% in comparison to the non-Aboriginal population at 8% (Statistics Canada, 2010; Statistics Canada, 2013). In 2006, the median age of Aboriginal and non-Aboriginal populations was 26.5 years and 39.2 years respectively (Statistics Canada, 2010). “Long considered to be the most disadvantaged group in an otherwise affluent society, Aboriginal people today paradoxically experience the kinds of health problems most closely associated with poverty, problems linked to their historical position within the Canadian social system” (Waldram, Herring, & Young, 2007, p. 3).

Although health conditions of North American Indigenous populations have improved since the time of European contact with North America over 500 years ago, health disparities among Indigenous peoples persist (Jones, 2006). Jones (2006) argues that future research should be guided by an investigation of the possible role that wealth and power play in causing health disparities, rather than lingering over the many attempts of previous research to examine etiologies of disparities among Indigenous people such as cultural practices and genetic predisposition. Jones’ (2006) hypothesis is consistent with other literature indicating that health inequities are the underlying causes of health disparities among Indigenous peoples—health inequities which are in themselves associated with structural inequities such as social and economic factors (Adelson, 2005). These health disparities are rooted in the historical relationship between Indigenous peoples and the Nation State (Adelson, 2005). For example, First Nations and Inuit health has been underfunded in comparison to the general population in both Canada (Adelson, 2005) and the United States (Jones, 2006). The essence of this argument is that structural factors affect health inequities, which subsequently lead to health disparities.

The proportion of new HIV infections among Indigenous, or Aboriginal, persons attributable to IDU in Canada increased from 63% in 2005 to 66% in 2008 (Yang et al., 2010). Similarly, other HIV incidence studies (Craib et al., 2003; Wood et al., 2008) and prevalence studies (Tyndall et al., 2006; Wood et al., 2008; Wylie, Shah, & Jolly, 2006), all conducted at some point between 1996 and 2005 and
involving PWID living in Vancouver and Winnipeg, revealed that Aboriginal ethnicity was positively associated with HIV infection. Concerning PWID, independent predictors of HIV infection were different between Aboriginal males (i.e., frequent cocaine injection and frequent speedball—combined cocaine and heroin—injection) and Aboriginal females (i.e., IDU binges, frequent speedball injection, and using condoms with regular sexual partners) (Craig et al., 2003). Wood et al. (2008) reported that, in comparison with non-Aboriginal participants, Aboriginal participants were more likely to be women, be younger, reside in the Downtown Eastside of Vancouver and be engaged in the sex trade.

From 1985 to 2004, Aboriginal MSM living in Ottawa and Toronto were 4.8 times more likely to be PWID than non-Aboriginal MSM living in the same cities; however, after controlling for Aboriginal ethnicity, IDU was not associated with being HIV positive (p = 0.57) (Lachowsky et al., 2011). This is particularly noteworthy when compared to previous studies that made a direct connection between IDU and HIV-positive test reports among Aboriginal people (Public Health Agency of Canada, 2010a).

A meta-analysis and systematic review conducted by Duncan et al. (2011) yielded 46 studies measuring independent correlates and incidence and prevalence of HIV infection among Indigenous, or Aboriginal, and non-Indigenous, or non-Aboriginal, people in Canada. This review revealed that in comparison to non-Aboriginal participants, those of Aboriginal descent had higher HIV incidence and prevalence rates where HIV-positive sero-status correlates among the Aboriginal participants included IDU and experiencing sexual abuse, with the most common correlate being Aboriginal ancestry. Furthermore, certain risk groups within the Aboriginal population (i.e., illicit drug users, street youth, and female sex workers) had higher HIV incidence and prevalence in comparison to similar groups within the non-Aboriginal population (Duncan et al., 2011). Elaborating on the risk group of street youth, Marshall et al. (2008) conducted a study from September 2005 to October 2006 and found that in comparison to street-involved non-Aboriginal youth, street-involved Aboriginal youth living in Vancouver were 2.5 times more likely to be infected with HIV, despite the Aboriginal youth being less likely to inject drugs and also less likely to be co-infected with Hepatitis C Virus (HCV). This seems to be an improvement from an earlier study conducted in Vancouver between May 1996 and May 2003, which found that Aboriginal youth who injected drugs were more likely to be infected with HCV in comparison to non-Aboriginal youth (C. L. Miller et al., 2006b). To appreciate health disparities among Aboriginal people within the context of HIV, it is important to examine co-morbidity and other related factors affecting IPLWH such as health status, health care and social determinants of health.

2.1.1. Health status.

As revealed in the literature, common health conditions experienced by Indigenous peoples, and IPLWH among them, include tuberculosis (TB), drug and alcohol addiction, Hepatitis B Virus (HBV) infection, HCV infection (Blenkush, Korzeniewska-Kozela, Elwood, Black, & FitzGerald, 1996;
Bowker, Soskolne, Houston, Newman, & Jhangri, 2004; Buxton et al., 2010; Konrad et al., 2013; J. D. Martin, Mathias, Sarin, & Byrne, 2002; C. L. Miller et al., 2004; C. L. Miller et al., 2006a) and overall poorer physical health-related quality of life (L. J. Martin, Houston, Yasui, Wild, & Saunders, 2013).

Using surveillance data, a study conducted by Blenkush, Korzeniewska-Kozela, Elwood, Black and FitzGerald (1996) involving the general population in BC compared HIV/TB co-morbidity among persons diagnosed with TB categorized by two time periods: 1984 to 1990, and 1990 to 1994. There was a significant difference in the proportion of Indigenous, or Aboriginal, persons with an increase in HIV/TB co-morbidity from the time period 1984 to 1990 to the period 1990 to 1994 at 8% and 35%, respectively (p < 0.01) (Blenkush et al., 1996). Although not reported by ethnicity, in their results, 36% of the total study population had a history of alcoholism (Blenkush et al., 1996). Regarding drug use disorder, a study conducted in BC from January 1992 to September 2000 reported HIV and HBV prevalence rates among First Nation persons entering an alcohol and drug treatment centre (J. D. Martin et al., 2002). Of the 2,345 First Nation clients tested for HIV, the HIV prevalence rate was 3.8 per 1000 (95% CI [1.3, 6.3]), and among the 2,166 First Nation clients tested for HBV, 23% (95% CI [21%, 25%]) tested positive for Hepatitis B surface antibody regardless of whether they tested positive for Hepatitis B core antibody (J. D. Martin et al., 2002). In contrast, using the Northern Alberta HIV Program Database, created in 2003, others (Pittman et al., 2014) have reported that as of May 2010 and among 2,579 people with HBV test results, the Hepatitis B surface antigen-positive group was less likely to be Aboriginal (14% versus 27.7%; p < 0.0006).

Based upon the literature review, the most common health condition experienced by IPLWH was HIV/HCV co-infection (Bowker et al., 2004; Buxton et al., 2010; Konrad et al., 2013; C. L. Miller et al., 2004; C. L. Miller et al., 2006a). The prevalence study conducted by Bowker, Soskolne, Houston, Newman, and Jhangri (2004) between January 1992 and December 1999 in Northern Alberta and involving a cohort of HIV-positive persons found that IPLWH were more likely than non-Indigenous PLWH to have HIV/HCV co-infection (p < 0.0001). The findings of the Bowker et al. (2004) study were consistent with another prevalence study conducted in BC, by Buxton et al. (2010) between 1995 and 2008 and involving a cohort of HIV-positive persons, where there was an independent association between HCV infection and Aboriginal ethnicity in females (HR = 2.09, 95% CI [1.34, 3.27]) (Buxton et al., 2010). The Buxton et al. (2010) study also revealed that that HCV infection was independently associated with IDU in both males and females (HR = 6.64, 95% CI [4.86, 9.07]), but these specific results were not categorized according to ethnicity. Two other BC studies, one conducted in 1996 (C. L. Miller et al., 2004) and the other between August 1996 and March 2002 (C. L. Miller et al., 2006a) also reported that Aboriginal persons were more likely to be HIV/HCV co-infected (all p < 0.001) (C. L. Miller et al., 2004; C. L. Miller et al., 2006a). In Saskatchewan, Konrad et al. (2013), reported significant correlations between HCV infection and Aboriginal ethnicity (p < 0.001), and between
Aboriginal ethnicity and IDU (p < 0.001) among an HIV-infected PWID population. In this same study, IDU and HCV infection were also significantly correlated (p < 0.001) and “among those that reported a history of IDU, 83% were of Aboriginal descent” (Konrad et al., 2013, p. 98).

Regarding hospital admissions in Winnipeg, Thompson et al. (2012), reported that the most common admission diagnosis was pneumonia among HIV-positive persons. Their study involved 679 admissions for 307 individuals recruited from four hospitals between October 2003 and May 2010. Sixty-two percent of the study population were of Aboriginal ancestry. The average number of hospital admissions per client was 2.2 admissions (Standard Deviation = 1.9). The most common pre-existing co-morbidities included HCV (46%) followed by drug and alcohol use (36%). The median CD4 count among the study population was 150 cells/mm$^3$, and 3.5% of them died in the hospital. Upon admission to the hospital, 67% of the clients had CD4 < 350 cells/mm$^3$ and among these, 66% were not taking ARV therapy.

Another study (L. J. Martin et al., 2013) based upon a cohort of people using the Northern Alberta HIV Program Database found that three groups—Aboriginal people infected with HIV by IDU (AB/IDUs) (p < 0.008), Aboriginal non-IDUs (AB/non-IDUs) (p < 0.002), and non-Aboriginal IDUs (non-AB/IDUs) (p < 0.002)—all had lower physical health summary scores than non-Aboriginal non-IDUs (non-AB/non-IDUs) after adjusting for years since starting HAART and socio-demographic factors. The physical and mental health summary scores were generated using the Medical Outcomes Study-HIV questionnaire. Although not statistically significant, AB/IDUs and non-AB/IDUs had worse mental health summary scores than non-AB/non-IDUs.

Summarizing the general health status of Aboriginal people in Canada, HCV infection is common followed by substance use and in particular, IDU. In comparison to non-Aboriginal people, health disparities exist among Aboriginal people. It is noteworthy that IPLWH presented late to care as indicated by their low CD4 counts upon hospital admission. In this regard, the next subsection (Health care) of this chapter will further explore the topic of health care of IPLWH.

2.1.2. Health care.

While no one would dispute that health care is important for all people, the practicalities of this point can prove challenging, especially for IPLWH who have special considerations related to their health condition, as is evident in the literature (Becker et al., 2010; A. Carter et al., 2014; Duran et al., 2010; Eyawo et al., 2011; Jackson & Reimer, 2008; Jaworsky et al., 2012; McCall, Browne, & Reimer-Kirkham, 2009; Mill et al., 2009; Plitt et al., 2009; T. Prentice et al., 2011; S. C. Thompson et al., 2009).

Plitt et al. (2009) conducted a study in Northern Alberta between May 1998 and December 2003 and found that IPLWH have decreased access to care, where care was defined as the time period between being diagnosed with HIV and having HIV viral load testing. In comparison to all other ethnic categories (Caucasian, 27 days; Asian, 22 days; African-Caribbean, 20 days; Other, 19 days), the median
time to care for IPLWH was significantly longer at 38 days (p = 0.001). In comparison to Caucasian PLWH alone, time to care was significantly longer for IPLWH (AHR = 0.82, 95% CI [0.68, 1.01]). In addition to those being of Indigenous, or Aboriginal, descent, Plitt et al. (2009) found those living in rural areas and being under 45 years of age took a significantly longer time to access care. Becker et al. (2010) conducted a similar study, published in a conference abstract, and indicated that most IPLWH in the Prairie Provinces of Canada (Alberta, Saskatchewan, and Manitoba) presented late to care between 2003 and 2007. Although the Becker et al. (2010) study did not specifically define the term late presentation, the study reported that 35% of the total study population (i.e., general PLWH) presented late to care with CD4 < 200 cells/mm³. In Ontario, Jaworsky et al. (2012) compared Aboriginal and non-Aboriginal people living with HIV and found that “Aboriginal ethnicity was significantly associated with having a CD4+ count < 200 cells/mll at the time of HIV diagnosis (OR 1.55 [95% CI 1.03 to 2.35]; P=0.04)” (p. e98). These three studies are somewhat consistent with another study noting that 23% (6/26) of Aboriginal youth from across Canada living with HIV reported they had AIDS at the time of their HIV diagnosis and 52% (13/25) of the same study population “had never accessed medical care or advice following diagnosis” (T. Prentice et al., 2011, p. 400). Furthermore, Jackson and Reimer (2008) reported that 48% of IPLWH were not accessing HIV treatment under federal, provincial and territorial drug plans; however, it was not clear in this study whether HIV treatment referred to ARV therapy or other HIV treatment such as medication used to treat opportunistic infections.

Regarding HIV drug resistance testing, a study conducted in BC in May 2009 found that Indigenous, or Aboriginal, ethnicity was associated with decreased baseline resistance testing after taking into account age (per year increase), education past high school, and number of years since HIV diagnosis (≥ 10 years vs. < 10 years) (AOR = 0.55, 95% CI [0.33, 0.91]) (Eyawo et al., 2011). This study found that Aboriginal persons post-HAART initiation, who made up a subsample totalling 42% (p = 0.744) of the entire study population, should have undergone resistance testing as warranted by virological treatment failure (Eyawo et al., 2011). The study goes on to explain “that the reduced use of resistance testing as reflected among...Aboriginal people does not necessarily reflect them not accessing the service; rather it reflects the physician not requesting the test” (Eyawo et al., 2011, p. 48). But the study did not specifically examine the impact of decreased HIV drug resistance testing on HAART adherence among IPLWH. Similar to this study, another study (A. Carter et al., 2014) found that Aboriginal women in their first year on HAART were more likely than non-Aboriginal women to have poorer quality of care. Quality of care was the primary outcome of the Carter et al. (2014) study, estimated using the Programmatic Compliance Score metric based on six indicators including:

- three indicators at baseline ((1) not having drug resistance testing prior to starting treatment; (2) starting on a non-recommended [ARV therapy] regimen (according to contemporary guidelines); and (3) starting therapy with CD4 less than 200 cell/mm³) and three indicators during the first-
year of follow-up ((4) receiving less than 3 CD4 cell count tests; (5) receiving less than 3 plasma viral load tests; and (6) not achieving HIV viral load suppression within six months of treatment initiation) (A. Carter et al., 2014, p. 2).

While these studies (Becker et al., 2010; A. Carter et al., 2014; Eyawo et al., 2011; Jackson & Reimer, 2008; Plitt et al., 2009) highlight general health care issues of IPLWH, other studies have examined the circumstances surrounding health care issues. The findings from the quantitative studies of health care use by IPLWH are enhanced by qualitative studies (Duran et al., 2010; McCall et al., 2009; Mill et al., 2009; S. C. Thompson et al., 2009) that have addressed the context of using health care.

In their study, McCall, Browne, and Reimer-Kirkham (2009) found a number of emerging themes vis-à-vis barriers, challenges, and successes when examining the perspectives of female IPLWH accessing health care services. For example, in seeking health care services, study participants experienced fear of being rejected as well as being stigmatized by health care providers due to their HIV-positive status or continued substance use (McCall et al., 2009). Similar experiences of feeling stigmatized, and experiences of feeling fear among IPLWH have been reported elsewhere in Canada (Mill et al., 2009) and in Australia (S. C. Thompson et al., 2009), respectively. In the McCall et al. (2009) study, participants also mentioned the value cultural identity played in helping them deal with such challenges. For example, cultural awareness, which came from having cultural identity, provided them with the ability to problem-solve in different situations. The value of culture and the effectiveness of using culturally-appropriate interventions to support IPLWH with their health care needs have also been reported in the United States (Duran et al., 2010). Yet, despite the supporting role that culture can play in health care among IPLWH, the McCall et al. (2009) study reports that, “[w]omen struggled to balance their need for HIV treatment with their needs for safe housing and food, and with gaining access to their children, avoiding abusive situations, and living with substance use issues” (p. 1776). Although this study examined the context in which health care use among female IPLWH takes place, the study methods involved convenience sampling and it was not entirely clear what such a sampling strategy specifically entailed. Had the study explicitly stated that it had used one type of purposeful sampling (e.g., maximum variation sampling, or criterion sampling) as described elsewhere (Patton, 2002), it would have conveyed an increased confidence in the trustworthiness of its overall design and subsequent findings.

2.1.3. Social determinants of health.

Finally, a brief review of the social determinants of health of Indigenous, or Aboriginal, people in Canada provides some helpful context for the research topic. The social determinants of health of all Aboriginal people share some similarities with socio-structural factors affecting ARV therapy use among IPLWH and they merit comparison and examination.
A study by Lima et al. (2006) conducted in BC between August 1, 1996 and September 30, 1999 found that there was no significant difference in regard to viral load or CD4 cell count response based on Aboriginal versus non-Aboriginal ethnicity among ARV therapy-naïve persons who initiated HAART. Despite this, the study reported that the IPLWH mortality rate was 3.12 times higher than non-Indigenous PLWH after controlling for confounding variables (V. D. Lima et al., 2006). Older age, decreased income, and non-adherence to HAART were associated with mortality among IPLWH (V. D. Lima et al., 2006). A similar study, also conducted in BC, found that there was no significant difference between Aboriginal and non-Aboriginal MSM in terms of their sexual risk-taking behaviour, though Aboriginal MSM (not previously tested HIV positive) had significantly poorer sociodemographic characteristics (e.g., less employment, decreased income, and unstable housing) and were more likely to experience depression than non-Aboriginal MSM (Heath et al., 1999). In comparison to non-Aboriginal MSM, a larger proportion of Aboriginal MSM had at least one occurrence of non-consensual sex (50% vs. 33%), which was statistically significant (Heath et al., 1999). This non-consensual sex experience involved a relative as the perpetrator in 50% and 25% of cases for Aboriginal MSM and non-Aboriginal MSM respectively. A larger proportion of Aboriginal MSM, upon their first occurrence of non-consensual sex, were 12 years of age and under (p = .04). At baseline, newly diagnosed HIV infection was higher among Aboriginal MSM in comparison to non-Aboriginal MSM (4% vs. 1%) although this was not statistically significant (Heath et al., 1999). A 2006 Ontario study involving IPLWH participants reported that there was an independent association between socioeconomic factors (i.e., decreased income and homelessness) and Aboriginal ethnicity; gender (i.e., being female or a transgendered women) was also independently associated with being Aboriginal (Monette et al., 2011). Although these studies revealed differences in sociodemographic characteristics between IPLWH and non-Indigenous PLWH, they did not examine the relationship between sociodemographic factors and ARV therapy use among IPLWH.

Using a prospective cohort design, the relationship between social determinants of health among Aboriginal youth (aged 14 to 30 years) who use illegal injection and non-injection drugs was studied by others in BC between October 2003 and April 2005 (Mehrabadi et al., 2008; Pearce et al., 2008; Spittal et al., 2007). The HIV prevalence was 3.8% and 12.6% for Aboriginal youth living in Prince George and Vancouver, respectively (Spittal et al., 2007). It was reported that youth who had been sexually abused were more likely to have suicidal ideology and to have ever self-harmed (Pearce et al., 2008). Lifetime sexual abuse among females was associated with sex work (Mehrabadi et al., 2008). The work conducted by others using inductive approaches (i.e., grounded theory) has explained the link between violence and HIV infection among female IPLWH while embedding its findings within the broader social determinants of health (e.g., stigma, discrimination, and low self-esteem) and subsequent outcomes (e.g., suicidal ideology) (Hawkins, Loppie-Reading, & Barlow, 2009).
It is evident that Aboriginal people are socially vulnerable. This contributes to their health disparities. A study conducted by Larkin et al. (2007) explored Aboriginal youths’ understanding of HIV risk where HIV risk was thought to be linked to social inequities (e.g., poverty) and disparities (e.g., sexual abuse and substance abuse) as a result of Aboriginal people’s experience with colonialism. Larkin et al. (2007) studied the understanding of both structure and the essence of Aboriginal youth’s (males and females aged 14 to 29 years) lived experience. The study used a participatory approach and a grounded theory method. The study indicated that some youth understood HIV to be associated with the effects of colonialism. Aboriginal youth were concerned about the effects of HIV on their communities within the context of structural inequities (e.g., poverty). The study by Larkin et al. (2007) highlights the fact that colonialism and structural inequities are determinants of health for Aboriginal populations. These findings have been supported by others along with an encouraging note regarding the role that culture and traditional knowledge play in preventing HIV transmission (Flicker et al., 2007). At the risk of vitiating the power of one’s culture to improve one’s situation, it needs to be noted that female IPLWH have reported that they have been emotionally traumatized by the abuse they experienced in their childhood and by bearing witness to the dysfunctional behaviour of their parents, which female IPLWH believe was linked to the legacy of Aboriginal residential schools (Hawkins et al., 2009). There is nothing platitudinous about the observation of Hawkins, Loppie-Reading, and Barlow (2009), who examined sexual violence experienced by female IPLWH and posited that “[d]espite the resiliency demonstrated by these [female IPLWH] in their healing efforts, the structural inequities responsible for their exposure to violence and HIV continue to make managing health and wellness a daily struggle” (p. 6). This finding points to the importance that structure plays in influencing behaviour and health outcomes of female IPLWH and the complex interaction of such factors.

2.2. Antiretroviral Therapy Use Among Peoples Living with HIV

The literature on general PLWH in Canada situates IPLWH-related issues specifically within the Canadian context. To this end, 24 studies using quantitative and qualitative methods, all published in peer-reviewed journals, inform this portion of the literature review. First, the 19 studies that used quantitative methods will be reviewed. This will be followed by the five qualitative studies.

2.2.1. Quantitative studies.

Moore et al. (2010) studied non-medically supervised treatment interruptions (TIs) from ARV therapy in BC from January 2000 to June 2006 and found a history of IDU (p = .02), HIV/HCV co-infection (p < .001), and higher baseline CD4 counts (p < .001) to be independently associated with TIs, where male gender had a protective effect against TIs (p < .001). Frequent heroin use was reported to be negatively associated with adherence to ARV therapy (Palepu, Milloy, Kerr, Zhang, & Wood, 2011). Regarding gender, other studies conducted in BC (Rusch et al., 2004) and Quebec (Godin, Cote, Naccache, Lambert, & Trottier, 2005) also reported male gender as a significant protective factor for...
accessing (Rusch et al., 2004) or adhering (Godin et al., 2005) to ARV therapy. Reasons for never taking ARV therapy included doctor’s advice or high CD4 cell count (59%), feeling healthy (40%), and being afraid of side effects (28%) (Rusch et al., 2004).

Studies conducted by Tapp et al. (2011), Uhlmann et al. (2010), and Palepu et al. (2006) analyzed data derived from cohorts of HIV-infected PWID. The role of gender was examined by Tapp et al. (2011) in their study conducted in Vancouver between May 1996 to April 2008, which reported that female gender was independently associated with decreased 95% adherence to ARV therapy (p = .006) despite the fact that methadone maintenance therapy (MMT) for both males and females was independently associated with their being adherent to ARV therapy (p < .001). Similarly, a cohort study conducted between May 1996 and April 2008 in the infamous Downtown Eastside of Vancouver (colloquially referred to as the poorest postal code in Canada) revealed that using MMT was independently associated with an elevated rate of ARV therapy initiation (log-rank p = .004) among study participants who were on MMT (64%) versus those who were not on MMT (44%) with 65% of study participants who initiated ARV therapy having 95% adherence levels (p = .019) (Uhlmann et al., 2010). Another study conducted between August 1, 1996 and November 24, 2003 in Vancouver found similar results among a study population of PWID co-infected with HIV/HCV, where MMT was positively associated with 95% adherence to HAART (p = .003) (Palepu et al., 2006). Others (Palepu et al., 2011) have also reported MMT to be positively associated with ARV therapy adherence (AOR, 2.33, 95% CI [1.86, 2.92]).

Although not specifically targeting a cohort of HIV-infected PWID, Braitstein et al. (2006) found that between July 1996 and August 2000, those with HCV infection were less likely to be adherent to ARV therapy regardless of IDU (AOR = 0.44, 95% CI [0.23, 0.87], p = .018) or non-IDU (AOR = 0.34, 95% CI [0.18, 0.64], p < .001). Contrary to the Braitstein et al. (2006) study, Rusch et al. (2004), using a study population derived from an AIDS service organization and using multiple logistic regression, reported that PWID in BC from May 2002 to September 2002 were less likely to be on ARV therapy even after adjusting for HCV. “In addition, current injection was associated with not being on therapy when compared to either non-injectors or former injectors (OR 0.16 (0.02 - 1.04); OR 0.23 (0.04 - 1.24), respectively)” (Rusch et al., 2004, p. 918). Adding to the evidence, from the data not specific to cohorts directly targeting HIV-infected PWID, O’Neil et al. (2012) reported that barriers to optimal ARV therapy adherence included past IDU (AOR = 0.46, 95% CI [0.29, 0.73]) or current IDU (AOR = 0.35, 95% CI [0.20, 0.58]). The findings from these three studies support the need for more research examining the contextual factors pertaining to current and past IDU and HIV/HCV co-infection.

One study examining IDU and adherence to ARVs begins to explain how others factors play a part in this phenomenon. Kerr et al. (2005) examined adherence among HIV-infected PWID in Vancouver between December 2001 and November 2002 and found that recent incarceration (OR = 4.84,
p = .022) and negative outcome expectations (OR = 1.41, p < .001) were independently associated with HAART being discontinued. The most commonly cited reasons for the study participants discontinuing HAART were their being in jail (44%) and having problems with side effects from HAART (41%) (Kerr et al., 2005). Others (Milloy et al., 2011) have reported a dose-response effect of incarceration on ARV therapy nonadherence: 1-2 incarceration events (AOR = 1.49, 95% CI [1.03, 2.05]), 3-5 incarceration events (AOR = 2.48, 95% CI [1.62, 3.65]), and > 5 incarceration events (AOR = 3.11, 95% CI [1.86, 4.95]). In an earlier study (Kerr et al., 2004) targeting HIV-infected PWID, where 66% of participants were less than 95% adherent, some other common reasons for missing HAART doses were forgetting (27%), sleeping through doses (24%), being ‘too busy’ (21%), being away from home (18%), and being ‘too high’ (13%). Two other factors were also independently associated with HAART discontinuance: adherence efficacy expectations (OR = 0.70, p = .003), self-regulatory efficacy (OR = 0.86, p = .05) (Kerr et al., 2005), and negative outcome expectation (OR = 0.8, p = .027) (Kerr et al., 2004). In another study, the most common barrier to ARV therapy adherence was difficulty remembering to take ARV therapy medication, with inconvenient timing being ranked second, followed by scheduling adherence to ARV therapy around food (Ostrop, Hallett, & Gill, 2000). Finally, in a study (Godin et al., 2005) conducted in Quebec involving study participants recruited from medical clinics, self-efficacy and positive attitude towards taking ARV therapy were measured by factors such as patients’ satisfaction with physicians, a high level of perceived social support, and no medication side effects. These factors were considered significant predictors of adherence (Godin et al., 2005).

Unlike other BC studies (Kerr et al., 2004; Moore et al., 2010) indicating decreased adherence to ARV therapy among HIV-infected PWID, one BC study (Mann et al., 2012) that conducted data analysis 3 to 6 years (2004 to 2009) beyond other studies (Kerr et al., 2004; Moore et al., 2010) was encouraging and found that

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\text{the proportion achieving at least 95% adherence increased over time, from 19.3\% in 1996 to 65.9\% in 2009 (Cochrane-Armitage test for trend: P < 0.0001). In a logistic regression model examining factors associated with 95\% adherence, initiation year was statistically significant (odds ratio 1.08; 95\% confidence interval 1.03-1.13; P < 0.001 per year after 1996) after adjustment for a range of drug use variables and other potential confounders (Mann et al., 2012, p. 596).}
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Although the Mann et al. (2012) study still reported that suboptimal adherence occurred in a substantial proportion of PWID in their study, after adjusting for variables such as drug and alcohol treatment, they interpreted that ARV therapy adherence had improved among HIV-infected PWID, most likely due to modern ARV therapy regimens with deceased toxicity and decreased pill burden such as once-daily ARV therapy. A study (Raboud et al., 2011) conducted in Ontario between October 2007 and May 2009 using multivariable logistic regression reported that one daily dosing of ARV therapy was
“independently associated with a decreased likelihood of missing at least one dose in the past 4 days (OR = 0.47, 95% CI (0.28, 0.78), Wald chi square = 8.33, P = 0.004)” (p. 1402). Despite these findings, it is important to note that the Raboud et al. (2011) study reported that 54% of the participants missed an ARV therapy dose within the past month. These studies indicate that in-depth qualitative inquiry is necessary to understand what facilitates ARV therapy adherence.

As seen in previous studies (Moore et al., 2010; Tapp et al., 2011), females are less likely than men to be adherent to ARV therapy. A November 2003 cross-sectional study involving women living in Vancouver identified the following factors as barriers to accessing HAART: fear that their HIV status would be suspected by others (46%), not being able to adhere to medication regimes (48%) or to make it to medical appointments (55%), lack of knowledge about the treatment (68%), and fear of side effects from HAART (72%) (Shannon, Bright, Duddy, & Tyndall, 2005). Studies conducted in BC (Rusch et al., 2004) and Alberta (Ostrop et al., 2000) also reported the fear of side effects and actual side effects, respectively, as reasons for not taking ARV therapy. Other barriers for women accessing HAART included the use of a community pharmacy (40%) or a clinic serving both men and women (42%) (Shannon et al., 2005). Factors reported to support the uptake of HAART included a number of community-driven approaches: the use of home delivery (75%) or delivery at a discreet location (52%), and having extended hours at a local support centre for women in Vancouver’s Downtown Eastside (74%) (Shannon et al., 2005). It is interesting to note that the Shannon, Bright, Duddy, and Tyndall (2005) study included a high proportion of Aboriginal women (49%), although differences between Aboriginal and non-Aboriginal participants were not compared.

Other socio-demographic characteristics affecting ARV therapy access and adherence have been reported by others (O’Neil et al., 2012; Ostrop et al., 2000; Rusch et al., 2004; Wood et al., 2000). For example, a study conducted by O’Neil et al. (2012) found that increasing age (AOR = 1.84, 95% CI [1.44, 2.33]) and being male (AOR = 1.68, 95% CI [1.07, 2.64]) were independently associated with being > 95% adherent to HAART. O’Neil et al. (2012) also reported that having an income of < $15,000 per year was independently associated with adherence to HAART being less than 95% (AOR = 0.47, 95% CI [0.31, 0.72]). Rusch et al. (2004) reported that being on welfare and having unstable housing were associated with not using ARV therapy (p = .006 and p < .001, respectively). Others have also reported homelessness to be negatively associated with adherence to ARV therapy (Palepu et al., 2011). Parashar et al. (2011), in their study targeting HIV-infected persons who were unstably housed, reported that in comparison to participants who did not attend a maximally assisted therapy (MAT) program, those who used the MAT program were more likely to be ARV therapy adherent ≥ 95% of the time (AOR = 4.76, 95% CI [1.72, 13.13]). Regarding transportation and ARV therapy use, Lima et al. (2009) reported that migration was negatively associated with adherence to ARV therapy. That is, general PLWH who migrated three or more times between August 1996 and November 2005 in BC were more
likely not to adhere to HAART than general PLWH who did not migrate (OR = 1.79, 95% CI [1.44, 2.21]) (V. Lima et al., 2009). Factoring IDU behaviour into this equation, the study confirmed that IDU acted as an effect modifier (V. Lima et al., 2009). In the City of Vancouver, Wood et al. (2000) found that general PLWH residing within one kilometer of a specific transit system (i.e., SkyTrain route) between July 1996 and March 1999 were more likely to access HIV drug treatment in comparison to persons not residing in close proximity to the SkyTrain route.

While these 19 quantitative studies report important correlates to access and adherence to ARV therapy among general PLWH, they do not focus on contextual circumstances surrounding the phenomena (i.e., the dynamic nature of access and adherence to HIV drug therapy). That is, it is not clear how or why such correlates interact with each other vis-à-vis causal pathways. Consequently, I examine five other major studies involving general PLWH and utilizing in-depth qualitative methods in order to find out how they complemented quantitative studies of access and adherence to ARV therapy.

### 2.2.2. Qualitative studies.

Using narration, Adam, Maticka-Tyndale, and Cohen (2003) interviewed 35 people in Windsor, Ontario to better understand how non-adherence to HAART operates. Their study revealed that the conflicting demands of complex medication regimens and side effects, and of work schedules and routine activities of daily living among general PLWH, combined with discrimination and PLWH making compromises, led to non-adherence to HAART. For example, as the study reported, “[t]he USA maintains an overtly discriminatory policy regarding the entry of seropositive people….Those for whom going home or to work requires crossing into the [United States] may compromise adherence schedules to avoid border inspection” (Adam et al., 2003, p. 271). Although this discriminatory policy is no longer in effect, it is an example of how socio-structural influences can impede HAART adherence.

While the Adam et al. (2003) study focused on non-adherence issues, another of its finding revealed that perception of drug effectiveness among general PLWH may lead to adherence to HAART (2003). The study participants’ belief in the effectiveness of HAART (i.e., combination therapy versus monotherapy) was based upon their personal experiences, the experiences of friends, and information gathered from the media (Adam et al., 2003).

The Adam et al. finding speaks to the importance that social support plays in HIV drug therapy adherence. Other qualitative studies have similarly found that social support can help (or hinder) HIV treatment success (Alfonso, Bernbach, Geller, & Montaner, 2006a; Alfonso, Geller, Bernbach, Drummond, & Montaner, 2006b; Veinot et al., 2006). Although it was not mentioned in the Adam et al. (2003) study, findings related to social networks bring into focus the role that theories of social networks can play in understanding access and adherence to HIV drug therapy. Adam et al. acknowledges that social class could influence personal autonomy insofar as arduous work schedules can negatively impact adherence to HAART; however, the study did not mention how social class could affect other correlates.
of adherence that may advance our understanding of how causal pathways lead to adherence to HAART. Furthermore, the Adam et al. study might have delved into the applicability of a theoretical perspective for understanding how the influence of social class on personal autonomy informs adherence to HAART. Other studies come closer to acknowledging a network of social and causal pathways. For example, Alfonso, Geller, Bemmoh, Drummond, and Montaner (2006b) interviewed 15 general PLWH using qualitative inquiry (i.e., critical incident technique) in order to study their adherence to HAART and found that limited finances affected self-esteem and led to negative impacts on social relationships. In the same study and two related studies, negative mood (e.g., depression and anxiety) (Alfonso et al., 2006a; Alfonso et al., 2006b; Veinot et al., 2006) and personal strengths (e.g., disclosing HIV status) (Alfonso et al., 2006a; Alfonso et al., 2006b) were found to hinder and help adherence, respectively. Alfonso et al. (2006a) reported that “[a] number of participants reported feeling shame, guilt, and embarrassment around being HIV positive. Some participants felt uncomfortable and vulnerable sitting in the waiting room of a HIV clinic, picking up prescriptions, or waiting for blood to be drawn” (p. 852).

In other words, socio-structural factors played an important part in influencing behaviour which then led to non-adherence to HAART. “Until the forces for and against treatment are identified, it is very difficult to take action to ‘tip the balance’ in favour of treatment” (Alfonso et al., 2006a, p. 856). This speaks to the importance of understanding the circumstances surrounding the use of HAART.

The effect of structural factors on access and adherence to HAART was highlighted in a study by Small, Wood, Betteridge, Montaner and Kerr (2009) involving PWID with a recent history of incarceration in BC. Using in-depth qualitative interviews, this study found incarceration brought with it many challenges for adhering to HAART. For example, “[i]nterviewees reported that due to high levels of HIV discrimination[,] prisoners living with HIV/AIDS will often not disclose their status, as inmates known to be HIV positive often experience violence or may be denied access to scarce resources (including drugs and syringes) by fellow inmates” (Small et al., 2009, p. 711). The study also reported that poor relationships between inmates and institutional healthcare personnel delayed access to HAART, not to mention that inmates perceived that the quality of HIV care while being incarcerated was substandard in comparison to care which they would have received in the community (Small et al., 2009). The impact of poor social relationships between general PLWH and healthcare providers and its impact on adherence to HIV drug therapy has been reported by others (Veinot et al., 2006).

It is increasingly evident how qualitative approaches help to further explain access and adherence to ARV therapy among general PLWH; however, it is worth mentioning the limitations of some of these studies. The most common limitation for all of these qualitative studies is that none made explicit reference to using a conceptual or theoretical framework in order to inform their inquiry. The Adams et al. (2003) study did appear to use some theoretical concepts (i.e., adherence and structure) to
guide their study; yet, these concepts where not described in depth nor did the study appear to apply them to any substantial degree.

On the other hand, methodologies—narration, grounded theory and critical incident technique—were articulated in most of the studies (Adam et al., 2003; Alfonso et al., 2006a; Alfonso et al., 2006b; Veinot et al., 2006), though in one study (Small et al., 2009) it was not clear what methodology was used. Furthermore, in regards to the critical incident technique (Flanagan, 1954), it would seem that this methodology is based more on a positivist stance, using associated terms such as specificity, validity, and the principle of minimizing biases (all to support empirical generalizations) as opposed to capitalizing on the strengths of qualitative inquiry, which uses theoretical or analytic generalizations such as transferability of the study results to similar situations, as described elsewhere (Schwandt, 2007).

Two acknowledged the limitations of their studies more overtly. Adams et al. (2003) acknowledged that their study did not address the role that ethnicity could have played in HAART adherence (Adam et al., 2003). Alfonso et al. (2006b) reported that non-whites, females and PWID were underrepresented in their study, therefore reducing the application of its results to such key populations (and likely to IPLWH). The Small et al. (2009) study only interviewed inmates, and it would have been interesting also to know how correctional facility staff (e.g., healthcare staff and guards) perceived issues affecting access and adherence to HAART among the inmates. Veinot et al. (2006) used a modified grounded theory approach involving 34 HIV-positive youth in Ontario from which four themes emerged: treatment knowledge (e.g., purpose of HIV drug treatment), treatment decision-making (e.g., not being involved in treatment planning), difficulties taking medications (e.g., social routines being interrupted), and treatment interruptions (e.g., remembering to take medication). However, as with the Small et al. (2009) study, Veinot et al. (2006) only examined the experiences and perceptions of general PLWH, not taking into account other interpersonal and socio-structural factors, which could be obtained by interviewing third parties (e.g., healthcare personal and significant others). This would have added more in-depth information pertaining to the relationship between personal, interpersonal and socio-structural factors affecting access and adherence to ARV therapy.

Thus far, in this literature review, I have examined major studies pertaining to ARV therapy use among general PLWH within the Canadian literature. However, most of the general PLWH-specific studies aimed for statistical generalizations and those studies that did examine circumstances surrounding access and adherence to ARV therapy use by PLWH may not be relevant to IPLWH. Regarding trends in the research, most of these published works (quantitative and qualitative studies combined) investigated the phenomenon of adherence to ARV therapy with very few of them examining access to ARV therapy. It is important to note that these studies did not address the concept of acceptance of ARV therapy or IPLWH explicitly. In order to further explore the broader discussion on the research problem, the major research literature on ARV therapy use among IPLWH in Canada and abroad was examined.
2.3. Antiretroviral Therapy Use in Relation to Indigenous Cultures

To date, only 17 studies addressing ARV therapy use among IPLWH have been conducted either in Canada (Bodenhamer et al., 2010; Chongo et al., 2011; Forbes et al., 2010; Gross et al., 2011; Littlejohn et al., 2010; C. L. Miller et al., 2006a; Milligan & Lavoie, 2012; Samji et al., 2014; Sauve et al., 2013; Tam et al., 2011; Tu, Littlejohn, Barrios, & Tyndall, 2010; Tyndall et al., 2007; Wilmot, Hagen, Skinner, Stone, & Larkan, 2013; Wood et al., 2003; Wood et al., 2006) or outside of Canada (Ka'opua & Mueller, 2004; Newman et al., 2007). With the exception of four of these studies (Chongo et al., 2011; Ka'opua & Mueller, 2004; Milligan & Lavoie, 2012; Newman et al., 2007), these studies drew statistical generalizations and were not focused on the contextual factors of the phenomena. Only seven of these studies (Chongo et al., 2011; Ka'opua & Mueller, 2004; C. L. Miller et al., 2006a; Newman et al., 2007; Tyndall et al., 2007; Wood et al., 2003; Wood et al., 2006) have been published as journal articles. The remaining ten were studies published in conference abstracts (Bodenhamer et al., 2010; Forbes et al., 2010; Gross et al., 2011; Littlejohn et al., 2010; Milligan & Lavoie, 2012; Samji et al., 2014; Sauve et al., 2013; Tam et al., 2011; Tu et al., 2010; Wilmot et al., 2013), and of these ten, four were based on program evaluations. While these 17 studies addressed access and adherence to ARV therapy among IPLWH, acceptance of ARV therapy among IPLWH was not examined. Of the four studies that examined contextual factors surrounding ARV therapy among IPLWH, two were conducted in Canada (Chongo et al., 2011; Milligan & Lavoie, 2012) and two were conducted outside of Canada (Ka'opua & Mueller, 2004; Newman et al., 2007). This section of the chapter will examine all the above-mentioned IPLWH studies in greater depth.

2.3.1. The Canadian literature.

Two of the 15 Canadian studies, both published in conference abstracts, addressed uptake of ARV therapy among IPLWH and specifically examined HIV vertical transmission in mother-infant pairs (MIP) using data from the Canadian Perinatal HIV Surveillance Program (CPHSP) since 1997 (Forbes et al., 2010; Sauve et al., 2013). The first CPHSP study (Forbes et al., 2010) used data from 21 sites across Canada and the second study used data from 22 sites (Sauve et al., 2013).

The first (Forbes et al., 2010) of the two CPHSP studies, which compared Indigenous, or Aboriginal, and non-Aboriginal MIP, found the rate of HAART uptake was 55% and 71%, respectively. The HIV vertical transmission rate was 5.6% and 3.1% for Aboriginal and non-Aboriginal MIP, respectively. It was not clear from this study whether rates were statistically significant. Although this study found that Aboriginal MIP were less likely than non-Aboriginal MIP to be on HAART and more likely to have higher HIV vertical transmission, it was not clear if this study addressed contextual factors of the phenomenon such as the underlying circumstances for why HIV vertical transmission occurs. Further, Aboriginal MIPs were only a subsample of the larger study population rather than being targeted for specific study. If an in-depth investigation were conducted, perhaps the HIV vertical transmission
among Aboriginal MIPs might have been explained. The second CPHSP study (Sauve et al., 2013) found that the proportion of pregnant Aboriginal mothers was less than pregnant non-Aboriginal mothers receiving > 4 weeks of combination ARV therapy (57% vs 71%, p < .001). The HIV vertical transmission rate was 4% and 1% for Aboriginal and non-Aboriginal MIP, respectively (Sauve et al., 2013), indicating a larger gap in the vertical transmission rates between the Aboriginal and non-Aboriginal groups when compared to the early study (Forbes et al.) published in 2010. The gap difference in the HIV vertical transmission rates between the two studies increased by 0.5% with vertical transmission being higher in the Aboriginal group.

The remaining 13 Canadian studies examining access and adherence to ARV therapy among IPLWH were specific to BC with the exception of one that was conducted in Saskatchewan, and another that combined BC, Ontario, and Quebec data in the analysis. With the exception of two (Chongo et al., 2011; Milligan & Lavoie, 2012), the remaining Canadian studies only included IPLWH as a subsample of their study population (Bodenhamer et al., 2010; Gross et al., 2011; Littlejohn et al., 2010; C. L. Miller et al., 2006a; Samji et al., 2014; Tam et al., 2011; Tu et al., 2010; Tyndall et al., 2007; Wilmot et al., 2013; Wood et al., 2003; Wood et al., 2006).

Nine of the 13 studies seemed to be dedicated research as opposed to program evaluations per se (Chongo et al., 2011; Littlejohn et al., 2010; C. L. Miller et al., 2006a; Milligan & Lavoie, 2012; Samji et al., 2014; Tyndall et al., 2007; Wilmot et al., 2013; Wood et al., 2003; Wood et al., 2006). Although one of these studies (Tyndall et al., 2007) had a large portion of IPLWH (44%) in their study sample, it did not compare the study outcomes by IPLWH and non-Indigenous PLWH. This BC study, conducted between January 1998 and November 2004, only indicated that the mean adherence rate was 85% among the total study sample (Tyndall et al., 2007). The three other BC studies (C. L. Miller et al., 2006a; Wood et al., 2003; Wood et al., 2006) found statistically significant lower levels of access (Wood et al., 2003; Wood et al., 2006) and adherence (C. L. Miller et al., 2006a) to ARV therapy among IPLWH in comparison to non-Indigenous PLWH; however, these studies touched very little on contextual factors of decreased access and adherence to ARV therapy among IPLWH. Interestingly, one of these three studies (C. L. Miller et al., 2006a), conducted between August 1996 and March 2002, found that in comparison to non-Indigenous PLWH, IPLWH “were more likely to receive double versus triple combination [ARV therapy]…, be less adherent in the first year on therapy…and to have a physician less experienced with treating HIV” (p. 968) and each of these three factors was statistically significant (C. L. Miller et al., 2006a). It was not clear in this study (C. L. Miller et al., 2006a) whether the investigators controlled for urban versus rural geographical locations, and on-reserve versus off-reserve jurisdictions. Another study examining access to ARV therapy among IPLWH reported that a limitation of their investigation conducted between May 1996 to May 2003 was that “it [was] not possible to know if the specific barriers to [ARV therapy] experienced by Aboriginal PWID are at the point of treatment or if the non-receipt of
HIV treatment [was] due to barriers that exist in the community” (Wood et al., 2006, p. 236). This observation speaks not only to the importance of incorporating the overlooked concept of acceptance of ARV therapy but also to incorporating social structure as it relates to personal and interpersonal factors affecting all of access, acceptance and adherence to ARV therapy among IHLWH. Yet another limitation of the Wood et al. (2006) study relates to its study population, recruited from the Downtown Eastside of Vancouver, which may not have been representative of IHLWH in other settings. Another BC study, published as a conference program abstract (Littlejohn et al., 2010) reported a significantly lower proportion of IHLWH adhering to their ARV therapy in comparison to non-Indigenous PLWH at 48.4% and 67.5%, respectively (p < .001). This study corroborated the point of the two journal articles (C. L. Miller et al., 2006a; Tyndall et al., 2007) dealing with adherence in BC.

While most of these studies were conducted in BC, one study was specific to Saskatchewan. Wilmot, Hagen, Skinner, Stone, and Larkan (2013) conducted a study among 100 people with 59% of the participants being of Aboriginal descent. Based on estimates, using self-reports and medication refill calculations, their study found median HAART adherence rates of 99% (self-report) and 98.9% (medication refill calculations). “Based on definitions of optimal adherence; 64.0% and 87.2% of participants were achieving adherence rates ≥ 95% and 80%, respectively” (Wilmot et al., 2013, p. 53A). The Wilmot et al. (2013) study reported the common barriers to HAART adherence to include: drug and alcohol use, being too busy, being forgetful, and being away from home. Although the results of this study are encouraging, the authors of the study did not report the limitations of their study. Such limitations could have acknowledged that the results of a study using self-reports of HAART adherence might be biased towards socially desirable reporting and that medication refill calculations might not perfectly indicate daily HAART adherence.

Aside from the province-specific studies examining adherence, one study (Samji et al., 2014) involving the Canadian Observational Cohort Collaboration of eight cohorts across Canada in the provinces of BC, Ontario, and Quebec examined incomplete adherence and treatment interruptions among HIV-positive individuals who were combination ARV therapy-naïve. Treatment interruptions were defined as ≥ 90 consecutive days off combination ARV therapy. The results of the study revealed that individuals with Aboriginal ancestry were at significantly higher risk for treatment interruptions (AHR 1.67 [95% CI 1.27 to 2.20]). Although the study concluded by saying that strategies are needed to support continuous ARV therapy, it did not provide enough context regarding treatment interruptions in terms of how best to support IHLWH with their adherence to combination ARV therapy.

The four remaining studies, published in conference abstracts, dealt with program evaluations in BC. They all revealed encouraging results. For example, Tam et al. (2011) found that self-management support (SMS) interventions improved ARV therapy uptake among their study participants, which included 60% Aboriginal persons, and helped to alleviate depression and anxiety, minimize illicit drug
use, and improve confidence in self-management around HIV care. The rate of ARV therapy uptake was found to be 95% (an increase of 8%) post-intervention, and the ARV therapy adherence rate was 91% (an increase of 4%) post-intervention. Gross et al. (2011) reported that SMS improved treatment literacy ($p = .06$) and self-efficiency ($p = .035$), which could have accounted for improvements in ARV therapy adherence among their study participants, including the 56% of the total study population who were Aboriginal. Possible improvement to ARV therapy adherence was reported by Bodenhamer et al. (2010), who suggested that SMS can improve ARV therapy uptake for their study population, comprising 52% Aboriginals. The post-intervention ARV therapy adherence score was reported at 86% (an increase of 11%) (Bodenhamer et al., 2010). In addition to these three studies that evaluated SMS, a similar study (Tu et al., 2010) revealed that their chronic care model-based program improved uptake to ARV therapy among their study participants, 53% of which were Aboriginal persons. The post-intervention ARV therapy uptake was 68% (an increase of 17%) in the Tu, Littlejohn, Barrios, and Tyndall (2010) study. Although these four studies showed encouraging results of program effectiveness on ARV therapy access and adherence, they are based upon program evaluations, which appeared not to have used in-depth qualitative investigation to fully explain ARV therapy behaviour or predict program effectiveness rigorously. In these four BC studies, it was also not clear whether SMS included the involvement of family or any other kind of social support.

Of the 17 studies in total, four of them were qualitative in nature and examined the context of access and adherence to ARV therapy among Indigenous, or Aboriginal, people living in Canada (Chongo et al., 2011; Milligan & Lavoie, 2012) and outside of Canada (Ka'opua & Mueller, 2004; Newman et al., 2007). The two Canadian studies examining adherence to ARV therapy were specific to BC (Chongo et al., 2011; Milligan & Lavoie, 2012). Using a phenomenological methodology and snowball sampling, Congo et al. (2011) recruited 22 Aboriginal men (>25 years of age) from Vancouver’s Downtown Eastside into their study and investigated the determinants of adherence to HAART. Employing thematic analysis, this study reported five main themes: patient factors (e.g., socioeconomic factors), interpersonal factors (e.g., stigma and discrimination), social supports (including MMT), history of residential school (and trauma), and complexity of HAART regimes. Milligan and Lavoie (2012) also examined adherence to HAART but within the context of IDU and focused their study sample on IPLWH resulting in 9 interviews. Based upon a grounded theory methodology, a major barrier to HAART adherence was “being high” and feeling disconnected from Aboriginal culture (Milligan & Lavoie, 2012). Examples of facilitating factors to adherence included having social supports (e.g., AIDS service organizations), trusting their healthcare providers, receiving MMT (Milligan & Lavoie, 2012), and “the knowledge of the health consequences of non-adherence” (Milligan & Lavoie, 2012, p. 59A). Although the Congo et al. (2011) and the Milligan and Lavoie (2012) studies were based upon specific qualitative research designs, it was not clear whether these studies used theory, either
implicitly or explicitly, to guide their methodology. Specific to these studies’ research designs, the Congo et al. (2011) study used phenomenology, which seemed to be more descriptive in nature and did not fully explain the complexities of the thematic categories used in the study’s analysis. While the Milligan and Lavoie (2012) study used grounded theory methodology, it was not clear if the study analyzed its data from a post-positivist perspective (Corbin & Strauss, 2008) or from an analytic method with either constructivist-interpretative (Charmaz, 2006) or postmodern underpinnings (Clarke, 2005).

2.3.2. The international literature.

Two studies examining ARV therapy use among IPLWH dealt with Indigenous populations living outside of Canada: One study was conducted in the United States (Ka'opua & Mueller, 2004) and the other study was conducted in Australia (Newman et al., 2007).

Although not statistically significant, a mixed methods (quantitative and qualitative) American study found Native Hawaiians were less likely to adhere to HAART in comparison to “white” HIV-positive adults using two types of outcomes measures: (1) a five-day adherence ratio $[X^2(1, N = 80) = 3.13]$; and (2) a self-assessment of overall adherence ratio $[X^2(1, N = 80) = .20]$ (Ka'opua & Mueller, 2004). In comparison to white HIV-positive study participants, Native Hawaiian HIV-positive participants were more likely to view family support systems (p < .01), close interactions with a health care provider (p < .05), and spiritual and relational harmony (p < .001) as critical strategies for adherence to HAART. Exploring the context of family, one of the Native Hawaiian participants stated, “The drugs are important [to health], but the family is more important. The family shares ha [breath of life] … and keeps things pono [right]. They give hugs and share their aloha [love]” (Ka'opua & Mueller, 2004, p. 59). Although the Native Hawaiians and white HIV-positive groups were not statistically different in terms of HAART adherence, the investigators concluded that such results could have been biased due to the methods of their study. For example, the study used a cross-sectional design, included self-reported measures of adherence, and “used a client sample that was currently prescribed HAART and did not include individuals who had discontinued their regime” (Ka'opua & Mueller, 2004, p. 60). The study concluded by saying that further research is needed in the area of understanding culture and family support systems among Native Hawaiians with respect to HAART adherence.

The Australian study examined the barriers and incentives to ARV therapy uptake in Indigenous, or Aboriginal, people, and suggested “that social and cultural values of Aboriginal people may facilitate treatment uptake in some contexts, and discourage it in others” (Newman et al., 2007, p. S16). Incentives to ARV therapy uptake included health services, which provided holistic care (e.g., welfare support) and the motivation for pregnant women to avoid passing HIV onto the fetus (Newman et al., 2007). However, once the infants were born, the study found that women would discontinue ARV therapy because they perceived themselves to be in good health, with low HIV viral load levels and high immune function measures (Newman et al., 2007). The major barrier to ARV uptake was the combined
fear of disclosure, lack of privacy and fear of discrimination, and the second most common barrier was alcohol consumption, which also affected ARV therapy adherence (Newman et al., 2007). Although the Newman et al. (2007) study examined contextual factors affecting ARV therapy among IPLWH, the study results were unique to Australia and may not be relevant to IPLWH living in Canada. Furthermore, it was not clear whether the method used in this study was based exclusively on an in-depth qualitative investigation or whether it used a mixed methods (quantitative and qualitative research) design. It appeared that a qualitative analysis was conducted using a subset of data taken from a larger quantitative study. Nonetheless, the study reported that its methods included semi-structured interviews conducted in 2003 among a study sample of 20 persons.

It is evident that there is a paucity of empirical research addressing access and adherence to ARV therapy among IPLWH and no studies examining the concept of acceptance of ARV therapy among this population.

2.3.3. Concepts of access, acceptance and adherence.

Three sensitizing concepts—access, acceptance and adherence—were chosen to focus on the research problem of ARV therapy use among IPLWH. These concepts were selected based upon the work of Friedland (2006) regarding determinants of ARV drug efficacy, which I subsequently adapted to help focus my study (see Figure 2).

**Figure 2: Concepts of Access, Acceptance and Adherence**

**ARV Therapy: The Relationships among Access, Acceptance and Adherence**

(adapted from Friedland, 2006)

*Within a broader socio-structural context: social inequalities, cultural differences, racism, mental health, and substance use disorder.*
The significance of Friedland’s work is that it helps one to appreciate the dynamic interplay between multiple (e.g., social, behavioural and medical) and multi-level (e.g., individual, interpersonal and structural) factors affecting access, acceptance and adherence to ARV therapy. His work also makes explicit how access and adherence to ARV therapy is related to the concept of acceptance of ARV therapy.

For this dissertation, and within the context of ARV therapy use, the terms accessibility and acceptability as described by Blankenship, Bray, and Merson (2000) have been used. Here, accessibility “is a function of social, economic and political power and resources” (Blankenship et al., 2000, p. S12). Access refers to the availability of resources. Acceptability speaks to social norms which are influenced by culture, values and beliefs (Blankenship et al., 2000). Acceptance is associated with a patient’s trust in medications and the healthcare system (Mostashari, Riley, Selwyn, & Altice, 1998), and refers to the process of ARV therapy initiation (Altice, Mostashari, & Friedland, 2001). Accessibility and acceptability can be addressed at three levels: individual (e.g., access to needle exchange programs, and anti-stigmatization campaigns to influence acceptance), organizational (e.g., government-funded social programs, and television programming initiatives), and environmental (e.g., decriminalization of sex work, and social marketing campaigns) (Blankenship et al., 2000).

When speaking to the concept of adherence to ARV therapy, the term as described by Lehane and McCarthy (2009) has been used. Adherence considers the medication-taking behaviour of the client (e.g., following prescription instructions and achieving intended outcomes) as well as person-centred interactions (e.g., the patient-care provider relationship, and the client’s beliefs, motivation, and habits) (Lehane & McCarthy, 2009) including the clinical setting, such as an amicable healthcare environment (Ickovics & Meade, 2002). It is evident that medication adherence is a complex behaviour involving many factors (Ickovics & Meade, 2002). The term compliance has been used interchangeably with adherence by some researchers; however, my study did not employ it since compliance has traditionally been associated with a view that clients are passive players in their self-care responsibilities (Kyngas, Duffy, & Kroll, 2000). The term compliance has also been associated with healthcare providers who use a paternalistic approach when interacting with their clients (Lehane & McCarthy, 2009). Furthermore, it has been reported that there is not a common understanding among interested parties as to how to define or measure compliance (Kyngas et al., 2000).

Unlike the concepts of access to medication and medication adherence, little is known about factors that support or impede acceptance of medication once it is offered to a client (Altice et al., 2001). Yet a study conducted by Altice, Mostashari, and Friedland (2001) has supported using the concept of acceptance, which seems to play an important role in ARV therapy behaviour among marginalized populations. This issue will be further explored in the next chapter (Chapter 3 Conceptual Framework:...
Understanding Indigenous Peoples’ Use of ARV Therapy) of this dissertation using a middle-range theory that focuses on the use of health services.

The sensitizing concepts (i.e., access, acceptance and adherence as well as structure, vulnerability and resilience) were used in the study as heuristic devices in conjunction with a middle-range theory that focuses on the use of health services—the Behavioral Model of Health Services Use (R. M. Andersen, 1968). Such heuristic devices were used to help theoretically understand phenomena and make inferences vis-à-vis sociological plausibility (J. Auerbach, Parkhurst, & Caceres, 2011). Auerbach, Parkhurst and Caceres (2011) suggest the “notion of ‘sociological plausibility’ as a way to hypothesize causal links between social drivers and [phenomena] where such associations ‘make sociological sense’—that is, where they are consistent with what is known about psychological, social, cultural, economic and political data in specific contexts” (p. S296).

2.4. Summary of the Literature

The major research literature was critically reviewed according to three main categories: (1) Indigenous peoples, health disparities and HIV; (2) ARV therapy use among people living with HIV; and (3) ARV therapy use in relation to Indigenous cultures.

It is evident that health disparities exist in Canada between Indigenous and non-Indigenous people. Of particular importance to population and public health is the rate of HIV infection among Indigenous peoples. HIV is higher among Indigenous peoples in comparison to non-Indigenous peoples. Among PWID, the HIV prevalence rates among Indigenous persons were much higher than among non-Indigenous persons. Furthermore, the time between diagnosis and access to care among IPLWH is longer compared to non-Indigenous PLWH. In addition, once care is accessed, IPLWH receive substandard care compared to non-Indigenous PLWH where substandard care includes receiving double versus triple combination ARV therapy or being under the care of a physician with less experience in treating HIV.

The literature pertaining to the health status vis-à-vis co-morbidity, health care, and social determinants of health among the general Indigenous population revealed that IPLWH experience co-morbidities such as living with HIV and a drug use disorder, and living with HIV/HCV co-infection. Other correlates associated with HIV included: Indigenous ancestry, experiencing sexual abuse, street youth, female sex workers, using illicit drugs and IDU. The literature also indicated that in comparison to non-Indigenous PLWH, IPLWH face unique challenges involving the complex interaction between social, economic, and cultural factors such as having decreased access to health services in general and, in particular, decreased HIV viral load testing and decreased HIV drug resistance testing.

There is a paucity of empirical literature or original work conducted in the area of access and adherence to ARV therapy among IPLWH, although between the two concepts, most of the work done focuses on adherence. Some literature showed that self-management support is conducive to accessing
ARV therapy. Factors affecting increased adherence to ARV therapy included having social supports, having trust in health care providers, and receiving holistic care. Impediments to ARV therapy adherence included complexity of HAART regime, stigma and discrimination, drug and alcohol use, and unstable housing. No studies have examined the concept of acceptance of ARV therapy per se among IPLWH. Most of the studies yielded statistical generalizations (versus theoretical or analytic generalizations) and very few of them addressed in any depth the circumstances surrounding the phenomena.

Other studies involving the general Canadian population found that IDU and being female were associated with ARV therapy non-adherence but they too presented results aimed at statistical generalization and did not provide an in-depth understanding of the phenomenon. Those studies that address contextual factors, such as social supports and socio-structural factors affecting inmates, did not appear to use theory to guide their inquiry, possibly preventing a deeper understanding of what it meant to use ARV therapy. Furthermore, for those studies that focused on general PLWH, the explanation of the phenomenon might not be relevant to IPLWH.

A study (Newman et al., 2007) from Australia examined the phenomenon in relation to discrimination and alcohol consumption among IPLWH; however, it was not entirely clear if this study used in-depth qualitative techniques. An American study (Ka'opua & Mueller, 2004) using mixed methods (quantitative and qualitative) mainly focused on predicting adherence to ARV therapy among Native Hawaiians and concluded that further research is needed in the area of understanding culture and family support systems among Native Hawaiians with respect to HAART adherence.

From the review of the major literature, not enough is known about how IPLWH understand ARV therapy, particularly within the Canadian context. In order to help investigate this phenomenon further, theory was used as a heuristic device.
Chapter 3 Conceptual Framework: Understanding Indigenous Peoples’ Use of ARV Therapy

“Where formal theories [deal] in abstractions—deviance, power, stigma—substantive theories [are] more oriented to the pressing practicalities of the here and now” (Dey, 2004, p. 83). Middle-range theory as opposed to macro theory was used to guide this study, given that the research problem was being approached from a substantive perspective; that is, investigating the research problem in order to understand the research phenomena at the personal and interpersonal levels with the aim of identifying the effects of wider structural factors, including social, political, and economic contexts on individuals and groups of individuals. As defined by Merton (1968), middle-range theories are:

theories that lie between the minor but necessary working hypotheses that evolve in abundance during day-to-day research and the all-inclusive systematic effects to develop a unified theory that will explain all the observed uniformities of social behavior, social organization and social change (p. 39).

Middle-range theories connect the broad propositions of macro theory (e.g., social class)—which involve the interconnected sets of general, abstract concepts—with empirical evidence such as the grounded, reportable and observable behaviour of individuals, groups, and people in various social settings (Green & Thorogood, 2009; Hammersley & Atkinson, 2007; Merton, 1968). My educational background and work experience also influenced my decision to use middle-range theory. My experience being a registered nurse in Ontario, epidemiologist, assistant professor and senior administrator working in Aboriginal health drew me both to a doctoral program specializing in social and behavioural health sciences (specifically, the health and behavioural sciences stream of the program) and to transformative research benefiting Aboriginal populations. The degree to which I used theory in order to guide the study is supported by others (Green & Thorogood, 2009; Malterud, 2001). That is, although theoretical considerations are necessary to attain quality assurance in qualitative inquiry, it is not expected that the health sciences researcher become a social scientist in doing such research (Malterud, 2001). “Middle-range theory thus deals with the delimited aspects of social situations in which the empirical and the analytic can be combined” (Maynard, 1995, pp. 276-277).

The middle-range theory that was used in order to theorize the study data is the Behavioral Model for Health Services Use (R. M. Andersen, 2008), which will be described in Section 3.1.2. (Behavioral Model of Health Services Use) of this chapter.

Theorized accounts provide a much more selected representation of the phenomena with which they deal. On the other hand, assuming that the theoretical ideas are well founded, they begin to give us much more knowledge about why events occur in the patterned ways they do (Hammersley & Atkinson, 2007, p. 161).

In addition, the following sensitizing concepts helped to analyze the data: structure, vulnerability, resilience, access, acceptance and adherence.
3.1. Social Structure

One interest in carrying out the study was to understand structure (i.e., social factors) and its effect on ARV therapy use among PLWH in their everyday settings. A social structure, or pattern of variables (e.g., social roles) making up a social system, is that context which determines actions and social interaction (Alvesson & Skoldberg, 2009; J. Auerbach et al., 2011; Parsons, 1951). “In essence, structure refers to the ways in which elements (parts) of any system (whole) formally relate to each other” (Prasad, 2005, p. 91). Structural factors have been described using terms such as social forces or social drivers (J. D. Auerbach, Parkhurst, Caceres, & Keller, 2009). Contextual in nature, social drivers are complex and non-linear, interacting dynamically with diverse factors (e.g., biological, behavioural and social), leading to various causal pathways and subsequent outcomes (J. D. Auerbach et al., 2009). This contextual characteristic of structural factors has been supported by other literature (Gupta, Parkhurst, Ogden, Aggleton, & Mahal, 2008). Structure is “the material and operational manifestations of social norms and networks, such as family units, organized religion, legislative and policy apparatus, educational systems, military and industrial organizations, etc., in which social interaction is patterned and often, controlled” (J. D. Auerbach et al., 2009, p. 2). The interacting causal factors are context-dependent; rather than operating independently, they change because of other mediating factors (J. D. Auerbach et al., 2009). These social forces or drivers can operate at either the micro level (e.g., individual) or macro level (e.g., population), having a direct (i.e., proximal) or indirect (i.e., distal) effect, respectively (J. D. Auerbach et al., 2009), on individuals and whole populations. The chance for unforeseeable outcomes increases the more distal the outcome is from its underlying social driver (J. D. Auerbach et al., 2009). These social drivers (e.g., income) lead to overall vulnerability or resilience in the social system and for the people living in such a social system (J. D. Auerbach et al., 2009).

3.1.1. Vulnerability and Resilience.

In this study, the term vulnerability was used as described by Delor and Hubert (2000), differentiating three dimensions of social vulnerability: (1) identity vulnerability, or the social trajectory (e.g., one’s lifecourse position, and biological fragility), (2) relational vulnerability, or the intersection of two or more social interactions (e.g., relational influences) and (3) contextual vulnerability, or the social contexts (e.g., macrosocial impacts). Each of these three dimensions (trajectory, interaction, and context) can intersect with one another, leading to an increased degree of vulnerability (Delor & Hubert, 2000). Furthermore, these three dimensions can be viewed from two perspectives: “that of ‘objective’ meaning or the meaning commonly accepted by all, and the particular meaning worked out by each individual” (Delor & Hubert, 2000, p. 1560). Examples of commonly accepted meaning include a person’s life cycle, or the setting where two individuals interact, or social inequalities, all of which are considered part of a socio-structural perspective. Examples of particular meaning worked out by an individual include a person’s perception of their future, or a person’s perception of others, or a person’s perception of social
norms, and are considered a socio-symbolic perspective (Delor & Hubert, 2000). The extent to which someone is affected by the three specific dimensions of vulnerability depends upon that person’s exposure to vulnerabilities, the capacity of that person to respond to vulnerabilities, and the potentiality or impact of vulnerabilities on that person (Delor & Hubert, 2000). The measure of the effect of social vulnerability on an individual, regardless of the dimension at which it occurs or the perspectives taken on it, is directly related to the concept of resilience. How one adapts to social vulnerability leads to the concept of resilience.

In the study, resilience is defined as the “ability of [an individual, or a group, or a population, or] a system to recover from perturbation; the ability to restore or repair or bounce back after a change due to an outside force” (Meadows & Wright, 2008, p. 188). Resilience involves a dynamic process of interacting systems, as opposed to a personality characteristic or trait (i.e., resiliency), where an individual, group, population or system is able to positively adapt to the circumstances surrounding adversity (Fleming & Ledogar, 2008; L. J. Kirmayer, Sehdev, Whitley, Dandeneau, & Isaac, 2009; Luthar & Cicchetti, 2000; Luthar, Cicchetti, & Becker, 2000). In this context, environmental forces (i.e., both vulnerabilities and protective factors) act upon adversity as modifying mechanisms (Fleming & Ledogar, 2008; L. J. Kirmayer et al., 2009; Luthar & Cicchetti, 2000), and occur at multiple levels of influence (i.e., individual, interpersonal and structural levels) (Fleming & Ledogar, 2008; L. J. Kirmayer et al., 2009; Luthar & Cicchetti, 2000). Remembering that the effect of social vulnerability upon a person can be measured according to exposure, capacity to respond, and potential impact, the concept of resilience possesses three complementary dimensions: one’s invulnerability to adversity; one’s ability to positively adapt in response to adversity; and the ability of one’s underlying mechanisms to fully recover from adversity (Fleming & Ledogar, 2008; Luthar & Cicchetti, 2000; Luthar et al., 2000).

It is always important to consider what qualities, conditions or circumstances create vulnerabilities that impede ARV therapy use and create resilience that contribute to optimal ARV therapy access, acceptance and adherence among IPLWH.

3.1.2. Behavioral Model of Health Services Use.

The Behavioral Model of Health Services Use (BMHSU) (R. M. Andersen, 1968) was developed to examine health disparities among people in the United States within the context of healthcare use (R. M. Andersen, 2008) and specifically to predict and explain health services use (R. M. Andersen, 1968; R. M. Andersen, 1995). Although the BMHSU has been revised four times (phases two to five) in response to trends in health services, policy and other emerging issues (Aday & Andersen, 1974; R. M. Andersen, 1995; R. M. Andersen, 2008), its fundamental components and their relationships have not changed (R. M. Andersen, 2008). Phase five of the BMHSU is made up of four main components (i.e., contextual characteristics, individual characteristics, health behaviours, and outcomes) that interact with one another (see Figure 3).
Phases one, two, three, four and five were developed in the 1960s (R. M. Andersen, 1968), 1970s, 1980s-1990s, 1990s, and 2000s, respectively (R. M. Andersen, 2008). The main differences between each of the phases are as follows: phase one focused on families as the unit of analysis and on the concept of equitable access; phase two of the model accounted for the healthcare system (e.g., health policy and healthcare organization) and consumer satisfaction; phase three incorporated the interplay between personal health practices and health services use, and recognized the importance of health status as perceived by individuals versus health professionals; phase four accounted for the dynamic nature (i.e., feedback loops) of the model’s components; and last, phase five of the model considered the value that individual characteristics versus contextual characteristics play in health services use as well as the importance to the process of medical care of the interactions between patients and providers) (Aday & Andersen, 1974; R. M. Andersen, 1995; R. M. Andersen & Davidson, 2007; R. M. Andersen, 2008).

The BMHSU helps to explain the interplay among the four domains of contextual characteristics, individual characteristics, health behaviours, and outcomes. Two of these domains—contextual and individual characteristics—each consist of three sets of categories; namely, predisposing factors, enabling factors, and need factors. The four domains and eight categories yield 21 constructs, which are further described in my study codebook, or coding scheme (Appendix A).
The BMHSU helps to describe various dimensions of access to care: potential access (i.e., presence of enabling resources), realized access (i.e., actual use of services), equitable access, and inequitable access (R. M. Andersen & Davidson, 2007; R. M. Andersen, 2008). Equitable access and inequitable access are viewed from the perspective of those causal factors of realized access that are dominant (R. M. Andersen, 1995; R. M. Andersen & Davidson, 2007). For example, equitable access is defined “as occurring when predisposing demographic and need variables account for most of the variance in utilization, whereas inequitable access occurs when social structure, health beliefs, and enabling resources determine who gets medical care” (R. M. Andersen, 2008, p. 651). These two definitions pertaining to the concept of equity of access are built upon the previous work conducted by Aday and Andersen (1981). Another concept that is important to the BMHSU, more from a programmatic perspective, is mutability (R. Andersen & Aday, 1978; R. M. Andersen, 1995). Mutability is defined as “the extent to which a given component can actually be altered to influence the distribution of health services” (R. Andersen & Aday, 1978, p. 535). Pertaining to the predisposing constructs of the BMHSU, demographic and social constructs have a low degree of mutability and health beliefs have a medium degree of mutability (R. M. Andersen, 1995). All the variables related to the enabling constructs of the BMHSU have a high degree of mutability (R. M. Andersen, 1995).

The BMHSU was initially validated using American population-based national survey data from 1975-1976 (R. Andersen & Aday, 1978; R. M. Andersen, McCutcheon, Aday, Bell, & Chiu, 1983). The BMHSU guided a study using 1990-1991 survey data from Los Angeles (LA), California involving homeless adults that examined variables such as residential history, victimization history, mental health, substance abuse, and competing needs, where outcome measures of the homeless population pertained to blood pressure; skin, legs and feet conditions; TB skin-testing; and vision function (Gelberg, Andersen, & Leake, 2000). Using these additional variables (e.g., residential history, etc.), the BMHSU predicted health services among vulnerable populations experiencing homelessness (Gelberg et al., 2000). This expanded version of the BMHSU called the Behavioral Model for Vulnerable Populations (Gelberg et al., 2000) was validated using a sample of homeless white, African-American and Hispanic women living in LA (J. Stein, Andersen, & Gelberg, 2007). Andersen et al. (2000) validated the BMHSU using a national sample of vulnerable adults (i.e., women, ethnic minorities, PWID and less educated) treated for HIV from 1996 to 1997 in the United States. However, in the Andersen et al. (2000) study, the following factors were not adequately measured: “discrimination, beliefs about the benefits and potentially harmful effects of drug therapy, mistrust of providers, and providers’ perspectives regarding differential adherence to therapeutic regimens according to ethnicity” (p. 413). Anthony et al. (2007) also validated the BMHSU, examining the use of HIV primary care among study participants recruited from a randomized controlled trial conducted in the United States between 2001 to 2002; however, their study mostly involved participants of non-Hispanic Black ancestry and males, and it was uncertain if
their study involved IPLWH. In order to address the potential issue of the relevancy of the BMHSU to the IPLWH population, the conceptual framework of this current study was orientated to both critical social and Indigenous research paradigms. That is, for the study, critical Indigenous qualitative research was used as a research paradigm (Denzin & Lincoln, 2008), which will be explained under Subsection 3.2.2. (Critical Indigenous pedagogy vis-à-vis critical Indigenous qualitative research) of this chapter.

3.2. Critical Social Paradigm

Critical Indigenous qualitative research complements the Indigenist pedagogy of Two-Eyed Seeing. Two-Eyed Seeing incorporates non-positivist Western sciences and Indigenous knowledge (Iwama, Marshall, Marshall, & Bartlett, 2009; D. Martin, 2012). Critical Indigenous qualitative research is influenced by both a critical social paradigm and an Indigenous research paradigm, with the latter paradigm enhancing the former vis-à-vis ontologies and epistemologies. The relationship between a critical social paradigm and an Indigenous research paradigm will be further elaborated on in Subsections 3.2.1. (Indigenous research paradigm) and 3.2.2. (Critical Indigenous pedagogy vis-à-vis critical Indigenous qualitative research) of this chapter immediately following a brief review of the relevance of ontologies and epistemologies to this study.

Ontologies, according to one serviceable definition, “are beliefs about the basic entities that make up reality” (Giacomini, 2010, p. 129). As a philosophy of the nature of existence (Abercrombie, Hill, & Turner, 2006), ontology also considers the nature of values and how such values relate to a phenomenon in question (Giacomini, 2010). But if ontology concerns the relation of values to phenomenon, it also concerns the potential of values, whether good or bad, to prompt action that affects social phenomenon (Giacomini, 2010). In other words, “How does one’s way of being potentially effect social change?” If the essential phenomenon of the substantive research topic is to be understood based upon the socially constructed ontological beliefs of the study participants, then knowledge must not only be generated but also understood in terms of the nature of that knowledge. In this study, the nature of the reality of the study participants’ ontological beliefs as socially constructed is of interest because it either facilitate or impede access, acceptance and adherence to ARV therapy among IPLWH.

To understand phenomena, researchers use epistemologies (Giacomini, 2010) that can be thought of colloquially in the form of the question: “How do we know what we know?” Asking ourselves how we know what we know about a research phenomenon is a necessary precursor to generating a good research question because epistemology will influence the research methodology (S. Carter & Little, 2007). The simple fact is that an ontological stance—the researcher’s own belief system and the belief system of research participants—flows into a researcher’s epistemological approach—the way the researcher ask questions and conducts research with study participants (Giacomini, 2010).

A critical social paradigm (CSP) has an idealist ontology that is based upon historical realism and it has a subjectivist/transactional epistemology, where findings are ultimately determined by
weighing the values of various people in a particular time and place (Giacomini, 2010; Guba & Lincoln, 2005). This paradigm creates new knowledge by interpreting qualitative data ideologically or creatively (Giacomini, 2010). The reality of the interpreted data exits in the mind of the person who creates the interpretation. The philosophy of *idealism* posits that reality is not independent from the mind (Schwandt, 2007). Nevertheless, it is also the responsibility of the researcher practicing such *subjective idealism* to understand that “the external social reality cannot exist independently from the everyday interactions and subjectivity of social actors” (Abercrombie et al., 2006, p. 189). The ontology of idealism dictates that the world has qualities that relate to one’s own ideas, and “that we have direct access only to our ideas and subjective experiences, and no empirical access to the world beyond, except through these ideas” (Giacomini, 2010, p. 131).

From a CSP perspective, the research findings that result from interpreting data according to the standpoint of marginalized parties have the capacity to create more equitable power relations (Giacomini, 2010). Researchers using a CSP “assume that hegemonic interests have constructed the prevailing accounts of reality” (Giacomini, 2010p. 133). In order to counter these prevailing assumptions, researchers challenge the social, economic, and political agendas behind hegemonic accounts of reality (Giacomini, 2010). Because of its ability to examine broader social structures affecting reality, a CSP seemed promising when considering this research question on access, acceptance and adherence to ARV therapy among IPLWH. However, in an Indigenous context, notwithstanding the potential of a CSP to combat paradigms that favour colonialist perspectives, it has failed “to address how [I]ndigenous cultures and their epistemologies were sites of resistance and empowerment” (Denzin & Lincoln, 2008, p. 9). In response to this negative consequence, Indigenous people as a group have often resisted research that uses a CSP and instead only engaged in research that meets their best interests (Smith, 2005). In this case, Indigenous people as a group “can be defined as the assembly of those who have witnessed, been excluded from, and have survived modernity and imperialism” (Smith, 2005, p. 86) and include those “who identify their ancestry with the original inhabitants of Australia, Canada, and other countries worldwide” (Wilson, 2008, p. 34).

One Indigenous research initiative that builds upon a CSP is *Kaupapa Maori research* (Bishop, 2005). Specific to New Zealand, this research challenges the dominant discourse and preferences “the need to recognize and address the ongoing effects of racism and colonialism in the wider society” (Bishop, 2005, p. 128). Kaupapa Maori research privileges practices with an Indigenous viewpoint by focusing values within an Indigenous-centred research paradigm as opposed to translating them from, or disguising them within, a dominant discourse of Western methodologies such as collaborative research (Smith, 1999). Promising as this approach is, one must always heed the caution of Kovach (2009) that such research risks being sublimated in the Western colonizing perspective.
Kovach (2009) has argued that an Indigenous-centred research paradigm that is incorporated into a CSP is characterized in relation to its approach to decolonizing methodologies, and is thus still consistent with the theoretical underpinnings of Western critical approaches because such Indigenous frameworks are still based within a critical theoretical perspective. Decolonization speaks to “the reevaluation of the political, social, economic, and judicial structures themselves and the development, if appropriate, of new structures that can hold and house the values and aspirations of the colonized people” (Burgess, 2000, p. 155). This conceptualization of decolonization is not restricted to governance but transcends all sectors including culture, language, and psychology, in order to divest colonial power (Smith, 1999). “Kaupapa Maori is a ‘local’ theoretical positioning which is the modality through which the emancipatory goal of critical theory, in a specific historical, political and social context, is practised” (Smith, 1999, p. 186).

To summarize, neither a CSP in general nor a CSP incorporating an Indigenous framework to understand phenomena experienced by Indigenous peoples, adequately explain some of the most pressing social issues faced by Indigenous peoples (Denzin & Lincoln, 2008; Kovach, 2009; Smith, 2005). So it is important to examine another research paradigm in more depth.

3.2.1. Indigenous research paradigm.

An Indigenous research paradigm (IRP) is considered to be non-Western in terms of its ideologies (Wilson, 2008). Researchers who employ an IRP can be described as Indigenists (Denzin & Lincoln, 2008). From a methodological viewpoint, “Indigenists resist the positivist and postpositivist methodologies of Western science because these formations are too frequently used to validate colonizing knowledge about [I]ndigenous peoples” (Denzin & Lincoln, 2008, p. 11). Unlike a CSP, which interprets data in order to level the playing field of power relations between marginalized and hegemonic groups, an IRP uses interpretative research strategies such as testimonies and personal performance narratives that are specifically appropriate to the lived experiences, including the culture, language, and traditional values of Indigenous peoples (Baskin, 2005; Denzin & Lincoln, 2008). The challenge here is to avoid having these strategies exploited by researchers unfamiliar with their unique interpretive strength. As Battiste (2000) writes: “the heritage of an Indigenous people is a complete knowledge system with its own concepts of epistemology, philosophy, language, and scientific and logical validity that needs protection from Eurocentric exploitation” (p. 195). Eurocentrism describes the preferencing by Western academics of European ideologies over non-European standpoints (Henderson, 2000). An IRP is not rooted in a dominant discourse in the way that a Western paradigm such as the CSP is, and it should not be compared to non-[I]ndigenous ideologies as a way of validating its legitimacy (Baskin, 2005; Wilson, 2008), especially considering that [I]ndigenous ways of knowing predate the participatory and narrative approaches recognized today by the dominant discourse as legitimate forms of research (Baskin, 2005).
Wilson (2008) explains that the ontology and epistemology of an IRP is specifically defined by Indigenous cultures. It has both a relational ontology and a relational epistemology (Wilson, 2008). Unlike the idealist ontology and historical realism of the CSP, the nature of reality in Indigenous research paradigms is based upon sets of physical, mental, emotional and spiritual component relationships (Baskin, 2005). “Therefore reality is not an object but a process of relationships, and an Indigenous ontology is actually the equivalent of an Indigenous epistemology” (Wilson, 2008, p. 73).

Battiste (2008) claims that the epistemology of an IRP is based upon the immediate ecology of Indigenous peoples and requires drawing from:

- experiences, perceptions, thoughts, and memory, including experiences shared with others; and
- from the spiritual world discovered in dreams, visions, inspirations, and signs interpreted with the guidance of healers or [E]lders. Most Indigenous people hold various forms of literacies in holistic ideographic systems, which act as partial knowledge meant to interact with the oral traditions (p. 499).

Elders are people of Indigenous ancestry who are recognized by their respective communities to be leaders respected for their wisdom, leadership in spiritual matters, and ability to connect cultural traditions and practices to the past, the present and the future (King, Smith, & Gracey, 2009). The epistemology of an IRP involves the dynamic interaction of variables, which are forever changing. Indigenous knowledge then is a “relationship within the global flux that needs to be renewed, kinship with the other living creatures and life energies embodied in their land, and kinship with the spirit world” (Battiste, 2008, p. 500). As Wilson (2008) proposes, the epistemology of an IRP is derived from multiple interacting relationships, including personal, interpersonal, socio-structural and, most importantly, spiritual relationships. Spirituality is an integral part of an Indigenous worldview (Baskin, 2005).

An IRP requires a methodology that is accountable to these relationships. And it requires an axiology and value system that is based upon respectful, reciprocal and responsible relationships (Baskin, 2005; Wilson, 2008). This is relational accountability that has local relevance to a specific Indigenous community (Baskin, 2005; Wilson, 2008). The methodology and axiology of an IRP as proposed by Wilson (2008) is consistent with the call by Denzin and Lincoln (2008) “for a collaborative social science research model that makes the researcher responsible, not to a removed discipline (or institution) but rather to those studied” (Denzin & Lincoln, 2008, p. 15). When researchers and the methodologies they employ are accountable to the research participants and the local Indigenous community, then research ceases to objectify Indigenous people and their knowledge (Baskin, 2005; Wilson, 2008).

An IRP, like a CSP, favours views that have been marginalized. Yet an IRP is more relevant to a study of social phenomenon experienced by Indigenous peoples, given its unique concept of relational
accountability. Although an IRP is not commonly used in the academy of health sciences, it is gaining some traction (Baskin, 2005; Lavallee, 2009; Rothe, Ozegovic, & Carroll, 2009). Unfortunately, when it comes to accessing the IRP epistemology with a methodology, such methodologies are not fleshed out enough in the existing literature.

Notwithstanding the limitations of both paradigms (i.e., a CSP and an IRP), a discussion can take place between the CSP and the IRP that will both aid social change in a way that is more culturally centred on Indigenous peoples and that will support the further articulation of a dedicated IRP. A critical Indigenous pedagogy vis-à-vis critical Indigenous qualitative research was used to support the conceptual and methodological frameworks of this study. It can offer strong support for ethical research involving Indigenous populations.

### 3.2.2. Critical Indigenous pedagogy vis-à-vis critical Indigenous qualitative research.

Critical Indigenous pedagogy (CIP) is a term used by Denzin and Lincoln (2008) to describe the connection between critical methodologies and Indigenous methodologies. CIP appreciates that research is political and moral and aims to attain social justice (Denzin & Lincoln, 2008). Although CIP seems similar to the purpose of a CSP, it actually gives greater value to Indigenous, subjugated knowledge and its ability to transform social structures to support Indigenous peoples (Denzin & Lincoln, 2008). As posited by Denzin and Lincoln (2008), a CIP “embraces the commitment by [I]ndigenous scholars to decolonize Western methodologies, to criticize and demystify the ways in which Western science and the modern academy have been part of the colonial apparatus” (p. 2). Decolonizing methodologies is a term used to describe the connection between an Indigenous perspective and a Western ideology (Smith, 1999; Wilson, 2008). However, according to Smith (2005), to realize such a paradigm shift within the academy, it is important that Indigenous researchers, other researchers, and Indigenous communities work together to educate the wider academic community. This is the pedagogical aspect of critical Indigenous pedagogy. Without such a connection, the dominant discourse of a colonial ideology leads to the continued destruction of Indigenous cultures (Smith, 2005).

According to Denzin and Lincoln (2008), critical Indigenous qualitative research connects Indigenous and critical methodologies. When practicing critical Indigenous qualitative research, the investigator always needs to be aware of how research can and should advance the self-determination of Indigenous people (Denzin & Lincoln, 2008). Critical Indigenous qualitative research should not be legitimized using neocolonial paradigms as a standard (Denzin & Lincoln, 2008). Furthermore, the researcher should be aware of the challenges associated with entering into any dialogue between Indigenous and critical non-Indigenous discourses. According to Denzin and Lincoln (2008):

- First, the legacy of the helping Western colonizing Other must be resisted…. Second…critical, interpretative performance theory and critical race theory, without modification, will not work within [I]ndigenous settings…. Critical theory must be localized, grounded in the specific
meanings, traditions, customs, and community relations that operate in each Indigenous setting…. [Third, c]ulturally responsive research practices must be developed. Such practices would locate power within the Indigenous community (pp. 5-6).

As previously mentioned, the ontology of idealism concerns the nature of values. According to Giacomini (2010), “[r]esearchers who work with ideas-as-facts (idealistic) cannot step outside their personal, social, or cultural perspective to view those ideas objectively” (p. 134). However, researchers who collect ideas-as-facts from the study participants must also contextualize them. In other words, whereas facts deal with “questions of what is…. [v]alues, in contrast, concern questions of what ought to be” (Giacomini, 2010, p. 133). Investigation using critical Indigenous qualitative research “holds that values are inherent in all facts…. [and that] values motivate researchers to ask certain research questions (and not others), so values drive the research enterprise” (Giacomini, 2010, p. 134). Consequently, epistemology, which is axiological or value bound, guides methodology (S. Carter & Little, 2007). In this study, experiences of the study population as they are socially constructed is valued, recognizing that the study participants’ reality is what they perceive it to be and that it also has a reality within their environment, a socially constructed environment that the researcher is also responsible for interpreting. The research implication here is that the subjectivist epistemological foundations of the study will construct the realities of the study participants. The focus of the research is to understand ARV therapy use among HIV-positive Indigenous populations from a holistic perspective employing critical Indigenous qualitative research supported by the BMHSU and the sensitizing concepts of structure, vulnerability, resilience along with access, acceptance and adherence.
Chapter 4 Methods

The research design of the study is critical Indigenous qualitative research (Denzin & Lincoln, 2008) using critical ethnography (D. Foley & Valenzuela, 2005; D. E. Foley, 2002; Madison, 2005; Thomas, 1993), and a community-based participatory orientation (Minkler & Wallerstein, 2008b; Wallerstein & Duran, 2008).

4.1. The Qualitative Approach and Ethnography

Compared to a positivist research design, qualitative inquiry, which is based upon idealistic assumptions of human behaviour, is more appropriate to study the phenomena in question given that understanding the nature of the phenomena is of interest. Unlike positivist research designs, which are based upon realism and tend to be applied to the natural sciences, qualitative inquiry focuses on human perceptions, which are complex and unpredictable, and therefore more suitably applied to human behaviour (Green & Thorogood, 2009). “A positivist philosophy is one that assumes that there is a stable reality ‘out there’ – that phenomena…exist whether we are looking at them or not, and that they exist in exactly the same way whether we understand them or not” (Green & Thorogood, 2009, p. 13). Consequently, this study is qualitative in nature, specific to one particular setting—Saskatchewan (i.e., Saskatoon and Prince Albert)—and focused on naturalistic inquiry. Focusing the study on a particular setting, the aim of the study was to produce a local account of the phenomena in question and one based upon the perspectives of the study participants (Green & Thorogood, 2009) and of the investigator as the “main research instrument for obtaining knowledge” (Kvale & Brinkmann, 2009, p. 74).

The study had an emergent design. Because it was not possible to know all the multiple realities of the study phenomena, the study design could not be fully planned prior to starting the investigation (Lincoln & Guba, 1985). As Lincoln and Guba (1985) explain, the research design of qualitative inquiry must be emergent because meaning is determined by context to such a great extent; because the existence of multiple realities constrains the development of a design based on only one (the investigator’s) construction; because what will be learned at a site is always dependent on the interaction between investigator and context, and the interaction is also not fully predictable; and because the nature of mutual shapings cannot be known until they are witnessed (p. 208).

As discussed in Chapter 3 (Conceptual Framework: Understanding Indigenous Peoples’ Use of ARV Therapy), the study used a critical Indigenous qualitative research design supported by the BMHSU and various sensitizing concepts. The methodology used to conduct the research was ethnography, which portrays the everyday life of a culture-sharing group in a holistic manner (Charmaz & Mitchell, 2001; Creswell, 2007).

In terms of data collection, ethnography usually involves the researcher participating…in people’s daily lives for an extended period of time, watching what happens, listening to what is
said, and/or asking questions through informal and formal interviews, collecting documents and artefacts – in fact, gathering whatever data are available to throw light on the issues that are the emerging focus of inquiry (Hammersley & Atkinson, 2007, p. 3).

Using various methods, ethnography as a methodology transcends common sense. The interpretation of critical commonsense understanding “goes beyond reformulating the [study participant’s] self-understanding—what they themselves experience and mean about the topic—while remaining within the context of a commonsense understanding” (Kvale & Brinkmann, 2009, p. 215). For example, instead of using qualitative methods to uncover social realities, anthropologists use such methods to constitute social realities by means of communication and analysis (R. Prentice, 2010). “Ethnographic knowledge is therefore interpretive, emerging from social interaction and negotiation” (R. Prentice, 2010, p. 167). This methodology was selected because it is consistent with the purpose of the proposed study to examine the contextual factors affecting the use of ARV therapy among IPLWH. This rationale is further explained in the planning framework developed by Auerbach et al. (2009), which compares ethnographic methods with other common methods used to research structural and social interventions.

Ethnography focuses on studying groups of individuals (C. M. Marshall & Rossman, 2011). There are many different types of ethnography, which can be classified as traditional ethnography (e.g., naturalist, inductive, and interpretative), and disrupted ethnography (e.g., critical and postmodern or deconstructive) where the former deals with the description of a culture, and where the latter deals with the ideological production of culture (Alvesson & Skoldberg, 2009; Koro-Ljungberg & Greckhamer, 2005). Critical ethnography (D. Foley & Valenzuela, 2005; D. E. Foley, 2002; Madison, 2005; Thomas, 1993) was employed in the research, which is consistent with critical Indigenous qualitative research (Denzin & Lincoln, 2008) and serves to examine “issues such as power, hegemony, and to advocate for certain groups” (Creswell, 2007, p. 71). With the use of theory, critical ethnography analyzes social phenomenon, thus creating transformative knowledge that can be applied to the discourses of social justice (Mertens, 2009). “Anthropologists strive to depict cultures, people, and practices not in isolation, but as embedded within broader social, political, and economic processes. Although different anthropologists will choose to emphasize different aspects of these, the foundational idea behind this principle is that we cannot understand social action separate from wider contexts” (R. Prentice, 2010, p. 170). Critical ethnography can also incorporate alternative approaches such as community-based participatory research (Israel, Schulz, Parker, & Becker, 1998; Leung, Yen, & Minkler, 2004), which is commonly used in research involving Indigenous peoples (Macaulay et al., 1999; Mooney-Somers & Maher, 2009). For these reasons, this study attempted to constitute the socio-structural vulnerabilities and resiliencies of access, acceptance and adherence to ARV therapy among a group of IPLWH.

The unit of analysis in ethnography usually consists of at least 20 individuals who have some common cultural characteristics (Creswell, 2007). The intent of the research is to understand how
cultural groups function around aspects such as beliefs, behaviours and hegemonic issues (Creswell, 2007). That is, ethnography concerns the explanation of discernible patterns of a culture-sharing group, and the successful ethnographer needs to have a grounding in the socio-cultural system that he or she is researching (Creswell, 2007). In particular, the study consisted of a focused critical ethnography. “In the focused critical ethnography[,] it is a question of making a fairly qualified interpretation of a more limited body of empirical material, on the basis of a relatively extensive knowledge about the object of study” (Alvesson & Skoldberg, 2009, p. 172).

4.1.1. Participant observation.

Participant observation is a term that describes “the practice of taking part in everyday activities while observing and recording impressions, ideas, and the words of informants” (R. Prentice, 2010, p. 160). The advantage of using participant observation is that data derived from such a method are based upon ‘real’ behaviour of study participants and, over time, such behaviour is unlikely to change as a result of the researcher’s presence in the field (Bogdewic, 1999; Green & Thorogood, 2009). Guba and Lincoln (1981) eloquently argue the advantages of employing observation in naturalistic inquiry:

> Observation (particularly participant observation) maximizes the inquirer’s ability to grasp motives, beliefs, concerns, interests, unconscious behaviors, customs, and the like; observation (particularly participant observation) allows the inquirer to see the world as his [study participants] see it, to live in their time frames, to capture the phenomenon in and on its own terms, and to grasp the culture in its own natural, ongoing environment; observation (particularly participant observation) provides the inquirer with access to the emotional reactions of the group introspectively—that is, in a real sense it permits the observer to use himself as a data source; and observation (particularly participant observation) allows the observer to build on tacit knowledge, both his own and that of members of the group (p. 193).

4.1.2. Fieldnotes.

Another method used in ethnography is fieldnotes. Fieldnotes act as “the expanded account, or permanent notes, that form the core of a participant observation study and the foundation for eventual analysis” (Bogdewic, 1999, p. 62). Using fieldnotes helped the investigator to record observations, observations that may normally have been taken for granted and processed unconsciously on a routine basis while engaged in interactions in social settings (Bogdewic, 1999). Emerson (2001) describes the value of fieldnotes:

> Fieldnotes are a form of representation, that is, a way of reducing just-observed events, persons and places to written accounts. And in reducing the welter and confusion of the social world to written words, fieldnotes (re)constitute that world in preserved forms that can be reviewed, studied and thought about time and time again (p. 353).
The added value of using fieldnotes is that they help the ethnographer take a critical approach to his or her own research by incorporating a reflexive stance via observation notes, methodological notes, theoretical notes, and personal notes (Silverman, 2005). “[W]riting fieldnotes, rather than writing finished ethnographies, provides the primal, even foundational moments of ethnographic representation: for most ethnographic monographs rely upon, incorporate and may even be built from these initial fieldnotes” (Emerson et al., 2001, p. 352).

4.2. Community-Based Participatory Research Orientation

The study used a community-based participatory research (CBPR) orientation, which balances research and action (Baskin, 2005; Horowitz, Robinson, & Seifer, 2009; Israel et al., 1998; Minkler & Wallerstein, 2008b). CBPR is “an orientation to research that focuses on relationships between academic and community partners, with principles of colearning, mutual benefit, and long-term commitment and incorporates community theories, participation, and practices into the research efforts” (Wallerstein & Duran, 2006, p. 312). CBPR includes principles such as: recognizing the identity of a community; conducting research that builds upon community resources; and facilitating collaboration, co-learning, and capacity building between all parties involved in the research (Israel et al., 1998; Israel et al., 2008). CBPR is consistent with a critical social paradigm and has its roots in neo-Marxist perspectives and liberation theology (Kemmis & McTaggart, 2005; Wallerstein & Duran, 2008). CBPR is popular in Canada, the United States and abroad (Flicker, Savan, Kolenda, & Mildenberger, 2008; Minkler & Wallerstein, 2008a), and is commonly used in Indigenous health research (Macaulay et al., 1999; Mooney-Somers & Maher, 2009).

4.2.1. Community partners.

The study was a collaborative effort between the investigator and eleven community groups: (1) AIDS Saskatoon, the 601 Outreach Centre and 601 North; (2) the Co-operative Health Centre, Prince Albert Community Clinic; (3) the Heath Canada, First Nations and Inuit Health Branch, Saskatchewan Region; (4) the Indian Métis Friendship Centre of Prince Albert; (5) the Saskatoon Friendship Inn; (6) the Saskatoon Indian and Métis Friendship Centre; (7) the Saskatoon Tribal Council, Health & Family Services; (8) the Saskatoon Westside Community Clinic; (9) the Prince Albert Access Place and Outreach Services; (10) the Prince Albert Métis Women’s Association; and (11) the Saskatoon HIV/AIDS Research Endeavour (SHARE). SHARE is “an HIV-specific, multi-disciplinary and multi-sectoral community-based research team and agenda” (Hagen, Meili, Stewart, & Skinner, 2012, p. 96A). SHARE was established in January 2011. The SHARE membership is comprised of community members and groups, health service providers, and university researchers (Hagen et al., 2012).

The community partners of the study worked with the investigator to determine the research agenda, plan and organize the research process and disseminate the research findings. Modeled after a research collaboration of the Canadian Aboriginal AIDS Network (2010), I drafted a research agreement
for use by the community partners and myself in order to guide the agenda, the process and the outcomes of my study (Appendix B). The research agreement includes attached letters of support from community-based agencies.

4.2.2. Planning and doing community-based participatory research.

Principles of CBPR were followed in all aspects of my study. I met with the community partners to plan the study before beginning the actual research phase of the study. Community partners also helped to analyze and interpret the data by participating in the development of the coding scheme for the data analysis, and study participants were included in interpreting preliminary results of the study through member reflections. Member reflections is “a practice that does not aim toward accuracy of a single truth, but rather provides space for additional data, reflection, and complexity” (Tracy, 2010, p. 848) to be contributed by the study participants. Additionally, the study participants developed some recommendations aimed at policy makers and health service providers in order to improve the lives of IPLWH. Finally, the findings of my research and this dissertation were shared with my community partners to gather their feedback.

The major components of CBPR are research, education, and social action (Leung et al., 2004). “CBPR begins with an issue selected by, or of real importance to, the community, and involves community members and other stakeholders throughout the research process, including its culmination in education and action for social change” (Minkler & Wallerstein, 2008a, pp. 1-2). With the use of theory, data were collected/generated and analyzed within the context of a CBPR orientation, where both the investigator and study participants generated the data together during the individual interview and group interview components of the study. The group interviews consisted of Indigenous sharing circles. (This sharing circle method will be described in Subsection 4.5.1 [Interviews: Individual and collective] of this chapter.) Member reflections occurred during the second Indigenous sharing circle that also allowed for co-learning among those present. The preliminary findings of the study were shared with IPLWH in the second Indigenous sharing circle interview. In other words, the research was a process of co-construction between the researcher and the research participants (Finlay, 2002). “Meanings are seen to be negotiated between researcher and researched within a particular social context so that another researcher in a different relationship will unfold a different story” (Finlay, 2002, p. 531).

I conceptualized, developed and revised the study proposal between January 2012 and February 2013 during which time I met with the community partners and other community groups. The purpose of these meetings was to share my research interests with the various partners and groups. Over the course of 11 months, I travelled from Ontario (where I live) to Saskatchewan five times in order to attend community meetings. Each meeting was attended, for the most part, by different groups. The first meeting was held in January 2012 in Saskatoon with SHARE at one of their regular meetings. The three subsequent meetings occurred in: February 2012 in Regina (with Health Canada, First Nations and Inuit
Health Branch, Saskatchewan Region; and the Saskatchewan Ministry of Health, Population Health Branch, Disease Prevention Unit); April 2012 in Saskatoon (with AIDS Saskatoon and the 601 Outreach Centre; Saskatoon Health Region, Mental Health and Addiction Services; Saskatoon Tribal Council, Health & Family Services; SHARE; and the Saskatoon Westside Community Clinic); and June 2012 in Prince Albert (with the 601 North Outreach Centre; Co-operative Health Centre, Prince Albert Community Clinic; Health Canada, First Nations and Inuit Branch, Saskatchewan Region; Little Red River First Nation; Northern Inter-Tribal Health Authority; Prince Albert Métis Women’s Association-HIV Health Promotion; Prince Albert Parkland Health Region; Prince Albert Access Place and Outreach Services; Sturgeon Lake First Nation; and the University of Saskatchewan, Department of Academic Family Medicine, Research Division). In November 2012, I made a fifth trip to Saskatchewan to meet with various parties: An Indigenous Elder; AIDS Saskatoon and the 601 Outreach Centre; Saskatoon Tribal Council, Health & Family Services and the Saskatoon Westside Community Clinic.

On April 25, 2012 and November 21, 2012, verbal support for my PhD research project was provided by the Saskatoon Westside Community Clinic, the primary site where the research took place. On November 20, 2012, AIDS Saskatoon provided verbal support for the research. I was provided with verbal support for the research from various groups on the following dates: February 17, 2012 (Health Canada, First Nations and Inuit Health Branch, Saskatchewan Region; and the Saskatchewan Ministry of Health, Population Health, Disease Prevention Unit); April 30, 2012 (AIDS Saskatoon and the 601 Outreach Centre, and the Saskatoon Tribal Council, Health & Family Services); June 18, 2012 (Northern Inter-Tribal Health Authority); and June 19, 2012 (The 601 North Outreach Centre based in Prince Albert; The Prince Albert Métis Women’s Association-HIV Health Promotion; and the Prince Albert Access Place and Outreach Services). On January 22, 2013 and January 23, 2013, I held telephone meetings with the Saskatoon Indian and Métis Friendship Centre (SIMFC) and the Indian Métis Friendship Centre of Prince Albert (IMFCPA), respectively, who were supportive of my research interests.

In October 2012, SHARE (three co-chairs and the Research Coordinator) reviewed my written doctoral thesis proposal and on November 20, 2012, I met with AIDS Saskatoon who provided me with feedback on the proposed research project. On November 21, 2012, I met with the Saskatoon Tribal Council, Health & Family Services, and the Saskatoon Westside Community Clinic who provided me with feedback on the proposed project. In December 2012 and January 2013, other SHARE member agencies (e.g., Health Canada, First Nations and Inuit Health Branch, Saskatchewan Region; Northern Inter-Tribal Health Authority; Saskatoon Health Region; and the Saskatoon Westside Community Clinic) reviewed my written research proposal. On January 23, 2013, I held a telephone meeting with the IMFCPA, which provided me with feedback on my written proposal. On February 11 and 13, 2013, I
met with the Saskatoon Friendship Inn and the SIMFC, respectively, who were supportive of my research plans. Everyone who reviewed my written proposal was supportive of the planned research.

4.3. Study Setting

“[Q]ualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them” (Denzin & Lincoln, 2005, p. 3). For this reason, I temporarily relocated from Ontario, where my primary residence is, to Saskatchewan where the study population was located and where the research phenomena was happening, as I recognized that “[i]n an ethnographic study, a single site, in which an intact culture-sharing group has developed shared values, beliefs, and assumptions, is often important” (Creswell, 2007, p. 122).

The study took place in the Province of Saskatchewan (specifically, the cities of Saskatoon and Prince Albert). For the one-year period of 2013, the HIV diagnosis rate for population of Saskatchewan as a whole (all ages of both non-Aboriginal people and Aboriginal people) was 11.4 per 100,000, which was 1.9 times the national all-ages HIV diagnosis rate of 5.9 per 100,000 for the same period (Public Health Agency of Canada, 2014). In 2013, 68% (88/129) of newly diagnosed HIV cases (88) in Saskatchewan were of Aboriginal ethnicity (Saskatchewan Ministry of Health, 2014). Between 2003 and 2007, Aboriginal people were overrepresented in the HIV epidemic in Saskatchewan; comprising the majority of new cases (Becker et al., 2012). What seems to be driving the HIV epidemic in Saskatchewan is IDU. In 2013, IDU was the main exposure category for 55% of the HIV cases (71/129) in Saskatchewan (Saskatchewan Ministry of Health, 2014). As previously mentioned in Chapter 1 (Introduction) of this dissertation, there was an increased trend in HIV drug resistance from 1999 to 2008 (p < 0.0001) with an overall transmitted drug resistance in Saskatchewan estimated at 15.1% (Public Health Agency of Canada, 2012a). According to the Saskatchewan Ministry of Health (2014), for those living in Saskatchewan:

- The average length of time between first being tested positive for HIV and being diagnosed with AIDS in 2013 was approximately 4.1 years (range 0 to 17 years). Under one-third of the AIDS cases (7 of 24) in 2013 had their initial positive HIV test at the same time they were diagnosed with an AIDS defining illness…. Less than half of the 24 HIV cases whose infection progressed to AIDS in 2013 have died (10 deaths) (p. 8).

The main study site was the Saskatoon Westside Community Clinic, which is a health centre that provides nursing and medical services to people living in the inner City of Saskatoon, where most marginalized populations live (Konrad et al., 2013), as well as to people in the surrounding areas, including the City of Prince Albert. Regarding the community partners who were based in Saskatoon, three of them (i.e., Saskatoon Friendship Inn, Saskatoon Tribal Council Health Centre and the Saskatoon Westside Community Clinic) were located in the Westside of the City where it seems that a large proportion of the Indigenous peoples resided near or frequented 20th Street West. This part of the City
was one of the more economically deprived neighbourhoods of Saskatoon. One of the other Saskatoon-based partner agencies (i.e., Saskatoon Indian and Métis Friendship Centre) was located in the downtown neighbourhood, which separated the Saskatoon Westside and Eastside districts. I observed that many Indigenous people frequented the downtown neighbourhood but not to the same extent as the Saskatoon Westside. Another partner agency (i.e., AIDS Saskatoon and its 601 Outreach Centre) was located towards the north end of the City off 33rd Street West. This neighbourhood did not seem as deprived as Saskatoon’s Westside Neighbourhood, nor did it seem that as high a concentration of Indigenous people frequented this northern neighbourhood as Saskatoon’s Westside.

“Often site selection is in practice a pragmatic decision, based on existing networks of colleagues and contacts” (Green & Thorogood, 2009, p. 160). In January 2012, upon suggestion of other researchers such as the Ontario HIV/AIDS Treatment Network (OHTN), I introduced myself to SHARE. At that time, I was a fellow of the OHTN-managed Universities Without Walls fellowship program (2011 to 2012)—a national training initiative for future HIV researchers linking communities, researchers, and policy makers (Universities Without Walls, 2012). I have also been involved with various Saskatchewan initiatives over the past 17 years as: a conference delegate at the University of Regina Community-Based Health Research Summer Institute (2011), where I was assigned as the Working Group Chairperson to work on a case study that assisted the Regina-based All Nations Hope AIDS Network with their research goals; the Assistant and Associate Director of the Canadian Institutes of Health Research-Institute of Aboriginal Peoples’ Health (2001 to 2008), where I supported the Indigenous Peoples’ Health Research Centre, a collaboration between the First Nations University of Canada, the University of Regina, and the University of Saskatchewan; the Epidemiologist of the Health Secretariat of the Assembly of First Nations (1999 to 2001), where I supported the National First Nations Health Technician Network, which included the Federation of Saskatchewan Indian Nations as one of its network members; and as a federal field epidemiologist for the Laboratory Centre for Disease Control of Health Canada (1997 to 1999), where I supported a Prince Albert, Saskatchewan HIV research project.

4.4. Study Sample

The study used purposeful sampling, also known as purposive sampling, where selective units for investigation such as people, communities and cultures were selectively sampled (Creswell, 2007; Patton, 2002) “for their relevance to the research question, analytical framework, and explanation or account being developed in the research” (Schwandt, 2007, p. 269). More specifically, a technique called maximum variation sampling was employed, which increased the likelihood that different explanations would be accounted for in the findings while identifying important thematic categories (Creswell, 2007; Kuzel, 1999). Maximum variation sampling was also used in combination with criterion sampling where “[a]ll cases meet some criterion; useful for quality assurance” (Kuzel, 1999, p. 39). These two types of sampling techniques were used simultaneously in order to ensure that the study
sample included diverse and multiple perspectives, while at the same time obtaining quality assurance (Creswell, 2007; Patton, 2002).

**4.4.1. Justification of the study sample.**

IPLWH are less likely than non-Indigenous PLWH to access (Forbes et al., 2010; Wood et al., 2003; Wood et al., 2006) and adhere (Littlejohn et al., 2010; C. L. Miller et al., 2006a) to ARV therapy. Also, there is a higher portion of IPLWH in comparison to “white” PLWH with transmitted HIV drug resistance in Canada for the period 1999 to 2008 (12.5% vs. 9.4%) (Public Health Agency of Canada, 2012a).

The target study population was English-speaking adult IPLWH (age 18 years or greater) and their health service providers and other key informants (e.g., government officials, and community leaders) who provided informed consent to participate in the study. The focus of the study was IPLWH. Sampling this specific population ensured access to the ontology of the study phenomena; namely, the personal, interpersonal and socio-structural factors affecting ARV therapy access, acceptance and adherence.

Targeting such a circumscribed study sample was meant to ensure that data saturation (i.e., thematic redundancy, when additional study participants do not provide any new information for the study) (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014; Lincoln & Guba, 1985) would be reached within the timeframe of the study. “Strong ethnographic work requires saturation of a wide range of categories, located in their cultural, historical or organizational contexts” (Charmaz & Mitchell, 2001, p. 167). Using the 21 constructs of the BMSHU as a guide, such saturation was achieved at 20 persons for the individual interviews. Six participant observation sessions yielded over 50 discrete observational units combined (i.e., settings, events and processes). Seven and eight participants were recruited into the first and second Indigenous sharing circle interviews, respectively. The Indigenous sharing circles consisted of key informants (e.g., health service providers, a government official and a community leader as well as IPLWH).

The main study sample included IPLWH to whom it was suggested by their health care provider that they consider accessing ARV therapy. Study participants only included those people who had been living in the Saskatoon and/or Prince Albert areas for at least the previous year in order to ensure that participants were familiar with their local context. “Care must be taken when choosing key informants to interview, to ensure that they can represent the interests of the whole community, and not just sectional interest” (Green & Thorogood, 2009, p. 165). Recruiting participants from two cities allowed me to analyze the study data and compare various findings to one another more comprehensively. For example, participants who had experience living in both Saskatoon and Prince Albert were able to share their perspectives on how different settings affected their experience with ARV therapy use.
In summary, the inclusion criteria for the study participants were as follows: IPLWH age 18 years or greater who were eligible to receive ARV therapy, and key informants, all of whom had been living in the Saskatoon and/or Prince Albert area for at least a year prior to enrolling in the study (and for the key informants had been working with IPLWH for at least the past year); and all of whom provided informed consent to participate in the study.

4.4.2. Recruitment of the study sample.

In the study, potential participants were recruited through most of the community partner agencies. The community partners were asked to disseminate the study’s recruitment information (Appendix C) via recruitment posters posted within their respective agency and recruitment flyers set out where potential study participants might see them and take one. Flyers were left in strategic, public areas (e.g., the Indian Métis Friendship Centre of Prince Albert common areas; the Prince Albert Access Place and Outreach Services waiting room; the Saskatoon Westside Community Clinic common areas; and the Saskatoon Tribal Council Health Clinic waiting room). The intent was that prospective study participants would volunteer to take part in the study. Potential participants contacted the investigator via a confidential telephone line, which was private and secure.

I explained the overall study to those who contacted me. For those potential study participants who contact me by telephone, I read an information letter (Appendix D) to them; and for those who contacted me in person, the information letter was provided to them in addition to me reading the information letter to them. If the potential study participants were still interested in taking part in the study, I determined their enrolment eligibility using a screening instrument (Appendix E) based on the inclusion criteria as previously discussed. If they were not eligible to take part in the study (or they refused to take part in the study), any screening information obtained from them was immediately destroyed by cross-cut shredder. For those eligible participants who contacted me by telephone, I read and explained to them the informed consent form that I would be asking them to sign when we met in person. For those who contacted me in person, if I deemed potential study participants eligible for enrolment into the study based on the preliminary screening interview, I provided, read and explained to them the informed consent form (Appendix F). Taking into consideration that a proportion of First Nations, Métis, and Inuit are a vulnerable population (e.g., decreased illiteracy, poor health status and decreased socio-economic status), I read and explained the consent form to each potential study participant to ensure that they understood what was being asked of them when they were being asked to provide voluntary and informed consent. I did this prior to asking for their signed consent, which “merely provides evidence (perhaps of questionable value) that consent has been given” (Guillemin & Gillam, 2004, p. 272). During the consent process, I asked study participants what they understood about the study. The potential IPLWH study participants had the option of taking part in any or all four
components of the study (i.e., Indigenous sharing circle #1; individual interview; participant observation session; and Indigenous sharing circle #2). Figure 4 illustrates the four discrete components of the study.

**Figure 4: Study Components**

The potential key informant participants had the option of taking part in one or both of the Indigenous sharing circles. The Indigenous sharing circle component of the study, as well as the other three study components, will be described in Subsection 4.5.1 (Interviews: Individual and collective) of this chapter. For those potential study participants who were interested in taking part in the study, an appointment was arranged for either one or both of the Indigenous sharing circle interviews and/or for the individual interview and/or to be observed (Note: Each of the four discrete components of the study could have had different study participants in them). At times, upon the study participant’s request, the individual interview took place immediately.

At the time of the interview or participant observation session, I provided study participants who had contacted me by telephone with the informed consent form and followed the same process used with participants who contacted me in person. I developed separate consent forms for the individual interviews of IPLWH and participant observation session, as well as for Indigenous sharing circle #1 of key informants and Indigenous sharing circle #2 of key informants (Appendix F). Ethical considerations will be further explained towards the end of this chapter.

### 4.4.3. Compensation of the study participants.

The study provided cash compensation (i.e., an honorarium) of $20 per hour for each interview (lasting from one to two hours), and for each participant observation session (lasting up to one hour). The study also provided travel expenses ($20 total) and childcare expenses ($40 total) for each interview and each participant observation session. Although no participants withdrew from the study, had they chosen to withdraw from the study, they would have been compensated at $20 per hour for every hour they participated, rounded up to the hour. To document receipt of the honorarium, I asked the participants to sign a form indicating that they were given an honorarium and had any travel or childcare expenses defrayed. Cash was given at the time of the interview and participant observation session.
As an Indigenous, cultural offering and gift, I gave a small tobacco bundle to all study participants and for those study participants attending the Indigenous sharing circles, a gift of a traditional, Indigenous feast was also provided. Such practice of gift-giving is an Indigenous, cultural protocol and a sign of respect for those who come together to share their stories (Baskin, 2005).

4.4.4. Recruitment challenges.

During the participant observation session, study participants (i.e., IPLWH) contacted and informed me once they scheduled an appointment with their health service provider so that I was able to meet the participant at the designated healthcare setting and accompany them to their healthcare appointment. At that time, I informed the IPLWH’s health service provider of my intent to observe the IPLWH and it was made clear to the health service provider that the health provider was not a study participant. I also communicated to the health provider that they would not be evaluated by me in any way. Once the health provider agreed to this process, I would conduct the participant observation of the study participant.

At times, it was a challenge to coordinate the execution of the participant observation component of the study. This was mainly due to the fact that I did not collect any personal contact information from the study participants, so I was unable to follow up with them once they had made their healthcare appointment. Also, there were a few instances when the participant called me back with a scheduled healthcare appointment, but I was unable to readily answer my telephone when they called. Some participants did leave their telephone number and I would try calling them back once or twice, but if they did not answer their telephone or if they were not available, I would destroy their telephone number within approximately 48 hours to secure their privacy. In this case, I would then have to rely on them calling me back. Some participants would eventually call me back, but at times this process was time consuming and not as efficient as if I had collected personal contact information from them; however, it was my priority to protect their privacy. An additional recruitment challenge was identified when some participants told me that they had a difficult time arranging their healthcare appointment within the time parameters that I was available.

Although the overall recruitment of participants into my study was a success, there were some cancellations and no-shows. One of the lessons I learned was to try not to schedule an interview too far from the date when the potential study participant first contacted me. For example, I was scheduled to conduct my first individual interview 11 days from when I first screened the potential participant into the study. When the interview date arrived, the potential study participant did not show up to the predetermined interview location. I believe that this no-show might have occurred as a result of the interview being prearranged too far in advance of the actual interview date and time. Moving forward, I learned that when I screened potential participants for the study, chances of participants showing up were improved if the interview was scheduled during the same week that I had screened them into my study.
Within the context of these recruitment challenges, I will describe the four components of the study (i.e., Indigenous sharing circle #1, individual interviews, participant observations, and Indigenous sharing circle #2) as it pertains to the number of people who were interested in taking part in the study, who were eligible or ineligible for the study, who cancelled their participation in the study prior to actually starting the study, and who did not show up to the study when it was finally time for them to actually take part in the study. The actual description of the means by which the data were collected and what it produced (e.g., observation notes, transcripts, etc.) will be discussed in Sections 4.5 (Data Collection/Generation), 4.6 (Data Management) and 4.7 (Procedures for Data Analysis and for Substantiating Qualitative Rigour) of this chapter.

4.4.4.1. Indigenous sharing circle #1.

Fourteen potential study participants expressed interest in attending the first Indigenous sharing circle interview. Three potential participants were ineligible to take part in Indigenous sharing circle #1, two potential participants cancelled and two potential participants did not show up to Indigenous sharing circle #1. There were seven participants involving Indigenous and non-indigenous men and women, IPLWH, health service providers, community workers, a government official and a researcher. Indigenous sharing circle #1 lasted a little over 1.5 hours and was conducted at the Saskatoon Westside Community Clinic.

4.4.4.2. Individual interviews.

Twenty-seven potential study participants expressed interest in the individual interview: Three potential participants were ineligible, one cancelled, and two potential participants did not show up for the individual interview. Of the 21 individual interviews of IPLWH conducted, 20 were included in the data analysis. One participant was lost to follow-up and therefore did not release his data for use in the study analysis. The average length of the individual interview was 1 hour (range: 30 minutes to 2.5 hours). The 20 individual interviews were conducted at the Saskatoon Westside Community Clinic (seven); Saskatoon Tribal Council Health Centre (five); AIDS Saskatoon-601 Outreach Centre (two); Saskatoon Friendship Inn (two); Prince Albert Access Place and Outreach Services (three); and Prince Albert Métis Women’s Association (one).

4.4.4.3. Participant observations.

Twelve potential study participants expressed interest in taking part in the participant observation component of the study. Of these 12 potential participants, two people were not eligible. Of the 10 IPLWH who agreed to take part in a participant observation session, one cancelled and three did not show at the predetermined time and place. Therefore, six IPLWH took part in the participant observation component of the study. Most of the observation sessions were conducted at the Saskatoon Westside Community Clinic (five), and one session took place at the Saskatoon Tribal Council Health Centre. For all observation sessions arranged with the study participants (i.e., IPLWH), both IPLWH
and their health service providers provided consent for the participant observation session to take place during the healthcare appointment.

4.4.4.4. Indigenous sharing circle #2.

Twelve potential study participants expressed interest in attending the second Indigenous sharing circle interview. All potential study participants were eligible to take part in Indigenous sharing circle #2. Of the 12 who were screened into Indigenous sharing circle #2, four did not show up. Therefore, eight Indigenous men and women living with HIV attended Indigenous sharing circle #2, which was approximately 1.5 hours in length and was conducted at the Saskatoon Tribal Council Health Centre.

4.4.5. Description of the study sample.

In order to contextualize the study findings, I asked everyone who attended the Indigenous sharing circles (15 participants) and an individual interview (20 IPLWH were included in the analysis because one was lost to follow-up) to complete a survey of socio-demographic and health information. The IPLWH (six participants) who took part in the participant observation sessions were not asked to complete the survey, because it was not feasible to administer the survey without disrupting the healthcare appointment between the IPLWH and their health service provider.

4.4.5.1. Indigenous sharing circle #1.

A total of seven participants attended the first Indigenous sharing circle interview.

4.4.5.1.1. Ethnicity, age and gender.

Most of the participants were First Nation (four); one was Métis and two identified as either White or Canadian. The age range of the participants was variable: 20 to 29 years (two); 40 to 49 years (two); 50 years or greater (three). The majority of the participants were female (four) and there were three males.

4.4.5.1.2. Residence.

Most of the participants lived in Saskatoon (six) with one living 90 kilometers away from Prince Albert. Most of the participants lived off reserve (six) and one lived on reserve.

4.4.5.1.3. Education, employment and income.

The education level of the participants varied: Grade 12 (two); professional designation (one); university undergraduate (two); university graduate degree (one); and childcare counselling (one). Most participants had full-time employment (four); and others were either part-time employed (one); self-employed (one); or a homemaker (one). Regarding total household income per year, the median household income was in the range of $20,000 to $69,999 (three) with two participants making less than $20,000 and two participants making greater than $70,000 (two).

4.4.5.1.4. Role working with IPLWH.

Most of the participants (six) worked with IPLWH (One participant indicated that the question pertaining to one’s role working with IPLWH was not applicable to them). Pertaining to their role
working with IPLWH, most of these participants were either health service providers or community support workers (four) and one participant was a researcher and another participant was a government official (No one identified as a community leader). Out of these six participants (because one participant indicated that the question was not applicable to them), the breakdown of time working in the area of HIV was spread equally among three categories: Less than 5 years; 5 to 9 years; and more than 9 years.

4.4.5.1.5. HIV status.
Regarding HIV status, most of the participants were HIV-negative (five) and two participants were HIV positive.

4.4.5.2. Individual interviews.
Twenty-one participants took part in the individual interview component of the study. However, only 20 of the participants’ data were included in the study analysis because one person was lost to follow-up and, therefore, I was unable to obtain his consent in order for him to release his interview transcript for use in the study.

4.4.5.2.1. Ethnicity, age, gender and sexual orientation.
Most of the participants were First Nation (13 status First Nations and one non-status First Nation) and six were Métis. Most of the participants (11) were in the age range of 30 to 39 years. Other participants’ age ranges were as follows: 18 to 19 years (one); 20 to 29 years (two); 40 to 49 years (five); and 50 years or greater (one). The majority of the participants were female (12) and there were eight males. Most of the participants’ sexual orientation was heterosexual (17). The other participants identified as gay or two-spirit (one), and bi-sexual (two).

4.4.5.2.2. Residence, history of incarceration and community relationship.
All 20 participants lived off reserve with 16 participants living in Saskatoon and four participants living in Prince Albert. Slightly over half of the participants had stable housing such as living in their own apartment (five) or in their own house (six) and the other participants either stayed with friends (three) or family (four) or lived in a hotel or motel (two). Based on the individual interview transcripts, some of the 20 participants reported a history of incarceration (six).

Also based on the individual interview transcripts, some participants had a relationship with an Indigenous community and others did not. Of these, some did not always feel welcomed by the Indigenous community or the general community, and they reported feeling discriminated against and stigmatized as a result of their HIV status and/or substance use disorder. Although it was not specifically reported by the participants, such discrimination and stigmatization might have caused a few of them to feel excluded from their Indigenous community or even prompted them to abandon their community. Most participants did not appear to have a connection with an Indigenous community. Despite not being connected with an Indigenous community, a few participants wanted to develop a tie with their Indigenous relations. Furthermore, of the participants who did not seem to have a connection with an
Indigenous community, most of them had attended Aboriginal residential school or had a history where at least one of their family members (i.e., parent or grandparent) attended residential school.

4.4.5.2.3. Education, employment and income.

Most of the participants’ highest level of education was Grade 12 or lower: elementary school (11); Grade 12 (eight); and university undergraduate degree (one). Most of the participants’ source of income was social assistance or disability (17) and other participants’ source of income varied: full-time employment (two) and unemployed (one). Most participants had a low total household income: Less than $20,000 (17); $20,000 to $69,999 (two); and greater than $70,000 (one).

4.4.5.2.4. HIV status and related biomarkers.

Participants were HIV-diagnosed between the years 2000 and 2013 and most of them were diagnosed within the last six years: 2012 (four); 2011 (three); 2010 (one); 2009 (four); 2008 (one); 2005 (four); 2004 (one); 2003 (one); and 2000 (one). Fourteen of the 20 participants knew what a viral load count was. When asked what their viral load count was, seven of them indicated that their viral load was undetectable. Other responses provided to this same question pertaining to viral load were as follows: high (one); 800 count (one); 61 count (one); and do not know what their viral load count was (four). Eighteen of the 20 participants knew what a CD4 count. When asked what their CD4 count was, the following responses were given: 350 or less (six); more than 350 (three); high (two); low (one); and do not know what their CD4 count was (six).

4.4.5.2.5. History of antiretroviral therapy.

All 20 participants had been suggested by their healthcare provider to take ARV therapy. Fourteen of the 20 participants had taken or were taking ARV medication. Of these 14 participants, eight at some point stopped or had currently stopped taking ARV medication. Of these 14 participants, most of them took ARVs once a day (12) with one participant taking ARVs twice a day and another participant taking ARVs three times a day. Of these 14 participants, most took three or four ARV pills every day: three pills per day (seven); and four pills per day (six); and five pills per day (one).

4.4.5.2.6. Co-morbidity.

Nineteen of the 20 participants had medical conditions other than HIV. These medical conditions were noted as follows: drug use disorder (19); HCV (17); alcohol use disorder (13); Attention Deficit Hyperactivity Disorder (three); bipolar disorder (one); cracked collar bone (one); Crohn’s Arthritis (one); crushed spine (one); diabetes (one); hypochondria (one); open heart surgery (one); and weak bones (one).

4.4.5.2.7. History of injection drug use and methadone maintenance therapy.

Most of the 20 participants currently inject street drugs (11). Based on the individual interview transcripts, most of the 20 participants appeared to have received MMT at some time (14) with one participant never receiving MMT. (For five of the individual transcripts, a history with MMT was never
raised by the participants.) Based on 20 individual interview transcripts and of those who currently inject drugs (11), most of them (eight) had received MMT at some time. Of the participants who appeared to have received MMT at some time (14), some of them did not currently inject drugs (six).

4.4.5.3. Participant Observations.

A total of six study participants took part in the participant observation component of the study.

4.4.5.3.1. Ethnicity, age and gender.

All of the participants were of Aboriginal ancestry. Three voluntarily self-identified as First Nation. The age range of the participants varied as follows: 20 to 29 years (two); 30 to 39 years (two); 40 to 49 years (one); and 50 years or greater (one). Most were female (four) and there were two males.

4.4.5.3.2. Residence.

All six of the participants lived off reserve and in Saskatoon.

4.4.5.3.3. HIV status.

All of the participants were HIV positive.

4.4.5.3.4. History of antiretroviral therapy.

All six participants had been suggested by their healthcare provider to take ARV therapy. One participant voluntarily indicated that she was not on ARV therapy. As for the other five participants, I was unable to ascertain their history of ARV therapy use.

4.4.5.3.5. Location of the participant observation.

Five of the participant observation sessions took place at the Saskatoon Westside Community Clinic and one observation was conducted at the Saskatoon Tribal Council Health Centre. All participant observation sessions occurred during a healthcare appointment between the participant and at least one of their health service providers. The health service providers, who were present during the observation session and who were not considered study participants, included counsellors (two), nurses (three), a pharmacist and a physician. (More than one health service provider could have been present during a participant observation session.)

I would like to emphasize here that the intent of the participant observation component of the study was to observe how participants responded to the physical and social setting of their health services appointment and not to evaluate the health service provider or the participant in any way. These observations were collected as fieldnotes, which became part of the data corpus of the study.

4.4.5.4. Indigenous sharing circle #2.

Eight participants took part in the second Indigenous sharing circle.

4.4.5.4.1. Ethnicity, age and gender.

All of the participants were First Nation. The age range of the participants varied as follows: 20 to 29 years (one); 30 to 39 years (four); 40 to 49 years (two); and 50 years or greater (one). Half of the participants were male and the other half were female.
4.4.5.4.2. Residence.

All eight of the participants lived off reserve. Most of the participants lived in Saskatoon (seven) and one participant lived in Prince Albert.

4.4.5.4.3. Education, employment and income.

The education level of the participants varied as follows: Grade Three (one); elementary school (three); Grade 12 (two); trade school (one); and university graduate degree (one). Some of the participants were on disability (three) with the other participants identifying as either, unemployed (one), homemaker (one), student (one), self-employed (one) or had full-time employment (one). All participants reported a total household income of less than $20,000 per year.

4.4.5.4.4. Role working with IPLWH.

When asked the question pertaining to one’s role in working with IPLWH, everyone indicated that the question was not applicable to them with the exception of one person who worked with IPLWH.

4.4.5.4.5. HIV status.

All of the participants were HIV positive and all of them had been suggested by their health service provider to start ARV therapy. All participants reported that they had taken ARV therapy at some point.

4.5. Data Collection/Generation

Study data were primarily collected/generated using in-depth interviews (individual and group) with the support of unstructured participant observation sessions, which are used in interpretist/naturalistic paradigms (Mulhall, 2003). A short socio-demographic and health survey was also conducted to contextualize the interview data. Throughout the interview and participant observation process, fieldnotes were developed in order to provide context for the study. These notes are also considered a data source (Morrow, 2005). Fieldnotes were recorded either during the event, immediately after the event had occurred, or by the end of the same day on which the event occurred. Analytic memos were developed regularly during the fieldwork, which helped the study to become more focused during subsequent fieldwork (Charmaz & Mitchell, 2001).

Study participants were given the option to smudge at the individual and the Indigenous sharing circle interviews. Smudging is a cultural ceremony commonly practiced among Indigenous peoples where traditional, medicinal plants and herbs are burned in order to spiritually connect one with the Creator and Mother Earth (National Aboriginal Health Organization, (n.d.); Wright et al., 2011). Smudging has been used in social science (Baskin, 2005) and HIV/AIDS (McKay-McNabb, 2006) studies involving Indigenous peoples. Smudging was provided by local, traditional ceremonial Indigenous helpers (i.e., Elders).
4.5.1. Interviews: Individual and collective.

The interviews all took place in a private and secure location. Participants in individual interviews were offered a choice of health and social service agencies where they might feel most comfortable meeting. I personally conducted all interviews (individual and Indigenous sharing circles). The interviews primarily took place at the Saskatoon Westside Community Clinic, the Saskatoon Tribal Council Health Centre in Saskatoon, and the Prince Albert Access Place and Outreach Services. If requested, the individual interview could have taken place at a participant’s residence, with a local, female traditional indigenous helper present, but all interviews were conducted in public agencies. Other places where the interviews took place were AIDS Saskatoon-601 Outreach Centre, the Saskatoon Friendship Inn, and the Prince Albert Métis Women’s Association.

First, I conducted an Indigenous sharing circle interview of key informants (e.g., health service providers as well as IPLWH) with the support of a traditional ceremonial Indigenous helper to open and close the circle at the Saskatoon Westside Community Clinic. The overall goal of the first Indigenous sharing circle was to help develop an interview guide to be used later in the study in order to conduct the individual interviews with IPLWH. An Indigenous sharing circle is a term used to describe a form of focus group interview that is appropriate to Indigenous people (Baskin, 2005; Lavallee, 2009; Rothe et al., 2009; Wilson, 2008). As explained by Kitzinger (1995):

- The idea behind the focus group method is that group processes can help people to explore and clarify their views in ways that would be less easily accessible in a one to one interview. Group discussion is particularly appropriate when the interviewer has a series of open ended questions and wishes to encourage research participants to explore the issues of importance to them, in their own vocabulary, generating their own questions and pursuing their own priorities (p. 299).

The data generated from this first Indigenous sharing circle interview helped refine the interview guide before conducting individual interviews with IPLWH (Appendix G). As described by Kvale (2009),

- The [focus group] moderator’s task is to create a permissive atmosphere for the expression of personal and conflicting viewpoints on the topics in focus. The aim of the focus group is not to reach consensus about, or solutions to, the issues discussed, but to bring forth different viewpoints on an issue. Focus group interviews are well suited for exploratory studies in a new domain, since the lively collective interaction may bring forth more spontaneous expressive and emotional views than in individual, often more cognitive, interviews (p. 150).

Data collection/generation occurred over two time periods. The first time period of the data collection/generation component of my study (February to March 2013) was followed by a preliminary analysis of the first set of interview data based on the Indigenous sharing circle interview and 17 individual interviews before I proceeded to the second time period of the data generation component of my study (July to August 2013). During the second time period, an additional three individual
interviews, six participant observations (to be discussed in Subsection 4.5.2. [Participant observation] of this chapter) and the second Indigenous sharing circle interview were held separating the data/generation into two time periods helped me to ensure that my study was progressing as planned in terms of data generation/collection, analysis and interpretation. Although it was not necessary for my study, any modifications to the study protocol (e.g., revising the conceptual and methodological frameworks) could have taken place from April 2013 to June 2013 (the time between the two time periods of the data collection/generation stage). Such a practice is not unusual for qualitative research design since it is often the case that one adapts a study design as the study progresses and according to new understandings of the research phenomenon and/or as situations changes (Creswell, 2007; Patton, 2002).

The data collection/generation stage of the study overlapped with a preliminary data analysis stage of the study insofar as the second Indigenous sharing circle interview was an opportunity to both collect/generate data and to present, discuss and interrogate some preliminary findings of the individual interviews and the first Indigenous sharing circle. Similar to the first Indigenous sharing circle, the second Indigenous sharing circle was opened and closed with the help of a traditional ceremonial Indigenous helper, and was followed by a traditional Indigenous feast. This second Indigenous sharing circle was again comprised of IPLWH informants, this time all the informants were IPLWH themselves, one of whom also worked with IPLWH. The purpose of the second Indigenous sharing circle was to allow an opportunity for participants to reflect upon the preliminary findings of the study (i.e., themes, sub-themes and categories) while creating an opportunity and the will to engage in social action to improve the lives of IPLWH. The second Indigenous sharing circle participants participated in developing practical recommendations that might be considered by multi-stakeholder groups vis-à-vis knowledge translation. They were thereby invited “to benefit directly from their involvement in the research through learning more about their circumstances, including possible alternatives to their situation, and then acting on this new awareness” (Heyl, 2001, p. 377). Also, the second Indigenous sharing circle helped me to further understand the phenomena in question vis-à-vis member reflections.

“Group work can actively facilitate the discussion of taboo topics because the less inhibited members of the group break the ice for shyer participants” (Kitzinger, 1995, p. 300). Some IPLWH seemed empowered to share in-depth information among their peers and in the presence of others. At one point during the first Indigenous sharing circle interview, two IPLWH responded to information shared by one of the other participants, a health service provider, regarding what might affect the use of ARV therapy among IPLWH. Earlier in the sharing circle, the two IPLWH declined to respond to some questions, but once the health service providers shared information, the two IPLWH had something to say and challenged what one health service provider/study participant said within the Indigenous sharing circle. “Focus group methods are…popular with those conducting action research and those concerned
to ‘empower’ research participants because the participants can become an active part of the process of analysis” (Kitzinger, 1995, p. 300).

Indigenous sharing circle #1 of key informants (comprised of a minority of IPLWH), the individual interviews of IPLWH, and Indigenous sharing circle #2 of key informants (comprised exclusively of IPLWH) were based upon semi-structured interview guides (Appendix G) with each interview forum lasting one hour on average (range: 30 minutes to 2.5 hours). A survey collecting socio-demographic and health information was self-administered by the study participants at the completion of the Indigenous sharing circle interviews (Appendix H). A similar survey was administered by me as the interviewer with the study participant upon the completion of each individual interview (Appendix H).

Based on the findings from the first Indigenous sharing circle interview, I felt better able to choose prompts to help elicit responses from study participants to some of the individual interview questions. Using the comments made in the first Indigenous sharing circle, the individual interview guide was revised somewhat by organizing the prompts to the interview questions more logically (e.g., from individual to interpersonal to socio-structural factors). The revision of the guide involved highlighting prompts I had developed that the sharing circle endorsed, and adding two explicit prompts: abuse (sexual, physical and emotional) and holistic care (e.g., integration of health services). I left in the individual interview guide other prompts that I had developed but that the sharing circle did not draw to my attention.

Also, once I had conducted some of the individual interview surveys, I made slight modifications to the survey questionnaire to include more appropriate responses for the participants to choose from in order to answer the closed-ended survey questions. For instance, upon individually interviewing one participant, I modified the individual interview version of the socio-demographic, health survey by changing the question “What is your employment status?” to “What is your source of income?” and added new variables (i.e., social assistance and homemaker) to better account for some participants’ financial situations. I also modified the list of potential responses to the survey question “How would you describe your current living accommodation?” to account for a new variable (i.e., live in your own house) pertaining to some participants’ living situation. “Sometimes the [qualitative] research questions change in the middle of the study to reflect better the types of questions needed to understand the research problem” (Creswell, 2007, p. 19).

Data collected/generated from interviews have been criticized for being individualistic and idealistic (Kvale & Brinkmann, 2009). Such knowledge is said to have a narrow focus, only examining the individual and not taking into account the broader social interactions in which the individual plays a part. It is also said that interview knowledge “ignores the situatedness of human experience and behavior in a social, historical, and material world” (Kvale & Brinkmann, 2009, p. 294). To counter these concerns, field observation was used to provide context-dependent knowledge. Such a method
helped me to explore any nuances, which guided subsequent interviews vis-à-vis the exploratory, emergent design of my study.

4.5.2. Participant observation.

The formal term for my secondary method of collecting and generating data is participant observation, as described earlier in this chapter. Participant observation allows the researcher to generate a more complete description of the phenomena (Adler & Alder, 1994; Bogdewic, 1999; Emerson et al., 2001). I observed interactions between IPLWH and their particular health services setting in a one-to-one interaction with their health service provider, usually at the Saskatoon Westside Community Clinic but, on one occasion, at the Saskatoon Tribal Council Health Centre. The participant observation data were collected using an unstructured observation guide (Appendix I). “From these questions, an ethnographer learns about context and content, meaning and action, structures and actors” (Charmaz & Mitchell, 2001, p. 163). Participant observation helped to further understand the research phenomena that was being studying. The respect, privacy and confidentiality of all study participants were protected. This is further explained in Section 4.8. (Ethical Considerations) of this chapter. While carrying out participant observation, the intent was not to evaluate health professional practice or scrutinize the client (i.e., study participant) in any way but instead to observe how the physical and social setting contributed to the behaviour of IPLWH in order to further understand access to, acceptance of and adherence to ARV therapy among IPLWH.

“The advantages of observation over interviews in such a setting are that they enable the everyday routines of practice to be analy[z]ed from an ‘etic’ perspective” (Green & Thorogood, 2009, p. 155). Participant observation was used because what people say they do is not always consistent with what they actually do (Charmaz & Mitchell, 2001). This could be on account of a number of reasons. For instance, interviewees may take for granted what they do, making it particularly difficult to articulate tacit knowledge around such activities to an interviewer (Charmaz & Mitchell, 2001; Green & Thorogood, 2009). Sometimes activities must be experienced by the researcher in order for them to be understood (Lincoln & Guba, 1985). “The ethnographer, as a stranger, can observe the minutiae of organizational life and, through analysis, offer an account of ‘what is happening’ in a setting that is rich, nuanced and based on a critical reading of insider accounts” (Green & Thorogood, 2009, p. 155). I ensured that such observation was empirical and “the idea [was] to describe what is going on, who is included, where it goes on and how, rather than one’s ‘impressions’ or ‘feelings’ about the setting” (Green & Thorogood, 2009p. 162). However, at times, the observation session evoked feelings within me that will be described in Chapter 5 (Accessing ARV Therapy) of this dissertation. With the guidance of the study’s conceptual framework, I had a preliminary idea of what I was to observe in the field; however, this changed over time as I generated data and become more familiar with the study setting (Mulhall, 2003).
4.6. Data Management

All interviews (individual and Indigenous sharing circles) were audio-recorded using a digital audio recorder. Participant observation sessions were not audio-recorded.

For all participant observation sessions, a small notebook was used to record jottings or on-the-spot notes efficiently and effectively. “Jottings translate to-be-remembered-observations into writing as quickly rendered scribbles about actions and dialogue” (Emerson et al., 2001, p. 356). Then, later that same day, once I completed a site contact, I used these jottings to help me to develop my fieldnotes. “Mental and/or jotted notes facilitate writing detailed, elaborate fieldnotes as close to the field experience as possible in order to preserve the immediacy of feelings and impressions and to maximize the ethnographer’s ability to recall happenings in detail” (Emerson et al., 2001, p. 356). In developing my fieldnotes, I did not separate out my own thoughts and reactions within the fieldnotes. This is not unlike some researchers who may augment their fieldnotes with personal journals or diaries (Emerson et al., 2001). “Such a journal or diary provides a running account of the conduct of the research” (Hammersley & Atkinson, 2007, p. 151). Fieldnotes were developed and used as described by Saldana (2009): “[T]he researcher’s written documentation of a participant observation, which may include the observer’s personal and subjective responses to social action encountered….may contain valuable comments and insights that address the recommended categories for analytic memo reflection” (p. 33).

My fieldnotes included various types of documentation or memos: observational and contextual, theoretical and analytic, methodological and personal response (Emerson et al., 2001; Rodgers & Cowles, 1993). “Memo-making involves researchers in an on-going process of analy[z]ing and writing and therefore reduces writer’s block and increases fluidity and depth” (Charmaz & Mitchell, 2001, p. 166). As suggested by others (Emerson et al., 2001), this process helped me to create my first analyses and interpretations.

All of the data collection instances were recorded as fieldnotes (Emerson, Fretz, & Shaw, 1995; Mulhall, 2003). It is important to point out here that “[a]lthough fieldnote descriptions are not mere reports of ‘the facts’, but rather implicitly theorized accounts, ethnographers generally seek to avoid explicit analysis and interpretation as much as possible” (Emerson et al., 2001, p. 358). As suggested by Patton (2002), I also used my notes to remind me of details I might want to analyze later and of questions raised in my mind during the interview. After each individual interview was completed, I listened to the digital audio-recording of the interview five times while writing my fieldnotes.

Two independent third parties were hired to assist with data management by transcribing the Indigenous sharing circle and individual interviews. The first party was a Vancouver-based company called Globalme Localization – Language and Technology that prepared a preliminary transcription of my interview data from digital audio recording to paper. Globalme Localization has been in business in
the United States and Canada since 2007 and they have worked with clients in a variety of industries including education, health care, high tech and media. Globalme Localization has experience in research transcription, having worked for the University of Toronto, SickKids Hospital, Providence Healthcare, San Francisco State University and, currently with researchers at University of British Columbia. The second company I hired was Pollon Qualitative Research: Research, Analysis, & Consulting who has been conducting qualitative research for over ten years. Based in Victoria, BC, Pollon Qualitative Research has worked in Canada and abroad with clients including the universities of Toronto and Waterloo, McMaster University, Nipissing University and the United Nations University. Pollon Qualitative Research helped with interview data transcription and provided me with training on NVivo 10 (QSR International Pty Ltd., 2012); a Computer-Assisted Qualitative Data Analysis Software program. Pollon Qualitative Research and Globalme Localization are highly professional companies and they conducted themselves according to the confidentiality and non-disclosure agreements between them and me (Appendix J). The narrative data from the individual interviews and the Indigenous sharing circle interviews were audio-recorded and then transcribed verbatim using transcription guidelines described by Poland (1995; 2001). I reviewed the transcribed data against each of the 23 digital audio-recordings three separate times to ensure that the data transcriber transcribed the data accurately.

The recordings were sent to the data transcribers in BC via courier (i.e., FedEx). In order to ensure the highest degree of data security during the transfer stage of the digital files from the field to the data transcriber, I sent the files on an encrypted USB jump drive/stick by courier (i.e. FedEx). After the data transcribers transcribed the data, the data transcribers returned the original digital and the transcribed data files to me again by the FedEx, using the same USB stick. There was minimal time (one to two days) that the recordings were in transit.

The audiotapes of the recorded interviews were destroyed using Bitdefender File Shredder (an antivirus software suite) once the interviews were completed and the audiotapes transcribed and reviewed. All transcripts have been stored on an encrypted jump drive in my supervisor’s locked, private office at the University of Toronto in locked filing cabinets. While the data were being analyzed, they were stored on my password protected computer (with firewalls and anti-virus software).

4.6.1. Data coding and data storage.

In the study, NVivo 10 was used to aid in the data management. NVivo allowed the data to be indexed before analyzing it (Creswell, 2007; Green & Thorogood, 2009; Hammersley & Atkinson, 2007; Silverman, 2005). The survey data of the study were first managed using Microsoft Excel 2010 before they were imported into NVivo 10. Participant observation notes were transcribed into MSWord 2010 before they too were imported into NVivo 10.

The transparency of the data analysis provides “a record of how coding schemes were developed and theoretical concepts emerged through recorded memos” (Green & Thorogood, 2009, p. 217).
Coding is the process of attaching keywords to text in order to identify analytic statements (Kvale & Brinkmann, 2009). A coding scheme/study codebook was developed for data analysis (Appendix A), which was revised once data collection/generation had begun. Community partners had the opportunity to add analytic codes but no partners added any codes to those I had developed. I coded the data using 122 different codes.

For data coding, two main types of codes were used. The first type of codes were provisional \textit{a priori codes} (a first cycle coding method) (Creswell, 2007; Saldana, 2009), which are predetermined codes based upon the literature review, the conceptual framework and the research and interview questions. The second type of codes were emergent, initial \textit{in vivo codes} that explained the phenomena coming from the data, and they were identified using words or phrases stated by the study participants (Creswell, 2007; Saldana, 2009). This is in contrast to codes constructed from the data, which are referred to as \textit{in vitro codes} (Alvesson & Skoldberg, 2009). The in vivo codes and in vitro codes (also first cycle coding methods) were then broken down into \textit{focused codes} (a second cycle coding method). “Focus[ed] coding means using the most significant and/or frequent earlier codes to sift through large amounts of data” (Charmaz, 2006, p. 57). Focused coding is used to “develop the most salient categories in large batches of data” (Charmaz, 2006, p. 46). Sixty-nine percent (66 of 96) of the data exemplars that were used to support the data analysis as presented in the study findings (Chapters 5 to 7) were comprised of in vivo and in vitro codes. Coding consisted of reading and rereading the data for subsequent data sorting and categorization. \textit{Categorization} is the process of conceptualizing a statement (Kvale & Brinkmann, 2009). I read the 20 individual interview transcripts five times each in the process of coding them. Data derived from the Indigenous sharing circle interviews and participant observations were not coded. Within seven years from the time that the data were collected and generated in 2013, it will be destroyed by the Bitedefender antivirus software suite or cross-cut shredder. All data will be destroyed by 2020.

\textbf{4.6.2. Data management challenges.}

The initial plan was to send the digital audio-recordings of the interviews via courier (i.e., FedEx) to the data transcribers in BC within a day of the qualitative interview being recorded. Instead, audio recordings were sent to the transcriptionist in bundles of 4 or 5 interviews. The rationale for this change was that it was more efficient, since the study was conducted in Saskatchewan and the transcriptionists were based in BC. In the interim, the audio recordings were secured on an encrypted USB flash drive kept within a safe in my temporary Saskatoon, Saskatchewan residence. All digital audio-recordings of the interviews were transcribed by the third party transcriptionists and I verified the transcripts against the audio file within five months of conducting each interview.
4.7. Procedures for Data Analysis and for Substantiating Qualitative Rigour

4.7.1. Data analysis.

The aim of analyzing qualitative data “is not just to make the data intelligible but to do so in an analytical way that provides a novel perspective on the phenomena we are concerned with, builds on previous work, and/or promises to tell us much about other phenomena of similar types” (Hammersley & Atkinson, 2007, p. 162). As Malterud (2001) puts it, “analysis implies abstraction” (p. 486).

4.7.1.1. Integrative approach.

An integrative approach was used to analyze the data, as described by others (Bradley, Curry, & Devers, 2007; W. L. Miller & Crabtree, 1999). The data were initially organized according to pre-existing theoretical categories—a deductive a priori approach—and then principles of inductive reasoning were applied—an inductive approach—where additional explanations of the phenomena came from the data (Borkan, 1999; Crabtree & Miller, 1999; Ryan & Bernard, 2003). Once the data were categorized according to the taxonomy of the BMHSU (R. M. Andersen, 2008), they were further analyzed inductively. This procedure is known as a phased style of analysis (W. L. Miller & Crabtree, 1999). A phased style of analysis was used to see patterns in the data that might help the researcher understand what structures and mechanisms were contributing to the research phenomena. Data analysis was conducted while the data were still being collected/generated. As a result, data analysis procedures continuously informed future data collection/generation in an iterative process. This integrative approach to analysis and phased style of analysis has been used by others (Fereday & Muir-Cochrane, 2006).

4.7.1.2. Thematic analysis.

The narrative data were analyzed using thematic analysis as described by Braun and Clarke (2006). Accordingly, thematic analysis is a “summary and analysis of qualitative data through the use of extended phrases and/or sentences rather than shorter codes” (Saldana, 2009). Specifically, within the context of critical Indigenous qualitative research, theoretical thematic analysis was conducted (Braun & Clarke, 2006) using the BMHSU (R. M. Andersen, 2008) and sensitizing concepts (i.e., structure, vulnerability, resilience, access, acceptance and adherence) as a heuristic device. “A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set” (Braun & Clarke, 2006, p. 82). That is, the process of coding and categorization leads to an outcome (Saldana, 2009). Of the three specific methods of thematic analysis (i.e., realist, constructionist and contextualist), the contextualist method was used, “which acknowledges the ways individuals make meaning of their experience, and in turn, the ways the broader social context impinges on those meanings” (Braun & Clarke, 2006, p. 81). The data were categorized according to repetitions (Ryan & Bernard, 2003) and recurrent themes (Green & Thorogood, 2009) or more simply, according to the classification of concepts that provided insight into the
experiences of individuals (Bradley et al., 2007; Ryan & Bernard, 2003). Thematic analysis is “a comparative process, by which the various accounts gathered are compared with each other to classify those ‘themes’ that recur or are common in the data set” (Green & Thorogood, 2009, p. 199).

Similarities and differences in the data were scrutinized (Ryan & Bernard, 2003). For example, data analysis included an examination of the distinctions between personal, interpersonal and socio-structural vulnerabilities and resiliencies, and access to, acceptance of and adherence to ARV therapy among IPLWH.

All the data analyses were based upon the practice of reflexivity (Davies et al., 2004; Finlay, 2002; Lynch, 2000). Once the themes were developed, the analysis was reviewed using deductive testing to confirm the authenticity of the interpretative thematic analysis and to question any potentially unusual cases (Patton, 2002).

4.7.1.2.1. In-process memoing and diagramming.

The data analysis occurred in two phases. The first phase began with pre-fieldwork activities and involved reviewing the research proposal and interview guides, including the research objectives and questions. Phase one continued into fieldwork activities (e.g., audio recordings, jottings), and then into the development of the fieldnotes. The literature was consulted as it related to the conceptual framework and methods of the study but only after the fieldnotes were developed and during the write-up of the research findings. “In ethnography the analysis of data is not a distinct stage of the research. In many ways, it begins in the pre-fieldwork phase, in the formulation and clarification of research problems, and continues through to the process of writing reports, articles, and books” (Hammersley & Atkinson, 2007, p. 158). A preliminary analysis of the data was conducted during in-process memoing, a preliminary writing technique that helped “to carry forward analysis contemporaneously with the collection of field data” (Emerson et al., 2001, p.362). Here, I provided my reflexive perspective on the original statement of the problem and purpose, focusing on the research question (i.e., How do IPLWH construct and understand their experiences of ARV therapy?), and reflecting on and engaging in reflexive practice with the fieldwork activities, constantly asking questions of the data vis-à-vis analytic questioning. In-process memos were “used both to address practical, methodological questions and to explore emerging theoretical possibilities. Such memos not only provided initial theoretical materials, but they also help[ed] to focus and to guide future observations and analyses” (Emerson et al., 2001, p. 362). Case summaries were also developed for each of the individual interview transcripts. These helped to address the issue of fragmentation that comes with coding data. Using case summaries as an analytic device provided analytic purchase by allowing me to see patterns within the data in one interview transcript.

Diagramming was used as a device to help analyze the data. After rereading and interrogating the interview transcripts, a situational analysis as described by Clarke (2005) was conducted along with the development of an abstract messy situational map of the elements of the experience of IPLWH.
concerning their use of ARV therapy. Situational maps are diagrams depicting the relationships between various elements of a phenomenon (Clarke, 2005). Examining the relationships between such elements in the map, the data could be viewed in a new way. The use of situational maps is consistent with a grounded theory approach to analysis (Clarke, 2005). First, an abstract messy map was developed in order to gain a broad view of the data. The elements of the map included my impressions and assumptions as well as specific information about the research topic that arose from reading and interrogating the interview transcripts. After identifying and dropping the data elements into a messy map, the messy map was transformed into an ordered situational map. This ordered situational map helped to glimpse new insights into what was going on with the interview participants and their use—or not—of ARV therapy. Through relational analysis, an interplay between the macro and micro perspectives of the participants regarding their experience with ARV therapy became apparent. Furthermore, the situational maps of the phenomena under investigation helped to systematically analyze how I PLWH constructed and understood their experiences of ARV therapy. The understanding of the experiences of the study participants as told in the stories of their transcripts shaped the analysis, which highlighted emerging patterns within the data.

An innovative communication aid known as a causal loop diagram was also used. A causal loop diagram “explain relationships between variables and primarily produce qualitative images of a situation” (Williams & Hummelbrunner, 2011, p. 41). These diagrams are used to model system dynamics, a data-driven visual model that can serve to explain phenomena (Fredericks, Deegan, & Carman, 2008). Causal loop diagrams help to illustrate the dynamics of the discrete factors within a social system and, in the case of this study, the underlying causal mechanisms leading to the use of ARV therapy among I PLWH. Using a causal loop diagram, the pertinent aspects of access, acceptance and adherence to ARV therapy could be conceptualized and their interconnectedness could be demonstrated using feedback loop mechanisms within the social system.

4.7.1.2.2. Analytic memoing.

The second phase of the analysis included analytic memoing. Before the analytic memos were written, all fieldnotes were read numerous times in order to gain familiarity with the data corpus and to look for patterns, unusual findings, and relationships among “common-sense knowledge, official accounts, or previous theory; and whether there [were] any apparent inconsistencies or contradictions [in the data]” (Hammersley & Atkinson, 1995, p. 210). Analytic memoing is a process which provides an opportunity to reflect on data management and descriptive accounts (i.e., assigning codes and categories, identifying themes/concepts, and establishing typologies), and explanatory accounts (i.e., detecting patterns, and developing explanations) (Charmaz, 2006; Miles & Huberman, 1994; Saldana, 2009; Spencer, Ritchie, & O’Connor, 2003). “Rather than coming to take one’s understanding on trust, one is forced to question what one knows, how such knowledge has been acquired, the degree of certainty of
such knowledge, and what further lines of inquiry are implied” (Hammersley & Atkinson, 1995, p. 192). In addition, as analytic devices to help me with my critical thinking skills, I read general literature associated with the research topic. Such literature pertained to Indigenous peoples (Dosman, 1972; Hamilton & Sinclair, 1991); social marginalization (Bourgois, 2003); social determinants of health (Meili, 2012); drug and alcohol addiction (Alcoholics Anonymous, 1952; Alcoholics Anonymous, 2001; Alexander, 2008; Mate, 2009; Narcotics Anonymous, 2008); and living with HIV and ARV therapy (Squire, 2013). Reading the general literature served as an analytic method that prompted me to compare these authors’ ideas with my data segments, compare data segments with one another for similarities and differences (constant comparison method) and contemplate the relevance of the literature to the phenomena I was studying (Corbin & Strauss, 2008).

4.7.1.2.3. Writing up my research.

“Qualitative researchers’ choices about what they will emphasize in their write-ups must fit the research purposes and methods” (Sandelowski, 1998, p. 377). To this end, a balance between description, analysis and interpretation was sought while conducting the data analysis. “Description here refers to the ‘facts’ of the cases observed; analysis, to the breakdown and recombinations of data that allow researchers to manage and see them in new ways; and interpretation, to the new meanings researchers create from their treatment of data” (Sandelowski, 1998, p. 376). Describing, analyzing and interpreting data in this way encouraged a process of defamiliarization (Thomas, 1993). This defamiliarization process is “about making the familiar foreign (Entfremdung, estrangement), about problematizing the self-evident and pointing out that future realities need not be a reproduction of what exists today” (Alvesson & Skoldberg, 2009, p. 170). While investigating the phenomena, it was ensured that any interpretations were grounded in the data. As advised by Sandelowski (1998), the analysis of the study was guided by the study’s purpose and methods, and was supported by data exemplars. “When you bring raw data right into your memo, you preserve telling evidence for your analytic ideas from the start. Providing ample verbatim material ‘grounds’ your abstract analysis and lays a foundation for making claims about it” (Charmaz, 2006, p. 82). When the research from the study was written, the results/findings sections were separated from the discussion section of the dissertation so as not to blur the distinction between data-based interpretations and the broader discussion about the findings (Morrow, 2005).

4.7.2. Qualitative rigour.

In the study, qualitative rigour was attained by ensuring that the research met two criteria: trustworthiness (i.e., confirmability, credibility, dependability and transferability), and authenticity (Guba & Lincoln, 1989; Lincoln & Guba, 1985; C. M. Marshall & Rossman, 2011). Other criteria were also used and will be described later in this subsection of the dissertation.
4.7.2.1. Trustworthiness.

The criteria for trustworthiness parallel the criteria used in positivist methods (i.e., objectivity, internal validity, reliability and external validity) while taking into consideration the assumptions of naturalist inquiry (Guba & Lincoln, 1989; Lincoln & Guba, 1985). The investigation was carried out in a natural environment “because phenomena of study, whatever they may be—physical, chemical, biological, social, psychological—take their meaning as much from their contexts as they do from themselves” (Lincoln & Guba, 1985, p. 189).

4.7.2.1.1. Confirmability.

I used the practice of reflexivity to ensure that the criterion of confirmability was maintained in the study. “[C]onfirmability is concerned with assuring that data, interpretations, and outcomes of inquiries are rooted in contexts and persons apart from the [researcher] and are not simply figments of the [researcher’s] imagination” (Guba & Lincoln, 1989, pp. 242-243). It is important to note that the study problem and design were framed on a set of values that were shared and co-constructed with the study participants and the analysis was influenced by my interaction with study participants (Lincoln & Guba, 1985). “Reflexivity involves critical reflection of how the researcher construct[ed] knowledge from the research process—what sorts of factors influence[d] the researcher’s construction of knowledge and how these influences [were] revealed in the planning, conduct, and writing up of the research” (Guillemin & Gillam, 2004, p. 275).

After coding the first three transcripts, I was uncertain about the description for one a priori code (i.e., predisposing demographic) so I consulted the literature pertaining to the BMHSU, which helped me to further understand the demographic concept of the BMHSU (R. M. Andersen, 2008). Consulting the literature also provided additional clarification on the remaining 21 constructs of the BMHSU. After revisiting the literature on the BMHSU, I reviewed the coding of my first three transcripts and made significant revisions pertaining to the data that I had initially coded. Throughout the coding process, I continuously made sure that I was coding the data consistently. For example, after coding another four transcripts, I verified that I did not incorrectly code data that were entered under one construct of the BMHSU; namely, Personal Health Practices. Personal Health Practices included stress reduction; however, I started to think about how this might relate to the Individual Predisposing Social construct of the BMHSU. Thus, I would verify that data pertaining to ‘current ARV use’ were coded within Personal Health Practices in addition to Social factors if appropriate, thereby allowing the same data segments to be coded using more than one code. Based on my particular review, there were no coding inconsistencies (re: stress reduction being a part of the coding definition of Personal Health Practices) and very few coding inconsistencies (re: current ARV use). In addition to verifying that the data were coded consistently using the a priori codes, the same verification process was used for the in vivo codes and in vitro codes.
In addition to using the practice of reflexivity to achieve the criterion of confirmability for the study, I also used reflexivity to meet other criteria such as, credibility, dependability, and transferability (Lincoln & Guba, 1985).

4.7.2.1.2. Credibility.

The criterion of credibility speaks to the study’s reconstructions of study participants’ constructed realities (Guba & Lincoln, 1989). Credibility is defined as “[t]he ‘truth’ of the findings, as viewed through the eyes of those being observed or interviewed and within the context in which the research is carried out” (Devers, 1999, p. 1165). In the study, specific techniques to assure credibility included: prolonged engagement in the field; persistent observation; negative case analysis; triangulation; member reflections; peer debriefing; and reflexivity (Guba & Lincoln, 1989; Lincoln & Guba, 1985; Tracy, 2010). In addition, during the interview process, I would clarify some of my interpretations with the study participants in terms of what I thought they were saying to me.

As described by Lincoln and Guba (1985):

the purpose of persistent observation is to identify those characteristics and elements in the situation that are most relevant to the problem or issue being pursued and focusing on them in detail. If prolonged engagement provides scope, persistent observation provides depth (p. 304).

The interview data transcripts were reviewed against the audio files in order to ensure transcription quality. That is, each transcript was reviewed three times as follows: (1) the first review examined any gross omissions and errors; (2) the second review ensured that the transcription of the audio file was always consistent with the vernacular of the study participant; and (3) the third review confirmed that transcript notations for details such as pauses, silences, overlapping, and laughing were always accounted for. In addition, I immersed myself in the data by listening to each digital audio-recording five times, as well as reading the transcribed interview data five times. Each of the five reviews consisted of the following strategies as suggested by Borkan (1999): (1) In the first review, key themes, emotions and surprises were examined; (2) the second review focused on evidence that supported or did not support the themes that were being generated; (3) the third review examined anything of significance that may have been missed related to the themes or surprises in the text; (4) in the fourth review, additional alternative explanations to the phenomena were analyzed; and (5) in the fifth review, discrepancies that were found in the analyses were linked. In addition to reviewing the interview audio-recordings and transcripts five times to ensure the adequacy of interpreting the data, fieldnotes were consulted continuously throughout the research process. These activities provided a deep understanding of the data as a whole; data corpus, data sets and data items.

In terms of negative case analysis, any representative instances were examined and discrepant findings or alternative explanations for the main patterns observed were searched for (Miles &
Negative case analysis provides an opportunity for the investigator to revise their working hypotheses with new information (Lincoln & Guba, 1985). Triangulation was mainly conducted through the concurrent use of individual interviews, Indigenous sharing circle interviews, participant observation sessions, fieldnotes and member reflections in order to assess the credibility of the research findings (Lincoln & Guba, 1985; Mertens, 2009; Schwandt, 2007; Tracy, 2010). Triangulation is a procedure “to examine a conclusion (assertion, claim, etc.) from more than one vantage point” (Schwandt, 2007, p. 298). As described by Mays and Pope (2000):

> [t]riangulation compares the results from either two or more different methods of data collection (for example, interviews and observation) or, more simply, two or more data sources (for example, interviews with members of different interest groups). The researcher looks for patterns of convergence to develop or corroborate an overall interpretation (p. 51).

Once the analytic codes to support the data analysis were developed, and in particular, the inductive codes, the community partners were asked if there were any other codes they wanted to be used for the analysis; the partners did not suggest any additional codes. “In qualitative research, a commonly used concept is inter-rater reliability. This refers to using a type of researcher triangulation by which multiple researchers are involved in the analytical process” (Kitto, Chesters, & Grbich, 2008, p. 244). Using the various methods and strategies as previously mentioned, triangulation also helped to search for alternative explanations or disconfirming evidence (Hammersley & Atkinson, 2007; Mays & Pope, 2000) vis-à-vis the phenomena in question. In summary, data sources, data collection methods, and theories (Lincoln & Guba, 1985) vis-à-vis critical Indigenous qualitative research were all triangulated.

As for peer debriefing, the process itself provided an opportunity for the study investigator to receive feedback on the study from another investigator who is experienced (Lincoln & Guba, 1985) and in the case of the study, the investigator’s doctoral thesis committee and community partners.

4.7.2.1.3. Dependability.

The criterion of dependability speaks to “[t]he extent to which the research would produce similar or consistent findings if carried out as described, including taking into account any factors that may have affected the research results” (Devers, 1999, p. 1165). While keeping in mind that the research is time- and context-bound (Lincoln & Guba, 1985), an extensive documentation system known as an audit trail was used for any strategy employed in the study whether its nature was contextual, methodological, analytic or a personal response (Guba & Lincoln, 1989; Lincoln & Guba, 1985; Rodgers & Cowles, 1993). I developed 72 pages of personal and methodological notes. I used the audit trail as part of my reflexive practice, and it was reviewed by my supervisor, “a third-party examiner to attest to the use of dependable procedures and the generation of [my] confirmable findings” (Schwandt, 2007, p. 13), or my doctoral thesis committee. In addition to being sincere vis-à-vis self-reflexivity, I ensured
that I was transparent about my research processes (e.g., the degree of my participation, and immersion in the study) and made a note of any methodological challenges that occurred during the study (Morrow, 2005; Tracy, 2010). I previously described such challenges pertaining to the recruitment of the study participants and data management. In Chapter 9 (Discussion, Part Two: Implications, Limitations and Future Research) of this dissertation, methodological challenges and implications will be discussed.

4.7.2.1.4. Transferability.

Within the set of criteria for trustworthiness, the last criterion employed was transferability. As described by Devers (2007), transferability is

[t]he extent to which findings can be transferred to other settings. In order for findings to be transferable, the contexts must be similar. Therefore, it is the role of the researcher to identity key aspects of the context from which the findings emerge and the extent to which they may be applicable to other contexts (p. 1165).

The transferability of the study findings were supported by ensuring that thick description of the context of the study was provided (Guba & Lincoln, 1989; Lincoln & Guba, 1985). Transferability “is achieved when readers feel as though the story of the research overlaps with their own situation and they intuitively transfer the research to their own action” (Tracy, 2010, p. 845).

4.7.2.2. Authenticity.

The set of criteria for authenticity were maintained throughout the study. This criteria is consistent with a constructivist research paradigm (Guba & Lincoln, 1989) and includes the following: fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity (Guba & Lincoln, 1989). “Fairness refers to the extent to which different constructions and their underlying value structures are solicited and honored within the [research] process” (Guba & Lincoln, 1989, pp. 245-246). To ensure fairness in the study, I employed the techniques of clarifying with the study participants what I thought they meant while I interviewed them, sharing individual interview transcripts with study participants who participated in the individual interview component of the study, and performing member reflections with the participants who took part in the second Indigenous sharing circle interview. Ontological authenticity “refers to the extent to which individual respondents’ own emic constructions are improved, matured, expanded, and elaborated, in that they now possess more information and have become more sophisticated in its use” (Guba & Lincoln, 1989, p. 248). This was illustrated in a number of the study’s individual interviews where participants made a point of saying they had learned about themselves or about ARV therapy, and was also illustrated by responses from IPLWH to the second Indigenous sharing circle interview who conveyed feelings of empowerment. Educative authenticity speaks to the study participants’ understanding of those constructions analyzed by the researcher (Guba & Lincoln, 1989). For example, during the data collection/generation process, I elaborated on my immediate understanding of what participants were sharing with me, and in response to
hearing my interpretations, they might agree with me or provide clarification or we would co-construct a shared understanding. Also, at the end of a couple of the individual interviews, I got the sense that participants were grateful to have taken part in the study interview because it gave them the opportunity to talk with another person, and to learn about a study that was relying on what they had to say about their own experiences with ARV therapy use. Catalytic authenticity and tactical authenticity are defined respectively by the degree to which social action is initiated, and by the degree to which study participants are empowered to take such social action (Guba & Lincoln, 1989). Catalytic authenticity and tactical authenticity were illustrated by a number of participants who said that, by taking part in the study, they had developed a deeper understanding of their own reality and were more appreciative of their life circumstances including their experiences with ARV therapy. Catalytic and tactical authenticity were also demonstrated in the second Indigenous sharing circle when study participants developed recommendations for policy makers and health service providers.

4.7.2.3. Other criteria.

Other criteria that were used to assess the rigour of the study—consistent with both constructivist and critical social paradigms—included: praxis (i.e., integrating theory and practice) (Patton, 2002); the co-construction of meaning of the phenomena with the study participants (Morrow, 2005); Verstehen or an understanding of underlying meaning of the phenomena in question (Alvesson & Skoldberg, 2009); particularity or “doing justice to the integrity of unique cases (Patton, 2002, p. 244)” and the adequacy of interpretation through the use of an analytic framework as well as through immersing oneself in the data (Morrow, 2005). In order to immerse myself in the data, thus allowing me to have a deep understanding of it, I carried out the following activities: personally interviewed the study participants (and recorded these interviews with a digital audio-recorder); listened to the audio-recordings more than once; assisted with the transcriptions of the audio-recordings, which were initially conducted by third-party transcriptionists; and read the transcriptions over multiple times (Rose & Webb, 1998). In addition to spending lengthy periods of time in the field, I also immersed myself in the data by reviewing my data corpus multiple times to the point where I could “move immediately to various locations in the data to compare and contrast one part of the data with others” (Morrow, 2005, p. 259). By immersing myself in the data, I was able to constantly double-check the data in relation to the analysis and interpretation of the data.

I also aimed to ensure that the meaning I attributed to the data was consistent with the logic of the study participants’ own experiences and that the analysis cohered not just with the study’s conceptual framework but the lives of the study participants (Miles & Huberman, 1994; Tracy, 2010), thereby “effectively interpreting the context, the ‘fit’ between purpose and style of investigation, and their relationship to the bigger picture” (Devers, 1999, p. 1173). Furthermore, using ethnography ensured that the methods allowed for the utilization of an appropriate theoretical perspective, which helped to theorize
the data, and therefore allowed theoretical or analytic generalizations to take place vis-à-vis critical Indigenous qualitative research.

Last, it was the aim in writing up the study to meet the criterion for quality known as resonance, which refers to the “research’s ability to meaningfully reverberate and affect an audience” (Tracy, 2010, p. 844). I attempted to produce aesthetic, evocative representations of the research that might encourage transferability of the study findings to other appropriate settings (Tracy, 2010). Here the following questions were used as a guide: “[i]s the written word congruent with experience?; [d]oes the story illuminate the studied world?; and [d]oes the reader gain new and deeper understanding of human experience more generally?” (Charmaz & Mitchell, 2001, p. 170). To this end, this dissertation supports three main purposes: (1) to represent the values of the research in terms of how the research problem was framed and how the study was carried out; (2) to provide thick description of the research findings; and (3) to provide a communication medium that will allow a vicarious experience for the reader (Lincoln & Guba, 1985).

4.8. Ethical Considerations

The University of Toronto and the University of Saskatchewan provided ethics approval for the study (Appendices K). Written operational approvals for the study were received from the Prince Albert Parkland Health Region, the Saskatoon Health Region, and the Saskatoon Community Clinic (Appendix L). The following five broad areas regarding the ethical conduct of the study were considered: (1) researcher-participant relationship and respect; (2) autonomy and consent; (3) privacy and confidentiality; (4) compensation; and (5) consequences of the study. In this regard, ethical guidelines as stipulated in the policy document, Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2014) (TCPS2) were used.


There has never been, nor currently is, any pre-existing relationship between myself as the researcher and the potential participants of the study. Despite this, I appreciated that my university affiliation might have created an inherent power differential, either actual (e.g., access to resources) or perceived (e.g., relationships), with the participants in the study. To address this issue, the study incorporated a CBPR orientation and adhered to CBPR principals such as facilitating partnerships in the research process, building the study on community strengths and resources, promoting co-learning, and building research capacity.

In addition to the TCPS2, I used the practice of reflexivity in order to be conscious of ethical issues as they arose throughout the research process itself (i.e., ethics in practice) (Guillemin & Gillam, 2004). Although reflectivity is “a process of critical reflection both on the kind of knowledge produced from research and how that knowledge is generated” (Guillemin & Gillam, 2004, p. 272), reflectivity also played a role in the ethical processes of the research. “Being reflexive in an ethical sense means
acknowledging and being sensitized to the microethical dimensions of research practice and in doing so, being alert to and prepared for ways of dealing with the ethical tensions that arise” (Guillemin & Gillam, 2004, p. 278). Reflexivity helped me to respond to ethics in practice (i.e., ethically important moments, which are specific and nuanced sensitivities; and microethics—every day research practices such as establishing trust between the researcher and the study participant) as opposed to procedural ethics (i.e., seeking approval from research ethics board) where ethics in practice could, for example, deal with a participant disclosing sensitive information during the data collection/interviewing process (Guillemin & Gillam, 2004). Ethics in practice is “the researcher’s willingness to acknowledge the ethical dimension of research practice, his or her ability to actually recognize this ethical dimension when it comes into play, and his or her ability to think through ethical issues and respond appropriately” (Guillemin & Gillam, 2004, p. 269).

Although I am licensed to practice nursing as a registered nurse (RN) in the Province of Ontario, where my residence is and where I attend university, I am not an RN nurse in the Province of Saskatchewan. For this reason, I did not enter into a therapeutic relationship with my study participants and I made clear to them that my relationship with them was that of a non-clinician researcher. At the end of one individual interview, a participant asked me what I was going to do now (as though he was inviting me to spend additional time with him and/or to go somewhere with him after the interview). Although I felt empathy for him, I had to remind myself that I was not his health service provider but a researcher and thus, I declined his invitation. Nonetheless, at the end of the individual interviews, when appropriate, I provided information to participants about health services in their area.

Although there were no physical risks for participants to take part in the study, I took care when engaging them in the research process (i.e., obtaining consent as well as collecting/generating data). For example, people with impaired cognitive abilities such as those with substance use disorder “may be less able to be ‘informed’” (Green & Thorogood, 2009, p. 73).

4.8.2. Autonomy and consent.

Informed consent was obtained from every study participant. Out of respect for their autonomy, steps were taken to ensure that the study participants’ understood exactly what was being asked of them and that their consent was entirely voluntary (Green & Thorogood, 2009). Four separate consent forms (Appendix F) were developed for the study: (1) individual interviews of IPLWH; (2) participant observation of IPLWH; (3) Indigenous sharing circle #1 of key informants; and (4) Indigenous sharing circle #2 of key informants. Each consent form outlined the purpose of the study and the risks, benefits and rights of potential study participants to participating in the study. The informed consent procedure was conducted at a minimum within a private office at the study location (e.g., Saskatoon Westside Community Clinic) and most times, also over the telephone if that was the first time the participant contacted me.
Study participants had the right to review their individual interview transcript and release it to me before I used their individual interview data in the study. The option to review their transcript was recorded on their consent form. Those who chose to review their transcript before releasing it to me for inclusion into the study analysis signed a transcript release form after reviewing their transcript and returned it to me. Participants also had the right to withdraw from the study at any time. If a study participant withdrew from the study, they could have asked to have their data deleted. Those participating in the Indigenous sharing circle interviews could ask to have their data deleted up until the time the audio recordings were transcribed. (Note: No participant actively withdrew from the study with the exception of one person who took part in an individual interview, who opted to review his transcript and who was lost to follow-up. Without his consent, his individual transcript could not be used in the study.)

4.8.3. Privacy and confidentiality.

Study recruitment, the consent process, and data collection/generation (i.e., interviews and participant observation) took place in a private and secure location (e.g., Saskatoon Westside Community Clinic). While carrying out participant observation, I did not document in the fieldnotes any information that was of a sensitive nature or violated people’s privacy. To further minimize insensitive behaviour on my part, I was discreet in recording my jottings as suggested by Emerson (2001): “One way to avoid such open violations of trust, and possibly awkward or tense encounters, is to try to conceal the act of making jottings while in the field” (p. 357).

The study did not collect the names, dates of birth or addresses of the participants. Study participants chose a pseudonym (i.e., “fake name”) that was used for the consent form and during their participation throughout the entire study. Furthermore, arbitrarily constructed participant identification codes (i.e., numeric codes for interview transcripts and other notes, and a nominal code invented by the Principal Investigator to report the study’s findings [i.e., interview quotations] in the dissertation) were randomly assigned to the files with the master identification list stored in a secured location separate from that of the data files. The first draft of the dissertation used numeric codes to identity interview quotations. The numeric codes were replaced with nominal codes in the final copy of the dissertation, since the use of a numeric code could have resembled past practices of some Aboriginal residential school attendees being assigned numbers instead of their own real names. In this dissertation, the real names of the participants were not collected. This was done to protect their privacy. From the outset of the study, the use of participant-selected pseudonyms was never intended to be used to report the study’s findings (i.e., interview quotations), again, in order to protect the privacy of participants and because there was a possibility that study participants might not have selected a pseudonym sufficient enough to protect their privacy. Finally, the only way to link the pseudonym on the consent form to the arbitrarily constructed participant identification codes would be via the master identification list, which resides on
an encrypted USB flash drive that is stored in a locked filing cabinet different from the locked cabinet storing the consent form and data files. All data were stored on an encrypted USB flash drive and stored in my supervisor’s locked, private office at the University of Toronto in locked filing cabinets and on password protected computers (with firewalls and anti-virus software).

The study data were not shared with anyone other than the research team (e.g., me, my supervisor, my thesis committee members and data transcribers).

Themes from the analysis were reported in aggregate form.

The ethical considerations of the study were guided by “formal frameworks that determine what kinds of research activity can and can’t be done” (Green & Thorogood, 2009, p. 67): legal frameworks, disciplinary codes of practice, cultural norms of ethical practice and ethical review. In addition to identifying legal exceptions governing access to information in the study consent forms, potential study participants were notified that confidentiality cannot extend to instances where harm to self or others (e.g., suicidal ideation, child abuse) is suspected, or when required by a court of law to surrender information. Under these circumstances, possible risks to the study participant included legal risks such as being detained or arrested, or being associated with a legally-compromised group. I ensured that the confidentiality of the participants was maintained while at the same time judging “the likely risks to individuals in the research setting and the likely benefits arising from the research findings” (Green & Thorogood, 2009, p. 72). That is, I ensured that confidentiality would not have been breached lightly. From the outset of the study, and before informed consent was obtained from them, study participants were made aware of the limits of confidentiality. It is important to acknowledge here that by outlining instances where researcher-participant confidentiality can be breached, the credibility of the data generated could be comprised (Green & Thorogood, 2009). I know of no instances where confidentiality was breached in my study. No information on participants was made available to service providers (e.g., physicians and social workers) or released to legal authorities because such legal circumstances never arose.

4.8.4. Compensation.

The potential range of cash compensation to any participant in my study was $20 to $140 (for a maximum of three interviews lasting 1 to 2 hours and one 1-hour participant observation session). This compensation acted as an incentive to encourage participants to take part in the study (Canadian Institutes of Health Research et al., 2014). Of the 42 study participants (one who was lost to follow-up, as previously discussed), five of them took part in more than one component of my study (i.e., one 2-hour interview and one participant observation session) yielding a total compensation of $60 for both study components combined. If the incentive that was provided to compensate participants were to be considered immoderate, it could unduly induce them to take part in the study, thus jeopardizing their voluntary consent (Canadian Institutes of Health Research et al., 2014). In comparison to research
conducted by others (Festinger, Marlowe, Dugosh, Croft, & Arabia, 2008; Festinger et al., 2005), the incentive that was offered to the participants in my study was not high enough “to encourage reckless disregard of risks…. and thus negate the voluntariness of participants’ consent” (Canadian Institutes of Health Research et al., 2014, p. 27). As an Indigenous cultural gift, a feast was provided at the Indigenous sharing circles and tobacco was offered to all study participants.

4.8.5. Consequences of the study.

There were no physical risks (e.g., bodily contact or administration of substances) for participants who took part in the study.

At times, a few participants found certain study questions difficult to answer (e.g., questions concerning the absence of appropriate health and social services). This could have resulted in psychological and/or emotional risks such as feeling uncomfortable, embarrassed, anxious and/or becoming upset. Participants had the right to stop the interview at any time and/or refuse to answer certain interview questions, and they had the right to withdraw from the interview and/or the study at any time, including having the right to withdraw their data from the study. “The potential harms to participants in qualitative social research are often quite subtle and stem from the nature of the interaction between researcher and participant” (Guillemin & Gillam, 2004, p. 272). Using the practice of reflexivity, I consciously did not probe participants to respond to interview research questions that I sensed might be sensitive to them. I did this in order to minimize—and ideally prevent—emotional or psychological discomfort. “[O]pen research interviews involve on-the-spot decisions about following up unanticipated leads from the [participants] with questions that cannot be determined” (Kvale & Brinkmann, 2009, pp. 64-65). In a couple of my individual interviews, I found myself interacting more with the participants in order to achieve a rapport with them, given that they seemed anxious about sharing their story, which seemed to bring up bad memories for them. In another individual interview, I found myself hesitant to prompt the participant in response to some unsolicited information shared with me concerning childhood experiences, though I certainly valued the trust in me to decide to share such sensitive information with me.

When a few of the participants did experience a risk-related issue (e.g., emotional upset) during the interview, I held off on the interview process and asked the participant if he or she wanted to take a break from the interview or stop the interview all together. There was one instance where I asked a participant if they wanted to end the interview early because they had a headache, which they reported was most likely due to a cold they had developed, and in this case, they accepted my offer to end the interview early. At the end of an interview, when appropriate, I provided some of the study participants with a list of health services in their area that they could contact for consultation.

Furthermore, I was conscious not to elicit interview responses that “can lead participants to disclose information they may later regret having shared” (Kvale & Brinkmann, 2009, p. 73).
Notwithstanding this, participants had the opportunity to review their interview transcripts before the data were analyzed. Such a verification process ensured that participants were comfortable with their interview statements. Three of the 21 participants who took part in the individual interviews requested to review their interview transcript before releasing it to be used in the study. One participant released the transcript with no modifications; a second participant released the transcript with minimal modifications; and a third study participant was lost to follow-up and therefore did not have the opportunity to release his transcript for use in the study.

If the recruitment strategy had involved healthcare providers as promoters of the study, potential participants may have felt coerced into taking part in the study because they may have felt obligated to participate in the study. In order to deal with this type of issue, the involvement of health service agencies was limited to disseminating the study’s recruitment information via posters and flyers left in strategic, public areas (e.g., waiting rooms) where potential study participants might see them and take one. Finally, I assured all study participants that if they withdrew from the study, it would not be reported anywhere.

Study participants were assured that their confidentiality and anonymity would be protected with the exception of data collected from group interviews (i.e., Indigenous sharing circles). Although Indigenous sharing circle participants were reminded that group discussions were to be kept private and confidential, I could not provide assurance that other group participants would do so and hence, breach confidentiality. During the consent process, I notified participants that I was unable to guarantee confidentiality, as there are limitations to confidentiality in group-settings/activities (e.g., focus group). Such a breach may cause possible social risks to the study participants such as possible loss of their privacy or the tarnishing of their reputation.

4.8.6. Ethical challenges and ethics in practice.

As was the case with the challenges that I faced with the recruitment for the participant observation component of the study, as previously discussed in this chapter, I was not always able to connect with potential study participants who had contacted me on the dedicated study telephone line about taking part in any one of the four components of the study. When not available to answer the study telephone, some callers would leave a message. At times, they would not include a contact number in their voice message.

When callers left a contact number, I would return their call; however, if there was no answer and it was not clear to me from the outgoing message that the voice message system belonged solely to the individual who had initially contacted me, I would not leave a voice message but would try to make contact one or two more times over a 48-hour period. If leaving a message, I would only indicate my first name and not their name on their telephone answering system. In the case where someone who was
not the potential participant answered my return call, I was careful not to leave any information identifying my study in order to respect the potential study participant’s privacy.

If unsuccessful in reaching potential participants directly by telephone, I would destroy their contact information. More specifically, if there was no answer and no answering machine, I would destroy the telephone number after three unsuccessful attempts within a 48-hour period. I did this to protect their privacy. Some potential participants with whom I had not had a chance to explain my commitment to their privacy may have been frustrated by my failure to make contact with them by returning their call(s). Such frustration may have been due to them wondering why they had not heard back from me, particularly if they called me days later and again did not leave a contact number at which I could reach them. They may have assumed that I still had a record of their telephone number from their earlier call.

4.9. Timeframe and Budget

The total timeframe to conduct the actual research of the study (i.e., fieldwork and research write-up) and dissemination of the study’s findings was slightly over two years, or between the period February 2013 and March 2015 (Appendix M—Gantt Chart).

The total budget required to conduct the study was $121,372. This figure accounts for both direct costs ($30,551) and indirect costs ($90,821). The direct costs covered budget items such as: incentive/honoraria for study participants as well as any travel and childcare expenses required for participants to take part in the study; consultant fees to hire traditional ceremonial Indigenous helpers; meals/feasts for Indigenous sharing circle participants; and fees for transcription. Indirect costs are in-kind contributions covering the 26 months of time for the Principal Investigator to work on the research project (Note: The Principal Investigator was a funded PhD Candidate during the research period of the study and the dissemination of its findings).

This methods chapter explained how the study was conducted. The next three chapters (Chapter 5 Accessing ARV Therapy, Chapter 6 Accepting ARV Therapy, and Chapter 7 Adhering to ARV Therapy) will present the study findings.
Chapter 5 Accessing ARV Therapy

5.1. Chapter Overview
This chapter mainly explores, yet also describes and explains, one aspect of the contextual circumstances affecting ARV therapy use among IPLWH; namely, access to ARV therapy.

As has been demonstrated in the academic research literature, IPLWH are less likely to access ARV therapy in comparison to non-Indigenous PLWH; however, the contextual circumstances surrounding accessing ARV therapy are not clear enough to suggest any viable solutions for addressing the imbalance or for improving the lives of IPLWH. As mentioned in the first chapter of this dissertation (Introduction) the research frames the question as follows: How do IPLWH construct and understand their experiences of ARV therapy?

The conceptual framework of the study, as discussed in Chapter 3 serves as a heuristic for understanding how social structure contributes to IPLWH accessing ARV therapy. The themes of this analysis are drawn from the personal accounts by IPLWH of how they personally construct and understand their experiences of accessing ARV therapy.

This chapter asks whether, how, and why the study participants access (or do not access) ARV therapy. It looks at the personal, interpersonal and socio-structural vulnerabilities and resiliencies that contextualize IPLWH access to ARV therapy, and it scaffolds this context using themes of respect, trust, holistic health care and culture. These themes were specifically chosen over other themes because they provide the most fodder for a theoretical understanding of the phenomenon. More specifically, the four themes that have emerged from the analysis are: (1) gaining and losing respect in the physical and social environments; (2) the timeliness of the provision of health services and its impact on trust; (3) holistic health care for IPLWH who are living with a drug use disorder; and (4) culture and accessing knowledge as a collective group.

5.2. Gaining and Losing Respect in the Physical and Social Environments

One noteworthy theme that emerged from the data analysis was the support that IPLWH often received from their physical and social environments. Although at times, these environments provided challenging circumstances for IPLWH in accessing ARV therapy, these same environments could provide respectful atmospheres that helped them in accessing ARV therapy.

5.2.1. Feeling comfortable living within the dominant culture.
All but one study participant reported having a substance use disorder. Many have MMT administered to them by a pharmacist along with their ARV therapy. A few study participants indicated that they preferred the Westside of Saskatoon over the Eastside because they felt more comfortable availing themselves of a number of health services offered in the Westside. They typically felt respected by providers in the health service agencies and other organizations in the Westside of Saskatoon, and they placed value on this respect.
Interviewer: So, you know, being on the Westside, um… versus the Eastside… like, does the Eastside, do you think (pause) like, caters more towards non-Aboriginal people or… they just don’t know how to… interact and… with Aboriginal people, like?-

Participant: (overlapping) Yup (long pause) Some places they do but not (pause) not as well as over here [Saskatoon Westside Community Clinic], but maybe it’s all in my head, but I don’t think it is. ‘Cause I used to have to go to ((Name of Avenue deleted)) for my methadone… an-n-nd they were good… for, like… they’re good there. But sometimes, like, you go to a pharmacies, like, when I was on ((Name of the Avenue located in the Eastside of Saskatoon deleted)), and it’s a tiny little place compared to the ones around [the Westside]. And… you get, people, like, non-Aboriginals, like… I was thinking, maybe I’m paranoid but it was, like, they’re looking at, like, “You junkie, needs methadone.” You know (long pause) I think it would be different. I know for a fact if I moved over there, I’d still come over to the Westside though.

(Pila: Female, aged 40-49 years.)

As Pila reported here, one non-Aboriginal pharmacist in the Eastside neighbourhood would look down on her as though she was nothing more than an Aboriginal “junkie,” and if she had to move to the Eastside, she would still go to the Westside to get her methadone. This is a particular example of a participant’s negative interaction with one pharmacy in the Eastside. In contrast, this participant and others confirmed many positive interactions with pharmacies in the Westside.

IPLWH interact with a number of agencies around the City of Saskatoon, and based on their individual and collective experiences, they are able to compare one agency to another. In a number of interviews, participants said they felt labelled in the Eastside, not just because of their substance use disorder but also because of their HIV status and their Indigenous ancestry. One participant described the different types of stereotyping he experienced:

Interviewer: And is, the discrimination against… um.

Participant: Well… it's not just, like… because I grew up, like, around it all my life; right? So, first it was, like, growing up as a kid. It was just Native; right? Being Native. And, you know… growing up xxx. And it was, like, uh… young offender; dangerous young offender. An-n-nd, you know, there's, like… the labels; right? And, then, uh… you know… gang member, organized crime, uh… member. Uh, violent offender… into, into HIV (laughing) you know, AIDS victim; right? (Laughing). Yeah. Um.

Interviewer: So it’s, like, um… like, quadruple, gazzuple… whammie.

Participant: Yeah, yeah. (Reth: Male, aged 30-39 years.)

Reth thought that the stereotyping he experienced in Saskatoon in general, regardless of the neighbourhood, was largely due to the conservative culture throughout Saskatchewan, which he described as the “Christian right.” Even hospitals and government offices labelled him once they knew
that he was of Indigenous ancestry or an ex-drug user or HIV-infected and, armed with this limited information about him, their attitude changed and they became unpleasant to him. He also reported feeling that a double standard exists in the minds of physicians and that they treat non-Indigenous people better than Indigenous. He claimed that the overall disrespectful labelling that Indigenous peoples face is borne of several generations of social relationships between Aboriginal peoples and the dominant culture, not the least of which is the Aboriginal Residential School legacy. He fervently believed that social practices of non-Aboriginal peoples have been passed on through generations and that the current generation of non-Aboriginal peoples have acquired a learned behaviour of oppressing Aboriginal peoples.

Because of the lack of respect they felt when they were in the Eastside, IPLWH would gravitate to health service agencies located in the Westside of Saskatoon. But, disrespect may occur anywhere. One participant spoke of the targeted labelling she felt exuding from one health service provider based in the Westside of Saskatoon:

Interviewer: So (clears throat) so when that dentist or, or the hygienist or whoever it was, um (clears throat) was, um… did you feel that they were, like, treating you differently because you have HIV or because?=
Participant: =Yup. Definitely.
Interviewer: Yeah. Do you think there is any other reason why, they could have been treating you differently?
Participant: No, because… the office is in the hood [neighbourhood]… so they gotta be, like… you know… used to [Indigenous] people like. (Pila: Female, aged 40-49 years.)

This dental clinic was disrespectful to Pila not because she was of Indigenous ancestry but because she had HIV. She was made to feel that she was unwelcome at that dental office. Pila claimed that, because the dental office was located in the “hood,” an area where a large portion of Indigenous peoples reside and many others frequent, the poor treatment she experienced was due to her HIV status and not her Indigenous ancestry. While there was not complete agreement on the respectful nature of health services in the Westside, most of the participants who were clients at the Saskatoon Westside Community Clinic, including its in-house dental services, experienced a sense of comfort that is a core feature of respect. As Pila shared, the Westside Community Clinic staff did not look down on their clients and there was a sense of a warm welcome that IPLWH felt from the individuals who worked there.

This feeling of respect was not unique to the study participants’ experiences at the Saskatoon Westside Community Clinic. A number of individual health service providers at other agencies in the Westside were centred out for their warmth and their respectfulness. During one of the participation observation sessions that I conducted at the Saskatoon Tribal Council Health Centre, located in the Westside of Saskatoon, I was able to feel first-hand the warmth from such supportive environments.
Located in the Westside of Saskatoon, the observation took place in the Saskatoon Tribal Council Health Centre where I observed a healthcare appointment of a female, aged 50+ years with a health service provider. The nature of the appointment was a counselling session, which took place in the kitchen space of the health centre. The participant seemed to want to seek advice from the health service provider on how the participant might help her own daughter with various health and social service related issues. In addition, it seemed that the participant wanted to use the health service provider as a sounding board—someone to talk to about her own life’s issues. The participant seemed to be satisfied throughout the healthcare appointment. The participant seemed very relaxed. The kitchen space of the health centre seemed family-like, and brought a communal feel to the overall environment of the healthcare appointment. The kitchen seemed to provide a sense of neutral ground for the study participant in comparison to a more clinical setting such as an examining room where such an environment might influence how the participant behaved in terms of a healthcare environment structuring the client to stick to a predetermined healthcare appointment agenda or outcome. The kitchen space invited a sense of everyday life experiences. The kitchen space seemed to be very conducive to establishing a comfortable setting where the participant could leisurely share her thoughts and feelings with a health service provider, freely and without any hesitation. Here the participant could also meet with the health service provider without worrying about getting in and out of the healthcare appointment as fast as possible because the organization of health services and the process of health care is ‘on the clock’ so to speak. Perhaps the physical environment affects how people will behave. In a kitchen, people might behave in a more relaxed way, whereas the environment of a client examining room within a healthcare agency might make the client feel like he or she has less control over interpersonal dynamics between them and the health service provider. Such a feeling of less control might cause them not to feel as relaxed as in a kitchen space setting where the health service provider is offering them a cup of tea, adding to the social nature of the environment. The manner in which the participant used the kitchen space, similar to how one would use their kitchen space at home, brought a sense of informality to the healthcare appointment. Most of the time during the participant observation period, the personal dynamic of the participant was joyful, as if she were meeting with a friend over a cup of tea at her own kitchen table. In fact, during this healthcare appointment, the participant shared personal photos of her family with the health service provider. The sharing of photos seemed to indicate that the participant really valued her relationship with the health service provider. The participant seemed to feel very comfortable in the Saskatoon Tribal Council Health Centre environment where she was enjoying a family-like, informal and non-rushed session at the kitchen table with her health service provider.
5.2.2. Living within a sober environment.

The Westside of Saskatoon is not a utopia, but more often than not, the benefits of accessing health services in this depressed area of the city outweighed the challenges, and the Westside was favoured over the Eastside by many IPLWH who were looking for health services. Still, for many participants, it was not always possible to travel to the Westside of Saskatoon as limited financial means impeded their access to transportation. Additionally, many IPLWH who were recovering from a substance use disorder preferred not to frequent the Westside because of the high prevalence of street drug interactions and the congregation of people living with active drug use disorders.

One participant (Queete) who lived in Prince Albert shared a similar concern. She indicated that living in the Prince Albert downtown core was not conducive to her recovery from her substance use disorder because of the prevalence of the drug-using culture in the city centre. Living in the Prince Albert city centre made it too easy for her to access drugs and alcohol. People recovering from a substance use disorder know they must completely remove themselves from an environment where they previously played out their active addictive behaviour. The same goes for past behaviours they indulged in while actively using their drug of choice. For example, one participant mentioned that when she first accessed and started ARV therapy, her physician supported the use of medical marijuana for side effects she was experiencing from the ARV therapy. She declined the medical marijuana as a treatment for such side effects:

And, um, before, um, I started my [ARV] regimen, when I first started them, I was smoking weed [marijuana] all the time to cope with, um, ‘cause, it, like, sometimes it helps with your, um, your [side effects] and that. And he was going to prescribe me, um, medicinal weed and he wrote the, he wrote a letter to my lawyer saying that, because I was, I was smoking so much weed, and I right out told him that… I don’t want the medicinal weed because it is going to get me into trouble. Like, I’m, I, I’ve sold weed before, and I know I can do it again to have easy money, and I’m, I want to live… an honest life, and… to be straight, and to be sober. (Queete: Female, aged 30-39 years.)

Furthermore, not living in or frequenting a desperate environment helps a person who is recovering from a substance use disorder think more positively, which helps them live a more sober life:

As to where I am living now, where I have the support, I… have all the means for me to live, and… it, now it, it makes me think; it, I think more in a positive way to-o… not use… just for that day. (Queete: Female, aged 30-39 years.)

Voluntarily being around substance users and dealers is anathema to the recovery process. Being around other people with a substance use disorder who are using drugs and alcohol or who are interacting with drug dealers can easily tempt a person who is recovering from a substance use disorder to use substances again.
Downtown Saskatoon, which separates the Westside from the Eastside of the City, poses similar challenges to the Westside. Though the downtown is trying to revitalize itself, it is nowhere near as prosperous as the Eastside. It was not at all hard to see during the interview with one participant who was living in a downtown hotel arranged for her by a social service agency how IPLWH with a substance use disorder were affected by their environment:

Participant: Um, I need to move from where I live. I live right in the hole xxxx (chuckles) I am living right at the ((Name of the Hotel deleted)) now, so… that’s not really great. Yeah, I have been in and out of there so long. I’m just… probably where I live right now is why I'm being so lazy and all that… yeah… ‘cause I don’t even move. I just stay in my bed… 24/7. Lately I've been doing that; I don't know why. Yeah. Maybe I should go back to ((Name of the Province deleted)). Maybe I should leave (chuckles) It will get out of the house more often (sniffs) (pause) People keep telling me I am falling in love (chuckles) It doesn’t work that way though.

Interviewer: And, and where you're staying now… um (clears throat) um… so you're saying that it's… um… how does, how does that… affect you in using or not using ARV?

Participant: Just… people are always drunk around me or high around me. Um… xxxx just… gets me out and… makes me want to do the same thing they're doing. Yeah, so. Um… it's a constant, 24-hour thing… back there. Yeah.

Interviewer: A lot of people using [drugs and alcohol] over there?

Participant: Too many. It gets annoying sometimes xxx. (Mintla: Female, aged 20-29 years.)

The hotel where Mintla was living was not conducive to her rehabilitation because people were always “drunk” and “high” around her, and being in such an environment made her want to start using drugs and alcohol again. She recognized that she was withdrawing from life, that she was not motivated to leave the residence, and that she could relapse into substance use. She noted that if she started using drugs and alcohol, she would start “bitching about.” Such negative thinking could easily prompt a relapse into drugs and alcohol use as a copying mechanism. In addition, negative thinking and the relapsing, alone or together, could act as powerful forces to discourage one from accessing ARV therapy. This was in stark contrast to the future that Mintla endeavoured to forge for herself. She clearly recognized that her current situation living in a hotel where other people with a substance use disorder lived could influence her to use drugs and alcohol and was not good for her sobriety. Mintla did say that others suspected that her reclusive behaviour was on account of her “falling in love.” True or not, she felt and knew the difference between withdrawing from people (for whatever reason) and lacking motivation to do anything. Others may have thought she was falling in love, but Mintla knew that her lack of motivation was due to her unhappiness living in a hotel where there was a lot of drug and alcohol use among the other tenants. People with a substance use disorder who are using their drug of choice will often seek to justify their own behaviour and the behaviour of others as a way to validate their substance use, and
perhaps those around her kept telling Mintla she was falling in love as a palatable explanation to themselves for her reclusiveness and lethargy rather than thinking they were losing a peer to recovery.

### 5.2.3. Having a sense of community and family.

Despite the challenges posed by the location of the Saskatoon Westside Community Clinic to IPLWH who were recovering from a substance use disorder, many IPLWH expressed high regard for the Westside Community Clinic. It was one of the few agencies—the Friendship Inn and the Saskatoon Tribal Council Health Centre were two others—that IPLWH went out of their way to visit because of the respect with which the staff treated clients. As voiced by one participant:

> Needle exchange and stuff, like, that and… Westside Clinic and… Friendship Inn, like… they really, really good people an-n-nd… you know they care. They’re not phony. They’re not like, “Okay I’m here for eight hours to deal with all these, like.” And in some places you can pick up those… vibes. (Pila: Female, aged 40-49 years.)

Respect facilitates the creation of a community, and the community of people with a substance use disorder (recovering and active) at the Saskatoon Westside Community Clinic included a large number of Indigenous peoples. Multiple health services delivered professionally and respectfully could make a group of clients feel they had found an oasis. Less romantically, it could provide the comfort, safety and communal feeling of a home.

One participant mentioned how the organization of health services at the Saskatoon Westside Community Clinic and the very respectful nature of that community clinic enabled him to access ARV therapy. He started by talking about the clinic’s regard for his own family. In the space of a few sentences, he described the clinic’s own familial characteristics:

> Interviewer: Is, is… is there something, like… um, particular… uni-, unique to the Westside clinic, that's kind of different from other places or?  
> Participant: Workers. ((Health service provider’s name deleted))… ((Same health service provider’s name deleted)), uh, the… workers that come. Actually come and see you and they come… get involved in your family and… actually care about you. Crying. Like, they cry even if one of your family members pass away. Or if you're… feeling bad about you or. They actually… come out for coffee and… you know what I mean? And these doctors give it to you black and white. Either you want to die or you want to live. Or… they sit down and they say, "Oh, man. You're really having problems." You… you know what? And they're not scared to touch you. They're not… “Oh, you can't get HIV just by touching someone.” Xxxx. Like, they don’t even have to put on gloves. They touch your face. You know what I mean? (Flen: Male, aged 30-39 years.)

As described above, access to ARV therapy was provided to IPLWH at the Saskatoon Westside Community Clinic in the context of their social circumstances. Caseworkers took into account IPLWH’s
family and the related social aspects of familial relationships. It was these social relationships that provided the foundation for IPLWH to take advantage of ARV therapy. Flen had a drug use disorder. The life of IPLWH with a drug use disorder can be chaotic at the best of times. Family and other social relationships can help IPLWH deal with chaos. With the seemingly callous attitude often associated with a caring yet forthright family member who can pull it off, the physicians at the Saskatoon Westside Community Clinic “give it to you black and white.” Bringing the family component into the health care system could make ARV therapy more accessible to IPLWH with a substance use disorder. By helping IPLWH deal with their immediate issues, such as a death in the family, these professionals established a genuine caring relationship that served to help IPLWH start thinking about other aspects of their health such as accessing ARV therapy. For Flen, the respectful attitude of health service providers at the Saskatoon Westside Community Clinic provided an environment of care and concern that invited him to respect himself more and consider accepting ARV therapy. Another participant shared with me how feeling close to health service providers made a huge difference in accessing health services:

Participant: ((Health Service Provider’s name deleted)) is, does a lot of counsellor, plus she’s one of my closest friends, we go out, like… see movies or I go hang out at her house; the ((Health Service Provider’s title deleted)). I talk to her a lot even though she’s not. She’s probably my best friend even though we come from, like… you know, like. Me and her are pretty… close.

Interviewer: Mhmm. That’s nice.

Participant: And they have a couple outreach workers here; ((Health service providers’ names deleted)). I’m close to them. And… right now that’s pretty much all I need.

Interviewer: Mhmm (long pause) So having, like… you know, intimate close friends. That’s… is that helpful?

Participant: Yup. (Pila: Female, aged 40-49 years.)

Yet another participant observation session corroborated the appreciation by IPLWH for respectful interactions with health service providers, and enhanced my own appreciation of what Pila had said to me about feeling a closeness towards one’s health service provider. Although this one particular observation session was not with Pila, I was able to see the friendship-like interaction between another participant and her health service provider.

The observation included a female participant, aged 30-39 years, who was undertaking a counselling session. The event occurred at the Saskatoon Westside Community Clinic in a counsellor’s office. The room was approximately 12’ long and 9’ wide with light coloured walls. The entrance was located in the bottom left corner of the room. There was one lamp in the far, upper left corner of the room with a second light that was built into the desk located in the bottom right corner of the room with a desk chair (where I sat). The lighting in the room was dim. There was a 3-person 6’-long
couch on the left side of the room and the participant sat on the end closest to the upper left corner of the room. A large coffee table was located in front of the couch. Against the back wall, at the head of the coffee table there was an armchair (where the counsellor sat). On the upper right side of the room was a smaller coffee table and a filing cabinet. Throughout the session, there was a ticking noise coming from the wall-clock. The participant introduced me to her counsellor upon entering the room. With the home-like set-up of the office with a couch and what may be best described as non-office furniture, not to mention the soothing dim lighting of the room, the environment seemed conducive to building a trusting relationship between the study participant and her counsellor. For the participant, the predetermined outcome of the counselling session seemed to be to convey to her counsellor information about her personal and social relationships and how they affected her negatively. Despite this, the participant laughed a lot during the counselling appointment, the same way one would laugh with his or her friends. She seemed to have a very comfortable rapport with her counsellor. It almost seemed she was having an open and friendly discussion with a friend. The discussion seemed unfettered, as though she had established a trusting and supportive relationship with her counsellor, a relationship that one would usually see flourish over an extended period. What I found comforting in observing the participant was her manner and her casual use of the vernacular. When she laughed, I sensed a laugh that is common among some First Nation cultures. It was similar to when one person says something and the other one follows up by saying, “an-n-n.” This whole exchange reminded me of how my fellow Indigenous relations and I would share a good talk.

Within the Westside health service agencies such as the Friendship Inn, Saskatoon Tribal Council Health Centre and the Saskatoon Westside Community Clinic, IPLWH felt a sense of community and of family. Having these agencies in the Westside was, in a way, seen as advantageous to IPLWH because there was a significant proportion of Indigenous peoples either residing in or frequenting the Westside agencies. And many study participants considered these agencies communities that provided respectful, comfortable and supportive places for socializing with staff and with others in their community. As described by one participant:

**Westside Clinic**, it just used to be right ((Proceedings interrupted due to building’s loudspeaker)) right downtown… and then, they moved up here but it’s, like. If you walk into the waiting room here and everybody, like… you’re waiting… most waiting rooms are real quiet but here it’s, like, you know everybody and it’s, like. And the staff are, just, like, they’re, they’re… they’re really good here and. They don’t make you feel, like (sighs) or look down on you. And there’s… places that I still feel look down… on people. (Pila: Female, aged 40-49 years.)

**5.2.4. Comparing health services: respect for knowledge.**

Having a collective of agencies and populations relegated to one part of a city has beneficial consequences. A constellation of health professionals helping specific populations invites networks for
sharing information and generating new knowledge that could benefit the clients of such health service providers. The beneficiaries of such innovative health care provision develop respect for their caregivers. Conversely, health care providers operating in relative isolation could lose the respect of their clients, who often sense the difference between prescriptive information and knowledge that is tailored to unique circumstances. Some of the participants reported that they felt unsettled about accessing health services from agencies located outside of Saskatoon’s Westside. The many IPLWH study participants who were recovering from an opioid use disorder with the help of MMT realized that they needed to get their addiction under control before they began using ARV therapy; however, at times, some addiction services in Saskatoon were not considered by IPLWH to be supportive. As one participant indicated:

I got kicked out of an NA [Narcotics Anonymous] meeting. Not, yeah, well not really. They said I could sit there but… eah. It’s the NA meeting on the Eastside [of Saskatoon] (clears throat) ‘cause I was on methadone. They told me, like, I’m not off drugs. (Pila: Female, aged 40-49 years.)

It is services such as NA that might potentially serve as IPLWH’s first point of contact leading to accessing other services such as ARV therapy. It was not that this NA group did not understand that methadone helps with drug addiction recovery. Rather, for this NA group, harm reduction strategies were not a part of their philosophy. Pila persevered and tried a slightly different group—a support group for people who are recovering from a drug use disorder and who were taking MMT. However, Pila shared that, after going to one of these sessions, she preferred not to participate in them again because the attendees tended mainly to share “war stories” focusing on participants’ experiences using illicit drugs and one-up-man tales of who did more drugs, rather than accounts of what helped them with their recovery from a drug use disorder. Perhaps Pila persevered with her recovery from a drug use disorder because she was able to establish and maintain a positive outlook on life by having support systems in place, other than NA, like her immediate friends and those healthcare providers in the Westside agencies referred to earlier in this chapter whom she respected and considered her friends.

Despite the challenges IPLWH faced due to the distribution of health services and their relative approachability in Saskatoon, an urban centre had advantages for IPLWH over rural areas of Saskatchewan in terms of accessing ARV therapy. IPLWH based in Saskatoon had networks of resources, including some progressive services, unavailable to those outside the city. As one participant noted:

Now that I am in the city, different groups, ‘cause there’s [AIDS Saskatoon-601 Outreach Centre] and stuff, like, that. You know what I mean? They don’t have places like that in ((Name of Rural Community deleted)). Other people with HIV are not that open. You know what I mean? As they are here [in Saskatoon]. Over there in [the Rural Community], it’s a small town,
like… they don’t say, “Oh” (pause) They don’t have, like, places, like, People Living with AIDS Network over there and all that. You know what I mean? They just, they just recently got a needle exchange program over there xxx (chuckles). (Switie: Female, aged 30-39 years.)

It is important to stress that the availability of services in an urban centre did not mean that services were structured in a way that was sufficient to meet the needs of IPLWH. For instance, participants from the City of Prince Albert and those who had lived in Prince Albert but who had moved to Saskatoon were able to compare the services offered in the two cities, and in doing so, voiced concerns that Prince Albert did not have the best or most progressive resources to meet the needs of IPLWH. They compared the services available in Prince Albert to those in Saskatoon:

They’re actually pretty good, all of them [AIDS Saskatoon, the Saskatoon Tribal Council Health Centre and the Saskatoon Westside Community Clinic]. Yeah. Like in… in Prince Albert, you’d never find one of these things. Like… like, you. There’s a needle exchange out there but… it’s not always there. And I don’t know. When I moved back to Saskatoon and… there was more help here than there was back there [in Prince Albert]; yeah. I think that’s the only reason I moved back to Saskatoon. Mhm. (Mintla: Female, aged 20-29 years.)

Mintla shared that when she was first diagnosed with HIV, people were not very accepting of her circumstances, especially in Prince Albert. She found that Saskatoon in general was more accepting of people who were HIV-infected. There was more help in Saskatoon, such as the Saskatoon Westside Community Clinic and the Saskatoon Tribal Council Health Centre, than in Prince Albert and that was why she moved to Saskatoon.

It was the integrated nature of health services in Saskatoon that were helpful to IPLWH. The structured and the contextual characteristics of available health service facilities determined whether IPLWH would better respond to their HIV condition. In other words, when IPLWH had a regular source of progressive and respectful care, it affected how they perceived their own health status, which ultimately determined whether they would then decide to access ARV therapy. It was evident that study participants, both those living in Prince Albert and those who had lived in Prince Albert, felt like HIV-care offered in Prince Albert was less than optimal. One participant elaborated on the experience she had when trying to access ARV therapy in Prince Albert. She questioned her physician’s knowledgeability in a sequence of appointments with him that caused deterioration in her respect for him and her collateral trust in him.

Interviewer: And then, um… and how, like, you were talking about, um, you know, like, um… your doctor, like, he says, “Do this, do this,” as opposed to working like a team. Um… do you trust your doctor? Or do… you don’t trust him? And then how does that… does that affect you in accepting the ARVs? You either trusting your doctor or not trusting?
Participant: (long pause) I kinda think, like, I kind of don’t trust him (laughing) because… when he told me at the start… or else I would, I would die within two years and then. And then… after my hospital stay, and then being released, and then coming back here, and then (pause) and then he looks at my charts and says, “Aww… we need to switch them [ARVs] I guess.” And then… and then he’s looking all confused, and now he’s… now… after that he’s… he didn’t know what to put me on. So he has to send all my information to the… HIV doctor in Saskatoon, then she will look at them and she will know what… they’ll… to put me on. Yeah, it was, like… he made me feel (long pause) like, I got myself into, like… what a dumb doctor, he should know, he’s a… HIV doctor, or I don’t know but. (Prace: Female, aged 40-49 years.)

It may appear that Prace did not respect this one particular physician because the physician communicated his uncertainty to her and needed consultative advice from another physician regarding ARV therapeutic guidelines; however, there was more here that compromised her respect for her doctor. It started with the initial relationship between the participant and the physician. The physician was prescriptive in his behaviour from the beginning. He only eventually included another physician in his approach to her care and never included Prace in the process of medical care. This awkward and unpleasant relationship caused the participant not to accept ARV therapy initially. Eventually she accepted the ARV therapy he prescribed as she adjusted her response to his demeanor. However, she reported that she never liked the manner in which the physician directed her to begin ARV therapy. The way the physician talked to her made her unresponsive to his directives. It was not what the physician said to her, but the way he said it to her. A few IPLWH reported being told by a physician at some point that they were in life-or-death situations. It has already been acknowledged by one participant that the “black or white” dictates of a physician (Saskatoon Westside Community Clinic), could be accepted when there was mutual respect and a sense from the physician of genuine care. However, Prace found her physician’s abrupt and authoritative communication style demeaning. And notably, there was never a mention of any other health professional around until the physician consulted an “HIV doctor in Saskatoon.”

Contrary to Prace’s experiences with the Prince Albert-based physician, another participant (Grinda) indicated that that same physician worked as a team player with her. Grinda and the physician would freely exchange thoughts with each other. The physician would not “sugar coat” any explanations of why she needed to take ARVs. She always liked the practice of the physician who, when he was uncertain about whether he should keep her on her existing ARV regime or switch them, would refer her to another physician for a second opinion. I thought about why Grinda and Prace had such different experiences with the same physician. Although both participants were recovering from a substance use disorder, Prace admitted to using alcohol and both street marijuana and marijuana pills (THC [tetrahydrocannabinol] pills). Her physician prescribed the THC pills, but the street marijuana helped
her to eat and sleep more. Perhaps this had something to do with why Prace had a strong emotional response to the manner in which the physician communicated to her. By using alcohol and illicit drugs as a copying mechanism, she may not have been able to mobilize more effective coping mechanisms in situations that caused her to have ill feelings. The responses of Prace may have been emotionally reactionary. Her own coping mechanisms may have been compromised. She may also not have had the luxury of talking her feelings through with anyone, let alone attempting to talk them through with her physician. Without the benefit of rationally considering alternative scenarios to her own situation, she may have resorted to more extreme emotional reactions when talking about her physician. Many study participants who were recovering from a substance use disorder realized that, in the past when they were using their drug of choice, they would have very strong emotional reactions to situations that would cause them to become angry without regard for the consequences. Such a situation was described by one participant:

When I was younger, it’s, like… impulsive. It’s, like… you know, I’d… break up with. Something emotional would happen and I just go, I just… you know, hop on that… bus xxx… ride the self-, you, know, regarding self-destruction, I just wouldn’t care; say whatever. And then in the end… I’d end up in prison… and… just because of those… that, those… moments at that time would seal my fate for the next, X amount of years or X amount of months… and… in the end, I would… wherever that was that, that caused me to feel that way. It would, I’d overcome it and everything would be good. It would be like, but it’s too late, I’m already, you know. I’m stuck and I’ve created this scenario that I have no choice but to follow it out and it’s too late for me to do anything. (Drane: Male, aged 40-49 years.)

Emotionally charged individuals can be self-destructive and even difficult to care for. Nonetheless, the power of mutually respectful relationships—including relationships between medical professionals and their clients who are in their care—cannot be overlooked.

5.3. The Timeliness of the Provision of Health Services and its Impact on Trust

Another noteworthy theme of my study was trust within the context of the efficiency of health services. One particular issue that frequently came to the fore during the individual interviews was the lack of readily available HIV biomarker testing, which was often a precursor to a physician initiating ARV therapy with a client. Before IPLWH, or any clients, begin ARV therapy, a physician usually conducts blood tests to determine what ARV regime is best to prescribe. As described by one participant:

Interviewer: Tell me about any barriers… or facilitators, like the bad things… or… the good things, that relate to you accessing and then also, once you have access to it, do you accept it?

Xxxx-
Participant: (Overlapping) Oh, um… uh… the barriers is, uh… like, blood work. It takes so lon-
n-n-g, man. You know what I mean? Has to be shipped to B.C-C., Vancou-, you know… and
then it has to come back here. We have to find the right kind of drugs to put you on. The barr…
like… we should have this in every city. Everyplace… where we can just… do it and… you
know. Get this… stuff started, because… maybe… the time that person… is diagnosed they’re
already had full-blown AIDS… and… they have to get… those drugs right away. That's the
barriers. (Flen: Male, age 30-39 years.)

Flen wanted to see blood work services provided within the Province of Saskatchewan instead of sending
blood work to be tested in British Columbia. Although this participant had a regular source of medical
care, this was not enough. He reported that the processing time for HIV biomarker testing was not
sufficient to meet his need or the need of others to access ARV therapy in a timely manner. Regardless
of whether the testing of HIV biomarkers was conducted directly in Saskatchewan or in another
province, one must ask: Is the health care system adequate to meet the needs of Saskatchewanians?

Another interviewee who had never used ARVs had managed to negotiate her living
arrangements and she had recently obtained stable housing for herself, which was a requirement that her
physician placed on her before providing her access to ARV therapy. Having secured stable housing, she
felt she was finally in a position to access ARV therapy. But the long wait time for results of her blood
tests were preventing her from starting ARV therapy.

Participant: I'm not even too sure what my count is. That's what I'm curious about. Like, I'm
still like… you know… in that kind of process. Like… they been taking a whole bunch of blood
off of me and… you know, then… they’re, uh… still is, like, it's slow (chuckles) The doctors are
slow.

Interviewer: Mhmm. Yeah (pause) Mhmm. Yeah. So maybe… you know… b-, because you
don't know what your… your… your… your blood results are, like, the.

Participant: Mhmm.

Interviewer: Your (sighs) CD4 count?

Participant: Yeah. That’s what I want to know. I just didn’t, uh… check it out now. I'm
supposed to, like, go for another blood test so… xxx xxx, like, “How many times?” How much
do they have to take off… off of me (chuckles)? (Odanie: Female, age 30-39 years.)

Odanie was interested in knowing what her CD4 count was so that, if her immune system was
suppressed, she could do something about it immediately. What was making her impatient and frustrated
was the long wait time to discuss her blood work results with her physician. She wanted to see the
physician so that she could access ARV therapy. Despite doing everything that her doctor had told her to
do, she was still not accessing ARVs. She just wanted to know from the physician what she had to do so
that she could get access to the ARVs. This exemplar speaks directly to the issue of why some IPLWH
were not accessing ARV therapy. It highlights the perception by IPLWH of the inordinately long time IPLWH felt they had to wait to find out their results from an HIV medical specialist or a general practitioner. If IPLWH are constantly feeling discouraged by delays in getting blood work results, it is little wonder that IPLWH lose trust in the efficiency of health services. The urgency to access ARV therapy was described by Odanie:

Participant: Well, they just told me that… you know, they… um… my thoughts is, like… I don't know… they just tell me-e, um… what's going on, but they haven't, I don't know. They're just like… they're slow (chuckles) That's all I xxx.

Interviewer: So it would nice if they… you know, speed it up a bit-

Participant: (overlapping) Yeah-h. Yeah. So, you know, and then… you know right away (snaps fingers) before it's too late, you know. Do this right away, you know. You know… do… they're the ones that's supposed to-o… y-, you know, help you and… what you need and that (long pause) And slow about it. ‘Cause I had actually pneumonia. They didn’t know what it was. I had an infection anyways. I’m, I’m… I don't know. They just said I had pneumonia (chuckles) They said, uh… the doctor put you in here, you know. Um… and said because you could have died. And they're telling me… like, holy. (Odanie: Female, age 30-39 years.)

Not only did this participant emphasize the need for timely access to HIV biomarker testing in order to know her health status; she also stressed that she wanted a process of medical care that would not increase her morbidity and prolong her negative health outcomes. She wanted to know why she was so sick. Perhaps being co-infected with HCV and HIV made her weak and tired. And being tired then made it difficult for her to go to all of her health appointments in a timely manner. This participant gave me no indication that she was an agent of the delay. Regardless, the educative power of knowing one’s HIV status vis-à-vis results of one’s HIV biomarkers could have a powerful influence on the behaviour of IPLWH, including their decision to ask, outright, for access to ARV therapy.

The lack of readily available HIV biomarker testing was only one issue of timeliness related to the provision of health services and its impact on trust. Another issue had to do with seemingly late presentation to care. One participant described her own process to accessing medical care and the negative health consequences as it related to her physician postponing ARV therapy:

Interviewer: And then, how about… like, other people's actions… affecting you in using or not using ARV therapy. Like… the doctor or… the nurse or anyone… do any of them, like, what they do or their actions… affect you in using or not using ARV?

Participant: No. They just, they usually just want you to get on them before anything else, before your blood count gets even lower. Yeah. They refer you to get on it… quicker… xxx xxx. Before it used to be, they wouldn't even have told you, like, if you were that low, like, your CD4 count was that low. They won’t have told you, “Oh you need to be on these
antiretrovirals.” And then… yeah… and started seeing even lower, lower counts… that’s when they started jumping on it, yeah. It was, like, up until last year I think it was. Yeah, something, like, that.

Interviewer: Mhmm. And when they started jumping on it… to basically… take the ARV medication, um.

Participant: Or they just didn’t want [HIV] to be full blown. (Mintla: Female, age 20-29 years.)

Asked a question about her own care, Mintla replied in the second person, perhaps even second-person plural. This grammatical inflection was noteworthy. It clarified a piece of potential confusion regarding the timeliness of her own and other people’s access to ARV therapy and it invited one to consider this participant’s case as a general one that was applicable to others in her situation rather than a unique case. Why did Mintla feel some people do not begin ARV therapy for so long? Was it because they were presenting late to care? Or were healthcare providers not offering them ARV therapy in a timely manner once they presented to care? Or was this participant simply reporting in the second person her own personal experience of not beginning ARV therapy in a timely manner? Did her healthcare providers not tell her immediately upon diagnosis that access to ARVs was an option? Or was it not until her CD4 level was quite low that the healthcare providers told her to begin ARV therapy?

Long wait times for the results of testing procedures and the impact they have on IPLWH accessing ARV therapy was only one problem. The timing of recommendations by physicians for IPLWH to begin therapy appeared to be another. Complication in accessing medication at a pharmacy was yet another. As described to me by one participant:

Well sometimes I-I-I… when I phone the clinic and I tell them that I need more… medication… and sometimes when I go there, they tell me that I have to go back the next day, or else the next day, to come and pick it up and I tell them that I don't have enough… treatment to that to… kind of… make it last. ‘Cause… every time when you miss, like, they tell me if I miss… a dose and that, I have to… double the dose for next time. So sometimes I don't really… want to do that ‘cause it… makes it… makes me feel a little bit more sicker. So, uh… I try… I try to, like, get them… I try to like. They tell me to phone, like, two days ahead, so… sometimes I phone, three days ahead… and, uh… that kinda helps me with that. (Zarn: Male, age 18-19 years.)

Zarn lived in Prince Albert, which has about one-fifth the population of Saskatoon. While Prince Albert was considered by some participants to be an urban centre, this did not guarantee Zarn access to ARV prescription refills in a timely manner. While this participant had learned to deal with the challenges of getting his ARV medication refilled at the pharmacy, other IPLWH may not always be as diligent. Complication with accessing ARVs at the pharmacy was not unique to Prince Albert; it had occurred in Saskatoon as well:
I used to go... down... into, um... down to the... to the pharmacist and the pharmacist would say... "Uh, we have to get funding first approved" (laughing) every single month. And, you know... now they changed it now, but... but before that's what it used to be, like, eh. It was, like, “Oh, you got to get your... this approved... first... before we can give you any, any.” You know. That means, that I’d be off the meds for... a few days... again, you know. That... that was another big challenge too in the beginning... was trying to get that... straightened out (sniffs) Trying to, like, uh... phone them ahead of time and... get them to... you know... make sure that... uh, the meds are there... when... when I took my last pill, the next day I could go and pick up my per-; right? So, like, continue taking them on a daily basis. That was a big challenge. And that was because of, you know, getting... funding... approved by Indian Affairs. (Reth: Male, age 30-39 years.)

Until recently, it was the practice of this participant’s pharmacist to seek funding approval on a monthly basis from his insurance company (Aboriginal Affairs and Northern Development Canada). This caused days of delays in getting prescription refills, thus comprising his access to his ARV therapy and preventing him from taking his ARVs regularly. Although this participant was eventually able to resolve the organization of his health care, one wonders how many other IPLWH who are beginning ARV therapy might encounter a similar problem with getting their ARV therapy covered in a timely manner by a third party insurer in Saskatchewan.

5.4. Choosing Between Active Drug Use Disorder and ARV Therapy: Holistic Health Care

For many study participants, living with a substance use disorder was an aspect of their lives that they could not ignore. They voiced that living with a substance use disorder was a part of who they were and as such, accessing ARV therapy needed to take into account their substance use disorder from a holistic healthcare perspective.

5.4.1. Feeling misunderstood as a person recovering from a substance use disorder.

Study participants with a drug use disorder spoke about their physicians denying them ARV therapy. These physicians denied participants access to ARV therapy because they held the view that the participants’ recovery was not at a stage where they could entirely abstain from using their drug of choice. This situation was described in my interview with one participant:

Interviewer: Did you feel that... did you feel... um... like, by the doctor that... you know, that you were being judged or... um.

Participant: Sort of. Yeah. Just, sort of, like, I said, a massive scolding from him; eh. Yeah. Like, you know. Even one time he said, he just said, you know, "If you don't straighten out then... um... you know, I'm not going to give you your [ARV therapy].” You know. Yeah. I've had him say that once... before. Yeah. You know, just ‘cause of (coughs) you know, I have a, I have a struggling addiction problem too... you know. Before it used to be, uh... the cocaine.
And this was, this was a few years back. But, uh… yeah, he told me, "You got to come back with a clean piss test or I'm not even giving you your meds" (chuckles) This, kind of, like… and at that time it was kind of, like, you know… it was when I was other, just coming out of a bad period. And, um… my CD4 count was low again too and stuff, like, that. (Reth: Male, age 30-39 years.)

Reth got upset when his physician scolded him for not adhering to his ARVs because he felt as if he was being judged when his physician spoke to him in a condescending manner. Many participants said that they did not like being judged and, in fact, some participants said that they felt contempt for those who judged them. Reth also shared that he thought that his physician did not think that he was taking his health and well-being seriously and that the physician did not appreciate and understand his unique life circumstances. These circumstances included all of the following: living with depression; being in transition with his biological family and adopted family and work friends; supporting his friends and family, while at the same time being ignored by his friends and family; and having unreliable social supports. Instead of giving tough love, the participant shared, physicians needed to demonstrate compassion towards their clients, particularly since physicians were supposed to be professionals.

The stage of recovery from drug use disorder at which the physician threatened to deny Reth his ARV therapy was unclear. The interpretation of the physician’s chastisement was also not unambiguous. Was the physician chastising the participant as a way to encourage the participant to abstain from using his drug of choice? Or was the physician simply impatient with a client and insensitive to the many challenges faced by such clients when trying to control their drug use disorder? What Reth did make clear was that he felt his circumstances merited a more nurturing environment.

Most study participants knew that a substance use disorder was a chronic disease with no cure, and that the process of coping with a drug use disorder was arduous to say the least. Relapses were a normal part of recovery. As described by another participant: “Sometimes I have my slips [relapses], sometimes I don't and I, I… like, I don't to, I don’t plan to have them. You know what I mean? They just happen.” (Switie: Female, age 30-39 years.) Through such relapses, people with a substance use disorder learn to cope with their disease and learn how to manage any further decline in their disease trajectory: “And I haven't had that much slips… since February. I had, like, two slips since Fri-, February and now it’s only, like, a onetime use and that’s it.” (Switie: Female, age 30-39 years.)

For someone with a substance use disorder, emotions can override rationale thinking. Particularly at the beginning of their recovery from a drug use disorder, they are learning new behaviours based on adjusted cognitive processes (i.e., thinking before acting), rather than favouring established behaviours premised on the reactive emotional response that held sway when they were using their drug of choice. Should IPLWH with a drug use disorder be denied ARV therapy even if it leads to the further deterioration of their HIV morbidity, possibly resulting in death? When a physician threatens to
withhold ARV therapy from IPLWH with an active drug use disorder, what is the alternative for the IPLWH? What is the consolation? I will interrogate this conundrum further in the next chapter on acceptance of ARV therapy.

5.4.2. Feeling coerced into methadone maintenance therapy.

In my interview with another participant, she described some medical practices pertaining to the co-administration of MMT and ARV therapy:

Interviewer: ‘Cause sometimes some people say that, you know, health… you know, professionals… are, like, pushy, you know, like, the pills down your throat saying… you know, “Go on this, go on that.” It’s like.

Participant: I know people where I get my methadone think that too because-(pause) you go there and they have to take a pill with their methadone and, and basically. I don’t know. It’s, like, they won’t get their methadone unless they take that pill. Or I don’t know who their doctors are or anything but.

Interviewer: Is that the ARV pill?

Participant: Yeah, HIV. Yeah. It’s because they don’t… take it every day. They… get hooked up by… I have a feeling it’s ((Physician’s name deleted)), um, but… I know one of them is [their] patient. And they don’t get their methadone unless they swallow their… five [ARV] pills a day… with their methadone and, uh, pharmacist gives [the ARV pills] to them with their methadone. And basically it’s, like, they can’t refuse or they don’t get methadone and… that doesn’t seem right, but… it’s not my doctor and it’s not me, so. (Pila: Female, age 40-49 years.)

Pila reported that some people who were recovering from a drug use disorder did not get their daily, directly observed MMT from the pharmacist until they consumed their ARVs. She believed that such a tactic was wrong and that physicians were too authoritative when they denied a person with a drug use disorder access to ARV therapy if they refused to take their MMT under a pharmacist’s supervision. For some people with a drug use disorder, MMT might not have been an option for them, either because they perceived MMT to be ineffective in their case or because they feared the potential side effects of MMT. Such side effects could include decreased levels of consciousness affecting their activities of daily living. However, at the same time, MMT was effective for many and had helped many study participants control their drug use disorder, which subsequently also helped them with their use of ARV therapy. This conundrum of MMT helping some and not others will also be further explored in the next two chapters.

5.5. Culture and Accessing Knowledge as a Collective

Study participants spoke about the value of accessing knowledge as a collective enterprise; namely, the effects that the power of education and mobilizing as a nation could have on them in terms of accessing ARV therapy.
5.5.1. The power of education.

Some IPLWH in this study raised concerns about an educational system that provided little applied knowledge about health and little incentive to stay in school. Culture-wise, uh, we don't really… like…we're so… far set back. Like, uh-h… culture-wise if we, uh, need to… As a people we need to-o… help each other more. Like, uh-h (long pause) like, uh, we have lack of information. People… dropping out of school early. Uh-h… drinking. A lot of drug use. You know what I mean? Like, we need to teach our people… schooling is the way. Uh, there… you know. Safe protection. Use… if you're a drug addict, use (knocks on the table) clean needles; use stuff. We need advocates, people talking about this, people going out to schools. People talking about… I don't know. Like, I don't know. That kind of stuff. Because when I was younger, no one taught me about this. (Flen: Male, age 30-39 years.)

This participant’s point may seem obvious: people need to teach one another. For a culture that has such a rich oral tradition, an educational model should preference the storytelling imperative.

Although ARV therapy is made available to IPLWH, they sometimes lack knowledge of the usefulness of accessing ARV therapy to treat HIV infection. This highlights the fact that the contextual characteristic of a social factor such as ineffective education works to the detriment of IPLWH, many of whom have not been given the opportunity to reach their full potential to access knowledge pertaining to ARV therapy. For example, one participant with a Grade 12 education who was not using ARV therapy indicated, “if it can… help me, then I’ll… I’m all for it. If not, then… I probably won't even bother with it at all (long pause) (clears throat) Like, I know a lot of people that have this and… know quite a few that have passed on already.” (Clom: Male, age 40-49 years.) This participant expressed his skepticism about the effectiveness of ARV therapy and its ability to improve his health. It is not that long ago that HIV was considered a death sentence in the wider population. Many participants mentioned that they were aware of the high prevalence of HIV infection among Indigenous peoples living in both Saskatoon and Prince Albert. This particular participant knew many people who were HIV-infected and who had died. Given this situation, it was not surprising that IPLWH who had limited knowledge of or access to knowledge of ARV therapy would think HIV is a fatal disease.

I had all kinds of misconceptions to… um, from, um, people, um… you know, that were scared of HIV and… you know, just, uh… just of kind of, um, information that’s out there… without, ‘cause I never did any research, I just… other people’s opinions, just talking about it and… so I just stereotyped… um… thoughts and feelings about, um… people with HIV. And so once, once I was, um… once it explained, I thought, I thought you could never, um… I was under the impression that once you got HIV you get… your life was, um… you only have a certain amount of time to live… and then you were gonna, eventually get, get AIDS and die from it. I didn’t
realize the med-., medication they give you out was at the point where it is today. (Blont: Male, age 50+ years.)

IPLWH in this study were often recipients of more opinion than fact and more news than knowledge, leaving one to question the quality of an educational system that could not retain many of them or provide them information in a culturally appropriate way that values the educative agency of storytelling in an oral tradition.

5.5.2. Mobilizing as a nation.

Like so many of the study participants, one participant concluded his interview with an impassioned note of thanks for the opportunity to talk and be listened to. What he said was telling because it elucidated how IPWH view access to ARV therapy as Indigenous peoples. He stressed that if IPLWH were to benefit from ARV therapy, then Indigenous people needed to speak more about the HIV epidemic and its specific impact on themselves as a nation. Through such self-determination, IPLWH and Indigenous peoples as a cultural-sharing group could reclaim their voice and salvage their unique identity. As described by this participant:

What I'd, like, to say about this is… we need to… as a people, as a… culture, as a… like… even… ourselves, we need to heal… and we need to talk about… to these people. It's okay to have HIV; it's okay. **We need (claps hands) antiretro drugs.** We need to help more people. There is… it's not a death sentence no more. It's… we need to help people… and… (claps hands) basically, um… like… we need advocates. People to tell… our younger children… "Look it (knocks on the wall) this is how we got HIV. Look it (knocks on the wall)… th-, this is how we're getting our lives back together" (knocks on table) And, uh… we need to prevent this… from spreading… to our people until we're wiped out. And that's, and I like this study because… it's going to help us. And I'm glad for you… for doing this study. Like… I wanted somebody, like… to come along and actually do this… and… help. I don't know; I'm a very open person. So, like, I have a big heart. I just said, like… and I'm, glad you're here… talking, like… and I'm glad I'm telling you about this. You know what I mean? (Flen: Male, age 30-39 years.)

Flen valued the importance of the collective Indigenous community. He wanted to see IPLWH tell their stories about “how we got HIV” and also “how we’re getting our lives back together.” He knew that by mobilizing, Indigenous peoples could unite and heal. In his own word, “**once we unite as a people** (knocks on the table)… **we're strong people.**” (Flen: Male, age 30-39 years.) He followed traditional cultural beliefs. He believed in the Creator while at the same time believing in the scientific assertion that ARV therapy was effective. He understood the educative value of storytelling and he wanted to see an educational system that was more effective when it came to teaching the benefits of practicing safe sex and using clean needles for injection drug use and preventing HIV transmission. Such an education
would put Indigenous peoples in a better position to acquire the knowledge to value the importance of accessing ARV therapy.

As a culture, Indigenous peoples need to heal and help one another through advocacy efforts to talk about ARV therapy. Flen’s relatives fought for First Nation treaty and Native women’s rights. This participant grew up with the stories of his people mobilizing to create a better world for Indigenous peoples and he knew that more still needed to be done if Indigenous peoples were going to persevere and triumph over the HIV epidemic and live long healthy lives, and not be “wiped out.”

Given the inequitable position of Indigenous peoples compared to the rest of Canadians, health disparities such as HIV persist. Flen went so far as to suggest that unless Indigenous peoples’ culture could be sustained and revitalized, IPLWH would not be in a position to access ARV therapy. Culture promotes education, which in turn cultivates healing. Without thoughtfully tailored educational opportunities, Indigenous peoples will continue to be marginalized and without recourse to advocate for themselves. The chapter in the life of an IPLWH should never end with the succinctness of these words from Flen on access to ARV therapy:

Fuck. All I just found out is I'm HIV positive. What do I do from here? They didn't tell me about antiretro drugs. They didn't tell me about nothing. They just said, "Oh… you're HIV positive. Okay. Live your life." Fuck. You know what I mean. Like, holy shit. (Flen: Male, age 30-39 years.)

5.6. Chapter Summary

This chapter has looked at personal, interpersonal and socio-structural vulnerabilities and resiliency factors mainly affecting access to ARV therapy by IPLWH. It has considered how IPLWH construct and understand their experiences of accessing ARV therapy through the lens of four key themes: gaining and losing respect in the physical and social environments; the timeliness of the provision of health services and its impact on trust; holistic health care for those living with a substance use disorder; and accessing knowledge as a collective.

There were multiple dimensions to the first theme, gaining and losing respect, which IPLWH perceived from self and others, and in particular, attesting to the fact that access to ARV therapy is situated within rather complex physical and social environments. These environments directly affected IPLWH living within a dominant culture not their own. IPLWH felt labelled and stereotyped based on their race, HIV status and substance use disorder, particularly in the Eastside of Saskatoon. This adversely affected their inclination to access ARV therapy. The respectful care provided to them by individuals working in agencies in the Westside of Saskatoon helped them access ARV therapy. The warmth of these individuals trumped the stereotyping they felt from many others and that they suspected was due to learned behaviour passed on over generations of dominant Eurocentric culture. While IPLWH were prepared to access ARV therapy in social environments where they were treated with
respect, these agencies were often located in a physical environment that was not conducive to the recovery of IPLWH living with a substance use disorder. For example, some IPLWH preferred not to frequent the Westside of Saskatoon because such environments, where street drug interactions take place and where people with a drug use disorder and who were using their drug of choice congregate, were not safe spaces for someone recovering from a drug use disorder. Being in such an unhealthy environment could cause a person with a substance use disorder think negatively and relapse into using substances. Nonetheless, the respect that IPLWH felt from agencies located in the Westside of Saskatoon translated into a positive sense of community and family. Resilient factors such as these supported IPLWH in counteracting structural vulnerability.

The second theme related to the lack of timeliness of the provision of health services and its impact on trust and its effect on IPLWH accessing ARV therapy. Some IPLWH felt they had to wait unnecessarily long for HIV biomarker testing to be conducted and to receive the results of such biomarker testing, and a few were frustrated with delays in accessing ARV therapy at a pharmacist. As a result, IPLWH lost trust in the efficiency of health services. They wanted a health care system that would not compromise their morbidity or prolong their negative health outcomes. The educative power for IPLWH of having timely results of biomarker testing explained to them as well as administrative explanations for delays in getting prescriptions refills was considered a vehicle for building and improving the likelihood that they would access ARV therapy.

The third theme, holistic health care, followed three general scenarios. One related to how IPLWH living with a drug use disorder felt as if they had to choose between living with their active drug use disorder and accessing ARV therapy. A second related to IPLWH living with drug use disorder who were denied access to ARV therapy by their healthcare providers because their recovery from addiction was not viewed by the health service provider as being at an optimal level to support successful adherence to a strict ARV regime. For many IPLWH who were living with substance use disorder, relapses were a normal part of their recovery as they learned to cope with their disorder and to manage living with a chronic illness. The third scenario related to the fact that in order to help some people recover from their drug use disorder, they received MMT under medical directive and only if they adhered to their ARV therapy as co-administered to them at the pharmacist. Such practices could have implications for those IPLWH who refuse to or are unable to go to the pharmacy to take their ARV therapy. In all these scenarios, IPLWH would have appreciated a more holistic understanding of their circumstances.

The last theme pertained to culture and particularly, Indigenous peoples sharing knowledge as a collective group based on their Indigenous ancestry. Such collective knowledge incorporates telling and listening to stories and provides a foundation of resilience that helps IPLWH access ARV therapy. For
example, some IPLWH were unable to acquire a sound base of fact about the effectiveness of ARVs to help them make an informed decision to access ARV therapy.
Chapter 6 Accepting ARV Therapy

6.1. Chapter Overview

As seen in the previous chapter, although accessing ARV therapy can be a challenging endeavour for IPLWH, perseverance makes it attainable. There were unique challenges, which many IPLWH strive to overcome, in order to access ARV therapy. Nonetheless, one needs to ask the question: Will IPLWH unconditionally accept ARV therapy once they have overcome the vulnerabilities associated with accessing it? This chapter mainly explores aspects of circumstances affecting the acceptance of ARV therapy by IPLWH once they obtain access to it.

The notion of acceptance has the potential to be very informative. This chapter mainly looks at the personal, interpersonal and socio-structural reasons why IPLWH accept—or do not accept—ARV therapy and it analyzes the contextual circumstances affecting their decision. Some issues that I will examine in this chapter focusing on the aspect of IPLWH accepting ARV therapy will include: whether IPLWH’s substance use disorder affects their decision to accept ARV therapy once it is offered to them; whether it seems sound to IPLWH with a substance use disorder for their physicians to deprive them of ARV therapy until the physician decides that IPLWH can accept it responsibly; whether having their ARV therapy and MMT co-administered helps IPLWH accept ARV therapy; and why it is that MMT helps some and not others.

As in the previous chapter, analysis of the empirical findings in this chapter drew directly from the personal accounts by IPLWH to provide an understanding of the phenomenon. Participant observation again contextualized some of the interview data. The conceptual framework of this study, as informed by the BMHSU and sensitizing concepts (i.e., acceptance, structure, vulnerability and resilience), within the context of critical Indigenous qualitative research, served as a heuristic device when exploring, describing and explaining the phenomenon.

The five themes of this chapter have been arranged into three domains: (1) respect and holistic health care for IPLWH living with a substance use disorder; (2) trust and culture and the after-effects of the Aboriginal Residential School legacy on Indigenous lives; and (3) family and friends as social supports and social networks for self-regulation of IPLWH.

6.2. Living with a Substance Use Disorder: Respect and Holistic Health Care

Regarding the thematic domain of respect and holistic health care for IPLWH living with a substance use disorder, there were a number of subthemes: (1) setting goals and improving one’s outlook in life; (2) committing to ARV therapy within a health determinants perspective; (3) working as a team towards accepting ARV therapy; (4) taking responsibility and managing one’s own care; (5) considering multiple interventions for those living with drug use disorders; (6) lobbying the healthcare system to support IPLWH with accepting ARV therapy; (7) the ineffectualness of respectful relationships in the
absence of alternatives to MMT; and (8) accepting ARV therapy and living with an active substance use disorder.

**6.2.1. Setting goals and improving one’s outlook in life.**

As tempting as it was for many study participants to indulge in their active addiction and to become resentful of the work involved in accepting ARV therapy, just as many were able to view their situation living with HIV as an opportunity to make a better life for themselves. As a person who was recovering from a substance use disorder and who was struggling with abstaining from using her drug of choice, having a goal that provided meaning and hope in the life of Prace was important. Furthermore, the desire to accomplish such a goal made accepting ARV therapy a means to an end and made the improvement of one’s health one stage in a bigger plan. She saw her HIV status as an opportunity not only to respect herself but to get out and help other IPLWH:

And so since, yeah, so… and then plus all good things I heard about them [the ARVs]. So I thought, ah well… I might as well, you know, since… I could get healthier and then I could do the stuff I want to do, what I always wanted to do; I always wanted to help people. And I always had… like, people inspired me, with their… stories and their talks and I always wanted to be like those people and. And I thought, well I can’t do that, I have nothing special… going on in my life, like, nothing tragic ever happened to me, and… and then when I had… them, when I found out about the HIV, I thought, “Oh, cool. Now I can help people.” At least it took that to… took something bad… from me, something bad to happen to me for… something good to come out (chuckles) So-o-o (long pause) that just, it… that helps me to stay on the [ARV therapy]. (Prace: Female, age 40-49 years.)

During the interview with Prace, it became apparent that what she was saying was that accepting the responsibility of ARV therapy gave a purpose to her life. Having this understanding and goal motivated her to live clean and sober, free from using drugs and alcohol. She accepted ARV therapy in order to prolong her life so that she could accomplish her goals and thus have meaning and hope in her life. While such a particular admission was unique to this participant, the underlying message was noteworthy and applicable to other IPLWH with a substance use disorder. Having a goal that gave meaning and hope to one’s life was a coping strategy that combated the personal struggle of IPLWH living with a substance use disorder to abstain from using their drug of choice.

**6.2.2. Committing to ARV therapy within a health determinants perspective.**

The HIV therapeutic guidelines used by health service providers presented structural constraints that influenced how IPLWH understood their experience of accepting ARV therapy, and the requirement that IPLWH living with a substance use disorder not be actively using their drug of choice while being on ARV therapy came with other rather specific socio-structural requirements for IPLWH.
IPLWH in my study recognized their own anxiety about factors affecting their ability to adhere to a strict regime of ARV therapy once they accept ARV therapy. In conveying what her physician had advised her, one study participant who was living with substance use disorder alluded to the gravity of adherence to ARV therapy:

My doctor says… once I started taking it, I can’t quit. So, I have to take it… now for the rest of my life, so… I have, I accepted it… part of my life now so… I xxx it…. my medication. There’s a need for me; it’s not a want… it’s a need (long pause) That’s it. (Switie: Female, age 30-39 years.)

With the help of her physician, and like so many other participants, Switie understood that once she decided to accept ARV therapy and begin on the regimen, she needed to adhere to her ARV therapy if she were to avoid developing HIV drug resistance. Her physician was unequivocal about the dangers of non-adherence. The health education that she received from her physician also helped her grasp the importance of recovering from her substance use disorder before accepting and beginning ARV therapy. In the process of accepting ARV therapy, she understood both that she would need to adhere to a daily regime and that adherence could be compromised if she indulged her substance use disorder and consequently found herself lacking daily routine, failing to plan ahead, and suffering from forgetfulness. In the moments of silence after her pronouncement that, for her, adherence was not a want but a need, it was hard not to feel that she was thinking about self-respect, a concept she was not comfortable articulating yet, but one that had moved her further along a continuum of recovery from her substance use disorder. She realized that she needed to stop using her drug of choice, and she had begun giving serious thought to what she needed to do to permanently choose ARV therapy over actively engaging in her addiction.

Switie had come to terms with both her HIV status and the responsibility involved in taking care of herself. Interrogating this participant’s interview transcript, it became apparent that, in addition to accepting ARV therapy, she was also accepting the broader social determinants of her health. That is, she had conceptualized that having a substance use disorder was a health determinant. Such a realization was not unique to this participant. Others also understood that ARV therapy was situated within a larger socio-structural environment where IPLWH needed to have social supports, stable housing, food security, employment, income and transportation if they were to be successful using ARV therapy. For many people with a substance use disorder who were using their drugs of choice, attaining these enabling health determinants was more challenging if they had not already made an effort to recover from their substance use disorder. The constraints on attaining these social enabling determinants of health were described to me by another participant who was in the process of addressing her substance use disorder:

I’m not even on [ARV] therapy right now. Uh… I just thought I… have a… I was homeless for a while. And I had to… get a… a… place… where they know where I am, you know; where they
know where I'm at (chuckles) So I'm not, like... you know, I’ve been around different places-s an-n-nd... xxxx. Xxx xxxx xxxx xxxx different places and I... and I just got to settle down and then, I. You know that, you know, I can... look after myself and just... stay home, take my meds and xxxx (chuckles) Yeah. Just... just it (chuckles). (Odanie: Female, age 30-39 years.)

Like many of the study participants who had a drug use disorder and who had used MMT, Odanie and Switie had unstable housing. Odanie, who was not on ARV therapy, knew herself well enough to realize that if she were going to accept ARV therapy, she first needed to have stable living conditions. After obtaining stable housing, one needed to consider the commitment involved in sustaining that housing. Only one effect of using substances was that it could predispose one to be less responsible, a struggle for many persons who were living with a substance use disorder, including those who had relapses from their recovery. Self-respect had many practical dimensions, as shall be seen in the following sections of this chapter.

6.2.3. Working as a team towards accepting ARV therapy.

Accepting ARV therapy was facilitated by teamwork. With some strenuous urgings from both his physician and his partner, one participant who had spent time in prison eventually realized that he would need to start down the road to recovery from his substance use disorder if he were ever going to commit successfully to the strict regime of using ARV therapy. If he continued using illicit drugs such as opioids, he would forget to take his ARVs, thus putting himself at risk of developing HIV drug resistance:

[The physician] told my common law, he said, “You might as well tell him not to bother taking them until he’s ready to commit to this ‘cause... this is the effect that it’s gonna have on him. That, the HIV is just gonna... build up an immunity... to the meds an-n-nd there’s nothing we’re gonna be able to do for him.” So, I just... you know, I-I-I pushed it aside and that’s, I focused on my, you know, my... my addiction [recovery]. So xx xxxx finally... I got on the methadone (Drane: Male, age 40-49 years.)

The participant was very open with his physician about his struggle with adherence, so it was little wonder the physician was so adamant with his advice. In this case, the physician went so far as to include the participant’s common law in the “intervention.” Drane knew his active opioid addiction was preventing him from adhering to his ARV therapy, so he decided to stop accepting ARVs all together until he could get his addiction under control. The physician was very clear about the risk of ARV drug resistance when an ARV regime was not adhered to. Dealing with opioid addiction was a crucial first step. Once an opioid use disorder was addressed, the person could start improving other areas of their life, which included accepting the ARV therapy responsibly and with a full awareness of its potential hazards. The support the physician supplied in the form of hard facts was taken in by Drane, who was grateful for the help.
In the case described immediately above, Drane understood his experience of accepting ARV therapy through the cooperative effort of working together with his physician and his common law partner. This tandem effort helped him to accept ARV therapy. Much depends on the behaviours of the health service providers when interacting with their clients. Respectful client counselling can facilitate consumer satisfaction and can directly influence how IPLWH construct and understand their experiences of ARV therapy. As just described, Drane and the health service provider together realized the need for working constructively as a team in order for Drane to come to terms with accepting ARV therapy.

Conversely, a power play between a physician and IPLWH can easily corrode the interpersonal relationship. There was never any indication from IPLWH participants that they expected their interactions with health service providers to be warm or effusive exchanges at all times. But none of them mistook, or easily looked past, an antagonistic relationship with a health service provider.

Antagonism is one of the most easily reciprocated emotions. It is also an emotion easily transferred onto a collective of individuals. One participant (Reth) was quite vociferous about what he perceived as an antagonistic dynamic between the entire healthcare system and IPLWH. Furthermore, predisposing beliefs by IPLWH about practices of health service providers at the contextual (e.g., policymakers) and individual (e.g., clinicians) levels can often be antagonistic if the practice of health service providers does not intersect with the wishes of IPLWH for personally tailored health services that may not conform to accepted medical guidelines. One example with many instances in this study included the practice by physicians of predicting the ability of IPLWH with a substance use disorder to adhere to ARV therapy. In this regard, the independent decision of Drane to stop accepting ARV therapy because he knew he could not adhere to the prescription regimen was an atypical scenario. Other IPLWH found their decision to accept ARV therapy was interfered with by physicians who assessed them as unable to adhere to their medication. It is crucial to acknowledge how rapidly antagonism can lead to dissatisfaction and resistance by IPLWH, especially for IPLWH with a substance use disorder. If IPLWH are not satisfied with the health care they receive, such consumer dissatisfaction can affect—potentially irreparably—their predisposing beliefs about health services use, which can subsequently influence their perception of whether it is a good idea to accept ARV therapy. But as one participant (Drane) argued quite strenuously, far more often than not, a supportive health care environment for IPLWH with an opioid use disorder could help them address their opioid use disorder, which could consequently help them accept ARVs. In other words, if the opioid use disorder of IPLWH could be addressed in a cooperative manner between IPLWH and their healthcare providers, there was a much better chance that IPLWH could improve other areas of their life, including managing the social determinants of their health, and accepting ARV therapy.
6.2.4. Taking responsibility and managing one’s own care.

Other participants living with a substance use disorder and receiving treatment for it were able to turn their circumstances into instances for social leveraging. Being on MMT meant they could also accept ARV therapy. The personal satisfaction that came with their daily recovery from a substance use disorder extended to their control over their HIV and provided them an elevated sense of social credibility. For many people with a substance use disorder, treating their condition responsibly gave them a sense of accomplishment. Daily doses of self-congratulations can go a long way, especially for someone who is not accustomed to receiving accolades. Furthermore, people who were recovering from their substance use disorder enjoyed their newly found sense of community as part of a group of other people who were recovering from a substance use disorder. And it got better. Those who were considered by their health service provider to be capable of managing their own care had the option of having weekly or sometimes even monthly refills for their MMT and ARV therapy, rather than daily. As one participant described:

“I’m… have creditability with my doctor to where I, I, uh… I’m allowed to take home, like, a month’s supply of my [ARV] medication. Uh… he, he knows that I’m, you know; like, I said I have creditability and that responsibility that I can… you know, administer my own… HIV meds. However, there are other people that I know that, have to go to the pharmacy, that are on methadone, that have to take [the ARVs] with their, their methadone. (Drane: Male, age 40-49 years.)

Drane was not alone in believing that self-administration of ARV therapy by IPLWH living with an opioid use disorder was far better than the current scenario for the many IPLWH with an opioid use disorder who had to go daily, within business hours, to get their daily dose of ARV therapy from a pharmacy along with their MMT. This sort of control exerted over IPLWH by sectors of the healthcare system affected the respect IPLWH felt they deserved.

One participant, who had to move to more affordable housing, could no longer walk to a pharmacy every day. The distance to the closest pharmacy was too great even for her to get to by bicycle. She had to rely on public transit.

“I, when I moved, I made sure that I got my methadone, um. Uh, what do you call that? I don’t know what it’s called but… so that I don’t have to come here [to the pharmacist] every… day. I just come in once a week. (Jupie: Female, age 30-39 years.)

When Jupie moved, she was able to negotiate with her physician to get her MMT and ARV therapy administered to her in weekly ‘bubble packs’ (a pill container that schedules a person’s medication doses). She reported that it would be better for her if she could get a one-month supply of medication instead of going into the pharmacy on a weekly basis. She felt it was disempowering to have the methadone and ARVs administered to her in a bubble pack because it made her feel as if she were being
treated like a child. Given all of her circumstances, she felt that the methadone and ARVs should be administered to her in accordance with her personal life circumstances, including her place of residence and childcare responsibilities. However, her physician was adamant about prescribing her ARV therapy in bubble packs because he believed that such an arrangement would help her adhere to her ARV therapy. As she explained it, her physician’s decision to adjust her ARV therapy and MMT regimen from daily to weekly was premised on her argument that she had to move herself and her children into more affordable housing. There was no indication in the interview what the physician’s assessment was of this participant’s recovery from her substance use disorder. But if the physician’s decision was predicated on his trust in the participant’s ability to manage her own care, she may well have thought the physician could endorse a monthly as readily as a weekly supply of medication. The participant believed that the practice of having her ARV therapy administered in weekly bubble packs was undignified and disrespectful and she was frustrated by her inability to manage her own care more efficiently around her other responsibilities as a mother.

6.2.5. Considering multiple interventions for those living with drug use disorders.

IPLWH living with more than one drug use disorder believed that they needed comprehensive support to help them to deal with their multiple addictions. One participant firmly believed that physicians needed to be more open to treating IPLWH who have an opioid use disorder with alternative forms of substitution treatment besides MMT until these IPLWH were comfortable using MMT. This participant also believed that physicians needed to be more understanding of people who have multiple drug use disorders—opioids and stimulants—because it took more than a proffered promise of improved health for IPLWH to accept ARV therapy. If it were absolutely necessary for IPLWH with a drug use disorder to stabilize their disorder before accepting ARV therapy, then this participant expected health service providers to recognize that such a process of recovery required time for the IPLWH, and therefore tolerance from the health provider.

I’d just like to emphasize, put emphasis on, uh (clears throat) people that are, have addictions. I’d be nice though if, uh, health care and, uh, physicians be more open to, uh… you know, assisting people, uh, that… have these addictions, such as opiates to, you know. Uh-h, be prescribed… the opiates that they need until… they can (pause) until they’re, they, uh, comfortable… being on methadone. And sometimes… they might… fall and use… stimulants, such as cocaine and Ritalin and… it-t-t, that gotta be understood that, you know, there’s also… there’s an addiction to simulants and opiates. Just because… the opiates side is dealt with… there’s, there’s a lot of drug addicts that still have… you know, an addiction to cocaine and stuff. And they feel, “Okay… you’re on methadone now you should have no problems with being, you know, taking morphine and stuff.” So they think, “Okay, you shouldn’t be taking… cocaine and everything else.” But there’s also that addiction, so, right away as soon (claps hands) as you
come dirty with that other stuff, you’re cut off. And, uh… there’s gotta be some kind of… leniency towards that and… tolerance… instead of just being black and white and rigid to the fact that, “Hey… you know, you got your methadone. You should just… you can’t come here and… have cocaine and stimulants in your, in your… you know, in your blood work… or in your, uh, drug scanning.” Because, uh… like, I said, with myself personally, I’ve seen it with everybody else, so, everybody that I’ve come in contact with that’s… addicted to drugs. It-t takes a while… to, you know, to be really stable and… and… be comfortable with yourself and… the, to where you can, uh… be consistent with taking antiviral drugs; medication. That’s, that’s pretty much it (Drane: Male, age 40-49 years.)

This participant was looking for more understanding from physicians for IPLWH with multiple drug use disorders and special needs. He felt that the prevailing political perspectives of the medical discipline on people with a substance use disorder should include more respect for the efforts of some people with an addiction to heal. If the contextual predisposing beliefs of medical authorities included more respect for the efforts of people with a substance use disorder, and if this effected better health policy for treating multiple drug use disorders, then this could directly influence the decision of IPLWH with a substance abuse disorder to accept ARV therapy. From the perspective of this one participant, opioid prescription treatment as an alternative to MMT would help IPLWH with their opioid addiction both because they found that MMT was not an effective means of controlling their addiction and because the side effects of MMT alone could be unbearable. Because it took time for people with a drug use disorder to stabilize their addiction and begin accepting and taking ARV therapy, physicians needed to be more open, patient and tolerant with them.

In a participant observation session, a male, aged 40-49 years (not Drane) desperately wanted to get his opioid use disorder under control and seemed to be looking for any alternative treatment possible, since his physician-prescribed MMT was not working for him.

The participant observation took place at the Saskatoon Westside Community Clinic. It was a counselling session that the participant had with his health service provider. The participant stated that his goal for the healthcare appointment was to seek health services information from the counsellor to aid him with his addiction recovery. The participant stated that he wanted to address his addiction on his own and that he was thinking of going to addiction treatment. Only a week prior to the observation, the participant had injected “down” using dirty needles. He appeared to be truthful when he was speaking with the counsellor. His honesty seemed to complement his self-directed approach to addiction services support. The participant stated that he had previously abused MMT and that his physician did not expect him to have a “clean piss test” for the first three months while he was on MMT. Although the participant stated that he had abused MMT in the past, it was almost as if he was saying to the counsellor that MMT had not worked for him when he previously
took it and, as a result, he continued to use opioids to satisfy his opioid use disorder. I felt that the participant was being sincere with the counsellor and that he had a genuine interest in getting his active opioid use disorder under control. Based on his previous experiences with MMT, he did not think MMT would work. He was looking for any alternative the counsellor might suggest.

Yet another study participant was entirely resistant to using MMT. He had seen the problems others with drug use disorders had with it and was not prepared to accept his physician’s advice to try it, despite his precarious health situation and his inability to improve his situation through his own efforts:

Well, I see Dr., Dr. (Physician’s name deleted) there for a while and he wants me to go on the methadone but... but I don't know; I been, uh. I seen what it's... what it's done... what it’s done to a lot of people. And I don't like it. And I see what it's... it’s done, a lot of good for a lot of people too (taps on the table) you know. But, I know... my... my friend, back home, ((Personal information about the participant’s friend deleted)). And he’s been on it for 18 and a half years; well, 20 years probably now. And he's been down to, like, two [milligrams] and he couldn't even function. You know, so, and that's one of the reasons why I don't like it. And it's very hard to come off. It's worse than heroin. It is, it’s, you know. (Wurt: Male, age 40-49 years.)

Although his physician prescribed him methadone, Wurt was not interested in taking it because he thought that the side effects from methadone outweighed its benefits and that, once you began taking methadone, it was hard to get off it. This participant knew about the possible side effects of MMT, including decreased cognitive and motor function and the decreased personal autonomy that may be the result of the side effects. For him, he says, “It’s worse than heroin.” He tried to deal with his heroin use disorder by examining some of the root causes of those uncomfortable feelings that he quelled with heroin. But he felt as if he had no effective mechanism to help him with his emotional struggle dealing with the past, most notably with respect to his Aboriginal residential school experience. Furthermore, his fear of the side effects of MMT trumped the negative consequences of his active heroin use disorder, including being refused better employment. When he was working, he managed to go into work every day, despite his use of heroin. He had never been on ARV therapy. Perhaps he would be more accepting of ARV therapy if he could treat his heroin use disorder with heroin prescription treatment:

Interviewer: How about your doctor? Like… you know… you know, like… the doctor you mentioned, like, being with him (yawning) or… getting him to help you with… whatever your… your health needs are. Do you think that doctor would… affect you in accessing… or not?-

Participant: (overlapping) Usually, when I’m... I don't, uh… I'm not a… doctor ori… orientated guy. I don't go see them. Like (long pause) when I used to. Now I just go get (taps on the table)... go get dope; right? (taps on the table) And that would be the end of it; right?

‘Cause my body is pretty beat up as it is, you know? I'm waiting for an operation now. And you know, he doesn't, uh… really say much to me. Like, what I'm, what I'm using and stuff. ‘Cause
all that’s I just use it fo-… use it for… you know. My pain and… and for my addiction… now. It's been for so many years; right? So (sniffs). We don't talk about anything, basically, anything else, you know (pause) I just told him, I said, “Well, you know, I've only had it, ‘til whenever. I only found out, like, you know… ten months ago, whatever.” I said, you know… so. I didn't want to talk about it, anyway, you know. He just xxx, “Well… xxxx not gonna. He's gonna, you know. He just… “When you're ready, then you'll talk about it; right? Trying to figure out something; right?” (Wurt: Male, age 40-49 years.)

Although he was not “a doctor orientated guy”, Wurt was waiting for an operation and had seen a physician who predicted that the participant would talk when he was ready. Perhaps his current heroin use was preventing him from being more honest with himself or others about wanting medical advice. Such lack of honesty could be due to his lacking in personal awareness as a side effect of his active addiction. Then again, some people simply are not good at talking about themselves.

**6.2.6. Lobbying the healthcare system to support IPLWH with accepting ARV therapy.**

A few IPLWH believed that the healthcare system needed to reform its policy on treating heroin use disorder with heroin prescription treatment. They were aware of the ongoing debate over treating a drug use disorder with opioid prescription. But contextual factors such as the predisposing beliefs of politicians, the national media and staunch advocates of more orthodox treatment regimens favour the current health policy. These same contextual factors ultimately determine whether IPLWH will chose to undergo drug rehabilitation and accept ARV therapy.

Societal values and norms play a large role in how drug treatment is organized and made accessible to those recovering from a drug use disorder. IPLWH, a subset of a social class that is already marginalized, are unlikely agents of change to the contextual characteristics that enable health policy. Still, IPLWH will try. One study participant (Drane) with an opioid use disorder described how he continually tried to turn the vantage of the healthcare system because he knew his opioid use disorder affected his lack of acceptance of ARV therapy. Nonetheless, he was powerless before the medical authority. This participant described how diligent his physician was about pushing him to treat his opioid use disorder using current drug policies that favoured the use of MMT. The process of medical care used by his physician involved ongoing health education surrounding the risk of developing HIV drug resistance through non-adherence to ARV therapy. Eventually this participant did adopt an addiction recovery program using MMT instead of opioid prescription treatment. But the operative word is “eventually.” He started after being on and then off ARVs and after being discontinued, at least once, from MMT, by his physician. As described by the participant:

I guess initially from when I first start, when I got on the meds… I was… using a lot of… narcotics. I was, uh… before I got on the methadone, I was… injecting a lot of opiates… cocaine. So, I take the [ARV] meds sometimes for a week and I’d quit. An-n-nd… then I go see
the doctor and try to get, you know, uh, prescribed… opiates… because of my addiction. And I said, “Listen I…” and he kept… concentrating and focusing on… taking the HIV meds, and, uh… I said, “Listen, like, you know, I’ll get in these but I want to get something, like, for my addiction.” And he’s like, “Nope, nope.” So… he said, “But, you should get on the ARVs meds.” Uh-h, I was like, “Yeah, I will.” And… you know, for a little while I tried. (Drane: Male, age 40-49 years.)

By his own admission, the participant’s drug use disorder hindered his acceptance of ARV therapy. He would “take the [ARV] meds sometimes for a week and [he’d] quit.” This co-morbidity hindered the participant’s ARV adherence. Later, when the participant’s physician discontinued MMT because he was using stimulants, the participant resorted to using opioids in addition to stimulants.

IPLWH with an active substance use disorder are disadvantaged when ARVs are denied them until they attain some acceptable degree of recovery. Although Drane was eventually able to stabilize his active opioid use disorder and accept ARV therapy, it took a persistent physician, possibly a very persuasive common law partner, and a great deal of time. Other IPLWH may not have the same resources or protracted timeline to do so. IPLWH would try to get the best for themselves under their circumstances; however, those who were not as fortunate as Drane might not succeed in addressing their addiction and accepting an ARV therapy regimen. Some IPLWH needed more understanding from the healthcare system, especially if they could not lobby for themselves. The ethical imperative of depriving IPLWH with a substance use disorder of ARV therapy until they can accept it responsibly is understandable. But physicians and the medical establishment may want to turn their ethical attention to alternative therapeutic approaches to drug use disorders as a means of helping many IPLWH who are living with a drug use disorder.

6.2.7. The ineffectualness of respectful relationships in the absence of alternatives to MMT.

It appeared that Wurt did genuinely care about his overall health status. He shared that one of the reasons he participated in the study was to learn more about ARV therapy. As for his heroin use disorder, he mentioned speaking with counsellors in the past about his problems in an effort to “get it out.” He knew that he had unresolved issues pertaining to his experience living in an Aboriginal residential school; however, he was not ready to begin talking about it. His partner had also encouraged him to “talk about [his] shit” with her (Wurt: Male, age 40-49 years.), which he eventually did until he did not want to talk about it any further. He had given addiction services a try. In some ways his behaviour was reactive, only seeking health services to obtain analgesics for the aches and pains that he was experiencing, both physically and emotionally. In addition to HIV-infection, he was living with other co-morbidities, which included a history of having HCV infection and a cracked collarbone. Although he may not have talked with people about his problem in any depth, he did have a supportive partner, counsellors and physicians. Furthermore, he was curious enough to agree to be a participant in
my study and learn about ARV therapy. Throughout the interview he described many instances where he received advice from health professionals about what he had to do before accepting ARV therapy. In all instances, he felt that the professionals respected the fact that it was ultimately his decision to take the appropriate steps to address his drug use disorder and accept ARV therapy. But in this case, and in the somewhat similar cases of other participants in the study, this respect had a less than optimal health services component. As a consequence of receiving respectful but ultimately ineffectual health services, Wurt had resigned himself to stop relying on others to help him out:

Interviewer: And, and… so… by not talking to other people (clears throat) like, everybody that knows, and… and then… and your partner… and, uh… not talking to other people, um… and keeping it to yourself and… you know, like, just… and everything inside and… keeping xx xxx. Participant: See, I know, I noticed, uh… about the old lady ‘cause, uh… you know, she always xxx xxx… she always does, "Ah, go sit in the corner and then you’ll lick your nuts, like, a good dog because you won't talk to me anyway; right?” I know xxxx it's… it's not important to me anymore, you know. I don't want to… I don't want to discuss it. You know, and so… just let it go; right? I tell her, you know, if you want to… you know. ‘Cause you're just going to get me in a mood where I'm going to get pissed off and because you bugging me to talk about shit and I don't want to talk about it. So it's better off just to, uh… to leave it where I got it, you know.

The way I look at it. I had, went to… I went to lots of counsellors and stuff, you know. I've been to… xxx addiction services about my problems, like that. And them too, you know… I managed to talk about it, you know, and get it out. Well, no; I don't… everybody doesn't need to know my problems. That’s how I feel… anyhow. If I was using the… ARV, I'd be, uh… that would be m-, my… be my… my… my decision and… and my… my problem. Not… anybody else's… right? (Wurt: Male, age 40-49 years.)

Injecting heroine and morphine helped Wurt avoid thinking about his HIV status and other issues that caused him emotional discomfort including his Aboriginal residential school experience. Although he seemed close to resigning himself to no longer relying on others for help, he admitted that he had participated in the study to see if he could learn more about ARV therapy.

6.2.8. Accepting ARV therapy and living with an active substance use disorder.

Although it was not clear to what degree they were adhering to their ARV therapy, the fact remains that some study participants who were living with an active substance use disorder reported to be both accepting and adhering to their ARV therapy. Perhaps what was prompting them to accept ARVs was the support systems they had in place. Some were in a 12-step program (i.e., a self-help program for people living with addiction issues). Others were taking MMT. Many of these participants understood that a substance use disorder was a permanent part of their life, which at times included relapses. Still, they would persevere with their recovery while accepting their ARV therapy to the best
of their ability. As described by one participant who was receiving MMT, having relapses from her addiction recovery and using ARVs was a reality that she was living with:

Interviewer: And um… so, like… when you said, like, don’t (sighs) (clears throat) if you don’t want to slip, don’t go where it’s slippery and… and… if, if… so you’re… you’re, you know, you’re avoiding situations, like, that… you know, for… for your own health… sounds, like. Um… if you do slip… do you think that will affect you in using or not using ARV therapy?

Participant: No. I… keep taking my [ARVs]. Like, I s-s-slipped back, when my best friend died… and [my physician] wasn’t here, I-I (pause) basically did cocaine and… drank every day. (Pila: Female, age 40-49 years.)

A few study participants who were living with a substance use disorder and not completely abstaining from using drugs and alcohol still continued to use their ARV therapy. In the case of Pila, although MMT was helping her with her overall addiction, she was still occasionally using cocaine and alcohol. It would be interesting to know what type of drugs other IPLWH were addicted to and how their addiction to a specific drug affected their ARV therapy use. According to another participant who was living with a multiple-drug use disorder, the factors affecting her drug use and their relation to her use of ARV therapy were telling:

Interviewer: And then, um… so in terms of any of the other things that affect you in using or not using, how about methadone maintenance?

Participant: Um, yeah (coughs) methadone. I don’t know if I… would be taking my antivirals if I wasn’t on methadone. And I highly doubt it because I use to be heavy xxx into the down still. So, I wouldn’t be emotionally… spiritually strong at all. Stronger… than what I am now. Like, I am now but … if I’ve… if I wasn’t on methadone, I think that I won’t be on them; I really highly doubt if I’d be on them.

Interviewer: Yeah. Yeah, so, the down… so the, uh, methadone helps with the down?=

Participant: =Yes; totally=

Interviewer: =(coughs) And then how about with the coke [cocaine] and the Ritalin?

Participant: Well… see that… oh my God. Nothing really could help with that, just have to be sick and tired of taking them, I think. Sick and tired of hurting yourself and people that love you. (Grinda: Female, age 30-39 years.)

Grinda reported that MMT helped her to be mentally, emotionally and spiritually strong and to accept and adhere to ARVs. Although MMT helped her with her opioid use disorder, it provided no help with her addiction to cocaine and Ritalin. She believed that nothing would help with getting over an addiction to uppers such as cocaine short of an inordinate amount of willpower to stop hurting oneself and others. Based on information provided in this interview and a few others, it was clear one needed to consider a number of questions if one were to further understand ARV use among IPLWH who were living with a
multi-drug use disorder. Such questions include: What specific drugs are they addicted to? What is the root cause of their drug use? What support systems do IPLWH have in place to help them cope with their drug use disorder? The remainder of this chapter considers some details surrounding these last two questions, starting with root causes and moving to support systems.

6.3. The Aboriginal Residential School Legacy and its Effect on Trust and Self-Help

Getting at the root cause of drug use disorder is a matter beyond the realm of this study and one that is ideally suited to a debate around nature versus nurture. Nonetheless, the frequency with which study participants referred to the Aboriginal Residential School System, the proximity of this topic to the topic of being misunderstood by authorities, and their resulting lack of trust in authorities invites some exploration, considering that all such participants identified themselves as having a drug use disorder.

Many participants hinted that the legacy of the Aboriginal Residential School System eroded their inclination to trust people in positions of authority. One participant who had never used ARV therapy had a physician who often suggested to him that he begin thinking about starting ARV therapy:

Interviewer: And how about… how about, um… you know, in terms of what affects you in accessing… or not accessing ARVs? How about bigger things? Uh… you know, like… like, um (pause) I don't know, like, cultural oppression or… the Residential School… legacy?
Participant: I haven't really thought about it… you know. I’d just like to kill the pricks xxx, you know. But I never… you know, it never… you know, that's-s… 20… 30 years… 35 years, 36 years ago; right? When that happened. Shit happened; right? So it's… you know… it's buried pretty deep… you know (long pause) I mean, I don't know, it's, uh… something I’ve been thinking about… my mediation hearing next month, xxx, you know, pretty hard. But… I mean that's about it really ((Proceedings interrupted due to participant answering a call on his cell telephone)). (Wurt: Male, age 40-49 years.)

Based on Wurt’s strong emotional reaction to the Aboriginal residential school authorities, one can hypothesize a pretty devastating experience that he preferred not to think about but that he could still pinpoint to the year, “36 years ago,” when he set his mind to calculate it, and that required his appearance at a mediation hearing in the next month. Although his addiction counsellors had encouraged him to talk about his past issues, he said he was not ready. The verbatim transcription records that this participant would suppress his feelings about his experiences in residential school by injecting heroin. For better or for worse, heroin was his coping mechanism to deal with his experiences of residential school. Heroin effectively helped him suppress his feelings of rage, “I’d just like to kill the pricks”; his feelings of resignation, “Shit happened”; his feelings of self-abnegation, “It’s buried pretty deep… you know”; and his feelings of confusion, “I don’t know, it’s, uh… something I’ve been thinking about.”

From one perspective, heroin was providing a fair bit of benefit. But heroin was also an ineffective coping mechanism insofar as it prevented him from talking about, understanding the benefits of,
committing himself to, and feeling good about accepting ARV therapy. That was a lot of drawback to heroin use. Over the course of the interview, it became increasingly clear that Wurt, like others, mistrusted most institutions and what they stood for—namely, the propagation of Eurocentric beliefs and behaviours and the assimilation and acculturation of Indigenous people into that dominant discourse. In the course of trying to protect and preserve the life of his spirit, he used heroin to suppress his negatives feelings, all the while effectively keeping himself from addressing his health and his HIV in a constructive manner. He wanted to learn more about HIV, but at the same time he did not want to speak about HIV:

Interviewer: Mhmm. Mhmm. Yeah. And... and, um... yeah. So by not talking to other people about it and... and keeping to yourself and... and, and your partner and... um. Do you think that... other people might, like, be... like... judgmental?
Participant: Well, it would probably be a... it sure would be a shock to them... you know. I, I just a... I... I'm pretty much a... quiet person. I'm always by myself, basically, you know, and, uh. I'm always working... you know. So... there's really not any chance of... you know, being involved with... with people. That would, uh... you know, treat me differently 'cause I got... I got HIV; right? You know? So, it doesn't... I don't think about it, you know. ‘Cause xxx xxxx. 'Cause really nothing... it really doesn't consider me. I got it. I'll deal with it. I don't, uh... I don't need to run around telling people, "Well I've got HIV, you know. You xxx... you got some spare money or whatever.” You know, or... you know, “Feel sorry for me.” You know (long pause) Look for help here and there because I have it or nothing, you know. I guess I... I'll look deeper into it as I go... you know? That's why I... I thought I'd come... and check you out; eh.
(Wurt: Male, age 40-49 years.)

This participant did not want to disclose his HIV status to anyone but a few people such as his significant other. Yet he, like many IPLWH with an active drug use disorder, wanted to reach out for help. The problem was that past negative experiences with authorities prevented many IPLWH from trusting larger institutions including the healthcare system that denied them ARV therapy as long as they were actively using their drug of choice. The sympathy they may garner from telling friends or acquaintances was a shallow substitute for trust in the medical establishment that had the capacity but lacked the inclination to provide them with critical health care. So street drugs serve as a coping mechanism to deal with such stressful situations. Along with suppressing negative and uncomfortable feelings (directly related to HIV or indirectly related to HIV by way of distal causes), there was the potential for street drugs to suppress any self-regulating capability or motivation IPLWH may have had to develop health-seeking behaviours that were a precursor to accepting ARV therapy. For many participants who attended Aboriginal residential schools, there was an inclination to internalize the devastation they experienced there and adamantly avoid future situations where they expected to feel subjugated, manipulated, coerced,
silenced, marked, interrogated, doubted or ignored. Furthermore, they would think twice about walking into any situation with a health provider where they could not trust that they would not be treated systematically different from non-Indigenous people living with HIV.

Wurt did not trust that, by reaching out for help, health service providers would reciprocate with the help he required. He felt misunderstood. Yet another participant talked about losing his ability to communicate. At the age of five, he was sent to Aboriginal residential school where he was strapped for speaking his First Nation language. Residential school had a tremendously adverse effect on who and how he was today:

Interviewer: Um, with the whole residential school thing, um… do you think that affected you… in terms of who you are today?
Participant: It really did affect me a lot. Like… I couldn't believe some of the stuff I went through. Like… especially when you get… taken away from your own family, and then. Well, I wasn't… I wasn't even six years old when they come and got me and my older brother. Just, literally took us away, like. Priests… nun… RCMP… social service. Xxxx, x xxx xxxx xxxx. Come get you in the Fall; bring you back… in the… Spring. You get to go home and you’re not allowed to talk to your own… language. I could talk five languages when I was a kid. Now I… I can talk Cree and… understand my own language but… ‘cause I’m a Woodland Cree. The Cree here is totally different; like, it's Saulteaux and Cree. I can understand some of it but… their dialect and my dialect. (Clom: Male, age 40-49 years.)

This participant had a lot to say about oppression and assault in Aboriginal residential schools. He was taken away from his guardians, who were also his grandparents. His multilingual talents were beaten out of him. And when a person’s language is taken away from them, along with it goes one’s cultural identity. It would not be hyperbole to say that this participant was robbed of his safety, his security, his language(s), his identity and his childhood spirit. Like Wurt, Clom never used ARV therapy. With all that these participants faced in residential school, it was no wonder they were having a difficult time accepting ARVs from a medical establishment—an establishment with authoritative and powerful figures that must have reminded them of how they had been treated in the past. As stated by Clom, “They’re… they're [healthcare providers] more pushy than anything, like, they’ll xxxx… they’ll demand. They won't ask you. They’ll demand that you take [ARVs].” (Clom: Male, age 40-49 years.) Both of these participants were injecting drugs to help them cope with their painful feelings. Although Clom shared more about his experience in residential school than Wurt, he was still hesitant at times about speaking in any depth about his experience in residential school:

Interviewer: In, in, um (sighs) in residential school… you… you mentioned that… you know… your experience there wasn't… as good as it could have been.
Participant: Yeah, lots of abuse. Lots of abuse. We were told if we talked our own language, we were talking... that's the devil's language. That is what we were told and. Lot of... straps and whatnot. Yeah, they were trying to get me to, uh... file for that money, for that. I wouldn't do it. I wouldn't talk about it. Lot of people entered... just for the money and that xxx... xxx... you know, bring up... bad... negative thoughts. Like, I figure, what's in the past, should stay in the past. Don't have to relive it over and over. (Clom: Male, age 40-49 years.)

Was it remarkable that Clom and Wurt were so resistant to the idea of speaking about their past sufferings? Neither of them had as yet spoken to the authorities responsible for compensating those who had been abused in Aboriginal residential schools despite urgings from others that they do so and despite the fact that the settlement money could improve their conditions and the colonially defined social determinants of their health. Neither seemed to trust they could communicate in a way that their past experiences would be understood. Their recourse had been to inject drugs that numbed their feelings, including feelings of hope and of motivation to accept ARV therapy.

Clom was raised by his grandparents in a strong Cree tradition and one that clearly instilled in him a sense of drive and curiosity. After he left residential school, he did not reconnect with his culture. Yet, it was interesting that, ideologically, he still felt drawn to his Cree cultural values and beliefs and anything else that was positive:

Interviewer: Do you ever think about, like... you know, Aboriginal... culture or First Nation culture or... and (pause) how that could either affect... you... in using or not using ARV therapy?
Participant: Um-m, not really. Never thought of that. Like... I kind of think it's... went... down to that traditional way then... the... the Elder would be all for it, like, in. They'd be pushing you toward it then. 'Cause everything xxx xx xxx in the long-run... well... do it.
Interviewer: Mhmm. Mmm. And then, um... and your, and your... your... your grandparents that raised you... were they... did they believe in their culture?
Participant: Yeah. They probably would have pushed me toward it (pause) Mmm. I won't say no to anything, like, if it's... has to do with our... way of life and our culture then... I'll do it. Other than that it's just... if it's... positive, I'll do it. If it's not positive, then I won't do it. But I'm looking... more into this than anything, so (tapping hand on table). (Clom: Male, age 40-49 years.)

Clom would not refuse anything that helped him, including ARV therapy. “I’m looking... more into this than anything,” he reports. Wurt made a very similar statement: “I’ll look deeper into it as I go.”

Neither had entirely given up on the possibility of building a trusting relationship with a professional who might yet understand them.

Another participant, Dapine, shared with me her experience in residential school:
Okay, I went to residential school. Yeah. And… you know, I was… sexually abused in there. And… when it came time, you know, when they had all this talk about the money and everything. When it came, when it came for me to go to court… you know, I was denied… because… the adjudicator… didn’t know what I was talking about and I told him, you know, what that guy did to me… you know, like. He didn’t know what he meant by him touching me down there. You know, like, him feeling me up, like. So… right now, I’m, I’m going through that… right now. I’m, we’re going to do another… uh… appeal… with that… with that adjudicator because… he doesn’t know what I’m talking about, you know, like. (Dapine: Female, age 30-39 years.)

The experiences of Dapine in Aboriginal residential school were certainly no less unpleasant than Clom and Wurt; yet, she was more receptive than the other two participants to speaking up about her past residential school experiences and about those issues she was currently struggling with and which were causing her emotional upset. These three participants all had a substance use disorder: however, Dapine had succeeded in abstaining from using substances and accepting ARV therapy. Her attempts to communicate about highly unpleasant topics without being misunderstood were no more successful or less frustrating than the two male participants. Perhaps what was giving Dapine the strength to continue talking about her issues was the empowerment she felt from the challenging work of recovering from drug and alcohol use disorders. Dapine was much further along in her healing trajectory, but, again, the salient issues of her story included the Aboriginal Residential School System, the proximal issue of being misunderstood by authorities, and an overall lack of trust in authorities.

Regardless of how participants were able to cope with the effects of their experience with the Aboriginal Residential School legacy, they collectively had their culture stripped away, they experienced difficulty speaking up and they experienced challenges in communicating their thoughts, experiences and emotions to others. It seemed indisputable that their experiences had a deleterious effect on how IPLWH who were living with a substance use disorder trusted authorities and accepted ARV therapy in a timely manner.

As will be seen in the next section, culture was a predominant theme of the study findings.

6.4. Wanting One’s Culture

Study participants reported the value that they placed on their cultural heritage and how their own beliefs and other people’s actions affected them. Two subthemes of IPLWH wanting their culture included: (1) connecting ARV therapy use and cultural identity; and (2) being discriminated by one’s own community.

6.4.1. Connecting ARV therapy use and cultural identity.

Clom, who had been taken away from his Cree grandparents and his culture, still knew in a way that could not be misunderstood as nostalgic that if ARV therapy use “has to do with our… way of life and our culture then… I’ll do it.” Many participants had a sense of and an appreciation for the concept
of holistic health care, but Indigenous culture was not necessarily a component in the holistic health care made available to them.

One participant indicated that he was grateful for and valued the holistic manner in which the Saskatoon Westside Community Clinic provided care to him within the context of ARV therapy. He talked about how the Westside Community Clinic had an integrated approach to health care that considered social and economic aspects relevant to the lives of IPLWH. There were other participants who shared this perspective. There were those who reported appreciating how the Saskatoon Westside Community Clinic, the drug and alcohol detox centre based in Saskatoon, and AIDS Saskatoon worked with one another. However, in my interview with this one participant, it became evident that what was missing from his description and understanding of holistic health care was an Indigenous cultural component, which many of my study participants alluded to as an essential part of any integrated health services strategy.

Interviewer: So for your cultural activities you would go to, like, another organization or… another?
Participant: Yeah, well… I might go to… my wife’s reserve… at, in ((Name of First Nation community deleted)). (Blont: Male, age 50+ years.)

For many of the participants in my study, culture was a predominant component of their experience with ARV therapy use if not with the health services they received per se. They recognized their cultural heritage as an integral part of their identity. Cultural identity had both an individual and a collective significance. One participant talked of many remarkable family members who, collectively, formed a nationhood that gave him courage:

My dad give me the biggest courage because… he told me never be ashamed of who you are and of your family. And, of your, like… of who you are; a Native person. Um… my grandpa always taught me that. My mom, my grandma, uh… was ((Grandmother’s name deleted)). She fought for women’s Natives' rights. My grandpa was, uh… like, he… signed, he walked for treaties, my great-grandpa. So, like… if they can do that… I can do my little small part; eh? And… this gives me strength to… even. (Flen: Male, aged 30-39 years.)

This participant’s “little small part” cannot be considered without acknowledging its connection to a larger whole. Specifically, he wanted his individual contribution to have significance in the larger family as a whole. His family, as he described them, were founders of a Nation. Furthermore, it merits pointing out that in most of the Indigenous communities in Canada that I know, the phrase, ‘all my relations’ is a wonderful expression that encompasses family members but also ramifies out through and across generations to include whole Indigenous communities, their ancestors, the Creator and Mother Earth. In this way, family, relations and culture are intimately connected concepts. Earlier in the individual interview, Flen mentioned how he used to be afraid of what others might think of him if he accepted
ARVs. He also feared being discriminated against for being HIV-infected. What gave him the courage to attend to his health was his father encouraging him to stand up for himself at all cost, in this case, including potential shame. His father told him: “never be ashamed of who you are.” As Flen began thinking about his culture and the importance it held for him, he also became interested in accepting ARVs. He shared that he was ready to accept ARV therapy and that he was looking forward to meeting with his physician, who was going to prescribe him ARVs.

Similarly, Thark, who was living with a drug use disorder and injecting his drug of choice, seemed receptive to engaging with his culture through this study. In the interview, he spoke of struggling with accepting ARV therapy, but expressed interest in re-engaging with cultural traditions.

The cultural component of this study of ARV use among IPLWH seemed to be a draw for him:

Interview: I’ll be going back to Toronto next month and then, um. But I’ll be back in July. So if you’re interested in that sharing circle.
Participant: Yes. Yeah. It should be nice, yeah. Is there a feast afterwards?
Interviewer: Yeah. Yeah (clears throat) we have a circle, Elder, smudge, feast after. And the purpose of the circle is to develop… you know. I am going to show my preliminary results to the circle and… and then develop concrete recommendations.
Participant: Oh, really?
Interviewer: Yeah. (Thark: Male, aged 30-39 years.)

Indigenous culture was an essential component of ARV therapy use for many IPLWH. Yet based on what many study participants shared, cultural components were lacking in their integrated health services strategy.

6.4.2. Being discriminated against by one’s own community.

Participants spoke of the importance of their culture within the context of ARV therapy use. They also spoke of how organizational structures might support this critical component. But Indigenous culture was not universally lauded as a panacea, and some participants referred to feeling centred out by their own Indigenous communities because of their HIV status:

‘Cause even (sniffs) like, the… some of the Elders, they don’t understand ‘cause they are so set in their ways and they don’t want to… um… come around and try and understand. So it’s hard to try and trust somebody to… like… go and try and offer tobacco and talk to them about it. ‘Cause… like… I don’t know what they’re going to say to me, like maybe they’ll just tell me to go away, and they don’t want, they don’t have nothing to do with me (sniffs) But I, I’m… I’m, I’m trying my best to… stay positive (pause) and think everything is going to be okay… for me (sniffs). (Queete: Female, aged 30-39 years.)

No society is without members who discriminate against others out of ignorance or lack of understanding. A fractured culture is no exception, and Queete noted that some Elders did not
understand HIV. This discouraged her from approaching them. It was hard for her to approach the Elders because she feared being turned away because she was HIV positive. Yet, culture was very important to IPLWH in the study. Their culture was who they were and it shaped their life as well as their outlook on life. As Queete described, she did not feel entirely welcomed by her First Nation culture, and this made her hesitant to embrace it fully. She shared that she wanted both Indigenous and non-Indigenous organizations to help her with her needs pertaining to ARV therapy use. However, if Indigenous organizations did not make her feel accepted or, worse yet, were to “tell [her] to go away,” this could prevent her from accepting ARVs. Furthermore, like most of the study participants, Queete had a substance use disorder. Many of these participants expressed that they did not feel they were wanted either by their own families or their respective Indigenous community.

One participant alluded to her father questioning whether he was her real father because she did not look First Nation, and she described how this affected her. Throughout her childhood, Queete did not feel loved by her own father for a culturally specific reason that, at first glance, may seem alarming but on further examination, had a twisted logic to it:

Interviewer: Mhmm… yeah. And you mentioned that… your Dad, um… abused you… in the past. Do you think about… um, and you mentioned to, um… that you think about other people first before you, um (clears throat) do you think there is a connection there? Like, with your Dad abusing you in the past and… and, how you… put other people before you?

Participant: I don’t know (crying) Maybe, like (sniffs) Out of me and my siblings, growing up… me and… my brother… and he’s the youngest, we’re the one that always got… the most beatings. And this was, like, on a daily basis… every day or every other day, so we’d be going to school with. And yeah, my older sister, ’cause there’s four of us, and there… my, my older sister and my brother were all fair with coloured eyes, and my Dad is dark with brown eyes, so… he was, like… he would favour my younger sister, because she was the only one that looked like him. And she didn’t get the… the beatings like we did. (Queete: Female, aged 30-39 years.)

There was no mention of a mother of Indigenous or non-Indigenous heritage. Nonetheless, the account of abuse hints at both normative cultural assumptions and a disturbing legacy of colonial oppression that plays out in the gradations of skin colour among members of one family, two factors that have an enduring effect on this participant’s conflicted connection to an Indigenous community that could potentially help her accept ARV therapy.

6.4.3. Cross-cultural challenges.

Although most of the study participants spoke about how they valued culture and how it had a beneficial effect on their use of ARV therapy, yet another participant shared the impact that her culture had on distracting her from accepting ARV therapy. In the individual interview, she appeared to be struggling with integrating Western and traditional First Nation healing practices:
Participant: Yeah, at first I was so-o… scared to go on the, uh-h, treatment… and I was trying to go the Indian way (chuckles) I was seeing a medicine man. And… because I-I heard a story once, my Dad had diabetes and he had to have hea-, heart surgery and all that, and he was seeing a medicine man, and… doctors went to test him and stuff, and his diabetes was gone. No diabetes. So-o… I was, like, “Well, hey, I want to do Indian medicine.” Like, xxx, ‘cause I believe in it. It worked for my Dad; it’d work for me. So I was kind of… confused on… which way to go at first. So, it took me a while to even to start on the meds (chuckles).

Interviewer: Do you still do Indian medicine? With the medication? With the ARV?
Participant: Once in a while I do… but I have something, yup. Because I was told that it doesn’t matter, you can-n use both-

Interviewer: (overlapping) And how’s that? (pause) Mhmm.
Participant: Yeah.

Interviewer: So, having them both, um… is that helpful?
Participant: Uh, yeah. Yeah. Except that I haven’t been able to get any Indian… stuff [medicine] for… a while now.

Interviewer: Mhmm. Yeah. Yeah, so it is almost like having, like, the holistic care, like… you know, like, the circle, like, your ARVs and, you know, like… the white way, you know, the pills and the doctors, and then also the Indian way… um… you know, whether you, um… go to sweats. Do you go to sweats? Or… is that what you mean?=
Participant: =Yeah. (Prace: Female, aged 40-49 years.)

Prace sometimes used traditional First Nations medicine alongside her ARVs, but reported that lately she had been having a difficult time finding traditional medicine. She valued traditional medicine. Initially, her thinking about the use of traditional medicine delayed her in accessing ARVs because she preferred traditional medicine over ARVs. Throughout the interview, it became apparent that she had become increasingly more comfortable using traditional medicine alongside Western medicine. As with other study participants who embraced Indigenous cultural practices and who had an interest in learning more about their culture, there was a calmness and a peace of mind in her demeanor.

I suspect that respecting cultural beliefs, values and customs had an effect on one accepting ARV therapy. Perhaps believing in one’s culture and accepting who one is helped IPLWH with their overall outlook on life, thus increasing their coping mechanism for dealing with risk and adversity. Some participants intuitively knew that what they needed in their life was to have a deeper connection with cultural traditions. As described by one participant:

That's why I am glad that I met the Elder here today… because I can, um (sniffs) I wanted to do something, like, that. Like… meet an Elder or… I just, ugh… there's so much stuff that I want to do, but I just don't know about how to go about doing it. (Indime: Female, age 30-39 years.)
Many of the study participants who spoke of using traditional Indigenous healing practices indicated that this had a positive effect on their overall health and wellbeing. One participant shared in some detail the traditional practices that helped him to accept ARV therapy:

Interviewer: How about, um… with also accepting or not accepting the ARVs… how about, like, Aboriginal traditional healing… s-, strategies, like… does any of that apply to you… in terms of?
Participant: Um… well, right now… I'm just starting to, uh, smudge more… and, uh… I'm trying to get more back into my culture with… my. My uncle he's, uh… sometimes puts on sweats and that. Some-, sometimes try to go with him but I’m just… I am too busy… with work.

Interviewer: Yeah. Actually (clears throat) that was, um, you know, because we had the interview sort of today, like, it was, it was kind of on the fly [last minute arrangement]… setting it up, um. Another thing that I offer people, you know, is, um, if they want to smudge before the interview… and if they do, then what I do is I bring a… like a, a traditional person with me… to do the smudging part. Um, so unfortunately… you know, I was unable to offer that to you today. Um… and, um (clears throat) so, so things, like, that… like, sweats or smudging, does that… affect you in using or acc-, accepting… ARVs or not accepting the ARVs… like, getting the cultural stuff in?

Participant: It makes me want to… accept it more.

Interviewer: Yeah. Yeah. And that’s, like, sort of, like, a holistic approach, like… you know, taking the ARVs and at the same time, doing the traditional stuff.

Participant: Yeah.

Interviewer: Like… you know, tapping into the best of both worlds (clears throat) What do you, does that help you in, in accepting?

Participant: Yeah. Yeah, it does.

Interviewer: (clears throat) You ever… wonder, like… how that is or… how does that make you feel or? Like, wanting to know more about your culture and-

Participant: Mmm (pause) Well, my-y… my uncle, really… helps me with that… every time when I see him… I (clears throat) we talk and that, like… when's the next, like, uh… sweat and… when's the next time, uh… we're gonna have, uh… a little get together, gathering for… smudging and, uh… for doing some more… traditional stuff. Um… he kinda helps me with that… and yeah, that kinda makes me want to accept [ARVs] more. And, uh… and I kinda, I still want to do both… ‘cause, like, I still want to keep myself healthy… and by taking the, the treatments and xxx tra-, traditional… I, uh… I kinda, like, really relieves my stress-s, relieves-s my depression and everything like that. So that kind of… helps me more. (Zarn: Male, aged 18-19 years.)
Zarn was trying to engage more with his First Nation culture by going to sweats and smudging and this helped him accept ARVs because it alleviated his stress, relieved his depression, made him feel healthier, and improved his outlook on life. Such an integrative approach to health care helped IPLWH accept ARV therapy by alleviating the negative stress that they may have had, such as depression, thus giving them a more positive outlook on life.

6.5. The Influence of Family and Related Social Supports on Self-Regulation

Another common theme of the study findings was the notion of family and friends. As previously discussed in Section 6.4.1. (Connecting ARV therapy use and cultural identity) of this chapter, family membership in Indigenous communities extends beyond what most people would define as family, such as parents, children, siblings and immediate family members. Study participants also included among family members those friends and other relations not associated through biological relationships. Family and friends as social support networks encouraged IPLWH to accept ARV therapy.

6.5.1. Thinking of one’s children.

For many of the participants, male and female, their children were a motivating factor in accepting ARV therapy. Still, two mothers in particular had never taken ARVs. The first expressed a genuine desire to start ARV therapy but was thwarted by her active substance use disorder. In her case, she wanted to take ARVs in order to live longer so that she could care for her children:

Interviewer: Is there something that… is there something that drives you? Um, like… you know, when you say, that… you know, like, I… I hope that, uh… that the ARV… medication will work. Is there something that drives you, like to… to want to be healthy, stay healthy, to like?

Participant: Yeah-h. I want to… yeah, for my daughters and (pause) to be healthy. Um… like, to see them… to see them, like… you know, when they’re older… and their kids, like… make sure they’re happy (chuckles).

Interviewer: Mhmm. Yeah, take care of them. Yeah.

Participant: I don't want to be, like… all of a sudden-n… you know… when my time’s up, like… next week and (laughing) (long pause: 25 seconds) (Odanie: Female, aged 30-39 years.)

Although Odanie was extrinsically motivated to accept her ARVs (i.e., having children was an incentive to accept ARV therapy), she was still actively using her drug of choice. If Odanie were to abstain from drug use and live a sober life, one wondered if she would enjoy an intrinsic motivation to take her ARVs. It is possible that she may not. Based on what was heard or observed in the study, an external motivating factor seemed to play a critical role in affecting the behaviour of a person with a substance use disorder. Odanie realized that if she did not start ARV therapy then her life expectancy would be shortened. But given her substance use disorder, the strong likelihood of her living a longer life was not a motivating factor for her. On the other hand, her motherly instinct was a motivation for her to accept ARV therapy;
and what appeared to be helping her most in accepting ARV therapy were the social networks and social supports, such as the AIDS Saskatoon-601 Outreach Centre. The second mother (Heenda), who had also never taken ARVs, voiced her hesitation about beginning ARV therapy. She feared that the potential side effects of ARVs taken in combination with MMT would negatively affect her health to a point where she would be unable to take care of her children.

Interviewer: How about, like, childcare responsibilities or… does that affect, affect you in either using… or, you know, the… accepting it, or not accepting?

Participant: Mhmm. Not accepting it=

Interviewer: Not accepting it=

Participant: =Yeah (pause) Because, like, I said… I don’t have… xxx, you know. I want to be able to look after my kids. An-n-nd… what if these things prevent me from not. Like, I said… the thing-g… is, I’m scared that they’re gonna make me sick. That’s, that’s… the main… thing.

(Heenda: Female, aged 30-39 years.)

Heenda was hesitant to accept ARV therapy because she was afraid of the potential side effects of combining it with MMT. This participant, who was recovering from a drug use disorder, clearly cherished her newly found sobriety and the concomitant ability it gave her to care for her children. She did not want to jeopardize this. With the help of her MMT, she was able to stay clean and sober and she feared that the ARVs would metabolize her methadone, thus placing her at risk of losing her sobriety. Knowing what it was like living in turmoil, and now knowing a life of caring for others, she hesitated to accept ARV therapy and risk regressing into a life of active addiction.

6.5.2. Social supports for the family.

For another participant who was recovering from a drug use disorder and who was using ARV therapy, what motivated her to accept ARVs was not only her unborn child and a desire not to infect her partner, but her social support networks:

Participant: I kind of, uh… fell off my wagon [relapsed] then (chuckles).

Interviewer: And, then you stopped using the ARVs?=

Participant: Yeah. It was just, like, uh, a never ending cycle for me. As soon as I fall off, xxx xxx… I just don’t care anymore I guess (sniffs).

Interviewer: What helps you to stay on the cycle or?

Participant: My baby now, actually… and ((Participant’s partner’s name deleted)) and=

Interviewer: =Your partner: ((Participant’s partner’s name deleted))?=

Participant: =Yup… so. And my, um… people are, people are, like… like, people that are here [Prince Albert Access Place and Outreach Services]… you know, like, they help me. (Grinda: Female, aged 30-39 years.)

Grinda acknowledged her need for social networks especially after relapsing into drug use. What helped
her to break the cycle of constant relapses was a mix of becoming pregnant, having a partner, and accessing health services from the Prince Albert Access Place and Outreach Services.

Often, for participants facing these challenges, the more extrinsic motivating factors they have, the better. And social services outside the immediate family are as important as any other. As shared by another participant, who was a single parent, the social support of a teenage daughter was not enough:

And I, I was talking to my daughter and I just think that it’s too much information that one. She’s still a kid, like, she’s, you know. Most 18-year-old are, like… running around and, you know… getting pregnant, drinking, you know… having boyfriends. She’s not like that, she’s just… she’s still a child and like… I have to realize that sometimes my… my feelings and that I cannot share with her, because it’s too much… that I don’t want to scare her. (Jupie: Female, aged 30-39 years.)

This participant, who was also struggling with a substance use disorder, realized that she needed social supports outside of her immediate family for the sake of her own wellbeing. To counteract such a vulnerability, she accessed the local AIDS service organization in Saskatoon called the AIDS Saskatoon-601 Outreach Centre, which provided the support she needed—support she could not get from a dependent family member no matter how committed to her recovery that family member happened to be.

6.5.3. Extrinsic motivation from the child welfare system that can provoke fear.

For IPLWH women with young children, accepting ARV therapy meant being a competent parent who could keep their children from being apprehended by the child welfare system. One participant explained that she accepted ARV therapy in order to keep her immediate family together:

A reason why I was also taking my [ARV] meds is that, I got, I was told by a friend of mine that… they, they [the children’s foster care system] could take my baby… if I wasn’t taking my HIV meds. And I don’t want that. Like, I already had one baby taken from me away from the hospital. And I just don’t know if I will be able to live through it. And I think, if we lost this baby, I, from, to Care… that, um, it would really mess ((Study participant’s partner’s name deleted)) and I up ((Papers shuffling in background)) Like, our relationship. Like, we are really close right now; it would probably distance us. (Grinda: Female, age 30-39 years.)

Grinda shared that her goal was to have her baby “normally,” by which she meant the baby not being born with HIV. If her unborn child had HIV, she did not know if she would be able to forgive herself for not preventing this by taking ARVs during her pregnancy. Furthermore, the fear of having her child apprehended by the child welfare system encouraged her to use ARV therapy. She believed she was doing everything she could—including taking her ARV therapy—in order to keep her entire family together. She felt that, if she lost her child to the foster care system after the baby was born, her partner would surely distance himself from her. In this case, it really seemed as if her perceived individual need
to take ARVs was much less significant to her than what accepting and adhering to ARV therapy could do for her social relationships, and in particular, her relationship with her partner.

Like many of the study participants who were living with a drug use disorder, Grinda valued the comfort of having family, friends, and other social support systems in place enough to abstain from using her drug of choice. Such comfort replaced loneliness, an emotional discomfort that people with a drug use disorder who are not in recovery suppress with that drug. In the past, when Grinda was not recovering from her drug use disorder and using her drug of choice, she lost her other children, immediately or eventually, to the foster care system. The grief brought on from losing her children caused her to regress further into her active drug use disorder. Within the context of using ARV therapy, she described what a traumatic experience it was for her to lose her children:

Interviewer: In general, tell me about how… your own thoughts and feelings affect you in using or not using ARV therapy?
Participant: (long pause) I guess xxxx xxxx for my thoughts before but (clears throat) xxx xxxx I just didn’t think it wouldn’t be that. Well, see I lost my kids to xxxx and Care… and… that really traumatized me and I just didn’t feel like… going on, so I figure well, what’s the point of taking [ARVs]. They’re gonna be sick anyways and… I’m not, not right in my soul. ‘Cause I don’t know, it’s just. Back then xxxx, I didn’t care for them ‘cause I didn’t (sniffs) care for myself, I guess ((Yelling noise in the hallway in the background)) I, I didn’t care if I come or go=

Interviewer: =And then, back then, were you using [drugs]?=
Participant: =Yeah, hard-core; like lots. (Grinda: Female, age 30-39 years.)

Some female study participants talked about their experiences related to accepting ARVs as they pertained to retaining custody of their children. Many of them talked about having felt threatened by the child welfare authorities who indicated that if the participants were not competent mothers, those same authorities would apprehend their children. When asked if there were any challenges that they faced in life that would affect their use of ARV therapy, these participants all categorically said “no.” It was as if they had a visceral response to protecting their children.

In interviewing participants, it appeared as if the socio-structural mechanisms that governed family and child services in Saskatoon and Prince Albert were not taking into account the larger social determinants of health affecting a family when a mother was on ARV therapy:

I’m on all these [ARV] pills and I’m, like. Well, like, I was falling asleep in programs and I was. And they were thinking that I was high. And I’m, like, it’s xxxx my meds. And then I had to frickin’… tell everybody. Like, I tell this person and this person. “Oh… should we take the kids away?” And I’m, like… “What? I’m, like”, you know… “I’m on these medications ‘cause”… this person, my doctor. “You and you’re the one who told me to see this doctor who gave me
this med. Now you’re gonna give, take my kids away? Because the doctor prescribed xxxx… these [ARV] pills that are making me a little tired and loofy, and,” you know. Like… and then they decided not to take them but then… I’m feeling sick to my stomach, and I’m feeling… gross; I can’t get out of bed, and it’s like. (Jupie: Female, age 30-39 years.)

Jupie was afraid that the very same child welfare system that recommended she see a physician in the first place and to whom she had explained that her ARV therapy was causing her lethargy would apprehend her children. The child welfare system perceived her lethargy as her being an unconcerned and incompetent parent, and did not take into account that such lethargy was a result of the side effects of the ARV medication. Jupie was in fact improving her health determinants.

6.6. Chapter Summary

This chapter mainly explored, yet also described and explained, how and why some IPLWH accepted and others did not accept ARV therapy once various obstacles to accessing ARV therapy were overcome. Specifically, this chapter examined how IPLWH construct and understand their experiences of accepting ARV therapy and how certain factors affect their acceptance of ARV therapy. These factors were collapsed into five themes, clustered in three domains.

The first two themes addressed respect and holistic health care pertaining to IPLWH who were living with a substance use disorder. IPLWH living with a substance use disorder and actively using their drug of choice realized that if they were to decide to accept ARV therapy, they would have to change their lifestyle radically. This meant addressing their substance use disorder and also taking on responsibility for maintaining stable housing and being financially solvent. For some, these responsibilities were too great to commit to. For others, the act of setting goals improved their outlook on life and motivation to make the necessary changes to their life, improve themselves, and accept ARV therapy to become healthier.

Taking on the responsibility of managing their own health care provided IPLWH with self-respect. Knowing that others saw them as having credibility added to their feeling of self-respect. Their ability to assure their primary healthcare provider that they were managing their own health helped as well. And working in a mutually respectful relationship with their health service providers was an invaluable component of the decision by IPLWH to accept ARV therapy. For instance, working together to address opioid use disorder improved the chances that IPLWH could recover from their addiction, improve other areas of their life, and accept ARV therapy. To this end, IPLWH believed it was important for the healthcare system to consider multiple interventions for those living with drug use disorder. In the case of IPLWH with an opioid use disorder, MMT was not always the best treatment for them, either because MMT did not help them in controlling their addiction to opioids or because they were afraid of the side effects of MMT. In such instances, IPLWH were hoping for advocates to lobby the healthcare system for better support of those living with an opioid use disorder. Furthermore, while
some did realize that substance use prevented them from thinking about what was good for them, at the same time, they felt they needed substances to help them with the physical, mental, emotional and spiritual ailments that caused them pain. Notwithstanding the many challenges faced by IPLWH who were living with a substance use disorder, there were some who were using their drug of choice who still accepted and adhered to their ARV regimen.

The third and fourth themes concerned the aspects of trust, culture and the Aboriginal Residential School legacy. Having trust in their physician determined how and why some IPLWH decided to accept ARV therapy. Other IPLWH who had attended residential schools remembered the abuses they experienced while being assimilated and acculturated into a Eurocentric culture and equated the authorities in healthcare establishments and the treatment they received from healthcare providers with Aboriginal residential school authorities and memories of their treatment there. For some of these IPLWH, the same self-help strategies they used to overcome the ill effects of the Aboriginal Residential School legacy acted as coping strategies to deal with healthcare providers and included turning to their specific Aboriginal culture or taking part in self-help programs as a way to supplement or even replace authoritarian or unhelpful health service providers.

In a number of individual interviews it was clear that when it came to ARV therapy use, Indigenous culture was not an evident component of the care provided by health agencies. Despite good efforts on the part of some health service agencies to provide holistic health care and integrated health services, an explicit component of Indigenous culture was lacking. The notion of culture brought mixed feelings to some IPLWH who felt discriminated against by their own Indigenous communities. Those who were accepted by their communities were at times caught in a dilemma over whether or not to treat their HIV-infection with traditional First Nations medicine or ARV therapy. Those fortunate enough to negotiate these dilemmas used healing strategies from both the Indigenous and non-Indigenous culture to help them with living healthy lives, emotionally, mentally, spiritually and physically.

The fifth theme dealt with family and friends. These relationships (i.e., social networks and social support) usually had a positive impact on how IPLWH regulated themselves and accepted ARV therapy. IPLWH who were mothers categorically wanted to live for the sake of their children. They also acknowledged the need for additional external supports to help them accept ARV therapy. The programs that various community groups provided, as well as the support from partners, helped IPLWH regulate themselves, live healthier lives, and accept ARV therapy. It is also undeniable that the threat of children’s aid workers potentially undermining the strides that IPLWH had taken to care for themselves and their families was a motivating factor to accept ARV therapy.

Given the struggles of IPLWH with gaining respect from health providers, obtaining holistic health care that incorporated Indigeneity, trusting the establishments that were designed with the intention of taking care of them, negotiating Indigenous and non-Indigenous healing practices on their
own, and finding family and social supports that they could trust not to backfire on them, accepting ARV was challenging. Respect, holistic health care, trust, culture, and family and friends are themes that helped understand the circumstances and obstacles related to the acceptance of ARV therapy among IPLWH. With a better appreciation of these aspects of the phenomenon, what remains to be considered are the circumstances surrounding the nature of adhering to ARV therapy once IPLWH accept it.
Chapter 7 Adhering to ARV Therapy

7.1. Chapter Overview

As has been described in Chapter 5 (Accessing ARV Therapy) and 6 (Accepting ARV Therapy), a substance use disorder was almost always an integral factor affecting access to and acceptance of ARV therapy use among IPLWH in this study. But as an explanation for IPLWH not readily accessing or accepting ARV therapy, a substance use disorder itself is an overly simplistic and non-granulated explanation. The case is similar for IPLWH with a substance use disorder who must negotiate a number of challenging circumstances in the process of attempting to adhere to ARV therapy.

This chapter will mainly describe, yet also explore and explain, contextual circumstances related to ARV therapy adherence by IPLWH. It will examine these socio-structural circumstances by five thematic areas. The five themes pertain to aspects of family and friends, culture, holistic health care, respect and trust. By now familiar, these themes are again drawn from the personal account by IPLWH and participant observation. This chapter will also again use the conceptual framework of the BMHSU and three sensitizing concepts (i.e., structure, vulnerability and resilience), within the context of critical Indigenous qualitative research, as heuristics to help understand the phenomenon.

Though the issue of substance use disorder colours the landscape of all five themes explored in this chapter, the focal point is the socio-structural circumstances affecting adherence to ARV therapy. The first two themes—family and friends, and culture—highlight the power of communities of support to influence IPLWH adherence to ARV therapy. The third theme concerns holistic health care and the quest for peace of mind by IPLWH. It highlights the importance of safe places and spaces and spirituality and is no less focused on structural agency despite any implication that a quest is a personal mission. The fourth theme concerns respect within the context of the effect of incarceration and law enforcement on ARV adherence. Finally, the theme of trust serves to focus the perceptions IPLWH who are living with a substance use disorder have regarding how the healthcare system might better support them in managing their drug use disorder and adhering to ARV therapy. The participants’ own ideas for transforming policies to support IPLWH living with drug use disorders will conclude this chapter.

7.2. The Influence of Family and Friends, and of Culture on Substance Use Disorder

The social networks of family and friends, and culture serve both an individual and a collective role in helping IPLWH adhere to ARV therapy and are no less important when trying to understand adherence to ARV therapy among IPLWH than they were to an understanding of access to and acceptance of ARV therapy.

7.2.1. Engaging with social supports while recovering from a substance use disorder.

There was only one participant in my study who reported not having a substance use disorder as a co-morbid condition with HIV. However, during his interview he talked about trying to control his use of alcohol and “smoking” (marijuana use) because such substances affected his ability to adhere to
ARVs. His case of trying to adhere to ARV therapy provided a good exemplar for the simplest benefits of family and friends to IPLWH living with HIV and a co-morbid condition of substance use disorder. Asked if any of his actions affected his using or not using ARV therapy, he responded:

Well, right now I just, I kinda of… I'm trying to, uh, quit drinking [alcohol] and smoking [marijuana]… and that, uh… kinda… affects me with my… my treatment that, uh. And that kinda of… I’m trying to, like… stop that ‘cause, uh… my doctors and that they really… think that I-I-I… I should stop drinking ‘cause of… my… immune system is really low. So right now I'm trying to… quit that and… try to… keep myself busy by, uh… hanging out with more of my friends who, who don't drink [alcohol] as much as, as my other ones. So I mostly hang out with them and, uh… I mostly hang out with, uh, my cousins too they… they support me and that and… and we basically just play, like… games and that… and just keep ourselves occupied… all the time. Like, we, we try to find something else new to go do, or else, somewhere to go… to go play… cards or… pool or anything, like, that. (Zarn: Male, aged 18-19 years.)

Zarn mentioned to how his use of alcohol and marijuana interfered with his adherence to ARV therapy. To counteract the allure of substances, he decided to associate with “friends who don’t drink [alcohol] as much.” Friends and acquaintances can have a powerful influence—for good or for ill—on individual behaviour. Other study participants who were living with a substance use disorder spoke of the effect that associating with those who were not in recovery had on them. Very often, like can attract like. As voiced by one participant, the positive influence of family and friends was not always enough to compel IPLWH who were managing a substance use disorder to adhere to their ARV therapy:

Interviewer: Do you have a strategy that helps you not to drink, like… um, I don’t know, think, think happy thoughts, positive thoughts, or… you know, maybe, social supports like talk to your friends and family, or go to… AA [Alcoholic Anonymous] meetings or?

Participant: I’m usually am… get into contact with my, friends that I know that don’t drink. And then I, try and keep my busy, I… keep myself busy, I-I… get into programs with my kids, just to get out of the house too. Like, I… look for programs, I phone around seeing what’s… what, what program I can take that involve the kids, or… they have transportation and childcare available. Just so me and the kids can… get out of the house too for a while and. And basically, probably just have to just to stay home (laughing) and I hardly even… come down here [Prince Albert’s city centre] anymore. (Prace: Female, aged 40-49 years.)

Although Prace made a point of associating with friends who did not use alcohol in order to help her control her own alcohol use, she realized that she also needed structured social supports to help control her substance use disorder. For her, socio-structural supports included various community programs that had a family-oriented agenda to them. In order for Prace to recover from her substance use disorder, she sought out social support activities in which she could involve herself and her children. When she
laughingly said she needed to “get out of the house” and “just have to just stay home” she was not contradicting herself. Her “house” was a place she tried to get herself and her children out of in order to keep busy and keep her children entertained, occupied and socialized. Her “home” was a state of mind that she had committed herself to staying in, and one that was psychologically as well as spatially apart from the distractions “down here” in Prince Albert’s city centre, where her interview was conducted and where, as we saw in Chapter 5, people with a substance use disorder and who were using their drug of choice congregated.

7.2.2. Staying close to one’s culture in spite of challenges.

Some study participants reported that they did not always feel welcomed by their Indigenous, cultural community and this interfered with their adherence to ARV therapy. One participant with a substance use disorder mentioned that her Indigenous community could make her feel unwanted and excluded at cultural activities:

Interviewer: And, and… taking part in those… cultural activities, how does that make you feel?
Participant: Um-m-m, makes me feel (pause) I don't know, like, sometimes… I'm not wanted around there (laughing) ‘cause I do too much drugs or something (laughing) Yeah. Mhmm. Like, they want to send you away with them… and that they're just there to help you (chuckles) Yeah (sniffs).
Interviewer: Yeah (pause) So… you know, like, when you go to those cultural activities and… you know, some people… you know, may not want you… to be around because… you do drugs or=
Participant: =Mhmm=
Interviewer: =Or anything else, um… like in a way that's discrimination; eh?
Participant: Yeah, it is.
Interviewer: Um… and does that discrimination… um… how does that… discrimination affect you… from using or?-
Participant: (overlapping) I don’t know. It just makes me feel, like, going out and using and doing [drugs and alcohol]… that I'm not supposed to be doing (laughing) Yeah; that’s about it. (Mintla: Female, aged 20-29 years.)

This participant found it hard to feel at one with her First Nation community when she believed her community was treating her like an outsider. Because she did “too much drugs” they wanted to “send [her] away with them.” It was unclear who “them” is. It was much clearer that she was sceptical of the good intention behind the community members who, she said with a chuckle, were “just there to help you.” This participant really wanted to connect with her First Nation community. But she was made to feel like an interloper in her own community. Nonetheless, she reported that she rode out the exclusionary vibes she was picking up on and she took part in cultural practices such as sweat lodge
ceremonies, which often seemed to help her with her overall wellbeing, though sometimes, she admitted, rejection just made her feel like “going out and using and doing [drugs and alcohol].” As came out from many study participants who were recovering from a substance use disorder, using substances negatively affected their adherence to ARV therapy.

The description by Mintla of her rejection was sad and moving. Add to this what other participants shared about feeling as if they had no cultural identify and no sense of community, and it seemed all the more remarkable that so many IPLWH with a substance use disorder who were made to feel socially outcast would nonetheless excuse or overlook the unhealthy attitudes they picked up on from individuals in the cultural community they identified with and wanted so desperately to re-enter. Add to this what other participants shared about feeling as if they had no cultural identify and no sense of community, and it seemed all the more remarkable that so many addicted IPLWH who were made to feel socially outcast would nonetheless excuse or overlook the unhealthy attitudes they picked up on from individuals in the cultural community they identified with and wanted so desperately to re-enter.

Despite feeling discriminated against due to their HIV status or substance use disorder, a number of participants persevered, stayed close to their cultural relations, continued to value their cultural traditions and, in the process, managed to adhere to their ARV therapy. For Mintla, it was her belief in her culture as opposed to the faults she witnessed in particular individuals that helped her adhere to her ARV therapy despite her struggle with IDU:

Interviewer: And how about, um… in terms of your own actions… how, how, same question: how your own actions affect you in using… or not using ARV therapy? How about… in terms of cultural activities? Do you… like, do… do you take part in cultural activities?
Participant: Yeah.
Interviewer: And, do. And do they help or?
Participant: Yeah; they do.
Interviewer: In terms of the… using or not using ARV therapy?-
Participant: (overlapping) Yup.
Interviewer: Did you ever wonder, like, how they helped? How is it that?-
Participant: (overlapping) Um-m… I don't know. My grandparents just telling me… depending when you go to the sweats and that… that, they would help me… they'll… they’ll help me pray. If I pray for whatever they help me for… or whatever I want them to help me for, it, it will always work. It will come; it come to you eventually. Yeah… and the grandfathers and that; they will pray for you and you will get what you… ask for… so. Yeah… I like going to sweats and round dances; I go to ceremonies and all that. My grandma got me into all those (sniffs) when I was younger. (Mintla: Female, aged 20-29 years.)
Despite not feeling universally welcomed at her community’s First Nation cultural activities because she was using drugs and alcohol, Mintla hung on to her cultural values and beliefs and persevered. The support she received from her grandparents had helped her to believe and not give up on her culture.

For many IPLWH recovering from a substance use disorder, connecting to their Indigenous culture helped them clarify their thinking, minimized their stress, and led them to better manage stress when they were under duress, even when some of that duress came from individual interactions with members of their own Indigenous community, thus leading to improved adherence to ARV therapy.

7.3. Searching for Peace of Mind: Holistic Health Care

7.3.1. Finding safe places and spaces.

Many participants, the vast majority of whom were living with a substance use disorder, indicated that finding safe physical and social environments, such as a stable home and a routine in their daily lives, helped them to adhere to ARV therapy. Stability and routine helped them avoid a relapse into substance use. One participant described how these fundamentals of daily living kept her from slipping back into her old ways of living and thinking:

Participant: Um-m (long pause) Um, I don't know. It… mmm… maybe. I don't know. I know that I was homeless from before, I was on… the… the dru-, on… the-e-e, antibiotics [ARVs]; that’s what I call them. And, um… I… I was… xxxx. Yeah, I think that probably would have stopped me. You know, ‘cause then you get back into that… that circle again; the bad circle… where, um… you got to hustle. And you got to find a place to stay for the night and… like (sighs) I never want to go back to that again; ever.

Interviewer: Mhmm (pause) So you think… like, not having a place to stay… that, that… that could affect… you… in… using… or not using… antiretroviral therapy?-

Participant: (overlapping) Mhmm. Yeah. I really think so. You need, um… like… I started [ARV therapy] when I was in the hospital so I got into a routine. And… I just need to have a nice… a… a routine I think and… be in a healthy environment… you know. And then you're probably, you know… want to live more longer and. 'Cause, when you’re not in a healthy environment… you know. Well… you're thinking, “Okay, what do I got left.” You know. “And I'm dying anyways; right?” That's how I used to think anyways. I'm, like, "Well, I'm dying anyways, so… who cares?" You know (long pause) But when it came… close to me almost dying. I didn't want that (chuckles) uh (pause) and obviously the Creator didn't want that either. (Indime: Female, aged 30-39 years.)

Stable housing afforded Indime a routine for her daily living, which subsequently helped her to adhere to her ARV therapy. As for almost anyone, for IPLWH a safe physical environment was a precursor to a safer social and mental environment. For those IPLWH with a substance use disorder, stability in their life staved off the struggle against a false sense of emotional security that came with medicating
themselves using drugs and alcohol. Participants who spoke of daily routine never once said it was dull. Rather, a routine counteracted their inclination to dull themselves with substances and it encouraged them to work towards a goal. The focus that comes with goal-setting gave participants living with a substance use disorder emotional security. Goal-setting served as a coping strategy that allowed IPLWH to avoid boredom and to think positively.

Some IPLWH with a drug use disorder who were also using MMT were acutely aware that, in order for them to stay clean and sober and adhere to ARV therapy, they required a routine. A simple routine could go a long way. One example was going to the pharmacy every day in order to have one’s directly observed MMT administered. One participant indicated to me that although her physician allowed her to have a supply of methadone to self-administer at her own home, she still preferred to go into the pharmacy every day to receive her MMT from the pharmacist:

Interviewer: So, and… so, do… do you, um… do you go to the pharmacy to take your methadone or do you… xxx xxx?-  
Participant: (overlapping) Yeah. Yeah, I go there every day to the pharmacy. I could get carries [take-outs of methadone to self-administer] if I wanted. But actually I told them, “No, not yet.” Because I like going out every day (chuckles) It gets me out of the house; at least until after my baby is here. Yeah. And that, that way too I get my meds every day. (Grinda: Female, aged 30-39 years.)

For Grinda, going to the pharmacy on a daily basis forced her to get out of the house and helped with her positive outlook on life. For many participants, this positive outlook on life was a constructive coping strategy. It prevented them from regressing into negative thinking, which could lead to a relapse into drug use, which could subsequently affect adherence to ARV therapy.

The satisfaction that came with breaking a vicious negative cycle with positive thinking, chores of daily living in a home, and even seemingly mundane routine, could not be underestimated in this study. Another participant with a substance use disorder talked about finding something, anything, to do to stay out of trouble:

Interviewer: Can you please tell me what led you to take part in my study?  
Participant: What led me to take part in the study? I don’t know. Just… wanted to take part in something… instead of walking around (chuckles) not doing nothing or staying home; watching TV. Do something positive I guess… with my time (pause) That’s about it (laughing) And to find new stuff to do… instead of just… getting myself in trouble or (pause) or just… not doing nothing. You know what I mean? Just keeping out of trouble (chuckles). (Switie: Female, aged 30-39 years.)

Switie tried to set daily personal goals for herself so that she would develop a more positive outlook on life. When this participant got bored, she started searching for coping mechanisms to preoccupy herself.
Given her substance use disorder, one of those strategies was drug use. But by replacing boredom with aspirations and goal-setting, IPLWH were more likely to want to adhere to ARV therapy. As another participant described it:

I wanna get my kids back. I want… I wanna live-e… normal. I wanna have a home. I wanna have a car. Now I’m thinking, I’m… I wanna be an addictions… worker. Like… I wanna tell my story… to, to… to teenagers, and let them, you know, see this is what… you know, drugs lead to this and then… the last step is, you know, HIV (pause) So it… it affects me by… probably… about using [ARVs], taking them. Mhmm (long pause) yup. (Heenda: Female, aged 30-39 years.)

The long-term benefits of adhering to ARV therapy were clear to all IPLWH in this study who had accepted ARV therapy. The rewards that IPLWH with a substance use disorder reaped from constructive daily routines in a stable home, and finding safe places and spaces provided repeated short-term benefits that could fuel their long-range goal of adherence to ARV therapy.

7.3.2. The consolations of faith, hope and spiritual practice.

For many ILPWH in this study, their short-term and longer-term goals for finding safe places and spaces and for adhering to ARV therapy fell on a continuum. That continuum was the realm of the spirit.

As previously mentioned by Indime, when she became very ill, she did not want to die. She believed that the Creator did not want her to die either. Spirituality was a common subtheme in this study. For IPLWH who were living with a substance use disorder, believing in a power greater than themselves offered hope. Such hope provided IPLWH the motivation to forge ahead to overcome bad spirits, entertain good ones, and more practically, to adhere to their ARV therapy:

Participant: So when I got back on to the [ARV] meds again and started taking the meds… daily… you know. You know, I just start getting better first, you know, ‘cause at first you get thrush and stuff, like, that; right? And you get, uh (coughs) you know, you just… have no drive… and, uh… and then the thrush starts to go away and then you start to get perky and… do you know what I mean? And then just, uh… and that, that spirit just kind of lifts right off you. For me it was, like, that spirit just left, right off of me and, I just kind of… like, I said, I got my hope back and… and the doctor, you know… that… you know, would do all the testing; the blood tests and stuff, like, that and. And it was positive.

Interviewer: Yeah. And… so… so, you know, when the spirit, like… um… you know, like, left you… that was a bad spirit?

Participant: Oh, yeah. Yeah. That was, like, death (laughing) like, a, that’s when I thought it was death. It was spirits, you know, it was just this… this ugly. It was the worst feeling that I ever felt in my life. (Reth: Male, aged 30-39 years.)
Hope gave Reth the strength to persevere and ultimately adhere to his ARV therapy.

Believing that something or someone greater than oneself is looking after them helped IPLWH to feel strong and provided them with courage and the desire to adhere to their ARV therapy on a long-term basis. The power of such spiritual belief became very evident as one participant explained her path to adherence:

Interviewer: Mhmm (long pause) (clears throat) Okay. In, in general, tell me about… how other people actions… affect you in using or not using ARV therapy.
Participant: Well just, like, I said, they’re happy that I, um… started it and everything. They’re so happy… and in a way they were concerned too… about it… like, “Why are you taking these? Didn’t you just find out? What’s, what is this, what is the [ARV] medication going to do? Is it… what kind of side effects? Mmm. Are you ready to take this? You’re going to take this, you can’t. If you’re going to start taking them and after, keep taking them, you can’t stop.” Stuff, like, that; I guess. Does it make sense?
Interviewer: Totally (pause) And when, when people treat you differently, like, when they say, “Why are you taking these medications?” Mmm. You know, “What will happen to you?” and… all this other stuff. Like, when people talk like that, how does that?
Participant: Some of it makes me upset. Xxx xxx xxx other people… at first. It all depends. My family is very supportive; some of my friends are, some of my friends are not. They have HIV and they’re not even; they are not on [ARV] medication, so it doesn't. They, they, they say you don’t have to be on medication. I believe in the power so I don’t know. As long as you quit the drugs… you won’t get sicker; that’s what they say. But me, I, I have a lot of slips. That’s because of my childhood and, so. That’s about it. (Switie: Female, aged 30-39 years.)

In the context of this section of the interview, “the power” for Switie was clearly the power of a supreme being. Despite this participant having recurrent relapses into drug use disorder, her belief in a higher power helped her to persevere. For her, a supreme being worked through others such as family and friends. Regardless of how IPLWH defined their higher power—whether through Christianity or Indigenous beliefs—spirituality was a critical component of their support program to adhere to their ARV therapy. Yet another participant credited her belief in God for helping her adhere to her therapy:

Interviewer: Yeah. And you, you… you seem… like, spiritual, um. Does that affect you… in using… or not using ARV?=
Participant: =Totally (clears throat) It helps me. It help… I’ve found God so it helps me… way better, way easier. It’s… I think that’s why I’m still taking them is ‘cause of my… my belief. And… yeah, it just… it does help; it helps big time. It helps me take them [ARVs] every night. Like, if I start feeling sick, I’ll just start praying and then… and, like, the xxxx… like, God when
xxx xxxx, like, fall asleep or something, you know, I don’t feel. (Grinda: Female, aged 30-39 years.)

For Grinda, spirituality and her belief in God helped her to adhere to ARV therapy.

For the majority of study participants, spiritual consolation came to them as part of their experiences dealing with their substance use disorder:

Interviewer: Do… is there any, is there any… like, any Aboriginal organizations or… the culture, you know… that affects you in using or not using ARV?
Participant: You know what? I've never even… went that way. Um… like, I am, like… what, like, third, fourth generation Christian. So… like… I was never ever… even, like… up until I was 30… I was nev-, I was brought up on the street culture, so I was never-r-r… brought up with any Native spirituality or any Christian spirituality. Um… or… you know, or religion. A little bit of religion probably… you know, ‘cause in schools; public schools when I was younger. But, uh… and a little bit of high school. Um… but other than that, no. Like in (long pause) until I was really, uh… yeah, until I actually started straightening out and started really, kind of, like, seeking God (chuckles) Like, get… get that spiritual… you know, started to… put all that spiritual… stuff together. (Reth: Male, aged 30-39 years.)

Reth, like most of the other study participants, only started seeking out spirituality after he was diagnosed with HIV and once he began addiction recovery.

When Reth shared news of his HIV-positive status with family and friends, they “drifted away”: It's just, like, um… getting shunned out. Yeah. Yeah. Like, uh… you know, I wasn't really close to my family growing up but, um (sniffs) I sort of had an extended family and I had, uh… um-m… like, people I worked with and stuff, like, that and… and also I ha-a-ad family, like, uh… my brothers and my sisters and… and they're sort of, like, my half brothers and sisters… and then I had the street family; right? And so… but when I, um… so I had three different groups of family, type of members to, to-o get support from and to-o, to… to, uh, get encouragement from or whatever; right? Uh, whatever. Or my needs met from them; right?

And also they looked to me… for, for, you know, they used to come to me too… at one time. And, um… and when I found out I was HIV positive and (sighs) and I also had to get on the meds… and I was very sick (sighs) You know, a lot of the family members an-n-nd… and all those different groups kind of sort of, slowly… drifted away. And so now… you know… um…

I'm by myself. (Reth: Male, aged 30-39 years.)

Reth shared that when he was involved in a street gang, the gang used to make fun of people who were HIV-infected and who were on ARV therapy. Reth did not disclose his HIV status and his ARV use to his fellow gang members for some time. Eventually, when he did disclose his HIV situation to his gang, they cut him loose, causing him to go into depression, which then made him stop taking his ARV
therapy.

Perhaps having a holistic approach to ARV therapy use that incorporated spiritual practices helped IPLWH who were recovering from a substance use disorder to persevere, despite those negative circumstances that were not always conducive to adhering to ARV therapy. Such spiritual practices extended from treating oneself and others decently through to believing in the reality of good and bad spirits.

Although taking part in spiritual practices seemed to help IPLWH with their use of ARV therapy, such practices were not without their challenges. The majority of IPLWH in this study alluded to spirituality at some point in their interview. Recognizing the existence of a spiritual realm was an easy notion for them. Finding space for spiritual practice often proved more difficult. One participant indicated that although smudging helped her with her recovery from substance use disorder, at times she was unable to find Indigenous, cultural medicines to smudge:

I smudge sometimes but, um… I’m kinda running out of sage now and I don’t even know where to get any. So-o… um… I think it helps me relax a bit and… I don’t believe in taking the Gravol… like, for when my [ARV] meds make me sick. So… usually I just try to smudge and relax and… kind of just meditate and pray… and that seems to help. Yeah. So-o… um… yeah, ‘cause I just don’t believe in taking that Gravol, ‘cause people get addicted to it and… with my addictive behaviour, I just… feel, like… I’d probably end up getting addicted to it if I took it. (Pristie: Female, aged 20-29 years.)

This study participant was in the relatively early stages of her recovery from a substance use disorder and as such, she was just beginning to create new social supports. For many IPLWH living in the city and with limited social supports, practicing one’s culture proved challenging. During my four months living in Saskatoon, travelling to Prince Albert, and interviewing study participants, I learned that some Indigenous cultural practices took place in the city centre as well as outside the city. Many of the IPLWH who lived in the city did not have the economic resources to engage in cultural ceremonies outside the city. Furthermore, they lacked the social networks to find out where cultural practices were taking place within the city centre. For IPLWH living in the city and with limited resources, not knowing how to engage in and sustain one’s cultural beliefs and values was an impediment to adhering to ARV therapy. For many of the study participants, traditional Aboriginal cultural practices were an important aspect of using ARV therapy. The value such practice served in helping one to use ARV therapy was described by another participant:

Interviewer: Mhmm. And, and you mentioned, um… like, Aboriginal traditional healing practices, like sweats and… um. Does that affect you in either using or not using ARVs?
Participant: Um-m… well yeah, it’s-s, it’s just my spiritual beliefs. Helps to, with my spiritual beliefs, yeah so. Yeah, strengthens my… xxx. (Blont: Male, aged 50+ years.)
Of course, any place can be turned into a sacred space, including a quiet room at home. Praying helped more than one study participant commit to their use of ARV therapy. It also helped one participant disclose her HIV status to significant others.

Participant: I usually-y, would… if I’m not concerned about something, I usually sa-, say a prayer. To ask God to give me a sign of some kind to let me know if it’s the right time or not. And that’s what I did yesterday too. ‘Cause I was… starting to really feel kind of nervous… about telling my kids. And, um… so I went into the room and I said a prayer and I-I just, like, talked, like, the way I am talking to you, I was talking, like, that. And then, um… and then I just said, xxxx, like, just show me some kind of a sign to, uh, let me know, help me… to let me know… if this is the right time to do it or not? Yeah, so.

Interviewer: So, so praying, um, does that… um, does that make you want to use the ARV more or not use the ARV more?

Participant: Praying… yeah. It helps… with lots of stuff. I… pray lots. (Prace: Female, aged 40-49 years.)

Praying helped Prace when she was uncertain about things including, in this case, disclosing her HIV status to her children. Prayer also helped her adhere to ARV therapy. For this participant, disclosing her HIV status to her children was particularly important because, given increased demands of childrearing, not having to hide her ARV pills from her children made it easier for her to adhere to her ARV regime. Regardless of how IPLWH refined their definition of spirituality, being connected to one’s Indigenous community meant that many IPLWH who were recovering from a substance use disorder found the strength to face the challenges of using ARV therapy. As summarized by one participant, spirituality is a critical aspect of the lives of IPLWH:

Participant: Oh, they [social support systems], um… they help me in a positive; in a positive way. Yeah I go to sweats and… or to (((Name of the First Nation Community deleted)) that is where my wife is from.

Interviewer: Mhmm. Yeah. So (clears throat)… so taking part in your, in your, like, in your… in your culture and having cultural identity… does?

Participant: (overlapping) That helps. Yeah. It helps a lot… yeah, yeah. You need, you need… you need spirituality xxxx. Even people without… any kind of problems still, they need it. You know, everybody needs it… not just. (Blont: Male, aged 50+ years.)

Another participant went so far as to say that all Western health care of IPLWH should incorporate traditional practices:

The most important thing… what I would like… for… doctors… is, like, to… incorporate that spiritual… and that mental… and… the physical. Yeah (clears throat) especially with Natives; right? I think that would go a long way (clears throat) Like, I was saying… earlier about the
doctors not asking xxx xxx. Well, let's ask the Creator… you know, let’s sit down and… and bring an Elder in; right? (clears throat) Or, whatever, or… a pastor. Whatever; right. Whatever the person's, uh… spiritual. I know that they… they've, um… incorporated, uh… like, a… nurses; right? Um, crack, uh, disease nurses… that come in… and sit down and talk with them if xxxx xxx, which is good. And I think, um… yeah, a person needs to be, uh. I think it's, uh… o-, overall… a full circle… walk. Yeah. Just to help them keep them balanced; right. (Reth: Male, aged 30-39 years.)

Reth believed that efforts by physicians to work with him on all of the physical, mental and spiritual aspects of his health status would help him adhere to ARV therapy. Furthermore, if physicians were to validate the spiritual context of recovery from substance use disorder, and even share in IPLWH’s spiritual practice during a healthcare appointment, this could encourage IPLWH to adhere to ARV therapy. By incorporating the spiritual into the physical and mental realm of healthcare practices, and by including the support of Elders and pastors, physicians could better help IPLWH to keep their balance.

By his own account, he was raised on “street culture” and was “never-r-r… brought up with any Native spirituality.” Once his friends and family “drifted away” and he was on his own, he drew some strength from a spirituality he never really knew but somehow grasped. As also reported by many other study participants, Reth was saying that holistic health care needed to be an integral part of ARV therapy use for IPLWH, and physicians needed to address the biomedical, behavioural and social aspects of care. They needed to incorporate the spiritual, mental and physical components of health care into their medical practice if they intended to commit themselves to supporting their clients with adherence to their ARV regimen.

For many of the study participants, the patience and the faith derived from their spirituality helped them to persevere in using ARV therapy despite the chaos they encountered in their lives and the deferral of gratification that faith demands. As described by one participant who was recovering from a substance use disorder and who seemed to be adhering to his ARVs, it was his faith in God that helped him:

I care about… myself… and… I know I can, like… I can live a good life, a happy life. And what causes suffering and grief in my life I’ve identified that and as long as I’m on top of those (pause) those things that would lead to my, you know… grief and everything else. As long as I stay away from those and… follow what I believe to be good in my life, I’ll, I’ll, you know, everything else I would just (pause) do that’s, needs, you know, that’s… do what I have to do (pause) to feel complete and healthy and happy (long pause) And once again, the foundation that I, I’d like to… believe that I have is… uh… my belief in God that, you know… there’s a heaven and hell and there’s… a God in my life that cares about me and what happens to me. And that he’s there… regardless of what happens to my life, as long as I always go back to that… you
know, things (snaps fingers) may not happen, like… instantly; things that I want to happen. And the things that don’t happen, there’s obviously a reason… that they don’t happen. And eventually they’ll, they’ll, you know, that reason will be revealed to me. That’s where I’ve come to an understanding with it. (Drane: Male, aged 40-49 years.)

Drane have spent part of his life running from the law and being incarcerated. Despite a chaotic life, his belief in God helped him to manage his stress, to keep his substance use disorder under control, and ultimately to adhere to his ARV therapy.

Having faith, hope and spiritual practices helped IPLWH in this study to adhere to ARV therapy. For many of them, having faith in a higher power brought them out of their despair and gave them the strength to persevere. Hope helped them to create goals for themselves such as attaining and maintaining their health by adhering to their ARV therapy. Last, while for some, spirituality meant practicing Christianity, for others it meant being grounded in their Aboriginal culture, and yet for others, it meant practicing both Christianity and Aboriginal spirituality simultaneously.

7.4. Respect: The Effect of Incarceration and Law Enforcement on ARV Therapy Adherence

It can be hard for IPLWH to improve a socio-structural organization such as the healthcare system without advocates. But within the context of this study’s population and setting, IPLWH were sometimes capable of influencing other social networks and supports, and even socio-structural norms to help them with their adherence to ARV therapy. What some study participants had learned over time was that collective human elements/actors, such as health service providers, family, and law enforcement and corrections personnel could be compelled to support them when it came to helping them adhere to ARV therapy. Drane spent a couple of nights in a correctional facility and a police officer agreed to go to the participant’s home to retrieve his ARV medication for him. The correctional services health staff were cooperative about administering the incarcerated participant his ARVs. Such an integration of services provided a holistic, albeit temporary, approach to ARV therapy adherence.

I was arrested… and I explained that I needed my… my HIV meds… and the police… did go to my place and they tried to… you know, get them for me… and they understood that I had to take them daily. And when I went to, when I was incarcerated for a short period there, ‘til before I was released, I only spent like two or three days in there. And right away the health care, at… professionals at the… like, the nurses and stuff… at the… uh, correctional centre they… you know, they administered them to me, like, the way they were supposed to be and… so, there was really no… issue or concerns there… regarding my… my medication. (Drane: Male, age 40-49 years.)

Drane did not say that he had to argue with the police but only explained that he required his ARV medication be retrieved from his home. With the correctional services staff, he did not have to reiterate his personal requirement. Rather, “they administered [the ARVs] to me, like, the way they were
supposed to.” The police and the correctional services health staff required only limited prompting to ensure that the participant adhered to his ARV therapy once the participant explained to them the necessity that he adhere to his medication. Law enforcement and correctional services in this specific case helped the participant adhere to his ARV therapy. Granted, at the same time, based on what was witnessed while interviewing him, the participant’s predisposing social ability probably made it possible for him to interact and negotiate with the correctional system. The study participant had the ability to influence the police who, in turn, were able to engage with correctional facility health service providers who administered the ARV medication to the participant. Perhaps this participant had the experience of having been arrested, detained and incarcerated on more than one occasion to help him negotiate the correctional services system and to adhere to his ARV therapy.

Does such cooperation demonstrated by all parties involved routinely occur when incarcerated IPLWH explain or even insist on their need to take ARVs daily? When another participant, this one with a drug use disorder and access to AVR therapy via monthly refills, was “picked up” by the police, the police would not facilitate her getting her ARVs. She has since made sure she has one dose of ARVs on her person at all times just in case her schedule unexpectedly changes and she needs them. In addition to her ARVs, she also carries her methadone on her person. However, she reported that if the police picked her up, the police would confiscate her methadone if it was not sealed properly. This was problematic for IPLWH who were on MMT because very few pharmacies in Saskatoon sealed methadone when dispensing it. This issue was described by her:

Participant: And now I hear what they’re doing is, like, the pharmacies, they’re using these bigger… like… they used to put that thing on that they… blow dry, seal shut but they don’t have those anymore, so if you. There’s only two pharmacies that do have them, so where I go… if I have my methadone on me, let’s say and if I went to jail on a Friday and I have two bottles for Saturday and Sunday when my… uh… anyways they dump it. ‘Cause there’s no seal on there.

Interviewer: Who dumps it?

Participant: The police.

Interviewer: Oh-h-h. Oh, I see. Okay.

Participant: They put some kind of little plastic thing and they use that thing that looks like a blow dryer and kind of melts around the… bu-u-ut, I don’t know whether that got too expensive or what. They don’t use those anymore. (Pila: Female, age 40-49 years.)

The social, spatial and temporal orientations to the world for this study’s participants can often be influenced by unexpected or unwelcome contextual characteristics. For instance, the extent of isolation and social distance that IPLWH might experience when incarcerated, and the potential for them to miss a dose of their ARV medication during incarceration, is influenced by the social interaction between them and the structures, such as police and correctional services staff, that IPLWH encounter.
In the case of Drane, the dialectical relationship between correctional services and himself meant he could use his social skills and his understanding of his own health to effect change positively. As a result, he was the beneficiary of integrated services that provided him a coordinated approach to his ARV therapy adherence. Such a holistic approach to ARV therapy was possible because of the social interactions skills that Drane had in order to influence the process of medical care vis-à-vis authorities. Of course, this case also speaks to the contextual characteristics of enabling health policy and the ability of the police and correctional services staff to help this participant. But if it seems ungenerous not to give more credit to the enabling organization of healthcare provision by health service providers, consider the case of Pila who had her methadone confiscated and needed her ARVs. Her experience might be seen as a symptom of larger socio-structural problems:

Well, I got picked up a few times. And… they won’t, even though, the police know I don’t have my… they know I have HIV but they won’t go get [my ARVs]. And I told them how important it is and they’ve… sat in on meetings ((Physician’s name deleted)) told me; ‘cause he’s the one that runs the program here… tha-a-at. And ((Physician’s name deleted)) was in the meeting too actually; that we need them when we’re in jail. Not only just, like, methadone and stuff, like, that. (Pila: Female, aged 40-49 years.)

Next to the case of Drane, the experience of Pila strongly suggests that her lack of agency was as significant a barrier to her negotiating access to her ARV therapy and MMT as were the contextual predisposing social characteristics (i.e., correctional and law enforcement services). She could not win over the support of these agents of authoritative structures. Nonetheless, socio-structural factors were the driving force of her ability to adhere to her ARV therapy while in the correctional facility. Given the experiences of Pila as well as the experiences of other study participants who had a history of incarceration in terms of them never using ARV therapy, it appeared the correctional services staff had little to no understanding of the importance of using ARV therapy for those living with HIV. The ability of Drane to interact with correctional health services staff in order to orchestrate health care from his cell began to feel exceptional when considered next to the experiences of some other IPLWH. It appeared that Drane convinced the correctional services staff of his own personal circumstances rather than of the application of HIV therapeutic guidelines—guidelines that the correctional services health staff ideally should be able to consult when practicing health care.

Based on these two contrasting cases, it appeared that adherence to ARV therapy by IPLWH who are incarcerated could sometimes be enabled by their individual characteristics. Sometimes, the agency of IPLWH to influence their larger socio-structural environments was inadequate. ARV adherence among IPLWH was not always facilitated in terms of how correctional services health care was offered to them. What can be surmised from this analysis is that socio-structural environments such
as correctional systems play an influential role in facilitating and impeding the adherence to ARV therapy among IPLWH.

7.5. Supportive Health Care and its Impact on Trust

As seen in Chapters 5 (Accessing ARV Therapy) and 6 (Accepting ARV Therapy), trusting relationships with health professionals can be a determining factor for IPLWH to access and accept ARV therapy. As many of the participants in my study revealed, trust also affects adherence to ARVs.

7.5.1. Working through methadone maintenance therapy.

Trust was developed between healthcare providers and IPLWH when they worked together, thus helping IPLWH adhere to their ARV therapy. This was illustrated by IPLWH with a drug use disorder who talked of planning their health care as it pertained to MMT along with their physician. MMT helped these IPLWH who were living with a drug use disorder to control their addiction to the extent that they were then able to adhere to their ARV regimen consistently. A few study participants talked about their successes working alongside physicians to ensure strategies that supported their adherence to ARV therapy. Here is one example:

I went to see my doctor and he had to up, my methadone doctor, and he had to up my… dose of methadone… to where… you know… it was consistent with my, my… how they, them… viral, HIV viral drugs were… affecting my, my, uh, metabolism. So, it finally came to a point where we, we… I (pause) I suggested to my doctors that… I take so much in the morning… an-n-nd I get to split my dose of methadone… because where I was before, I was taking the whole dose in the morning and by three or four o’clock in the morning I was already, like, it wa-, it already burnt out all my methadone because being on the HIV meds. So, I suggested that, you know, I take half in the morning and I take the other half home with me and I take that at, like, say, 8 o’clock at night. And, you know, we tried that until… we came up with a proper amount of dosage where, it, I, you know, it would suffice… ‘til the next day. So, once we were, you know, we figured that out, it was, we were good. (Drane: Male, aged 40-49 years.)

Drane recognized that the ARVs increased the rate of metabolism of his methadone. The way that the MMT was initially prescribed to him was not effective. However, he and his physician worked together to find a schedule for administering MMT that could work with his adherence and help him avoid the circumstances that would trigger reverting back to using illicit drugs to feed his opioid use disorder and compromise his ability to adhere to his ARV therapy. As a result, he asked his physician to split his daily methadone dosage. Self-management in conjunction with continuous medical care and support from an attentive physician helped this participant adhere to his ARVs. This is an example of how the perception by IPLWH of their own health can influence how physicians evaluate their clients’ need for medical care. The constructive interaction of a physician with a client can create a nexus that supports adherence to ARV therapy by IPLWH. This issue was described by the same participant:
I finally got back on the methadone... got back on different meds this time. He [the physician] said well, it was only, it’s better for me to take these because... he didn’t want to risk, I don’t know, whatever reasoning for continuing with the old meds that I had. And these meds metabolized, same, same effect with the old ones. But... um, I had no, uh... uh... I didn’t have no nightmares no more or anything, and everything’s been fine since. You know, I stopped using the... the other stimulants; no more narcotics. (Drane: Male, aged 40-49 years.)

An alternative ARV regime that did not cause adverse side effects such as nightmares allowed the participant to cope more effectively and avoid street drugs, thereby allowing him to adhere to his ARV therapy. The physician and participant together worked out a revision to the medication regime. And when the nightmares subsided, the participant did not need street drugs as a coping mechanism and could adhere to his ARVs. When MMT works as a treatment option for IPLWH with an opioid use disorder and when healthcare providers encourage and support the self-management by IPLWH of their overall care, the ensuing environment of trust can support adherence to ARV therapy. It must be pointed out that this participant is the same participant who was able to negotiate his ARV therapy use from his prison cell. One might question whether trust in health service providers is always so easily gained from IPLWH within the context of their substance use disorder.

7.5.2. Transforming policies to support drug use disorders.

When IPLWH with drug use disorders proposed more unorthodox approaches to managing their own health care, physicians were often less confident interpreting medical guidelines, and trust by IPLWH in a physician’s inclination to support a collaborative healthcare agenda deteriorated. One participant who shared her account of adhering to her ARV therapy and the additional challenge she faced living with co-morbidities, depicted a strained interaction with her physician. She saw herself as an object acted upon by the healthcare system. This participant, who was living with opioid and stimulant use disorders as well as Attention Deficit Hyperactivity Disorder (ADHD), believed that the larger healthcare system needed to undergo a transformative change if IPLWH who are living with substance use disorders were to adhere to ARV therapy. Physicians have at their disposal the evaluated health outcomes of their clients who are IPLWH living with a drug use disorder. They also have the professional judgment to influence health policy and improve the organization of the healthcare system to better serve the interests and the health issues of IPLWH living with a substance use disorder and other mental health disorders. Granted, medical care is supported by medical guidelines; however, such protocols may fall within the subjective domain of both individually specific interpretation and global revision. The medical academy could influence health policy change in order to improve the process of medical care for IPLWH with a substance use disorder. And IPLWH know this. This participant described how the process of medical care affected her satisfaction with her own health care and her communication with her physician:
And then… to put that on me, that he [the physician] has to… tell his… higher ups that, “Oh, well, I got… to fig-, I gotta… figure out why I’m giving you this.” “Well… you’re my doctor… you know me, like, why, why would you have to figure out why… why, what’s to tell them?

There’s no reason why you would have to figure out why you tell them because you know why. I’ve been doing really good. And… I’ve been taking my [ARV] pills. I am feeling anxiety.”

Not… well, pills give you anxiety. Just taking them every night gives me anxiety. “And you’re telling me, ‘Oh, my whole life isn’t, like,’” you know. It’s still a struggling. “And you’re telling me you can’t. You got my anxiety just for, like… a couple of weeks, a week.” You know… like, that doesn’t make any sense. And… his, his thing is that he’s got, he’s got to figure out why he’s doing. I don’t know. It’s not my problem; I’m not going to deal with it. (Jupie: Female, aged 30-39 years.)

This participant tried to persuade her physician that medical regulations governing physicians’ practices were affecting her adherence to ARV therapy. She wanted to know why her physician was prevaricating about treating her overall health, which included HIV-infection, a substance use disorder, ADHD and an anxiety disorder. She tried to appeal to the physician’s professional judgment so that her use of personal health services could include obtaining medically prescribed Valium to treat her anxiety, a disorder that she felt she needed to get under control if she were to adhere to her ARV therapy. She had frequent nightmares about an abusive relationship in her past. As she described it, she was terrorized by a recurring dream where certain people had discovered she was HIV positive and wanted to kill her. In her waking hours, she was haunted by her former lifestyle, which had precipitated her contracting HIV. And whenever she took her ARVs, she would be reminded of all this. For this participant, what her HIV and her ARV therapy represented for her caused her anxiety:

Positive meanings and negative meanings, about why the [ARVs] you, your (pause) you gotta take them every night. It’s not the reason, it’s not… why your, like, how you’re taking them or. It’s the reason… behind them (sighs) (pause) The [ARVs] are there to make you live. Make you… live longer… (sighs) but they are also the reason why you made a mistake (pause) and that would be the reason why I feel shitty tomorrow (long pause) (crying) And that is the reason why I am depressed (crying) You know, the only reason why you find joy out of life. There is more meaning to life now… every day you just look at those [ARV] pills and thinking… something new every day because there’s always something else, like, those pills are connected to (long pause) It’s, like, you hate them xxx but… xxx not to take them xxx ((There is 40 seconds of silence before the interviewer responds)). (Jupie: Female, aged 30-39 years.)

Although she was recovering from a substance use disorder, Jupie believed that taking Valium under the care of a physician could effectively treat her anxiety disorder and, in the long term, help her to adhere to
her ARV therapy. However, given her history of addiction, her physician was hesitant to place her on prolonged use of Valium. She described what her physician had told her:

“If I [the physician] give you this, I’m enabling you and I have to, I have to talk to… these doctors at the university and tell them: Oh… well, this is why I am giving it to her. They’re gonna look at your file and they’re going to say, well, this girl has been doing this and this and this, you know, give. I, I’ve been giving her this every three or four months xxx.” You know. And I’m [the participant] sitting there thinking, like, “Well, that’s not my problem, I’m your patient. You’re struggle with the [university] doctors to convince them, then maybe you should really look at the people you are actually giving it to.” You know. “Oh, well, obviously it’s helping because you’ve been giving them every three months or something, but I’m doing way better.” And I don’t need them [Valium] every two weeks… like, I was taking them; the anxiety pills. I don’t need them every two weeks. I, I… I need them every three, four months. And even then, I’m need… every six months. “Well, look how good she’s doing.” “You can’t… you’re telling me that you can’t tell the doctors.” “Yeah, well, look at her file. Look at what she’s been up to.” I mean, “You see me… and you know me, my needs, you know my kids, and you’re trying to tell me that I’m playing you? And it’s really hard to convince your… higher ups that… you’re doing a good thing? Or you’re not enable-, enabling me?” Well, that’s wrong? I know it’s wrong. So, you see something that I did and… you know, and he got mad because… I guess he’s been struggling, you know. That’s not my problem, that’s his. And now you’re make it my problem because it just gets frustrating. That’s wrong. I know it’s wrong, and he knows, I know it’s wrong, so. It’s, like, a lot of, um… he’s struggling with the fact that he has… a level to maintain, and he hasn’t been maintaining, or he’s, you know. (Jupie: Female, aged 30-39 years.)

Many IPLWH were unable to adhere to their ARV therapy on account of having insufficient personalized health services to help them with their co-morbidities such as substance use disorder and anxiety. Perceptions by IPLWH with substance use disorders that healthcare provision could be re-evaluated was not completely unfounded. In fact, it was legitimated by the prescribing patterns of a small number of physicians including those who would not deny ARV therapy to IPLWH who experienced relapses of their substance use disorder and those who were prepared to work together with IPLWH on MMT dosages, as seen earlier in this chapter. On the other hand, at least one participant in this study had a difficult time trusting a physician who spoke about having to justify his prescribing patterns to a board of university physicians, because it implied that, under other circumstances he could have prescribed different treatment to this participant. IPLWH who were clients of other physicians resigned themselves to obtaining street drugs, which did not help them to adhere to their ARV therapy. Ultimately, one is left questioning the healthcare system and the regulations governing the discipline of
medicine. IPLWH whom I met with believed that physicians conformed to unintuitive health policy at the expense of the health needs of their clients and, further, that the health system’s organizational structures were preventing IPLWH from recovering from their drug use disorder and adhering to their ARV therapy. IPLWH wanted to be under the care of a physician who would treat their co-morbid conditions within a controlled medical environment instead of their having to obtain illicit drugs off the streets to medicate themselves.

IPLWH with a substance use disorder bear the brunt of a larger problem of inequitable treatment. The collective definition of this situation works against an individual’s prospects for using personal health services to meet his or her perceived health needs. This was described by one participant:

I guess they have, they’re, they’re sort of, like… fighting with the… a little bit with the government and, and with the… this, you know. The government… the government sanctions that watch over, what they prescribe to us; right? An-n-nd… and us, right? … like, to making sure that we're just not drug seeking… right? But… as an addict an-n-nd stuff… and what I need to come. What I need… to make myself, um… be successful daily so that I can take my meds every day… um… I think I know that more than anybody else. (Reth: Male, aged 30-39 years.)

In light of the discourse of the discipline of medicine and system-wide regulations, it is important to consider how contextual characteristics of enabling health policy might influence how the organization of health services and how the process of medical care affects ARV therapy use. As Jupie explained, the physician was hesitant to prescribe Valium to a client with a drug use disorder on a long-term basis since the physician’s medical regulatory body might perceive such action as not in the best interest of IPLWH with a drug use disorder from a medical perspective. Yet, if a drug use disorder is not controlled, then IPLWH will likely not be able to adhere to their ARV therapy. And by not adhering to their ARV therapy, IPLWH face the grave consequences of co-morbidities, including the very real possibility of developing a drug-resistant strain of HIV as well as HIV-specific mortality. All this seemed very clear to the IPLWH who I interviewed in my study. Is it any wonder they hesitated to access health care, or they struggled with acceptance of ARVs when the challenges of adhering to their therapy were so great and the likelihood of ending up a medical statistic of premature mortality was so high? In the words of Reth, who lives this reality, “What I need… to make myself, um… be successful daily so that I can take my meds every day… um… I think I know that more than anybody else.”

7.6. Chapter Summary

This chapter mainly described, yet also explored and explained, the contextual circumstances surrounding adherence to ARV therapy by IPLWH. It described how IPLWH construct and understand their experiences of adhering to ARV therapy and it explained the personal, interpersonal and socio-structural vulnerabilities and resiliencies affecting adherence to ARV therapy.
The themes of family and friends, and of culture served to highlight how IPLWH who are living with a substance use disorder would choose social supports that would help them address their substance use disorder and adhere to ARV therapy. However, social networks alone were not always optimal, and IPLWH required structured social supports in addition to family and friends. For example, IPLWH who were recovering from substance use disorder would at times need socio-structural supports such as organized community programs, in addition to their more localized networks of children and significant others, to contribute to their overall success at living a sober life and abstaining from substance use.

The third theme concerned holistic health care and the quest for peace of mind by IPLWH. This quest was not so much a personal mission as an effort to negotiate socio-structural resources that could provide safe and ongoing shelter. Once they had safe places and spaces, many IPLWH were able to establish a stable social routine with a stable physical environment such a home. For IPLWH who were living with a substance use disorder, having a stable routine kept them from falling into boredom and loneliness, which then placed them at risk of using substances as a coping mechanism to deal with these uncomfortable feelings. Furthermore, having a routine helped people who were living with a substance use disorder with setting goals, which provided them a sense of emotional security, which offset the lure of ineffective coping mechanisms such as using substances, which placed people with a substance use disorder at risk of being non-adherent with their ARV regimen. Similarly, spirituality (e.g., Aboriginal spirituality and Christianity) helped IPLWH who were living with substance use disorder to adhere to their ARV therapy. For such IPLWH, believing in a power greater than themselves gave them hope. In addition, hope provided them with the motivation to cope better with daily life, which included adhering to their ARV therapy. However, attaining and maintaining such spirituality was an effort for some and for IPLWH practicing Aboriginal spirituality, at times they did not know how to engage or sustain their cultural tradition, again finding their peace of mind challenged by socio-structural determinants.

The fourth theme concerned respect within the context of the effect of incarceration and law enforcement on ARV adherence. IPLWH who were living with a drug use disorder and who were being treated with MMT often faced challenges when arrested and detained by law enforcement. While some IPLWH might have had the social capacity to persuade correctional services personnel to help them with adhering to their ARVs while incarcerated, others were not as fortunate. In addition, law enforcement authorities were known to discard MMT that IPLWH had on their person when they were incarcerated, thus contributing directly to IPLWH non-adherence to ARV therapy.

The fifth and last theme dealt with the issue of trust; namely, how IPLWH who were living with substance use disorder perceived that the healthcare system might better support them in terms of MMT and other maintenance therapy for opioid use disorder. To this end, they spoke about transforming policies to support drug use disorders. Self-management support helped IPLWH to better control their drug use disorder, particularly when such a strategy involved them working closely with their physician.
as a team. For instance, IPLWH who were taking MMT and who could speak with their physicians if their therapy was ineffective were in a better position to adhere their ARV therapy. Although self-management support helped IPLWH, such support was nested within a larger socio-structural environment. At times, physicians were forced to conform to restrictive health policy, which may not always have been in the best interest of IPLWH who were living with a drug use disorder. Physicians of some IPLWH were hesitant to prescribe narcotics or other drugs that might have adverse effects on IPLWH with a substance use disorder. Such IPLWH wanted to be under the monitored environment of their physicians so that they could receive effective assistance in addressing their health concerns. However, if a physician decided not to prescribe drugs such as Valium or opioids to IPLWH with a drug use disorder, the IPLWH was placed at risk for obtaining such drugs from the streets, thus increasing the likelihood that IPLWH would be non-adherent with their ARV therapy.
Chapter 8 Discussion, Part One: An Integrative Summary

8.1. Chapter Overview

The purpose of this chapter is to provide an integrative summary of the study findings regarding the experiences of ARV therapy use among IPLWH. This summary will interpret the findings and place them in the context of the research question, the research objectives and the literature review. This chapter will explain where the study findings converge with, clarify and contradict past findings, and it will discuss implications of convergent and divergent findings with the intention of improving upon past investigations and yielding some findings regarding ARV therapy use among IPLWH that have not been uncovered to date and some interpretations that have yet to receive due consideration in the scholarship on this critical subject.

8.2. ARV Therapy Use among Indigenous Peoples Living with HIV

Returning to the original research question of how IPLWH construct and understand their experiences of ARV therapy, this chapter considers the study findings in relation to the works discussed in the literature review chapter and new work that has appeared in the scholarly literature since this study began while concentrating on the pivotal role played by the socio-structural environment in explaining how and why IPLWH use (or do not use) ARVs. The socio-structural circumstances surrounding how IPLWH use or do not use ARV therapy are analyzed through the five predominant themes of this study: respect, trust, family and friends, holistic health care, and culture. These themes were drawn from examination of individual interviews, participant observation and Indigenous sharing circles, and they were critical to all three interrelated yet distinct components of ARV therapy use: access, acceptance and adherence. All three of these components of ARV therapy use among IPLWH existed within a wider context than HIV itself. The context includes socio-structural, behavioural and biomedical issues that intersect, creating a complex environment (Friedland, 2006). This discussion will consider the components independently and then integratively.

8.2.1. Focusing on ARV therapy access.

Social environments affected the comfort level of IPLWH. The most obvious detrimental social environment was a discriminatory one. In my study, the participants understood racial discrimination against Indigenous peoples as a learned behaviour of non-Indigenous people, passed through many generations. Other researchers (Adelson, 2005; King et al., 2009; Waldram et al., 2007) indicated that Indigenous peoples’ experience of health disparities today is associated with their historical and their current position within the socio-structural environment, a social system based on the historical relationship between the Nation State and Indigenous peoples. Additionally, my study found that IPLWH experienced discrimination based on their HIV status and substance use disorder. They felt stigmatized by their Indigenous relations as well as by non-Indigenous people. Their HIV status, substance use disorder (particularly involving IDU), and Indigenous ancestry and culture all
compounded their struggle to access ARV therapy. My study findings were consistent with what others (Lang et al., 2013) have found, revealing that PWID living in Saskatoon faced discrimination based on their race where such discrimination acted as a barrier to them accessing health services. My study found that respectful relationships helped IPLWH to access ARV therapy.

Physical environments also affected the comfort level of IPLWH. My study found that the most helpful healthcare agencies were based in neighbourhoods that were not conducive to the health and sobriety of a person who was recovering from a substance use disorder. Unhealthy neighbourhoods for people recovering from a substance use disorder were those where other people with a substance use disorder and who use their drug of choice congregated and where street drug interactions occurred. An unhealthy physical environment placed a person who was recovering from a substance use disorder at risk for thinking negatively, jeopardizing their sobriety and questioning the effectiveness of ARVs. This negative thinking could also lead people who are recovering from a substance use disorder to relapse and, further, cause them to have a poor outlook on their health, health care and the overall trajectory of their lives. My study findings converged with and helped to explain what Kerr et al. (2005) identified in their study: negative outcome expectations were significantly and independently associated with ARV non-adherence. Although Kerr et al. used a different study design than this dissertation (quantitative versus qualitative), both study populations included HIV-infected PWID. The study population in this dissertation revealed that there can actually be positive outcome expectations from unhealthy physical environments when the respect that IPLWH received from individuals working at agencies located in unsafe neighbourhood outweighed the danger of the location itself, and when the positive sense of community and even family that these people with a substance use disorder felt from inclusive healthcare agencies counteracted the vicinity of the agency. Nonetheless, this quotient did not always tilt positively for IPLWH, and some IPLWH minimized their visits to such environments or accessed ARV therapy from other areas in the city that they considered more conducive to their maintaining a positive outlook. These environmental circumstances held true for study participants from both Saskatoon and Prince Albert. Further exacerbating this structural vulnerability, some IPLWH who lived in Prince Albert or had previously lived in Prince Albert believed that this city did not have the resources required to support IPLWH. The city had less than optimal community-based support services such as HIV peer support.

My study found that IPLWH did not always trust the healthcare system. In the individual interviews, some IPLWH made their lack of trust in the healthcare system conspicuously clear when they questioned the timeliness of HIV biomarker testing such as HIV viral load testing. IPLWH reported that the long wait times for a viral load test and to receive test results prevented them from accessing ARV therapy in a timely manner. In comparison to other studies that examined this issue in a general way, my study’s findings yielded very particular contextual factors regarding these experiences of IPLWH with health services. For example, existing studies indicated that, based on the time between first being
diagnosed with HIV and the time of their first viral load test, most IPLWH in Alberta, Saskatchewan and Manitoba presented late to HIV care (Becker et al., 2010; Plitt et al., 2009). My study found that IPLWH wanted a health care system where they could receive HIV care in a timely manner. IPLWH indicated that knowing their HIV status in a timely manner was directly related to their being able to decide for themselves how soon they would need to access ARV therapy. Based on the frustration of some study participants with long wait times and their genuine interest in understanding their health situation, it seemed unlikely that these IPLWH would consciously postpone accessing HIV care in a timely manner. Lang et al., (2013) in their Saskatoon study also revealed that PWID experienced a lack of healthcare system resources and long wait times to see a health service provider.

In their study involving Indigenous people in Australia, Newman et al. (2007) found that access to ARV therapy was facilitated by health services provided in a holistic manner and also by the motivation pregnant women had to prevent transmitting HIV to their newborns. However, once the child was born, if mothers perceived they were in good health and knew they had a low HIV viral load and good immune status, Newman et al. found that women would discontinue their ARV therapy. In another study (M. Stein et al., 2000), although the ethnicity of the study participants was not reported, having a child in the household was significantly associated with not accessing HIV care from a physician among both male and female caregivers. Although my study did not examine in any depth the use of ARV therapy among pregnant women, one of my study participants reported that she accepted ARVs because she wanted to prevent her child from being born with HIV infection. My study did examine in some depth the provision of health services in a holistic manner, particularly within the context of IPLWH living with a substance use disorder and accessing ARV therapy. My findings helped explain what other studies have described. Wood et al. (2006), who studied access to ARV therapy among IPLWH who were also PWID, indicated that one limitation of their investigation was the inability to ascertain the point at which access to ARVs was impeded. Was it at the originating point of accessing treatment or later and in the community?

The desire for holistic health care was a predominate theme throughout my study. Given their situation, participants in my study felt they had to choose between living with their active drug use disorder and using ARV therapy. They spoke of health service providers refusing them and other IPLWH access to ARV therapy because their stage of addiction recovery was not considered optimal, or at least not at a point sufficient for IPLWH to be expected to maintain an adequate level of adherence to their ARV therapy for it to be effective. Should IPLWH who are living with an active drug use disorder be deprived ARV therapy if such deprivation contributes to their further deterioration, their HIV morbidity and possibly their death? A study conducted in North America among 662 providers with 5.3% of the study population recruited from Canada found that “HIV providers are significantly less likely to recommend [ARV] therapy at any CD4+ cell count for patients who engage in any injection
drug use” (Westergaard, Ambrose, Mehta, & Kirk, 2012, pp. 9-10). Although some researchers (Kerr et al., 2004; Moore et al., 2010) found HIV-infected PWID to have decreased adherence to ARV therapy, others (Mann et al., 2012) reported that adherence to ARV therapy among PWID had improved over years, adding that this was likely due to newer ARVs with less toxicity and decreased pill burden. Furthermore, a meta-analysis of 38 studies (Malta, Magnanini, Strathdee, & Bastos, 2010) found “that adherence to HAART among HIV-positive drug users falls within the range observed among [people living with HIV/AIDS] in general, which is approximately 60%” (p. 739). In my study, participants felt that relapsing into substance use was a normal part of a recovery process where they learned to cope with their disorder over time, thereby improving their chances of abstaining permanently from drugs and alcohol. Many participants believed ARV therapy use needed to take into account their substance use disorder, whether they were actively using substances or not. Furthermore, despite their own awareness of the chronic nature of a substance use disorder, participants in this study believed that they needed to persevere in trying to manage their ARV therapy use to the best of their ability. To them, in this context, the provision of holistic health care was notional at best.

**8.2.2. Focusing on ARV therapy acceptance.**

Acceptance of ARV therapy use among IPLWH has not been studied per se, and studies examining access to ARV therapy did not fully examine how and why IPLWH chose (or chose not) to accept ARV therapy once it was offered to them. My study contributes to the literature on ARV therapy use by investigating in depth the issue of acceptance of ARV therapy by IPLWH.

In my study, I found that IPLWH living with a substance use disorder and actively using their drug of choice realized that they must radically change their lifestyle if they were genuinely to accept ARV therapy. For many of them, this meant much more than impulse control. It meant obtaining stable housing and being financially secure. And for some, this also meant committing to go into their pharmacy on a daily basis for directly observed ARV therapy and MMT co-administered by a health service provider, a condition they usually found humiliating. They were embarrassed, felt degraded, and were sometimes left with no choice but to refuse ARV therapy altogether. My study findings were consistent with those of other researchers who have recorded both Indigenous and non-Indigenous PLWH’s experiences of embarrassment, fear and feelings of stigmatization (Alfonso et al., 2006b; Mill et al., 2009; S. C. Thompson et al., 2009). Newman et al. (2007) found that the combined fear of HIV disclosure and discrimination, made worse by lack of privacy, was a major barrier to “ARV uptake” among Indigenous people in Australia. Others (McCall et al., 2009) have found that women living with HIV had a difficult time balancing their competing needs for HIV treatment, food and shelter, and access to their children, not to mention dealing with issues pertaining to abusive relationships and living with a substance use disorder. However, in my study, I found that sometimes setting goals improved the
outlook on life by IPLWH. Furthermore, developing a positive outlook on life helped IPLWH with a substance use disorder accept ARV therapy.

In my study, I also found that working within a team environment helped IPLWH accept ARV therapy. For instance, when health service providers offered IPLWH assurance, it helped IPLWH manage their own personal health practices and motivated them to engage with the healthcare system and to use ARV therapy. Furthermore, encouraging self-management helped IPLWH develop self-respect. IPLWH who were living with drug use disorder were also more receptive to accepting ARV therapy when a health service provider proposed multiple interventions. For instance, for those with an opioid use disorder, MMT was not always considered the most viable treatment option. Some IPLWH feared the possible side effects of MMT, including decreased cognitive and motor functioning. Others felt that MMT was simply not effective in controlling their opioid use disorder. As a potential solution, a few study participants referred to alternative opioid-substitution treatment options such as opioid prescription treatment. To this end, IPLWH wanted advocates to help them lobby the healthcare system to better support them with their opioid use disorder. Interestingly, other researchers (Oviedo-Joekes et al., 2009; Rehm et al., 2001) have found that injectable diacetylmorphine prescription (medicalized heroin) had better health outcomes and retention rates than oral MMT for opioid addiction refractory to treatment. As indicated by Krusi, Wood, Montaner, and Kerr (2010):

In light of the challenges associated with treatment retention for MMT, heroin prescription carries unique potential to facilitate HAART access and adherence for HIV-positive [PWID]. Unfortunately, due to the structural constraints imposed by restrictive narcotic regulations, this form of treatment remains elusive in many countries internationally (p. 7).

In 1991, the Royal Commission on Aboriginal Peoples was established to investigate the Aboriginal Residential School legacy in Canada. The Royal Commission on Aboriginal Peoples concluded that Aboriginal and non-Aboriginal relationships needed to be restructured (Waldram et al., 2007). In my study, I found that a number of IPLWH mistrust institutions such as healthcare establishments that have authoritative powers similar to residential schools, structures that Indigenous people learned over many decades to mistrust. Larkin et al. (2007) found in their study that health disparities and social inequities were directly attributable to Indigenous peoples’ experiences with colonial acts of violence vis-à-vis Aboriginal residential schools. Aboriginal residential schools adversely affected both the individual lives and the collective culture of Indigenous people, leading to the nation-wide health disparities they experience today (Waldram et al., 2007). The Larkin et al. (2007) study highlighted the fact that structural inequities were determinants of health. In further exploring the structural vulnerabilities and resiliencies affecting IPLWH, my study found that, for some IPLWH, self-help strategies provided a powerful antidote to combat these inequities. Study participants reported on self-help strategies that included a collective component that preferred cultural identity and also
reported on more structured, non-culture-based, addiction recovery programs, all of which helped IPLWH to minimize the impact of the Aboriginal Residential School legacy.

Despite the value most IPLWH in my study placed on their culture, their own sometimes complicated identity within their culture at times brought with it mixed feelings regarding accepting ARV therapy. Some IPLWH felt discriminated against by their Indigenous community on account either of their HIV-status or their substance use disorder. For those who were accepted by their community, some were in a dilemma over whether or not to accept ARVs or to treat their HIV-infection with traditional First Nation medicine. However, most IPLWH wanted to use healing strategies drawn from both Indigenous and non-Indigenous cultures to help them with their emotional, mental, spiritual and physical health and wellbeing. Other researchers (Cain et al., 2013) have found that, even though IPLWH were stigmatized by their family, friends and communities, “reconnecting to community was often described as a key source of strength” (p. 821). From a programmatic perspective, for many IPLWH in my study, cultural aspects of health and wellbeing were not a part of the usual healthcare services they received. The notion of holistic health care and integrated health services lacked the progressive inclusion of an Indigenous cultural component. This remained the case despite the findings of the Aboriginal Healing Foundation (DeGagne, 2007). The Aboriginal Health Foundation investigated the intergenerational trauma experienced by Indigenous peoples as a result the Aboriginal Residential School System and found that “culture is good medicine,” and that the most effective holistic healthcare systems are those that used Aboriginal cultural healing strategies (e.g., the use of Elders and traditional ceremonies) in conjunction with Western health care interventions. Results of my study supported the dictums of the Aboriginal Healing Foundation and found that culture is a pivotally important determinant in helping IPLWH to accept ARV therapy.

My study also found that social networks played an important role in how IPLWH regulated themselves, thus affecting their acceptance of ARV therapy. For the IPLWH who were mothers, a motivating factor for accepting ARV therapy was the hope of prolonging their lives for the sake of their children. Despite this motivation, many of them also required other external supports to help them accept ARV therapy. Parent support and community programs helped these IPLWH regulate themselves, live healthy lives, and accept ARV therapy. In particular, these motivating factors helped offset one particularly insidious threat to many IPLWH who are mothers: the threat that children’s aid workers would apprehend their children if they were not caring for their children to the satisfaction of the authorities.

8.2.3. Focusing on ARV therapy adherence.

In their research, Kerr et al. (2005) found that adherence efficacy expectations and self-regulatory efficacy were significantly and independently associated with continuing ARV therapy. My study findings helped to explain what Kerr et al. found and revealed that social supports such as family
and friends helped IPLWH cope and have a positive outlook. For IPLWH who were living with a substance use disorder, having a positive outlook helped them abstain from using drugs and alcohol that could potentially place them at risk for ARV non-adherence. Further to what other studies (Ka'opua & Mueller, 2004; Milligan & Lavoie, 2012) have found regarding the relevance of social supports to levels of adherence to ARV therapy by IPLWH, my study also found that while social supports helped IPLWH adhere to their ARV therapy, such supports were not enough, particularly for female IPLWH. In addition to having family and friends to support them, IPLWH also required more structured supports to help with their ARV adherence. They required the individual support of AIDS service organizations and the communal support that family outings or activities in the community could provide. Such structured social supports helped IPLWH who were living with a substance use disorder abstain from using drugs and alcohol and live a more sober life. While my study findings converged with what Tapp et al. (2011) found, my findings also helped to further explain the phenomenon. Tapp et al. found that female gender was significantly and independently associated with decreased 95% adherence to ARV therapy, despite the fact that MMT for females (as well as males) was significantly and independently associated with being adherent to ARV therapy. Further exploring the findings from the Tapp et al. study, this study found that female IPLWH who were raising children and who were living with a drug use disorder and receiving MMT had an exacting need for social support to help them cope with their stress. Based on a synthesis of 24 qualitative studies, others (Vervoort, Borleffs, Hoepelman, & Grypdonck, 2007) found that, although childcare was a risk factor for ARV therapy non-adherence among women, raising children also motivated them to stay alive, leading them to adhere to their therapy.

My study also found that the peace of mind that comes with having safe places, spaces and spirituality helped IPLWH adhere to ARV therapy. Other studies (Alfonso et al., 2006a; Alfonso et al., 2006b; Veinot et al., 2006) have found that a negative mood (e.g., anxiety) impedes ARV adherence. In addition to my study confirming this finding, I also found that having a safe physical environment, such as stable housing, helped IPLWH with their mood and hence their adherence to ARVs. Having a stable social routine was equally important in helping IPLWH adhere to their ARV therapy. For IPLWH who were living with substance use disorder, having a routine kept them from becoming bored and lonely, thus preventing them from becoming anxious. Boredom and loneliness were triggers for IPLWH with a substance use disorder, prompting them to think about using substances in order to cope with the uncomfortable feelings associated with feeling bored and lonely: atavistic feelings of discrimination, isolation, deprivation and loss. Setting goals also provided IPLWH who were living with a substance use disorder with a sense of emotional security that helped alleviate anxiety. Peace of mind was a common goal among the IPLWH in my study who had spirituality in their lives, whether Indigenous or Christian. For IPLWH living with substance use disorder, spirituality helped them avoid substances, and believing
in a higher power provided them hope, which motivated them to adhere to their ARV therapy. Nonetheless, gaining spirituality was an effort for some IPLWH, particularly those who practiced Indigenous spirituality, because oftentimes they did not know how to engage or sustain their cultural traditions. According to Cajete (2000), Indigenous spirituality is ecological in nature. “It is the intimate relationship that [Indigenous] people establish with place and with the environment and with all of the things that make them or give them life” (Cajete, 2000, p. 184). Somewhat related to this, Milligan and Lavoie (2012) also found in their study that IPLWH who felt disconnected from their Indigenous culture had a difficult time adhering to their ARV therapy. Ka’opua and Muller (2004) also determined in their study that IPLWH identified spirituality as important with respect to supporting ARV adherence. What my study found corroborates the findings of Milligan and Lavoie, and Ka’opua and Muller, explaining some of the factors contributing to feelings of disconnectedness and describing some practical benefits of a spiritual focus.

Kerr et al. (2005) found that recent incarceration was significantly and independently associated with PWID choosing to discontinue ARV therapy. What my study contributes to the existing literature on this topic is an exploration of how and why incarceration affected adherence to ARV therapy among IPLWH. Being assertive and articulate helped some incarcerated IPLWH adhere to their ARV therapy because they could communicate with and persuade corrections staff of their reasons for needing to adhere to their ARVs. Other IPLWH in my study who were living with a drug use disorder, who were on MMT, and who had been arrested and detained in prison found themselves in a more precarious position. Police would discard any methadone that IPLWH had on their person if the methadone container was not sealed, thus jeopardizing their addiction recovery. For IPLWH who were on MMT, methadone helped them control their cravings for street drugs. For IPLWH in my study with a substance use disorder, street drugs were not good for them because such drugs could interfere with their adherence to ARV therapy. My study’s findings were consistent with what other researchers (Chongo et al., 2011; Milligan & Lavoie, 2012) have found regarding MMT supporting ARV adherence among IPLWH who were living with a drug use disorder. And others (Palepu et al., 2006; Palepu et al., 2011; Uhlmann et al., 2010) have found that MMT was significantly and independently associated with 95% adherence levels to ARV therapy. My study described some of the socio-structural circumstances surrounding the issue of adherence to ARV therapy among IPLWH who were being treated with MMT for their drug use disorder. Co-planning of healthcare interventions, such as ensuring that MMT was tailored to the needs of IPLWH, was critical.

With respect to ARV adherence, Gross et al. (2011) found that SMS (self-management support) was significantly associated with self-efficacy and treatment literacy among both IPLWH and non-Indigenous PLWH. Others (Bodenhamer et al., 2010; Tam et al., 2011) have found that SMS interventions helped similar study populations adhere to their ARV therapy. Consistent with these
studies, my study showed that SMS helped with ARV adherence. For IPLWH in my study, the vast majority of whom were living with a substance use disorder, SMS helped them to better control their substance use disorder, thus helping them with their adherence to ARV therapy. SMS helped IPLWH work more closely with their physicians, not only on their HIV care but also with their addiction recovery, thus leading them to adhere better to their ARVs. However, IPLWH who were working with their physician in this regard did not always agree with their physician on what was best for them in terms of their own care. Some IPLWH sensed that physicians felt they had to abide by restrictive health policy, which was not always in the best interest of IPLWH. For example, some IPLWH who were recovering from a drug use disorder and were prescribed MMT did not feel that MMT was the most effective treatment option for them. They either questioned the effectiveness of MMT or they feared the possible side effects of MMT. As an alternative to MMT, some IPLWH preferred that their physician treat their drug use disorder with narcotics, such as opioid prescription treatment, administered within a controlled medical environment and under the care of a professional. To this end, IPLWH believed existing drug policies needed to be transformed vis-à-vis MMT to better meet the needs of people who were recovering from a drug use disorder and help them adhere to their ARV therapy. Those IPLWH who were unable to persuade their physician to prescribe them narcotics obtained narcotics on the street. For some, this meant forsaking their physicians’ involvement in their care and choosing narcotics obtained from the streets over ARV therapy. Regarding the importance of trust and of cooperation between IPLWH and their health service providers in maintaining ARV adherence, my study findings were consistent with what other studies (Ka’opua & Mueller, 2004; Milligan & Lavoie, 2012; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004) have found. My study findings also explain what Godin et al. (2005) found. In the Godin et al. study, self-efficacy and positive attitude were measured by clients’ satisfaction with their physicians and a high level of perceived social support, and they found that self-efficacy and positive attitude were significant predictors of ARV adherence.

8.2.4. The interconnections of ARV therapy use: access, acceptance and adherence.

My study showed how IPLWH construct and understand their experience of ARV therapy. To my knowledge, no qualitative studies to date have been conducted targeting a study population of IPLWH and taking into account all three components of ARV therapy use: access to ARV therapy, acceptance of ARV therapy and adherence to ARV therapy. By examining ARV therapy use this way, and by concentrating on individual, interpersonal and socio-structural vulnerabilities and resiliencies, my study was able to highlight and explain the gravity and complexity of the phenomena.

In Canada, two dedicated qualitative studies (Chongo et al., 2011; Milligan & Lavoie, 2012) investigated ARV therapy use among IPLWH. Both studies addressed the discrete factor of adherence to ARV therapy. Somewhat consistent with my study, Newman et al. (2007), in their study of IPLWH in Australia, found that one key incentive to “HIV treatment uptake” was health services that provided
holistic care, but “uptake” in the Newman et al. study was not clearly defined. However, in my study, by examining the phenomena with respect to all three components of ARV therapy use, I was able to provide new insight. My study did not limit its scope to one or even two single components of ARV therapy use but examined it from all three aspects: access to, acceptance of and adherence to ARV therapy. In doing so, my study demonstrated how one subsystem (e.g., acceptance of ARV therapy) relates with other subsystems (e.g., access and adherence to ARV therapy).

Figure 5 (Factors Affecting Antiretroviral Therapy Use among Urban Indigenous Peoples Living With HIV in Saskatchewan) uses a causal loop diagram to depict three main subsystems that are at play: access to ARV therapy, acceptance of ARV therapy, and adherence to ARV therapy.

**Figure 5: Factors Affecting Antiretroviral Therapy Use among Urban Indigenous Peoples Living With HIV in Saskatchewan**

The relationship among these subsystems makes up one large complex system.

At first glance, access to ARV therapy could be viewed as a relatively simple system of four linear processes. However, the interplay between access and the other two systems (acceptance and adherence) creates a dynamic process (i.e., feedback loops) that suggests policy resistance. Despite the relatively simple processes for accessing ARV therapy, IPLWH may resist or accept ARV therapy for various reasons (e.g., negative thinking and positive outlook) related to socio-structural vulnerability and resilience (e.g., discrimination and respect). As one example of socio-structural vulnerability, restrictive health policies guiding treatment for drug use disorder contribute to the resistance by IPLWH to accepting and adhering to ARV therapy. Consequently, they choose not to go on MMT, which then subsequently places them at risk for relapse. An alternative, socio-structurally resilient system of care
that treats opioid use disorder with heroin or morphine could strengthen the causal pathways leading to the facilitation of the access subsystem, as well as the acceptance subsystem and the adherence subsystem. The nexus of factors around acceptance of ARV therapy is much more complex and includes many more nonlinear causal pathways through the larger system that can impede the acceptance of ARV therapy among IPLWH once ARV therapy is offered to them. But one very proximal factor contributing to IPLWH not accepting ARV therapy is the feeling of embarrassment associated with having directly observed ARV therapy administered to them at a pharmacy in a relatively public setting that affords them limited privacy. As seen in Figure 5, the causal pathways of other, more distal, factors to the subsystems of acceptance of and adherence to ARV therapy are circuitous in comparison to the access subsystem. For instance, the large and complex environment in which the ARV adherence subsystem is nested means that the adherence or non-adherence of IPLWH depends very much on the specific factors at play. It is unlikely that one would think, based on Figure 5, that there is a simple solution to redress the problems with accessing, accepting and adhering to ARV therapy. But to draw a conclusion that the systems affecting ARV therapy use are too chaotic to address would be even more misguided. The figure demonstrates that the underlying mechanisms of socio-structural factors greatly influence what one might mistakenly view as discrete individual behaviours affecting decisions by IPLWH to use ARV therapy.

Chapter 1 (Introduction) of this dissertation included a causal loop diagram (Figure 1) depicting possible personal, interpersonal and socio-structural factors affecting access to, acceptance of and adherence to ARV therapy among IPLWH. Figure 1 was developed based on a review of the literature as well as my reflexive thought processes before my study began. Figure 5 is more specific than Figure 1, particular to the population of my study, and unique to the empirical findings and conceptual framework of my study, which used the BMHSU and sensitizing concepts (i.e., access, acceptance, adherence, structure, vulnerability and resilience), within the context of critical Indigenous qualitative research, as heuristic devices to analyze and interpret the data. In addition to access and adherence to ARV therapy, acceptance of ARV therapy, in both figures, plays a large role in how IPLWH construct and understand their experiences of ARV therapy. This is not say that the concepts of access and adherence are any less important than the concept of acceptance; however, if one is to fully understand the use of ARV therapy, then the concept of acceptance must be duly considered.

By examining the relationship among access to, acceptance of and adherence to ARV therapy among IPLWH, I believe I have shed light on the ability of Indigenous culture to negotiate solutions to ARV therapy use among IPLWH. Jones (2006) argues that future research investigating the causes of health disparities among Indigenous peoples should focus on the possible role that wealth and power play, rather than other factors pertaining to culture. Notwithstanding Jones’ findings about wealth and
power, my study shows that culture is a powerful tool as well as an important theme to consider when investigating health disparities among Indigenous peoples.
Chapter 9 Discussion, Part Two: Implications, Limitations and Future Research

9.1. Chapter Overview

This chapter begins by delving more deeply into the implications of my study for theory, methodology and practice surrounding ARV therapy use among IPLWH (Section 9.2. Implications). It is beneficial to IPLWH for researchers to refine their understanding of the phenomena surrounding ARV therapy use among IPLWH, rethink the way they theorize Indigeneity, and alter the way they typically carry out research involving Indigenous peoples. Furthermore, it should be possible for health service providers and institutions to revisit some current practices that result in less than optimal experiences with ARV therapy use for IPLWH.

This chapter then moves to a discussion of the limitations of the study (Section 9.3. Limitations of the Study), focusing primarily on methodological decisions made about how to conduct the research and subsequent challenges that arose as the research progressed. This section will also explain how the study’s design limitations were addressed.

The next section of this chapter discusses directions for future research (Section 9.4. Directions for Future Research), suggesting questions that others might want to ask and issues others might want to examine in light both of the findings presented in this study and some of the design modifications and methodological changes suggested. Having unravelled some hitherto unexplored population characteristics among IPLWH and new distinctions regarding their experiences with ARV therapy use, this section proposes questions and issues that might provoke more thought and that could merit follow-up if one is to understand more fully the phenomena with the goal of caring for IPLWH.

The final section of this chapter (Section 9.5. Conclusion) provides some concluding remarks and emphasizes the importance of a more thorough understanding of the experiences with ARV therapy among IPLWH.

9.2. Implications

9.2.1. Theory.

In my study, I used the BMHSU (R. M. Andersen, 2008) as the prevailing logic to access my study data and explore some key aspects in depth. I also used the BMHSU to account for and to help focus my thinking around how IPLWH construct and understand their use of ARV therapy, and in particular, to spot patterns in issues I identified regarding access to, acceptance of and adherence to ARV therapy among IPLWH. To my knowledge, my study is the first to use the BMHSU to conduct qualitative inquiry involving ARV therapy use among IPLWH, and with Indigenous populations in general for that matter. Andersen (2008) suggested that the BMHSU had the potential to serve defined populations. His recommendation was consistent with that of other researchers who used the BMHSU to examine homeless adults and who proposed that future research should be conducted to test the model on other vulnerable populations (Gelberg et al., 2000). “What is important is that [any model does not] take
the form of prejudgements, forcing interpretation of the data into [the model], but [rather employ it as a
guide] to make sense of the data” (Hammersley & Atkinson, 2007, p. 163). To this end, I used the
BMHSU as a heuristic to help me explore the use of ARV therapy among IPLWH.

The BMHSU postulates that health services use occurs within a complex environment of 21
constructs gathered under four domains—contextual characteristics, individual characteristics, health
behaviours and outcomes—that interact with one another, thus affecting how and why people use
personal health services, and in the case of my research, use of ARV therapy. The domains of contextual
characteristics and individual characteristics are comprised of predisposing, enabling and need
categories, which further organize some of the 21 BMHSU constructs. The implicit assumption of the
BMHSU is that socio-structural factors are driving forces that influence patterns of peoples’ use of
personal health services. The BMHSU presupposes that there are four socio-structural dimensions of
access to care: potential access, realized access, equitable access and inequitable access. Importantly,
equitable access and inequitable access are two dimensions of access to care that are also causal factors
affecting realized access to care (R. M. Andersen, 1995; R. M. Andersen & Davidson, 2007).

Drawn to its overall internal consistency, I used the BMHSU as a part of my conceptual
framework upon which to build my theoretical understanding of ARV therapy use among IPLWH. In
particular, it helped me with my initial attempts to organize my data and pattern my original thoughts on
the multiple issues surrounding access to, acceptance of and adherence to ARV therapy among IPLWH.
The end result of my research may have stretched the BMHSU. Still, it has been a serviceable theory. I
will explain the usefulness of the BMHSU, then describe one limitation of the model, and finally, discuss
how I dealt with this limitation.

What the BMHSU helped me explain was that social structure, health beliefs, the resources of
health policy and the organization of health care are critical drivers of the experiences of IPLWH with
ARV therapy use. Other contextual characteristics of the model proved less significant to my research.
It was very telling that, among the contextual characteristics of the BMHSU, neither the demographic
construct (variable) nor the need variables accounted for much explanation in the use of ARV therapy
among my study participants. Among the individual-level characteristics, the need variables were of
similarly little account when looking at the explanation for the use of ARV therapy. Rather, according to
the propositions of the BMHSU, IPLWH in my study had inequitable use of ARV therapy. According to
Andersen (2008), equitable access (or in the case of my study, equitable use) is defined “as occurring
when predisposing demographic and need variables account for most of the variance in utilization,
whereas inequitable access [use] occurs when social structure, health beliefs, and enabling resources
determine who gets medical care” (p. 651). In this respect, my study findings are consistent with the
propositions of the BMHSU.
However, I need to highlight one potential limitation of using the BMHSU in my study. A limitation of exclusively using the BMHSU for my study, or any other theoretical approach for that matter, is that “theories are self-confirming in the sense that they instruct us to look at phenomena in particular ways” (Silverman, 2005, p. 99). My data were not so compliant. The BMHSU did not allow for a thorough examination of all data that I felt were germane to my research question. Much of the data confirming inequitable use of ARV therapy simply did not fit logically within the model itself. I believe my unique study population accounted for some of the “uncompliant” data. To elaborate, I think that the model’s contextual predisposing and individual-level predisposing variables called beliefs need further definition or granulation if they are to preference Indigenous peoples’ values and account for in-depth explanations of the phenomena specific to IPLWH. As a predisposing variable, and in the context of my study population, “beliefs” speaks to the theme of spirituality, but it is also a tautology for culture, trust and respect and even for the very practical ability of Indigenous peoples, including IPLWH, to survive the demands of life on their own terms. Very clear yet amalgamated notions of culture, spirituality, trust, respect and holistic health care influence what IPLWH think about the use ARV therapy. So in my study, instead of asking IPLWH what they thought about the process of accessing, accepting and adhering to ARV therapy, I needed to explore, describe and examine how IPLWH thought about, understood and engaged with ARV therapy. What I found in my study was that IPLWH who were living with a substance use disorder had very particular ideas about the use of ARV therapy that flooded the “predisposing beliefs” variable (contextual and individual) of the BMHSU.

Regarding the constructs in the BMHSU that speak to the enabling resource of health policy, I found that IPLWH often questioned whether established policies actually enabled them or were in their best interest. For example, my study found that the use of MMT as the standard of care to treat people with an opioid use disorder was one recurring example of an enabling health policy IPLWH questioned. Another was the risk that IPLWH who were unable to abstain from using their drug of choice would be denied access to ARV therapy. Some IPLWH who were living with such an addiction simply opted out of using ARV therapy and tried to manage their addiction in the best way that they could rather than giving credence to health service providers who insisted on MMT therapy before prescribing ARV therapy. As a result, the policies and guidelines governing the healthcare system and the medical establishment had unintended consequences for IPLWH who were living with a drug use disorder. Critics (Pescosolido, Brooks Gardner, & Lubell, 1998; Pescosolido, 2006) of general health utilization models such as the BMHSU indicate that such models assume that individuals are rational decision-makers. These critics also argue that utilization models do not focus enough on the role that social networks play in the use of health services. That is, utilization models do not fully explain how socio-structural environments affect individuals, their behaviour and health outcomes. A study conducted by Pescosolido, Brooks Gardner, and Lubell (1998) found that while some clients with serious mental health
illnesses such as bipolar disorder were decision-makers in accessing health services (45.9%), others were coerced into (22.9%) or entered into health care by “muddling through”, where they neither sought out nor resisted treatment (31.2%). While some of the participants in my study were certainly motivated to take ARV therapy by their social networks and muddled their way through using ARV therapy, many of them demonstrated salience when considering the rationale for using, or not using, ARV therapy.

My study found that ARV therapy use by IPLWH who were living with a substance use disorder challenged conventional thinking about the use of ARV therapy. While most of the IPLWH in my study had access to ARV therapy, they did not always accept it. Instead of assuming that the will to access ARV therapy existed for IPLWH, the following were important aspects to consider: (1) living with substance use disorder; (2) the effects of the Aboriginal Residential School legacy and the ongoing discrimination against Indigenous peoples; (3) wanting one’s culture; and (4) recognizing the value of family and friends. In the BMHSU, the individual characteristic of predisposing beliefs does not adequately explain how and why IPLWH choose not to accept ARV therapy. What I found in my study was that the BMHSU does not fully explain what it means to be IPLWH within the context of ARV therapy use.

To enhance the BMHSU, I gave preference to explanations of the phenomena that came from the participants in my study, thus giving greater value to Indigenous, subjugated knowledge vis-à-vis the critical Indigenous qualitative research design of my study. The words of the study participants provided me with the participants’ own understanding of the phenomena. I capitalized on a set of words repeatedly used by the participants in my study and concepts I constructed from the data: culture, respect, family and friends, holism, and trust. An Indigenous research paradigm that is based upon component sets of physical, mental, emotional and spiritual relationships (Baskin, 2005) favoured this inductive approach. For instance, as seen throughout my study, culture and spirituality were powerfully linked concepts that yielded a tremendous amount of data on the study participants’ self-awareness as well as their understanding of ARV therapy use. As reported by Getty (2010) “unless the [critical social theory], being used as a lens through which to view the research data, is based on Indigenous systems of knowledge and philosophical approaches to issues, the research process could in fact miss what is most relevant to the Aboriginal people” (p. 12).

A more extreme example of this approach, from Getty (2010) who abandoned her original theoretical approach partway through her study of an Indigenous population, is illustrative. Getty conducted a qualitative study and provided a narrative of her own experience as a “white” researcher planning to conduct research with First Nations (Mi’kmaq) men using an advocacy/participatory paradigm. The study involved the researcher and Mi’kmaq men. The results of the study included the researcher’s initial use of a postcolonial framework that she later abandoned and replaced with a critical Indigenous framework using a Mi’kmaq ontology (e.g., living in harmony) and epistemology (e.g., “the
realm of the earth”). This revised framework allowed Getty not just to make the Mi’kmaq an integral part of her research process; it changed the viewpoint of her research entirely. Getty believed that if she continued using a postcolonial framework to carry out her research, its authenticity would be limited. Her completed study supports Mi’kmaq research with an advocacy/participatory paradigm and it recommends the emancipation (through self-determination) of the Mi’kmaq from hegemonic groups.

Unlike Getty (2010), I am of Indigenous ancestry, and I felt I had to ask myself as a researcher: “[H]ow, when you are a part of a culture, can you become aware of things that are normally taken for granted?” (Mulhall, 2003, p. 309). Studying a group to which I ethnically belong:

poses particular methodological problems for maintaining a productive balance between [insider] and [outsider] perspectives and in making the familiar ‘strange’. The advantages are clearly that…the researcher is already familiar with the [insider] perspective…. However, such ‘insider’ researchers face a far greater challenge in gaining analytical distance from their data, and may have to work much harder to treat the data theoretically (Green & Thorogood, 2009, p. 154).

For this reason, I employed both “insider” and “outsider” points of view, or emic and etic perspectives, respectively. My study attempted to explain the phenomena in question from the perspective of my study participants (emic) as well as from my own perspective as a researcher using theoretical models and concepts (etic) (Green & Thorogood, 2009). As Green (2009) argues:

without the [etic] perspective, such accounts will be limited…. In a research setting this process of social learning has to be made explicit, and the researcher will then reflect on how the rules were learned and what their significance is…. [T]he researcher has to guard against…being merely a participant in the field, rather than an active participant observer. The [etic] element of the role has to be consciously maintained, in order to be able to ask the naïve question and analyze social life from a theoretical perspective (p. 153).

In my study, I theorized the data using the etic perspective of the BMHSU but within the context of critical Indigenous qualitative research that allowed for both emic and etic perspectives on the research question and on the predetermined sensitizing concepts of access, acceptance and adherence, and structure, vulnerability and resilience. Analyzing the data from emic and etic perspectives helped me to move between two contexts of interpretation—my study participant’s own understanding of the phenomena, and a theoretical understanding of the phenomena—in order to explain the phenomena conceptually; and it helped me to understand the overall research problem from what I would like to think is a novel perspective (Green & Thorogood, 2009; Hammersley & Atkinson, 2007). The added value of using emic and etic perspectives is that it provided an “abductive process that conjoins theory and empirical fieldwork, [which] eventually produces constructs or heuristic devices used for mapping and representing (“objectivating”) the taken-for-granted cultural and political practices observed” (D. E. Foley, 2002, p. 477).
9.2.2. Methodology.

I used ethnography as the methodology for the study. “Ethnography is…a holistic approach to research, involving interviews, observation and the interpretation of material culture” (Green & Thorogood, 2009, p. 151). Ethnography expands the narrative researcher’s toolbox of methods—interviews and documents—by including field observation (Patton, 2002), specifically participant observation (Adler & Alder, 1994; Bogdewic, 1999; Green & Thorogood, 2009; Patton, 2002) with the support of fieldnotes (Emerson et al., 1995; Patton, 2002; Silverman, 2005). I would like to highlight methods and strategies that I used in my study and that I believe are important to consider for future investigations using ethnography and involving Indigenous peoples; namely, participant observation, fieldnotes and Indigenous methods.

Participant observation is a method unique to ethnography. One issue with using participant observation is that observational data are open to more interpretation by the researcher than interview data (Mulhall, 2003). Qualitative studies need to be justified based upon the internal consistency of epistemology, methodology, and methods (S. Carter & Little, 2007). “If a researcher keeps a firm grasp on her/his methodological and epistemological decisions and remains flexible, the methods should evolve to serve the study” (S. Carter & Little, 2007, p. 1326). If the study explicitly outlines its theoretical and methodological frameworks, the reader will be clear on how the researcher arrived at such interpretations.

Using interviews, I tried to understand the phenomena from an insider or emic perspective. But I also recognized that “[i]f the aim of research is to understand a phenomenon, rather than people’s accounts of it, then observational methods are often cited as the ‘gold standard’ of qualitative methods, given that they provide direct access to what people do, as well as what they say they do” (Green & Thorogood, 2009, p. 148). Participant observation was useful in my study given that I was trying to understand the nature of how IPLWH construct and understand their use of ARV therapy vis-à-vis the personal, interpersonal and socio-structural vulnerabilities and resiliencies affecting their access to, acceptance of and adherence to ARV therapy. I used participant observation to contextualize individual interview data. Participant observation, as “unstructured observation [that] is used to understand and interpret cultural behaviour” (Mulhall, 2003, p. 306) proved very informative in my study. It enhanced my understanding of both the socio-structural factors and the personal and interpersonal factors. Using participant observation, I was able to capture additional context for my study by understanding how the physical environment in which health service providers interacted with IPLWH influenced processes of using ARV therapy. That is, by using observation, I examined “the whole social setting in which people function, by recording the context in which they work” (Mulhall, 2003, p. 308).

In my first few participant observation sessions, I recorded as much as possible to acquire thick descriptions (Morrow, 2005; Tracy, 2010) of the field, keeping in mind that there may be observations
that might have seemed banal to me but which might eventually turn out to be important. I was guided by the caveat that “[a]s representations, fieldnote texts are inevitably selective. The ethnographer writes about certain things that seem ‘significant’, ignoring and hence ‘leaving out’ other matters that do not seem significant” (Emerson et al., 2001, p. 353). Eventually though, I found myself recording more observed events about which I had a hunch that they would prove significant to the phenomena in question.

It is also important to consider fieldnotes when conducting ethnographic research. I would highlight a methodological caution about using fieldnotes in the way I have. While some will use fieldnotes to conduct their preliminary analyses and interpretations of the data, I chose to use them primarily to provide descriptive accounts of the study setting (e.g., scenes, situations, events, and dialogue) and my subjective personal experiences (Emerson et al., 2001). Although there are some opposing views on how to use fieldnotes (Emerson et al., 2001; Hammersley & Atkinson, 1995), it is important that researchers are clear on how and why they are using such notes. However one chooses to use fieldnotes, “[t]he difference for the participant observer is that consciously recording the specific details of that which we might normally take for granted begins to show how meanings are constructed in this particular organization or setting” (Bogdewic, 1999, p. 51). During the process of developing my fieldnotes, I became more conscious of my own assumptions and interpretations in observing the events. “[F]ieldnotes are an expression of the ethnographer’s deepening local knowledge, emerging sensitivities and evolving substantive concerns and theoretical insights” (Emerson et al., 2001, p. 355). As useful as they were, fieldnotes are selective and, as such, a researcher should not invest exclusively in such a tool, because notes cannot provide a complete account of the study setting (Hammersley & Atkinson, 2007). “[I]n some instances, fieldnotes provide only surface summaries that almost inevitably fail to capture the intuitive, holistic understandings that are critical for ethnographic insight and analysis” (Emerson et al., 2001, p. 363). Rather, the researcher should use their “memory to fill in and recontextualize recorded events and utterances” (Hammersley & Atkinson, 2007, p. 147).

Last, I would like to stress the value of conducting research in a manner that is relevant to Indigenous peoples. I employed local traditional ceremonial helpers (Elders) to smudge at the beginning of individual interviews when it could be arranged, and when smudging was permitted indoors, and when my participants accepted the ceremonial offering. The logistics sometimes made it impossible to offer the ceremony, and not all participants accepted the offer of the ceremony to open the interview when it was proposed at the time of establishing the date and place for the interview, but all those who did accept it made a point of expressing their appreciation for the ceremony and I believe it brought a respectful, communal, even intimate element to many of the one-to-one confidential individual interviews. Of the 20 participants who took part in the individual interview component of my study and whose data I used in the analysis, five participants accepted the smudging ceremony, 9 participants
refused the ceremony, and for the remaining participants (six), it was not possible to offer or conduct the ceremony. When it was not possible to hold the smudging ceremony, the reasons were because the facility where the interview took place had a restrictive policy which did not allow smudging within their building (affecting three study participants) or there was not enough time to arrange the ceremony with an Elder due to the interview being arranged at the last minute (two participants), or I forgot to offer the smudging ceremony to the participant (one participant). Despite the logistical challenges, I would include a smudging ceremony if I conducted the study again.

Furthermore, I would like to elaborate in a little more depth on the two Indigenous sharing circle interviews I conducted, one before I began the individual interview component of my study, and a second sharing circle towards the end of the data collection/generation phase of my study. For my study, I chose to use an Indigenous sharing circle interview instead of a focus group interview. An Indigenous sharing circle is not just a term that means something to Indigenous people; it is a method relevant to Indigenous cultural reality that provides a means to exchange knowledge in a sacred way that is respectful of this culture (Lavallee, 2009). This sacred space is:

the relationship between the individual and a recognized spiritual entity, the Land, kinship networks (including all plant and animal life) and Ancestors. This relationship is both spatial (where the individual is inclusive of the family and the community) and temporal (where the present generation is inclusive of past and future generations). In this sacred space, there is an interconnectedness founded on purity, clarity, peace, generosity and responsibility between the recognized spiritual entity, the Land and the Ancestors (Canadian Institutes of Health Research, 2011, p. 1).

Because of the sacred nature of the Indigenous sharing circle, I did not feel that it was appropriate to audio record all parts of the Indigenous sharing circles. When the Elder opened and closed the Indigenous sharing circle, I turned off the audio recorder out of respect for the sacred Indigenous knowledge that was being shared. In addition, because the Elder stayed for the entire sharing circle yet was not a study participant, I deleted from the Indigenous sharing circle transcript anything that the Elder said during the Indigenous sharing circle.

As the title of Shawn Wilson’s (2008) book makes clear, within the context of research involving Indigenous people, research is ceremony. In this context, any piece of ceremony demands respect. And so, when one of my study participants who I interviewed in Saskatoon found out that I would be travelling to the City of Prince Albert to conduct more interviews for my study, he gave me a tobacco bundle and asked me to tie it on a tree in his home territory. Prince Albert is his traditional First Nation territory. It is where he felt he belonged and where he felt grounded. He was offering tobacco as a prayer for other IPLWH. I was honoured to carry out his request and felt as if I were not just the agent of his request but a ceremonial link in his chain of offering, since this was the same tobacco bundle that I
had offered to him for participating in my study. I often felt that my study was very much research as ceremony. This is but one instance.

I am confident that the various Indigenous aspects I incorporated into the methods helped me to gain a better understanding of the use of ARV among IPLWH. Despite the challenges I faced with using participant observation and fieldnotes, the assembly of all my methods helped me “to generate in-depth knowledge about a setting…over time, in order to understand how and why people believe and behave as they do” (Green & Thorogood, 2009, p. 23). As I mentioned in Chapter 3 (Conceptual Framework: Understanding Indigenous Peoples’ Use of ARV Therapy) of this dissertation, Indigenous research methods and methodologies are not described enough in the scholarly literature. And as others (Baskin, 2005; Lavallee, 2009; Rothe et al., 2009) have noted, despite the limited use of an Indigenous research paradigm when conducting research in the academy of health sciences, it is slowly gaining support. I believe that my use of Indigenous research methods is a respectful way that supports research that is relevant to Indigenous peoples and not only builds upon what others (Lavallee, 2009; McKay-McNabb, 2006) have done in their studies, but contributes to future scholarship on methodological approaches for research involving Indigenous peoples.

**9.2.3. Practice: from implications to recommendations.**

Perhaps the most significant insight of my study is the value of addressing the use of ARV therapy by IPLWH from a holistic perspective on care. It became abundantly clear that holism in this context must include addressing Indigenous cultural values, beliefs and traditions, as well as co-morbidities that IPLWH may be living with including, in the case of the vast majority of participants in my study, a substance use disorder. My study findings suggest that there is a dynamic interplay among medical, behavioural and social factors affecting ARV therapy use. Living with a substance use disorder is part of this interplay. So are other predisposing contextual factors affecting the physical, mental, emotional and spiritual living conditions of IPLWH. An overarching factor is their cultural identity.

Based on experiences of the HIV outbreak among PWID in Vancouver, BC in the late 1990s, others (O’Shaughnessy, Hogg, Strathdee, & Montaner, 2012) suggest that “as Aboriginal populations work to heal residential school system and cultural dislocation legacies, the demographic profile of the Aboriginal population (younger, disproportionately [PWID] and living in poverty…) requires resources to prevent new HIV outbreaks” (p. 396).

Historically, Indigenous peoples in Canada lost their culture, wealth and power on account of structural policies enacted upon them by the Nation State (Adelson, 2005). This led to their marginalization within Canada. The loss of their cultural identity, the loss of their economic resources and the loss of their power to exercise self-governance made them vulnerable in ways that are still poorly understood. In the broadest of social and economic domains, losing their culture resulted in them being robbed of their spirit. The loss of spirituality left Indigenous people with a void to fill, a void
predisposing many of them to substance use disorder (Alexander, 2008). This has everything to do with ARV therapy use among IPLWH. From a social determinants of health perspective, the distal and proximal factors contributing to what is here euphemistically called “loss” provide the socio-structural context for how IPLWH construct and experience their use of ARV therapy.

Access to ARV therapy among IPLWH with a substance use disorder is dependent upon their stage of recovery. They may choose not to take it. Or their use of ARV therapy may be contingent upon decisions of others. Some who are not abstaining from drug and alcohol use may be denied access to ARV therapy by their physicians who are basing these decisions on the rationale that people with substance use disorders who are using drugs and alcohol are not likely to adhere to their ARV regime. Others who intermittently recover from their substance use disorder without sustained success in maintaining abstinence and sobriety may also be denied ARV therapy. These examples speak to social structure, political power and resources. It is also more “losing out” for Indigenous people. Yet they persevere. For many of the participants in my study, living with a substance use disorder is a part of their life. So is perseverance. And many manage their HIV status to the best of their abilities, including accessing, accepting and adhering to ARV therapy. Regarding the potential for the emergence of HIV-drug resistance due to HAART non-adherence, a meta-analysis of 12 studies conducted by Werb, Mills, Montaner, and Wood (2010), concluded that “[e]xisting evidence does not support the common practice of withholding ARV therapy from HIV-positive [PWID] on the basis of an elevated risk of [ARV] resistance [and that t]herapeutic guidelines should consider reassessment of this issue” (p. 464).

Accepting ARV therapy once it is made available to IPLWH is another interpretative layer adding to the context of ARV therapy use. IPLWH want to be involved in planning and managing their HIV care and they want to be respected. In terms of the social norms regarding how ARV therapy is made available to them (Blankenship et al., 2000), IPLWH believe they know best what is good for them. They may struggle with a substance use disorder, and they may relapse, but those who are recovering from their substance use disorder know that when something triggers their non-sober thinking, they need to mobilize quickly to prevent further deterioration and descent down the trajectory of their substance use disorder. For many of them, this means retaining a positive outlook on life, and drawing on their social networks and supports, particularly their Indigenous culture.

Adherence to ARV therapy as well as acceptance of it is facilitated by a positive outlook. Consistent with the work conducted by others in the area of ARV acceptance and adherence (Altice et al., 2001; Ickovics & Meade, 2002; Lehane & McCarthy, 2009; Mostashari et al., 1998), I found that IPLWH can often build trust with the healthcare system and social welfare system, which ultimately helps them with their initiation into ARV therapy use and ARV administration instructions, ultimately resulting in HIV viral load suppression. This trust is built through respectful relationships that involve IPLWH in the co-management of their care alongside health service providers. Furthermore, it is
through such respectful relationships that IPLWH might then become the beneficiaries of health service providers’ cultural safety practices (Papps & Ramsden, 1996). Cultural safety has the potential to enhance the use of ARV therapy among IPLWH when health service providers truly grasp this concept and change their “thinking about power relationships and [IPLWH’s] rights” (Papps & Ramsden, 1996, p. 493).

Based on what I found in my study, it was evident that innovative solutions were required to address ARV therapy use among IPLWH. To this end, I conducted a second Indigenous sharing circle interview involving IPLWH exclusively. The objective of this Indigenous sharing circle was for IPLWH to reflect on the preliminary themes, subthemes and categories of my data analysis and to initiate and engage in social action to improve the lives of IPLWH within the context of ARV therapy use. Based on this Indigenous sharing circle, study participants, along with myself as the facilitator, developed the following six broad recommendations:

1. Policy makers and health service providers should involve IPLWH to a greater and more meaningful extent in all affairs affecting them. For instance, IPLWH who are living with a drug use disorder want to be involved in and see their peers administering needle exchange programs on the model of the Vancouver Area Network of Drug Users (Vancouver Area Network of Drug Users, (n.d.)). Efforts like this are important for IPLWH because they know what is needed to support their peers.

2. Health service providers should not prejudge IPLWH who are living with a substance use disorder. If IPLWH living with a substance use disorder are under the influence of substances, health service providers should treat them with empathy. When IPLWH who are using substances present themselves to health service providers, immediate and caring engagement with the healthcare system is critical; it gives IPLWH courage and hope in order for them to help themselves. Some health service providers try to help IPLWH living with a substance use disorder based on “textbook stuff.” At times, textbook learning is not relevant to the reality of IPLWH. It is unlikely that a health service provider can learn how to be compassionate from reading a textbook; however, one can develop compassion through experience and over time.

3. Health service providers should help IPLWH who are new in their recovery process from a substance use disorder to mobilize resources to help them succeed in the recovery process. At times, this could mean helping them locate and establish healthy living environments that are conducive to their addiction recovery. IPLWH who are recovering from substance use disorder need continuity of care in terms of being supported and guided through the addiction service continuum from alcohol and drug detoxification to a structured treatment program to ongoing follow-up care.
4. Policy makers and health service providers should help IPLWH who are living with a substance use disorder to keep their family together, which includes taking into account the broader social determinants of health such as the importance of family cohesion. At the first sign that IPLWH may be having trouble staying clean (abstinent) and sober, health and social service providers should not immediately reprimand such behaviour by recommending to childcare authorities that children be apprehended. Instead they should work with the IPLWH to improve the social determinants of their health and create supportive environments that enable them to effectively cope with their stress and gain effective childrearing knowledge, skills and abilities.

5. Policy makers and health service providers should support IPLWH with their ARV therapy use by ensuring that Indigenous cultural values, beliefs and customs are an integral part of health services. For IPLWH who would like to be engaged in their culture, policy makers and health service providers should help them to integrate with their cultural traditions by including Indigenous Elders in all aspects of health services. Other traditional Indigenous healing strategies could include sweat lodge ceremonies. Culturally appropriate and safe care could also include recruiting more HIV medical specialists who are educated in Indigenous health as a medical specialty.

6. Policy makers should ensure that health clinics have all the various necessary types of health service providers to meet the needs of IPLWH from a holistic perspective, including a full-time Indigenous Elder-in-residence who specializes in providing HIV support to IPLWH within the context of Indigenous traditions. A holistic approach to health care should include all aspects of health such as spiritual and mental wellbeing (e.g., to address substance use disorder) and not just focus on HIV care and treatment. In addition, the health records of IPLWH should be managed between various health agencies in a coordinated approach allowing for an integrated healthcare system of various types of health services, health professions and disciplines (e.g., addiction/pain medical specialist and infectious diseases specialists).

At first glance, these recommendations may not all seem relevant to ARV therapy use among IPLWH. However, from the outset of my study it was necessary to understand how IPLWH constructed and understood their use of ARV therapy. In the process of answering this research question, what I found was that something else was happening in terms of the underpinnings of HIV and ARV therapy use for IPLWH. Medical practices contradicted some core Indigenous notions of health. IPLWH were not prepared to simply accept the conventional guidelines for ARV therapy use as defined by the scientific world. Offering something that was empirically proven to keep someone alive did not mean a people who had survived generations of having land, livelihood and lives taken away would
automatically accept it. Thinking a pill is the panacea for big problems does not address the systemic and the immediate problems of life and living as Indigenous peoples in Canada.

Common among these recommendations are the themes of culture and holistic health care vis-à-vis mental health among IPLWH who are living with a substance use disorder. Traditional Indigenous healing has suffered enormous setbacks over generations, largely on account of epidemic diseases and colonialism; nonetheless, many traditional health practices have begun to reemerge (Waldram et al., 2007). Studies have indicated the necessity of incorporating traditional Indigenous approaches (i.e., epistemology and ontology) when addressing Indigenous health while understanding competing paradigms between modern medicine and Indigenous traditions (Bartlett, Iwasaki, Gottlieb, Hall, & Mannell, 2007; Cochran et al., 2008; Hunter, Logan, Goulet, & Barton, 2006; Labun & Emblen, 2007; Myers et al., 1999; Ten Fingers, 2005). Notwithstanding the challenges of incorporating traditional Indigenous health and healing practices with Western medicine and health sciences “…it is clear that ‘traditional’ Aboriginal healing, with its attendant base in spirituality, continues as an essential cornerstone of Aboriginal cultural revitalization” (Waldram et al., 2007, p. 292).

Given the social, epidemiological and historical perspectives concerning the health of Indigenous peoples raised in this dissertation, what becomes apparent is the need for Indigenous peoples’ self-determination; that is, Indigenous populations taking control of their own health services on one end of the self-determination spectrum, and Indigenous self-government on the other end. “It was the federal government’s new ‘Indian Health Policy’, unveiled in 1979, that sparked the process of self-determination in Aboriginal health care…. What was required was increased input by Aboriginal people themselves” (Waldram et al., 2007, p. 264). Indigenous health is not there yet.

From a health determinant approach to ARV therapy use, there are lessons to be learned from the study conducted by Kirmayer, Simpson, and Cargo (2003) who researched Indigenous health issues (e.g. social, individual, intergenerational, community) within the context of colonialism and developed strategies which were culturally appropriate for Indigenous peoples. They revealed that mental health problems among Indigenous populations are associated with their cultural oppression and recommended that mental health promotion strategies aim at strengthening cultural identity and empowerment of the Indigenous community.

9.3. Limitations of the Study

In this section, I would like to acknowledge five limitations of my study specifically to do with the methodology I chose for conducting it. I will also explain how I dealt with these limitations. First, given that the research design was critical Indigenous qualitative research, my intent for this study was never to generalize my study findings statistically using a positivist paradigm. However, “[t]he capacity to make conceptual generalizations from the local context of a qualitative study to other settings is the desired outcome” (Kitto et al., 2008, p. 243). Despite this, one limitation of my study’s design is its
circumscribed transferability. The findings from a distinct case can only be transferred (i.e., through theoretical inference) to a theory and other similar settings or contexts (Schwandt, 2007). As posited by others (Curtis, Gesler, Smith, & Washburn, 2000; Miles & Huberman, 1994), such generalizations are not applied to the wider population but instead are applied to existing and new theories and in the case of my study, any theory of how ARV therapy use works. For instance, my study involved IPLWH, the majority of whom were living with a substance use disorder and as such, their ARV therapy use was nested within the broader socio-structural context of holistic health care vis-à-vis supporting IPLWH while taking into account their co-morbid condition of living with a substance use disorder. I must count on the readers of my dissertation to consider applying my study findings to other contexts that they believe are similar to my study. Throughout this dissertation, I specified the conditions under which my study was conducted and their relevance to other theories, and I provided thick description of my study findings, thus facilitating analytic generalization and allowing the “assessment of the applicability of the study conclusions to one’s own situation” (Firestone, 1993, p. 18).

The second limitation of my study was that I could not use member checks to review my study findings. Member checking, or respondent validation, “includes techniques in which the investigator’s account is compared with those of the research [participants] to establish the level of correspondence between the two sets” (Mays & Pope, 2000, p. 51). This technique allows the researcher to assess the original intentions of the study participants, correct any misinformation pertaining to recorded facts and interpretation, and allow participants an opportunity to provide any new information (Lincoln & Guba, 1985). I did not employ member checks in my study for one main reason: it was not feasible to contact the study participants myself, since I intentionally did not collect personal, identifiable or contact information from them, as I have discussed in Chapter 4 (Methods), Section 4.8. (Ethical Considerations). I could have had participants contact me, but the earliest that I would have had the study findings available for their review would have been 15 to 21 months after they had completed their interview with me. Follow-up with study participants who wanted to review their interview transcripts (three of the 21 participants), was challenging enough, as they had to meet me at a pre-determined date following the interview. In the case of two of the participants, their transcript was going to be ready for review within a month of their interview, and both contacted me and reviewed their transcript, but the third participant’s transcript was not going to be ready until I returned to Saskatoon from Toronto for my second two-month stay, and this participant was lost to follow-up at six months. To offset the lack of member checks, I carried out three strategies to strengthen the confirmability of my study findings. First, during the individual interview itself, I made a point of sharing with the participants my interpretations of what I thought they were saying to me. This allowed participants to correct me on the spot if I misinterpreted what they were saying, and it also allowed them to clarify what they meant. This dynamic interchange between the study participants and me allowed us to co-construct the data. Second,
I offered the study participants the opportunity to review their interview transcripts. Last, I decided to use member reflections instead of member checks. Member reflection is “a practice that does not aim toward accuracy of a single truth, but rather provides space for additional data, reflection, and complexity” (Tracy, 2010, p. 848). In my study, the second Indigenous sharing circle interview involved member reflections where I presented my preliminary study findings (i.e., themes, subthemes and categories) as a prompt for knowledge exchange. Arguably, I felt that the Indigenous sharing circle offered more analytic purchase than member checks would have offered. As explained by Schwandt (2007),

many researchers see [member checks] as a problematic notion in several aspects. First, on epistemic grounds, it is not entirely clear how the procedure actually helps establish the truth of findings…. Second, implementing member checking may be coupled with the assumption that researcher effects must be minimized…. Third, member checking may be more of an ethical act than an epistemological one…. The consensus seems to be that member checking is not profitably viewed as either an act of validation or refutation but is simply another way of generating data and insight (pp. 187-188).

The Indigenous sharing circle offered an occasion to collect/generate more data and insight without raising the epistemic or moral conundrums of member checking. In terms of the trustworthiness of some of the analysis of my study, I presented some of my study findings at an international Indigenous HIV/AIDS conference attended by Canadian delegates including a large delegation of Indigenous peoples. At this conference, I received very positive feedback regarding the relevance of my study findings to Indigenous populations.

The third limitation of my study was that the study findings were limited to data mostly collected/generated from individual interviews conducted with IPLWH as opposed to other data sources such as individual interviews conducted with health service providers. If I had individually interviewed health service providers, such additional data might have provided another layer of analytic insight to further explain the phenomena. Yet, the study findings based on the individual interviews conducted with IPLWH were corroborated by the first Indigenous sharing circle interview, comprised mostly of health service providers and community workers who worked with IPLWH. The objective of the first Indigenous sharing circle was for participants to help me develop an interview guide for the individual interview component of my study. In retrospect, the reflections of this Indigenous sharing circle interview were consistent with many of the findings from the individual interview component of my study. This first Indigenous sharing circle provided nine key reflections, all of which were confirmed by the individual interviews: (1) IPLWH have unique challenges maintaining Indigenous, cultural values and beliefs, particularly while living within a dominant non-Indigenous culture; (2) configurations of care such as large and busy waiting rooms are not conducive to maintaining a sense of privacy or
confidentiality; (3) treating IPLWH differently and depriving them of medication for pain management that non-Indigenous PLWH would more readily be prescribed means that IPLWH may more readily resort to using street drugs; (4) there is a prevalence of substance use disorder among Indigenous peoples in the cities of Saskatoon and Prince Albert and a need to offer more options besides MMT to support the recovery process from substance use disorder so that IPLWH can take better care of themselves, address the chaos in their lives with resources and supports, and treat their HIV infection; (5) co-morbidities among IPLWH include HCV infection and mental health issues; (6) some IPLWH do not use ARV therapy but rather use traditional First Nation medicines and consult cultural medicine men; (7) there is added value to integrating health services for ARV therapy and addiction recovery; (8) the issues affecting the use of ARV therapy among IPLWH are multi-layered and thus, better coordination is needed among addiction services, infectious diseases services, social supports, community-based organizations, case management and population health for a more holistic approach to care; and (9) other issues affecting the use of ARV therapy among IPLWH include lack of trust in health service providers and the healthcare system.

The fourth limitation of my study has to do with my use of participant observation. I saw the value in using participant observation and comparing what participants said in interviews to what they do, but I had mixed views about employing it in my study. “The idea of observational data being the ‘gold standard’ in terms of their validity…with observations often provided as illustrating the truth about some event or process, in…contrast to interview accounts, or statistical records” (Green & Thorogood, 2009, p. 148) made me wonder to what degree participant observation was consistent with naturalistic inquiry. Despite this, I appreciated arguments put forth by others (Lincoln & Guba, 1985) for the meaning of the phenomena being based upon its context. These arguments spoke to the importance of investigating phenomena in its natural setting. Still, the argument that “ethnographic methods are the ‘gold standard’ against which other sources of data could be compared is one that does make some rather positivist and empiricist assumptions, in which there is a rather idealistic view of the ‘real’, which can be reflected by a trained observer’s eye, and perfectly recreated in the research write-up” (p. 149). When initially collecting data, the researcher is inevitably selective about what to record (Emerson et al., 2001); however, I think that I minimized this limitation by using a conceptual framework to guide my study, thus leading me to collect data that was relevant to the focus, approach and question of my study rather than to seeing truth. Moreover, I decidedly did not use participant observation to convey the ethnographic description of the health services context in its entirety. “Participant observation, for example, may focus on an aspect of the scene, rather than an entire setting, and may not entail the extent or depth of involvement of an ethnography” (Charmaz & Mitchell, 2001, p. 161). To this end, the main data source of the findings of my study was individual interviews, which helped to put the participant observation data into perspective.
The fifth limitation of my study was that two of the 13 interview questions used in the individual interviews seemed to be too complicated for many of the study participants to understand. The objective of the questions was not clear to my study participants. These two questions were: (1) Tell me about any barriers (or facilitators) that are directly related to your access to and acceptance of ARV therapy; and (2) Tell me about any barriers (or facilitators) that are indirectly related to your access to and acceptance of ARV therapy. To minimize this limitation, I broke up and separated both questions into multiple questions. Furthermore, I felt that the other 11 interview questions compensated for the lack of clarity of these two questions, and responses from participants to the other questions yielded a much thicker description of the research topic and the phenomena in question.

9.4. Directions for Future Research

To my knowledge, my study was the first qualitative study in Canada that investigated ARV therapy use exclusively among IPLWH and in a manner that takes into account the explicit relationship between access to, acceptance of and adherence to ARVs. The comprehensive nature of my study inevitably raises other questions that require further investigation. Some questions and issues that my study findings raise are as follows:

1. Do IPLWH who have HIV/HCV co-infection understand and experience ARV therapy use differently from IPLWH who are not HCV-infected? A large number of study participants reported that they were HIV/HCV co-infected. Although I asked participants if they had ever stopped taking ARVs, I did not explicitly examine the reasons for treatment interruptions from ARV therapy. Did their HCV infection affect them in using ARV therapy? Most talked openly about their substance use disorder but did not provide thick description of the effects of HCV on their use of ARV therapy. I would still want to know more about the circumstances surrounding treatment interruptions among those who have HIV/HCV co-infection. For example, did HIV/HCV co-infection affect the decision of IPLWH’s physicians in denying IPLWH ARV therapy if IPLWH who were living with a substance use disorder were also using street drugs and alcohol. Within the context of PWID, other studies (Braitstein et al., 2006; O’Neil et al., 2012; Rusch et al., 2004) provided inconsistent results concerning the differential effects of non-injectors, former or current IDU, and HCV infection on ARV adherence. The inconclusiveness of the findings from these other studies support the need for more research examining the contextual factors pertaining to current and past IDU and HIV/HCV co-infection. If I were to conduct my study again, I would further explore the contextual circumstances surrounding access and adherence to ARV therapy among a study population of IPLWH who are non-injectors, former injectors and current injectors and those with HIV/HCV co-infection.

2. For IPLWH who are living with a drug use disorder, what do we know about their drug use in terms of them moving in and out of specific drug careers? In addition, what role do specific
street drugs play in terms of their effect on ARV therapy use? For my study, I used a survey of socio-demographic and health information to contextualize my individual interview data, but I only asked my study participants if they had other co-morbid conditions such as a drug use disorder and if they injected street drugs. I did not ask them what their drug of choice was nor did I ask them whether certain drug use behaviours made them more vulnerable or resilient in various aspects of their lives. Nonetheless, in comparison to participants who used stimulants, I noted that participants who used opioids seemed to have more resources to help them with their drug recovery. As indicated by Malta, Magnanini, Strathdee, and Bastos (2010), “[a]lthough opioid substitution therapy may be associated with better HAART adherence among people who use heroin and other opioids, illicit stimulant use remains a key problem” (p. 743). Future directions for research in this area could include investigating whether different types of drugs (e.g., heroin, cocaine and Ritalin) had differential effects on the use of ARV therapy among IPLWH, and exploring the socio-structural vulnerabilities and resiliencies surrounding specific drug use.

3. In my study, I explored the effects of overnight incarceration on ARV therapy use among IPLWH. Despite six of my study participants having a history of incarceration, only those two who were using ARV therapy spoke in any depth about the effects of incarceration on their ARV therapy use. For those participants with a history of incarceration who had never used ARVs, I was unable to obtain thick description of their (lack of) experience with ARV therapy use in terms of their incarceration history. Small, Wood, Betteridge, Montaner and Kerr (2009) reported in their study involving PWID with a history of incarceration that “[i]nterviewees reported that due to high levels of HIV discrimination[,] prisoners living with HIV/AIDS will often not disclose their status, as inmates known to be HIV positive often experience violence or may be denied access to scarce resources (including drugs and syringes) by fellow inmates” (p. 711). My study could be refined to focus exclusively on IPLWH who have a history of incarceration and/or a criminal history or history of being involved with the law to determine what effects these circumstances have on all aspects of ARV therapy use among IPLWH (access, acceptance and adherence). It would also be interesting to know more about how such circumstances of incarceration affect IPLWH use of ARV therapy once they are released from prison. Moreover, research into how correctional facility staff (e.g., healthcare staff and guards) perceive issues affecting ARV therapy use among IPLWH could be instructive. Furthermore, Milloy et al. (2011) reported an increase in ARV therapy non-adherence with increased incidence of incarceration among people living with HIV with 39.2% of the study sample reporting Aboriginal ancestry. The Milloy et al. study did not report a statistical difference between Aboriginal and non-Aboriginal study participants in terms of non-adherence to ARV
therapy. Although the participants in my study talked about how incarceration negatively affected ARV adherence among IPLWH, it would be interesting to know how multiple incarcerations affect the use of ARV therapy among this population.

4. According to the socio-demographic and health information survey that I administered to my study participants, more females (5) than males (3) reported ever having stopped ARVs. In my study, females talked about their unique circumstances pertaining to caring for children as they related to ARV therapy. I think that more research is required to determine whether female IPLWH are less likely to access, accept and adhere to ARV therapy in comparison to male IPLWH. In addition, it would be interesting to know what socio-structural circumstances might affect female IPLWH. What role might being a single parent with childrearing responsibilities play in their use of ARV therapy?

5. In Canada, others (Sauve et al., 2013) reported that among HIV-infected pregnant females, IPLWH were statistically less likely than non-Indigenous PLWH to receive > 4 weeks of combination ARV therapy. Furthermore, others (Newman et al., 2007) found in their Australian study involving IPLWH that pregnant women would discontinue ARV therapy once they gave birth because they perceived themselves to be in good health. In my study, I only interviewed one study participant who was pregnant. Her pregnancy was an incentive for her to use ARV therapy because she did not want to vertically transmit HIV to her infant. Future research might explore in more depth the use of ARV therapy among IPLWH mothers in Canada.

6. Regarding the six broad recommendations that were put forward by the study participants who attended the second Indigenous sharing circle interview, as previously discussed in this Chapter (Section 9.2.3. Practice: From implications to recommendations), feasibility studies are required to determine the practicability of the recommendations. In addition, intervention research could be conducted to determine the effectiveness of the six broad recommendations and how best to operationalize them.

7. This dissertation used a theoretical paradigm involving critical Indigenous qualitative research to examine how IPLWH constructed and understood their experiences of ARV therapy access, acceptance and adherence. Although critical Indigenous qualitative research helped to further understand this phenomena within the context of who IPLWH are as Indigenous peoples, more research is needed to fully appreciate the value of using such a paradigm to benefit Indigenous communities. Ontologies and epistemologies of Indigenous peoples need to be further explored and reconciled in relation to other forms of research.

9.5. Conclusion

I discussed my study findings in relation to the scholarly literature and the question: How do IPLWH construct and understand their experiences of ARV therapy? In addition, I explained how
conceptual and methodological frames of reference were used to investigate and understand how and why IPLWH access, accept and adhere to ARV therapy. I stressed the value of using a critical Indigenous qualitative research design to research this phenomena.

The study argued that IPLWH who are living with a substance use disorder have unique circumstances surrounding their use of ARV therapy. They live with three dimensions of vulnerabilities: their identity as IPLWH, their substance use disorder, and their social contexts as a culture-sharing group impacted by historical relations between Indigenous peoples and the Nation State of Canada. These three interacting dimensions of social vulnerability compound the degree of their vulnerability. Despite this, IPLWH are able to adapt positively to such adversity, all the more so when appropriate underlying socio-structural mechanisms are in place to support their resilience. A concerted effort among IPLWH, health service providers and policy makers is required if IPLWH are to access, accept and adhere to ARV therapy.

My findings explain why interventions to support the use of ARV therapy among IPLWH should be based upon holistic health care that is founded on Indigenous values, cultures and beliefs. The use of ARV therapy among IPLWH should incorporate biomedical, behavioural and social aspects to care that take into account individual, interpersonal and socio-structural factors. For IPLWH who are living with a substance use disorder, emphasis should be placed on strengthening the healthcare and social welfare systems. At the same time, social factors and the beliefs of IPLWH need to be given serious consideration by all parties if the health care and social welfare of IPLWH are to be strengthened in a way that is relevant to IPLWH. By focusing on these issues, there is great potential to redistribute existing resources so that health services among IPLWH in the cities of Saskatoon and Prince Albert are made more equitable and so that demographic and need variables drive the use of ARV therapy among this population.
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Appendices

Appendix A: Coding Scheme

Codebook for Data Analysis

Main Research Question: How do Indigenous peoples living with HIV (IPL.WH) construct and understand their experiences of antiretroviral (ARV) therapy?

Structure: Structure is “the material and operational manifestations of social norms and networks, such as family units, organized religion, legislative and policy apparatus, educational systems, military and industrial organizations, etc., in which social interaction is patterned and often, controlled” (J. D. Auerbach et al., 2009, p. 2).

The following is the coding scheme using access to ARV therapy as an example (Note: Although not shown here, this coding scheme will also be used for the concepts of acceptance and adherence to ARV therapy). For coding, I use two types of codes. The first type of codes are provisional *a priori codes* (a first cycle coding method), which are predetermined codes based upon my literature review, conceptual framework (i.e., Behavioural Model of Health Services Use) and my research questions. The second type of codes are initial *in vivo codes* where explanations of the phenomena come from the data and are stated by the study participants; codes that I constructed from the data are termed *in vitro codes* (Alvesson & Skoldberg, 2009). The in vivo codes and in vitro codes (a first cycle coding method) are then broken down into *focused codes* (a second cycle coding method). “Focus[ed] coding means using the most significant and/or frequent earlier codes to sift through large amounts of data” (Charmaz, 2006, p. 57). Focused coding is used to “develop the most salient categories in large batches of data” (Charmaz, 2006, p. 46).

A Priori Codes

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<tr>
<th>1.</th>
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<td>Population Health Indices</td>
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<td><em>Individual Characteristics</em></td>
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<td>1.116</td>
<td>Personal Health Practices</td>
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<td>Process of Medical Care</td>
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<td>1.118</td>
<td>Use of Personal Health Services</td>
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<td><em>Outcome</em></td>
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<td>1.119</td>
<td>Perceived Health</td>
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<td>1.120</td>
<td>Evaluated Health</td>
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<td>1.121</td>
<td>Consumer Satisfaction</td>
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<td><strong>Resilience</strong></td>
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Adherence considers the medication-taking behaviour of the client (e.g., following prescription instructions and achieving intended outcomes) as well as person-centred interactions (e.g., the patient-care provider relationship, and the patient’s beliefs, motivation, and habits) (Lehane & McCarthy, 2009) including the clinical setting such as an amicable health care environment (Ickovics & Meade, 2002).

Vulnerability
Three dimensions of social vulnerability: (1) identity vulnerability, or the social trajectory (e.g., one’s life course position and biological fragility), (2) relational vulnerability, or the intersection of two or more social trajectories (e.g., relational influences) and (3) contextual vulnerability, or the social contexts (e.g., macrosocial impacts). The extent to which a person is affected by the three specific dimensions of vulnerability depends upon one’s exposure to vulnerabilities, the capacity of one to respond to vulnerabilities, and the potentiality or impact of vulnerabilities (Delor & Hubert, 2000).

Resilience involves a dynamic process of interacting systems, as opposed to a personality characteristic or trait (i.e., resiliency), where an individual, group, population or system is able to positively adapt to the circumstances surrounding adversity (Fleming & Ledogar, 2008; L. J. Kirmayer et al., 2009; Luthar & Cicchetti, 2000; Luthar et al., 2000). Resilience possesses three dimensions: (1) one’s invulnerability to adversity; (2) one’s ability to positively adapt in response to adversity; and (3) the ability of one’s underlying mechanisms to fully recover from adversity (Fleming & Ledogar, 2008; Luthar & Cicchetti, 2000; Luthar et al., 2000).

| Contextual Predisposing | “the age, gender, and marital status composition of a community” (R. M. Andersen & Davidson, 2007, p. 4). |
| Demographic | - “independent variables affecting use of health services” (Hulka & Wheat, 1985, p. 445). |
| | - Social class and race (Hulka & Wheat, 1985). |
| | - Veteran status (Gelberg et al., 2000). |

| Contextual Predisposing | “describe how supportive or detrimental the communities where people live and work might be to their health and access to health services. Relevant measures include educational level, ethnic and racial composition… employment level, and crime rate” (R. M. Andersen & Davidson, 2007, pp. 4 & 6). |
| Social | |

| Contextual Predisposing | “underlying community or organizational values and cultural norms and prevailing political perspectives regarding how health services should be organized, financed, and made accessible to the population” (R. M. Andersen & Davidson, 2007, p. 6). |
| Beliefs | |

| Contextual Enabling | “are authoritative decisions made pertaining to health or influencing the pursuit of health” (R. M. Andersen & Davidson, 2007, p. 6). |
| Health Policy | |

| Contextual Enabling | “resources potentially available to pay for health services… Other… are incentives to purchase or provide services, such as rate of health insurance coverage, relative price of medical care… and method of compensating providers” (R. M. Andersen & Davidson, 2007, p. 6). |
| Financing | - Income or insurance (Hulka & Wheat, 1985). |
| | - Social services resources (Gelberg et al., 2000). |

| Contextual Enabling | “includes the amount and distribution of health service facilities and personnel as well how they are structured to offer services…. Structure also includes how medical care is organized in a particular institution or delivery system where people receive care, as with office hours and location of service, provider mix, utilization and quality control. |
| Organization | |
oversight, and outreach and education programs” (R. M. Andersen & Davidson, 2007, p. 6).
  - “community resources, such as medical facilities and manpower” (Hulka & Wheat, 1985, p. 440).
  - Health maintenance organizations (Hulka & Wheat, 1985).
  - Ambulatory medical care (e.g., individual or groups of physicians, hospital outpatient departments, community-supported or industry-supported sources) (Hulka & Wheat, 1985).
  - Primary care programs (e.g., solo or group practice, health centre, primary care centre) (Hulka & Wheat, 1985).
  - “entry, structure, and process of care” (Gelberg et al., 2000, p. 1277).
  - “volume (physician-population ratio, hospital-bed-population ratio)” (Gelberg et al., 2000, p. 1277).
  - Crime rates (Gelberg et al., 2000).

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<th>Contextual Need</th>
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<td>“include health-related measures of the physical environment, among them the quality of housing, water, and air (for example, residing in a country that met national ambient air quality standards throughout the year).” Other measures suggesting how healthy the environment might be are injury or death rate (such as rate of occupational injury and disease and related deaths) as well as death rates from motor vehicle injuries, homicides, and firearms” (R. M. Andersen &amp; Davidson, 2007, p. 6).</td>
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<th>Contextual Need</th>
<th>Population Health Indices</th>
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<td>“are more general indicators of community health that may or may not be associated with the physical environment. These indices include general and condition-specific rates of mortality…; morbidity…; and disability” (R. M. Andersen &amp; Davidson, 2007, pp. 6-7).</td>
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<th>Individual Predisposing</th>
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<td>“such as age and gender of the individual represent biological imperatives suggesting the likelihood that people will need health services” (R. M. Andersen &amp; Davidson, 2007, p. 7).</td>
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  - “independent variables affecting use of health services” (Hulka & Wheat, 1985, p. 445).
  - Social class and race (Hulka & Wheat, 1985).

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<th>Individual Predisposing</th>
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<td>“an individual’s education, occupation, and ethnicity. Expanded measures might include people’s social network and social interactions that can facilitate or impede access to services” (R. M. Andersen &amp; Davidson, 2007, p. 7).</td>
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  - “residential history (dwelling or lack thereof); living conditions (e.g., running water, sewers, heat and air conditioning, electricity, lead paint, and unsafe structures)” (Gelberg et al., 2000, p. 1278).
  - “severity of the women’s homeless history” (J. Stein et al., 2007, p. 796).
  - “mobility (moves between communities and dwellings)” (Gelberg et al., 2000, p. 1276).
  - Family size (Gelberg et al., 2000).
  - “childhood characteristics (e.g., foster care, group home placement, abuse and neglect history, and parental illness)” (Gelberg et al., 2000, p. 1276).
  - “Acculturation/Immigration/Literacy” (Gelberg et al., 2000, p. 1278).
  - Sexual orientation (Gelberg et al., 2000).
<table>
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<th>Individual Predisposing Beliefs</th>
<th>“are attitudes, values, and knowledge people have about health and health services that can influence their subsequent perception of need and use of health services” (R. M. Andersen &amp; Davidson, 2007, p. 7).</th>
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<td>Individual Enabling Financing</td>
<td>“involves the income and wealth available to the individual to pay for services. Financing also includes the effective price of health care to the patient, determined by having insurance and cost-sharing requirements” (R. M. Andersen &amp; Davidson, 2007, p. 7).</td>
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<td>Individual Enabling Organization</td>
<td>“describes whether or not the individual has a regular source of care and the nature of that source (private doctor, community clinic, emergency room). It also includes means of transportation and reported travel time to and waiting time for care” (R. M. Andersen &amp; Davidson, 2007, p. 7).</td>
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<tr>
<td>Individual Need Perceived</td>
<td>“is how people view their own general health and functional state. Also included here is how they experience and emotionally respond to symptoms of illness, pain, and worry about their health condition. Perceptions about the importance and magnitude of a health problem or symptom lead to a decision to seek medical care (or not to do so)” (R. M. Andersen &amp; Davidson, 2007, pp. 7-8).</td>
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Individual Need Evaluated

- “represents professional judgement and objective measurement about a patient’s physical status and need for medical care.... It also has a social component and varies with the changing state of the art and science of medicine, clinical guidelines and protocols, and prevailing practice patterns, as well as the training and competency of the professional expert doing the assessment” (R. M. Andersen & Davidson, 2007, p. 8).
- “a condition characterized by the lack of... medical care that is useful for maintaining a desired level of health” (Hulka & Wheat, 1985, p. 440).
- based on a *client* perspective (Hulka & Wheat, 1985).

Health Behaviours Personal Health Practices

- “include diet and nutrition, exercise, stress reduction, alcohol and tobacco use, self-care, and adherence to medical regimens” (R. M. Andersen & Davidson, 2007, p. 8).
- Food sources (Gelberg et al., 2000).
- Hygiene (Gelberg et al., 2000).
- Unsafe sexual behaviours (Gelberg et al., 2000).

Health Behaviours Process of Medical Care

- “the behaviour of providers interacting with patients in the process of care delivery.” General process measures might relate to patient counselling and education, test ordering, prescribing patterns, and quality of provider-patient communication. Process measures might also describe the specifics of caregiving for particular conditions, such as whether a provider checks a CD4 cell count in a person with HIV disease or reviews the patient’s record of home glucose monitoring in a diabetic” (R. M. Andersen & Davidson, 2007, p. 8).

Health Behaviours Use of Personal Health Service

- “health services use, measured rather broadly as units of physician ambulatory care, hospital inpatient services, and dental care visits” (R. M. Andersen & Davidson, 2007, p. 8).
- Long-term care (Gelberg et al., 2000).
- Alternative health care (Gelberg et al., 2000).

Outcomes Perceived Health

- “indicates the extent to which a person can live a functional, comfortable, and pain-free existence. Measures include reports of general perceived health status, activities of daily living, and disability” (R. M. Andersen & Davidson, 2007, p. 9).

Outcomes Evaluated Health

- “is dependent on the judgment of the professional, on the basis of established clinical standards and state-of-the-art practices. Measures include tests of patient physiology and function as well as diagnosis and prognosis regarding their condition. Outcome measures of perceived and evaluated health may appear suspiciously like perceived and evaluated need measures. Indeed, they are. The ultimate outcome validation of improved access is to reduce individual needs previously measured and evaluated” (R. M. Andersen & Davidson, 2007, p. 9).

Outcomes Consumer Satisfaction

- “is how individuals feel about the health care they receive. It can be judged by patient ratings of waiting time, travel time, communication with providers, and technical care received. From a health plan perspective, an ultimate outcome measure of patient satisfaction in this era of managed care might be whether or not enrollees choose to switch plans” (R. M. Andersen & Davidson, 2007, p. 9).
In Vivo Codes and In Vitro Codes (Note: In vivo codes are denoted with “quotation marks”)

“ADDITION” – Any reference to living or struggling with drug and alcohol addiction whether it is actively using drugs and alcohol, being in recovery and/or having relapses. Living with dual addiction such as being addicted to both opioids (e.g., heroin) and stimulants (e.g., crack cocaine). Triggers (e.g., negative thinking) that may impede sobriety versus being clean. Learning to be comfortable with oneself within the context of not needing to use drugs or alcohol. Any reference made to competing priorities such as having to choose between ARVs or staying clean and sober. For example, IPLWH would choose addiction recovery instead of ARV therapy if ARVs metabolize methadone during methadone maintenance therapy (MMT). Hesitation of taking ARVs during MMT in fear that synergistic side effects may occur (e.g., nausea and lethargy). Continuity of care (e.g., detox, rehab and integration back into society). Support services that facilitate recovery such as MMT and removing oneself from the streets. **Focused Codes: Challenges of Recovery; Choosing Active Addiction Over ARVs; Choosing ARVs Over Active Addiction; Choosing Both Active Addiction and ARVs; and Down Versus Uppers.**

COMING TO TERMS – Any instances of coming to terms with one’s HIV status such as disclosing own HIV status to one’s children and asking questions about HIV and ARVs. Accepting life. **Focused Codes: Welcoming but with Resistance; and Welcoming with Support from Others.**

CO-MORBIDITY – Any reference made to living with HIV and other morbidities other than drug and alcohol addiction (e.g., ADHD, anxiety, diabetes). Any reference made to having difficulties (e.g., emotions) of living with co-morbid conditions. **Focused Codes: Daily Struggles; and Not Being Understood.**

“COURAGE” – Any instances of or references to courage such as having the courage to speak up. **Focused Codes: Experiencing Grief; and Thinking it Through.**

“CULTURE” – Any instances of or reference to culture such as being Aboriginal or not. Could include how one feels about their culture and how other people’s thoughts/actions pertaining to the Aboriginal culture affect the IPLWH. Practicing or not practicing one’s First Nations culture. This could include residential school experiences. Having trouble because of one’s own “Indian” ethnicity. Culturally appropriate health services such as the Saskatoon Tribal Council Health Centre. Using traditional Indigenous medicines such as sweet grass. Coming from a family who are “traditional people.” Having elders work with clinics and physicians for those infected with HIV. Opening oneself to the “Creator” and going to sweats. Having ceremony at the clinic. Honoring people with tobacco. **Focused Codes: Cultural Disconnect; Discriminating Past and Present; Familial Relations; Integration; Mobilizing as a Nation; Traditional Practices; and Wanting One's Culture.**

“DENIAL” – Any instances of or reference made to denial such as avoiding something and hiding behind things in order to avoid reality. For example, wanting to know more information about ARV therapy before accepting it; or stating that he/she doesn’t want to accept ARVs because his/her children may accidentally take their ARVs. **Focused Codes: Breaking Through; Denial as a Safeguard; Distancing Oneself; Never Considered It; and Suspecting Denial in Oneself.**

“FAMILY/FRIENDS” – Anything that indicates the use of family members—defined broadly, such as friendship—(e.g., roommates, common law partner, and son) and friends as social support networks for taking ARVs. Could also include being unable to count on family members because they discriminate against you. May include not having a family or not disclosing one’s HIV status to his/her family or being an “outcast” from the family. Not fitting into the family and losing one’s way (e.g., being the “bad-ass” of the family). Abuse occurring during one’s childhood and abuse later in life, such as by one’s partner. Family members enabling a person with a substance use disorder. References made to an HIV-positive parent dying before his/her child is grown up (e.g., becoming self-sufficient). Not wanting to lose one’s children (i.e., apprehended by child services) as a result of actively using drugs and alcohol and thus, consequently, not having a life with one’s children. Not accepting or adhering to ARVs due to side effects (e.g., lethargy), which could impact how others view her/his childcare practices in relation to childcare responsibilities. **Focused Codes: Blocking My Feelings; Children and Unborn Child; Familial Relations; Having Someone or No One; Nationhood; and Social Networks.**

HOLISM – Any instance of or anything about the integration of health services with what some may view as non-health sector activities (e.g., correctional services). Any reference to health promotion activities, such as exercising and adhering to medical regimens. Holism could also pertain to the lack of holistic and integrated health care. **Focused Codes: Continuity of Care; Cultural Worldview; Integrated Healthcare; Non-Health Sector Activities; and Specific Policies.**

“HONESTY” – Any instances of or reference to honesty such as being honest with oneself or with others. **Focused Codes: Disclosure and Nondisclosure; Involvement from Others; and Self-Honesty.**

IMPULSE – Anything that indicates impulses leading to acting out emotional states of mind regardless of the consequences (e.g., incarceration). Any references made to being self-destructive (e.g., being stubborn). Any instances of learning to cope with impulses and not act upon them, including acting upon such impulses in an appropriate manner. **Focused Codes: Acting Out, Self-Pity and Revenge; Getting Angry; and Thinking Before Doing.**

“JUDGEMENT” – Any instances of or reference to being judged by others (actual or perceived) or acts of prejudice related to HIV and being “Native.” Could also include the consequences of such judgement. For example, after death, not having your
body buried in your home community because you’re HIV-infected. Disclosing one’s HIV status to any person without
knowing if such disclosure is safe for oneself. Others having stereotypical images of an “Indian” (regardless of how “articulate”
the Indian is). Focused Codes: Being Aboriginal; Coping; Having HIV; Institutional Influence; Othering; and Places.

KNOWING ONESELF – Anything that indicates knowing oneself and believing in oneself, being self-confident and therefore
possibly leading to self-care. This could also refer to empathy such as IPLWH knowing what other IPLWH are going through in their
respective lives (e.g., being in the same boat). Being understood (e.g., HIV-negative people don’t seem to understand HIV
and those living with HIV). IPLWH knowing other IPLWHs and therefore the value of peer support (e.g., needle exchange).
Focused Codes: Amongst Peers; Drugs and Alcohol; Reflecting; Self-Esteem and Self-Care; and What Others Can Do.

OUTLOOK – Any instances of or reference made to thinking about or having an outlook for the future (e.g., hope for the
future, negative thinking, being lonely). This could include being around people with attitudes that are positive or negative (e.g.,
passionate doctors, friends who are against ARVs thinking that ARVs kill HIV-positive people faster). Any reference made to
encouragement such as being encouraged by a health care provider. This may include being uncertain about living with one’s
HIV infection or receiving medical care (e.g., delays and wait times). Living one-day-at-a-time. Becoming established (e.g.,
accessing social services and collecting GST tax credits). Focused Codes: Family; Friends and Society; Health Services and
Healthcare; Peers; and Self.

PERSEVERANCE – Not giving up the fight of having a substance use disorder as well as being HIV positive. For example,
working with the doctor to find the right dose of MMT; methadone which is believed by the IPLWH to be metabolized by the
ARVs. Any instances of persevering despite not adhering to ARVs and/or having a relapse related to drug and alcohol addiction
and/or persevering because one does not want to die. Focused Codes: Addiction; ARV Access and Adherence; Dealing with
One’s Past; Family; Health, Sickness, Living and Dying; and Reaction to Influences.

“RESPECT” – Anything that indicates having respect for oneself and from others, such as others referring to you as “you got
AIDS.” Not being respected by others because of one’s being on welfare or being an “Indian.” Not being respected by
physicians who can’t or won’t work with HIV-positive people. Being understood by your doctor as a person recovering from a
substance use disorder; a person with a substance use disorder who knows what is working for his/her own respective recovery
(e.g., have your doctor prescribe morphine or opioid prescription treatment instead of methadone because MMT is not as
effective for oneself). Being patronized by other people. Being talked to in a condescending way by health professionals.
Working with the doctor so that the doctor will work with you (vis-à-vis better communication). Not prostituting oneself in
order to maintain one’s addictive lifestyle. Not feeling loved at home. Being respected by one’s children (not having children
look down upon their parent). Being proud of oneself such as for having one’s viral load count decrease or plateau and/or
having one’s CD4 count increase. Being proud of oneself for being self-sufficient. Living a good life and a happy life. Being
sociable and compassionate. Focused Codes: Family; Health Services; Neighbourhood; Non-Health Sector Authorities;
Self; and Society, Acquaintances, Friends and Peers.

“SPIRITUALITY” – Anything that indicates becoming strong (e.g., courageous) in order to heal properly. Having faith,
believing in God and praying. Believing in heaven and hell. Any instances of or references to hope. Believing that someone or
something who is greater than ourselves is looking after us/over us. Having a higher power. Opening oneself to get off the
street by those who are willing to provide guidance (vis-à-vis his/her higher power acting through others). Any instances of
or references to cultural beliefs. Focused Codes: 12-Step Program; Christianity; Cultural Traditions; General; and
Spiritual Growth.

“TRUST” – Any instances of and reference made to trust of and trust in other people. This could include disclosing personal
information (e.g., HIV status, living with addictions) about oneself to others, such as to health care providers and family
members. Trusting health care professionals knowing that one’s private, personal information is not going to leave the room.
Not being able to trust too many people. Focused Codes: Culture, Spirituality and Residential Schools; Family and
Friends; Health Service Providers; Others and Society; Self; and Work.
Appendix B: Collaborative Research Agreement and Support Letters

Collaborative Research Agreement

Research Project Title
Access to, acceptance of and adherence to HIV antiretroviral therapy among Aboriginal people in Saskatchewan

THIS COLLABORATIVE RESEARCH AGREEMENT is made this 2nd day of January, 2013.

BETWEEN:
Drs. Ryan Meili, Steve Sanche, and Kris Stewart
Co-chairs
Saskatoon HIV/AIDS Research Endeavour
(referred to as the “Community Partner”) AND
Earl Nowgesic
PhD Candidate
Dalla Lana School of Public Health
Faculty of Medicine
University of Toronto
(referred to here as the “Principal Investigator”)

The named Principal Investigator and the Community Partner agree to conduct the named collaborative research project in accordance with the principles and conditions outlined in this agreement.

Parties
This document constitutes a collaborative research agreement between Earl Nowgesic, PhD Candidate at the Dalla Lana School of Public Health, Faculty of Medicine, University of Toronto (Principal Investigator) and the Saskatoon HIV/AIDS Research Endeavour, or SHARE (Community Partner). Established in January 2011, SHARE’s membership is comprised of community members and groups (e.g., AIDS Saskatoon, Northern Inter-Tribal Health Authority, and the Saskatoon Tribal Council), health service providers (e.g., Health Canada, First Nations and Inuit Health Branch, Saskatchewan Region; Parkland Health Region; Saskatchewan Ministry of Health; and Westside Community Clinic) and university researchers (e.g., University of Saskatchewan).

Purpose and Scope of the Research Project
The purpose of this qualitative study is threefold: (1) to engage communities in community-based participatory research from a critical, indigenous perspective; (2) to understand the use (i.e., access, acceptance and adherence) of antiretroviral (ARV) therapy among Aboriginal persons living with HIV/AIDS (APLWHA) who reside in the Saskatoon and Prince Albert areas; and (3) to understand
factors (i.e., individual, interpersonal and structural vulnerabilities and resilience) affecting ARV therapy use. The findings of the study can be applied by interested parties to develop effective health systems, services and policies to support APLWHA. The type of information that will be collected in the study will be interview data, observation data and baseline socio-demographic data.

Methodology, Methods and Procedures
The research proposal will be developed by the Principal Investigator. The Community Partner will review the proposal and provide feedback to the Principal Investigator. The Community Partner will also have the opportunity to provide consultative advice to the Principal Investigator throughout the research process (e.g., data collection, analysis and interpretation).

The research will be based upon a critical, indigenous qualitative research paradigm, which values indigenous ontologies and epistemologies. The orientation of the research will be community-based participatory research. The research will combine critical and indigenous methodologies. Methods of the research will include individual interviews, observation and indigenous sharing circle interviews. Data will be collected by use of jottings, memos, journaling, audio-recorder and transcription. Data will be analysed using thematic analysis.

The Community Partner will help to disseminate the study’s recruitment information via postings on their premises and indirectly via the distribution of flyers to potential study participants by leaving such recruitment notification flyers in strategic, public areas (e.g., the AIDS Saskatoon-601 Outreach Centre waiting room; the 601 North Outreach Centre waiting room in Prince Albert; the Prince Albert Sexual Health Clinic-Access Place waiting room; the Saskatoon Westside Community Clinic waiting room; and the Saskatoon Tribal Council Clinic waiting room) where potential study participants might see them and take one. The intent here is that possible study participants will then volunteer to take part in the study (Note: No direct outreach to possible participants will be done).

The Community Partner will provide physical space for the Principal Investigator to conduct interviews. Within the parameters of informed consent by all parties involved, the Community Partner will provide opportunities for the Principal Investigator to be invited to observe health appointments of APLWHA with their health care provider.

The Community Partner will help the Principal Investigator engage a local, traditional ceremonial indigenous helper to open and close the indigenous sharing circles, and offer smudging during all interviews (individual and indigenous sharing circle).

The Community Partner will help the Principal Investigator engage a local indigenous food catering company to provide food and beverage services for the study’s two indigenous sharing circles.

The Community Partner will be offered the opportunity to serve as a co-author for any manuscripts developed for publication submission. Specially, the three co-chairs of SHARE will be invited to be co-authors on any publications/articles moving forward from the study. Recognizing that each journal has its own policies regarding authorship, anyone else in addition to the SHARE co-chairs who were involved in conducting the research, as represented by the article, will be invited to be a co-author on the publication.

The Community Partner will help the Principal Investigator to disseminate the findings of the research.

Given the emergent nature of qualitative research, the title, objectives and design of the research project are subject to change. Any such changes will be reviewed by the parties of this collaborative research agreement.
Expected Outcomes, Benefits and Risks
The expected outcomes of the research project are a research report and published journal articles, findings of which will be presented at conferences and workshops. The results of the study may help to create new knowledge that can be applied broadly by interested parties in order to develop effective health systems, services and policies to support APILWA within the context of ARV therapy.

The research project will benefit the Principal Investigator in learning how to become an independent researcher working with community-based groups. The project will be used by the Principal Investigator to meet the requirements for his PhD degree from the University of Toronto. The project is expected to benefit the Community Partner by providing new knowledge to support policy and health services. The project will also help the Community Partner to learn about qualitative research, and will provide opportunities for collaboration between all those involved in the research project.

Some of the questions asked in the study can be of a sensitive nature and may be uncomfortable for study participants to answer. Such risks will be minimized by the Principal Investigator not probing participants to respond to interview research questions. If the participant does experience a risk-related issue (e.g., emotional upset) during the interview, the Principal Investigator will hold off on the interview process and then ask the participant if he or she would like to take a temporary break from the interview or stop the interview altogether. At the end of the interview, the Principal Investigator will provide a list of appropriate health care resources to the participant whom the participant may contact for consultation.

Although the participants of the indigenous sharing circle interview (focus group) will be reminded that group discussions are to be kept private and confidential, there is no assurance that other group participants will do so and they may breach confidentiality. During the consent process, the Principal Investigator will notify participants that he cannot assure confidentiality on his own as such confidentiality pertains to data collected through focus group settings. Such a breach may cause potential social risks to the study participants such as possible loss of their privacy or tarnishing of their reputation.

Ethical Considerations
Ethical codes of conduct for the research project will be guided by the Tri-Council Policy Statement. Research ethics guidelines from both the University of Toronto and the University of Saskatchewan will also be applied to the research project. Furthermore, cultural codes of conduct and community protocols will be used for the research study.

Obligations and Responsibilities
The Principal Investigator will coordinate all administrative matters of the research project. With the cooperation of the Community Partner, the Principal Investigator will plan and organize the research, and disseminate the research findings as outlined in this agreement.

Funding
The research for this project is made possible through a fellowship award that the Principal Investigator received from the Canada Institutes of Health Research (CIHR) (i.e., CIHR Fellowship in Health Services/Population Health HIV/AIDS Research).

Principles of Ownership, Control, Access and Possession
The research team acknowledges and supports the principles of ownership, control, access and possession as outlined below:

- Parties of this collaborative research agreement acknowledge and respect the Aboriginal right to self-determination, including the jurisdiction to decide about research in their communities. In doing so, the research process shall be built upon meaningful engagement and reciprocity.
between the research team and Aboriginal communities. Further, the research team agrees they will strive to respect the privacy, dignity, culture and rights of Aboriginal Peoples.

- Parties of this collaborative research agreement will strive to include meaningful participation from Aboriginal community members as outlined in this agreement and in particular ensure that the research is relevant and beneficial to Aboriginal communities. Parties of this collaborative research agreement may demonstrate such support of the research by obtaining and attaching letters of support from Aboriginal community agencies at the local level who may be involved in conducting the research study.

- Parties of this collaborative research agreement will provide meaningful and appropriate research capacity building.

- In situations where the parties of this collaborative agreement are in disagreement, they will strive to resolve conflict by working to achieve a significant degree of consensus.

**Term**

This collaborative research agreement will be in effect throughout the entire research process from the development of the research proposal through the preparation and submission of the ethics review protocol, the development of the research objectives and questions and the data collection/generation and analysis phases of the project and into the dissemination of findings.

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Dr. Kris Stewart on behalf of the SHARE  
24/11/13  
Date

Earl Nowgesic  
29/11/2013  
Date
January 28, 2013

Re: Support Letter for Earl Nowgesic, Dalla Lana School of Public Health, University of Toronto

We are pleased to be supporting Earl Nowgesic while he conducts his PhD thesis research project (re: access to, acceptance of and adherence to HIV antiretroviral therapy among Aboriginal people in Saskatchewan).

Over the past year, Earl met with us at both our Saskatoon office (April and November 2012) and at our Prince Albert satellite office (June 2012)—The 601 North Outreach Centre—while he was developing his research proposal. We have reviewed his proposal and commended him for a well thought out plan that encourages HIV/AIDS community-based research.

We will help to advertise Earl’s study by placing his study recruitment posters in the common waiting/public areas of our outreach centres.

Once Earl has recruited study participants, we invite him to conduct his PhD research interviews out of our offices in Saskatoon and Prince Albert. Also, within the scope of informed consent by all parties involved, we encourage Earl to be invited to observe outreach appointments of his study participants, which will involve Aboriginal persons living with HIV/AIDS (APLWHA).

In addition to the above, we are committed to supporting Earl during his thesis work by providing him with guidance.

We are hopeful that Earl’s work will lead to supporting APLWHA.

Sincerely,

Heather Byrne
Interim Executive Coordinator
February 11, 2013

Attention: Mr. Earl Nowgesic and the University of Saskatchewan Research Ethics Board

The Saskatoon Friendship Inn supports Earl Nowgesic in conducting his PhD research on access to, acceptance of and adherence to HIV antiretroviral therapy among Aboriginal persons living with HIV.

The majority of our clients here at the Friendship Inn are of First Nations and Metis ancestry.

We are able to support Earl in his doctoral work by allowing him to post his recruitment flyers and conduct his research interviews within our agency. As well, we can provide meeting space to Earl should he require it in order to hold any of his research team meetings.

We look forward to reviewing Earl’s research findings.

Sincerely,

Lynda Brazeau
Executive Director
Saskatoon Friendship Inn

Charitable Tax No.119140937RR0001
February 13, 2013

Re: Support Letter for your PhD study

Dear Earl

I am so very glad that we had an opportunity to reconnect today after such a long time. Your continuing commitment to Aboriginal people who are infected and affected by HIV is truly inspirational. It is through this type of dedication that lives are changed and inroads made in the battle with this disease. For that I thank you.

Your current research project addressing access to, acceptance of, and adherence to HIV antiretroviral therapy among First Nations, Metis and other Aboriginal people living in Saskatoon and Prince Albert is bound to have far reaching importance. Culturally sound intervention, for Aboriginal people is imperative if we hope to stem the contraction and progression of HIV in our communities.

I am delighted to see that your research is community-based and incorporates the cultural values of Aboriginal Peoples. This is truly research that is not only about Aboriginal people but by and for Aboriginal people who are affected by HIV. We will be pleased to help you in any way we can, including posting your study recruitment information.

We look forward to a continuing dialogue with you regarding strategies that will assist us all toward healing for ourselves, our families and our communities. We wish you the best and are excited to see the results of this important PhD study.

In Spirit and Faith

Patti Tait
Family Violence Worker
February 4, 2013

Dear Earl Nowgesic,

Re: Support letter regarding your PhD project

We understand that you and SHARE (Saskatoon HIV/AIDS Research Endeavour) were introduced to each other over a year ago and have decided to work towards common goals in the area of HIV research. The Saskatoon Tribal Council (STC)-Health and Family Services is a supporting agency of SHARE.

The STC is pleased to support your PhD thesis project called, “Access to, acceptance of and adherence to HIV antiretroviral therapy among Aboriginal people in Saskatchewan”.

We are able to post your PhD study recruitment poster within our STC Health Centre located at 1514 20th Street, Saskatoon. Also, if you need to, you may conduct your study interviews within our cultural room at the STC Health Centre.

Your research is relevant to First Nations culture and values. We can introduce you to local First Nation Elders who may be able to support you while you conduct your interviews.

We look forward to reviewing the results of your study. Your project is useful and has the potential to further understand how to better support First Nations people living with HIV/AIDS.

We wish you all the best with your studies.

Sincerely,

Lynne Johnson
Community Health Program Manager
January 14, 2013

To U of S Ethics Board

This letter is to confirm that Westside Community Clinic is supporting Earl Nowgesic in his doctoral research in Saskatoon. Westside Community Clinic is a satellite clinic of the Saskatoon Community Clinic.

Earl has been met the requirements of The Saskatoon Community Clinic research process and has been approved to conduct his research a tour site.

Earl will be posting recruitment posters at our site and will be suing our building when there is space for his focus groups and individual interviews.

At Westside community clinic we see a large number of HIV and Aboriginal clients so we are looking forward to Earl sharing his research findings on HIV adherence in the aboriginal community with us.

Sincerely

Cheryl Hand

Coordinator of Westside Community Clinic
January 23, 2013

Earl Nowgesic
Student
Dalla Lana School of Public Health

RE: Access to, acceptance of and adherence to HIV antiretroviral therapy among Aboriginal people in Saskatchewan

Dear Sir

Thank you for considering Indian Métis Friendship Centre of Prince Albert as a host agency from which you can access and interview Aboriginal/First Nations people living with HIV. We work with clients who lead exceptionally high risk life styles. So many do not have a regular family physician to work with when it comes to serious medical conditions, and many have no understanding of living with HIV and the supports available.

Your study, once completed, will be an invaluable resource for agencies such as ourselves to better assist the clients we now work with. It will allow us as well a better understanding of the process and how the health care system can reach out to those that lead high risk lifestyles.

We would be more than happy to offer private interview space as well as act as a liaison with the client should they ask it of us. Their privacy is of the utmost importance, and we respect that.

Once you are ready, please feel free to send us contact and information posters to hang in our main lobby, and upstairs evening program. Unfortunately, we do not have the staff to assist you, but will try to help in any way we feasibly can to assist you in obtaining this very important data. Clearly, it has taken too many years to get to this point and we congratulate your efforts in trying to open the doors of health care to these very marginalized men and women.

Should you require anything else, please do not hesitate in asking.

Sincerely and in friendship,

Connie Farber
Executive Director
Extension 223
January 14, 2013

To whom it may concern,

It is our pleasure to write this letter of support for Earl Nowgesic's PhD research project.

We understand that Earl's research will mostly be recruiting Aboriginal persons living with HIV/AIDS (APLWA) who are living in the City of Saskatoon given that he is working directly with the Saskatoon HIV/AIDS Research Endeavour (SHARE), which includes AIDS Saskatoon as one of the SHARE member agencies. AIDS Saskatoon has a satellite outreach center in the City of Prince Albert called, the "601 North". Therefore, there is an opportunity for Earl to recruit some APLWA into his study who are living in the City of Prince Albert. We welcome this opportunity since the City of Prince Albert is sometimes underserved when it comes to Aboriginal HIV research initiatives.

Earl's thesis work will involve interviewing APLWA whose stories will then help to develop suggestions on how to help other APLWA access and adhere to antiretroviral therapy, and in particular, female APLWA who are overrepresented in the HIV epidemic in Saskatchewan.

Earl was introduced to our HIV Health Promotion Coordinator, Donna Lerat, in June 2012 and since that time, he has kept in contact with her. We reviewed Earl's thesis proposal and we support his research. When Earl begins his research, he will work with Donna Lerat in a consultative manner in order to ensure that the best interests of APLWA living in Prince Albert are addressed in his research.

Thank you,

Darlene McKay
President
Prince Albert Métis Women's Association Inc.

Cc: Earl Nowgesic, 1309-500 Sherbourne Street, Toronto, Ontario M4X 1L1
earl.nowgesic@mail.utoronto.ca Fax: (416) 978-5503
February 26, 2013

RE: Earl Nowgesic Doctoral Dissertation - Access to, acceptance of and adherence to HIV antiretroviral therapy among Aboriginal people in Saskatchewan

To whom it may concern,

I have recently had the privilege of reviewing and discussing the aforementioned dissertation with Mr. Earl Nowgesic. The Access Place and Outreach Services is both excited and honored to be able to partner on such an exciting research study. We have been able to distribute flyers in our clinic as well as during outreach, and have a poster present in our two waiting rooms. In addition, we will be able to facilitate space for interviews as needed, and potentially the opportunity to observe clinic interactions with participants.

Saskatchewan currently has approximately two times the national average rate of new HIV diagnoses, with a disproportionate representation of aboriginal peoples. There are often many challenges and barriers associated with engaging Aboriginal people living with HIV/AIDS with Anti-retroviral treatment. This ethnography study will provide an opportunity to better understand and address this issue abroad, but also here in Saskatchewan at a very critical juncture.

Sincerely,

Brett Dow MN
Manager of Access Place and Outreach Services
Prince Albert Parkland Health Region
Access Place
101 - 15th St E
Prince Albert, SK, S6V 1G1
Phone: 306-765-6542
Cell: 306-960-3201 (25DSF531)
Fax: 306-765-6543
Email: bdow@paphr.sk.ca
First Nations and Inuit Health Branch
Health Protection Division
3rd Floor, 2045 Broad Street
Regina, Saskatchewan S4P 3T7

February 8, 2013

Attention: Research Ethics Board, University of Saskatchewan

Re: Earl Nowgesic’s PhD thesis research entitled Access to, acceptance of and adherence to
HIV antiretroviral therapy among Aboriginal people in Saskatchewan.

It is a great pleasure to support Earl’s efforts to complete his research thesis. This research has
high merit, is very patient focused and will certainly bring an excellent wealth of knowledge for
understanding core issues related to HIV patients. The research will help tremendously in
shaping future programming and planning among the very vulnerable population in
Saskatchewan.

This study will be taking place off-reserve where many of HIV clients live. Access to HIV
medications is a challenge and still many that are on HIV medications face barriers continuing
their therapy. Through Earl’s research, which will be conducted in Saskatchewan’s main cities
like Saskatoon and Prince Albert, we hope we learn more about why we see these trends and
what the possible solutions are.

I am willing to support and provide him the expertise he needs and also help him in
accomplishing his research goals.

Yours sincerely,

Dr. Ibrahim Khan
Regional Medical Health Officer
Health Protection Division
First Nations Inuit Health Programs - Saskatchewan Region
Telephone: (306) 780-6561
Fax: (306)780-8826
Email: Dr.Ibrahim.Khan@hc-sc.gc.ca
I am pleased to write this letter of support for Earl Newgessic, PhD candidate, University of Toronto (UoT) who is planning on conducting his research project in Saskatoon, Saskatchewan (SK) over the coming two years. I am an Assistant Professor in the Department of Medicine at the University of Saskatchewan and a community general internist with an interest in HIV, HCV and TB medicine. I am co-founder of SHARE (the Saskatoon HIV/AIDS Research Endeavour). SHARE is an interdisciplinary, community-based research team of over 20 individuals consisting of community members (e.g., AIDS Saskatoon, Saskatoon Tribal Council, etc.), service providers (e.g., Westside Community Clinic), policy makers and researchers.

Earl has made four trips to SK since January of 2012 and has met with members of SHARE several times. As well, Earl has kept us informed of his progress over the last several months. He has successfully built a relationship with me and others in our research group, including Dr. Ryan Meili (co-lead of SHARE) and our research coordinator Briana Hagen. Earl has established relationships with members of the Westside Community Clinic (WSCC) and aboriginal communities in Saskatoon and Prince Albert, SK.

Briana Hagen, Dr. Meili and I have reviewed Earl’s research proposal and we have discussed the project with him. Earl plans to function as a participant observer while interacting with and interviewing 20 aboriginal persons living with HIV/AIDS (APLWA) in the Saskatoon and Prince Albert health regions. As well, Earl will participate in two traditional indigenous sharing circles with these individuals along with key informants (e.g., health service providers). Earl intends to explore and analyze what variables contribute to APLWA’s access to, acceptance and adherence of antiretroviral (ARV) therapy. Ultimately he seeks to provide insight into how and why APLWA use ARV therapy. The research question is very relevant to the delivery and study of HIV care in SK. SHARE welcomes Earl’s presence here and we enthusiastically invite him to conduct his proposed research. Earl is committed to receiving ethical approval from the University of Saskatchewan as well as permission to conduct his work from all local and region health authorities, including the WSCC and the Saskatoon Health Region.

SHARE fully supports Earl’s PhD project as described in his UoT ethics protocol that is based on his thesis proposal. We plan to facilitate his work and anticipate that once complete, the project will provide valuable insight into one of our region’s greatest challenges.

Sincerely,

[Signature]

Dr. Kris Stewart, DDS, MD, FRCP
Co-Lead, Saskatoon HIV/AIDS Research Endeavour (SHARE)
Assistant Professor, Division of Medicine, College of Medicine
University of Saskatchewan

Royal University Hospital, 103 Hospital Drive, Saskatoon, SK S7N 0W8
Phone: (306) 655-1775, E-mail: stuart.rakimer@usu.ca
Appendix C: Recruitment Information

Indigenous Red Ribbon Storytelling Study

Would you like to improve the health of Aboriginal persons living with HIV/AIDS (APLWA)?

Are you a First Nation, Metis or Inuk aged 18 years or older living with HIV/AIDS?

or

Are you a health service provider, governmental official, community leader or APLWA working with APLWA?

Have you lived in the Saskatoon or Prince Albert area for at least the past 12 months?

I am a PhD student working in partnership with the Saskatoon HIV/AIDS Research Endeavour (SHARE) to recruit eligible individuals to take part in my PhD student research study to help understand access to, acceptance of and adherence to HIV antiretroviral therapy among First Nations, Metis and Inuit living in the Saskatoon and Prince Albert areas.

If you are interested in participating in this study, please call Mr. Earl Nowgesic in either:

Saskatoon (306) 880-0886 or
 Prince Albert (306) 797-0123

Potential study participants will be asked to be screened for study eligibility. Actual study participants will be asked to take part in an interview and/or a focus group interview (i.e., indigenous sharing circle) and/or to be observed during an appointment with one of your health service providers. You do not need to give your real name to participate in the study and no contact information from you is required.

This study is being led by the University of Toronto (Principal Investigator, Earl Nowgesic) and has been approved by the research ethics board of both the University of Toronto and the University of Saskatchewan.

UNIVERSITY OF TORONTO
DALLA LANA SCHOOL OF PUBLIC HEALTH
Appendix D: Information Letter for the Study

[INSTRUCTIONS]: The researcher will give a copy of this form letter to each potential study participant and read it over with them.

Dear Potential Study Participant,

Re: Invitation to participate in the Indigenous Red Ribbon Storytelling Study

Thank you for your interest in the above-named study being conducted by myself as the researcher (Principal Investigator) in partnership with the Saskatoon HIV/AIDS Research Endeavour (SHARE). I am a PhD student at the University of Toronto, Dalla Lana School of Public Health. This research is being supported by the Canadian Institutes of Health Research, the University of Toronto and the University of Saskatchewan.

The purpose of my qualitative study is threefold: (1) to engage communities in community-based participatory research from a critical Indigenous perspective; (2) to understand the use (i.e., access, acceptance and adherence) of antiretroviral (ARV) therapy among Aboriginal persons living with HIV/AIDS (APLWHA) who reside in the Saskatoon and Prince Alberta areas; and (3) to understand factors (i.e., individual, interpersonal and structural vulnerabilities and resilience) affecting ARV therapy use.

Specific objectives of the study are:
1. By means of an Indigenous sharing circle, to engage communities in the design of a qualitative study (i.e., individual interview guide) to investigate ARV therapy among APLWHA.
2. By means of individual interviews, to understand (i.e., explore, describe and explain) factors affecting ARV therapy use from the perspective of APLWHA in the Saskatoon and Prince Albert areas of Saskatchewan, Canada.
3. By means of participant observation, to contextualize individual interview data in terms of how the physical and social setting of health services contribute to the behaviour of APLWHA in order to further understand ARV therapy among APLWHA.
4. By means of an Indigenous sharing circle, to corroborate the preliminary results of my study while creating opportunities and the will for communities to engage in social action to improve the lives of APLWHA.

By taking part in the study, you will be helping the Researcher (Principal Investigator) and SHARE to understand ARV therapy use and the overall health of APLWHA.

You are being asked to participate in this study given your expertise pertaining to living with HIV/AIDS or working with APLWHA and because you have been living in the Saskatoon and Prince Albert area for at least the past 12 months prior to entering the study.
Your participation in the study will involve being interviewed for 1-2 hours in an individual interview with myself, and/or being interviewed in a group setting with key informants (e.g., health service providers, government officials and community leaders as well as APLWHA), and/or being observed during an appointment with one of your health service providers.

Your voluntary and informed consent to take part in the study will be sought once we have given you further information on the study (e.g. scope of the study, your responsibilities as a research participant, potential harms and benefits of the study, confidentiality, compensation etc.).

If you should have any question prior to this time, please contact me directly.

Thank you.

Earl Nowgesic, BScN, MHSc, PhD Candidate
Researcher (Principal Investigator)
The Indigenous Red Ribbon Storytelling Study
Prince Albert: (306) 797-0123
Saskatoon: (306) 880-0886
Toronto: (416) 838-6998
Dalla Lana School of Public Health
University of Toronto
155 College Street, Room 547
Toronto, Ontario
M5T 3M7
Appendix E: Screening Instrument

Date: ______________________________    Time: ______________________________

Thank you for your interest in the Indigenous Red Ribbon Storytelling Study. Before I can invite you to take part in the study, I need to find out if you are eligible to take part in my study. So I need to ask you a few questions first.

If you are not eligible to take part in the study (or they refuse to take part in the study), the screening information obtained from you will be immediately destroyed by cross-cut shredder.

The questions will take about 5 minutes. Okay?

For APLWHA

1. Are you Aboriginal?
   [If no, terminate].
   [If yes, continue].

2. How old are you? ________
   [If < 18 years, terminate].
   [If ≥ 18 years, continue].

3. Do you live in the Saskatoon and/or the Prince Albert areas?
   [If no, terminate].
   [If yes, continue].

4. How long have you been living in the Saskatoon/Prince Albert area?
   [If < 12 months, terminate].
   [If ≥ 12 months, continue].

5. Are you HIV positive?
   [If no, terminate].
   [If yes, continue].

6. Has a health care provider (e.g., physician) ever suggested that you consider taking HIV antiretroviral therapy?
   [If no, terminate].
   [If yes, continue].

For Key Informants

1. Do you work with APLWHA or are you an APLWHA yourself?
   [If no, terminate].
   [If yes, continue].

2. What is your role in working with APLWHA? [suitable answers include: health service provider, government official, community leader or APLWHA peer supporter]
[If the participant does NOT work with APLWHA or is NOT an APLWHA themself, terminate].
[If the participant does work with APLWHA or is an APLWHA, continue].

3. How long have you been working with APLWHA?

[If < 12 months, terminate].
[If ≥ 12 months, continue].

4. Do you live in the Saskatoon and/or Prince Albert areas?

[If no, terminate].
[If yes, continue].

5. How long have you been living in the Saskatoon/Prince Albert area?

[If < 12 months, terminate].
[If ≥ 12 months, continue].

IF TERMINATED, READ: I’m sorry but you’re not eligible to take part in the study. EXPLAIN WHY.

IF ELIGIBLE FOR THE STUDY, READ: Okay. You’re eligible to take part in the study. Are you still interested in taking part in the study?

[If NO, READ: Thank you. It was nice speaking with you].

[IF YES, CONTINUE.
- Explain to the potential study participant that he or she can take part in any or all the four components of the study (dependent on whether he or she is an APLWHA or non-APLWHA key informant).
- Proceed to inform potential study participant of the informed consent process. If the potential study participant consents take part in the study, let the participant know that he or she can review the consent process again a second time at the actual interview and/or participant observation session and at which time he or she can sign the consent form.
- Arrange interview and/or participant observation session. [IF THE LOCATION IS IN THEIR OWN RESIDENCE OR ANOTHER PRIVATE LOCATION, THEN ASK: Would it be possible if one of my female colleagues (i.e., traditional ceremonial Indigenous helper) also came to the interview? IF NO, READ: In this case, the interview would need to take place at the study location instead. IF YES: Arrange interview.]

Interview or participation observation date: ______________ Time: ________ Location: ____________

(Remind study participant of date, time and location for the interview and/or participant observation session.)
Appendix F: Informed Consent Forms

Four different consent forms were used in this study. They are as follows:
Appendix Fi: Informed consent form for Indigenous Sharing Circle #1;
Appendix Fii: Informed consent form for individual interview of IPLWH;
Appendix Fiii: Informed consent form for participant observation;
Appendix Fiv: Informed consent form for Indigenous Sharing Circle #2;

Consent forms Fi to Fiv are found in the following pages.
Appendix Fi: Consent Form to Participate in Indigenous Sharing Circle #1 of the Indigenous Red Ribbon Storytelling Study

[INSTRUCTIONS]: The researcher will give a copy of this form to each potential study participant and read it over with them.

My name is Earl Nowgesic. I am inviting you to Indigenous Sharing Circle #1 for my study called the Indigenous Red Ribbon Storytelling Study. If you agree to help me by being a part of the sharing circle, you need to sign this consent form using a fake name. We will use your fake name from now on.

The information provided in this consent form is intended to inform you on key aspects of the study and will assist you in providing voluntary and informed consent to participate in the study. Let me explain my study and how you can help. Please ask me questions at any point.

Why am I running the Indigenous Red Ribbon Storytelling Study?
I am a PhD student at the University of Toronto. I am studying public health. This research project is for my PhD degree. I want to find answers to these three questions:

1. How do HIV+ Aboriginal people in Saskatoon and Prince Albert find out about HIV medication?
2. How do they choose to start taking HIV medication?
3. How hard is it to stick to HIV medication?

I think there are many answers. Some people make a personal choice to take HIV medication. Some people consider the lives of people around them where making a choice. Sometimes people do not feel they have a choice. And sometimes others make the decision for them. But I know that I do not have all the answers. That is why I want to hear your story.

When my study is finished, I hope to give advice to health and social services in Saskatoon and Prince Albert in order to help Aboriginal people who want to take HIV medication. I also hope to develop ideas for policies that will help support Aboriginal persons living with HIV/AIDS (also called APLWA).

Why am I asking you to be in my study?
I am looking for key informants (i.e., health service providers, government officials, community leaders as well as APLWA) who have lived in Saskatoon or Prince Albert for the last 12 months. Your involvement in my study will help me to develop an interview guide that I will use to individually interview APLWA over the next several months.

What do you have to do in my study?
If you volunteer, you will take part in an Indigenous sharing circle, which is a form of focus group interview. There will be up to 9 people in the sharing circle including a traditional
ceremonial Indigenous helper who will open and close the circle. The sharing circle will take place sometime in February 2013. It will be held at the Westside Community Clinic in Saskatoon. All volunteers will use fake names when we talk. The interview will last 1-2 hours. I will tape-record the interview. We can smudge before and after the sharing circle, using a traditional ceremonial Indigenous helper.

**How will I use your feedback?**
After the Indigenous sharing circle, I will pay a private data transcriber to type out every word of the tape-recording. I will use numbers instead of fake names to identify speakers in the transcript as well in my own notes. They will not have your real name anywhere. I will use your feedback and the feedback from others to develop an interview guide that I will use when I interview APLWHA one-on-one over the next few months.

I will keep all the information you give me private. I will store it in a safe place for up to seven years and then destroy it. The tape recordings will be erased as soon as they are transcribed. Only my research team will know where the information is stored and locked.

My final report will include a summary of the Indigenous sharing circle. I might use parts of your feedback in workshops and conferences. If I ever quote your words directly, I will not mention any personal details about you. In addition to your story being used in oral and poster presentations during conferences and workshops as well as being published in my detailed PhD study report, the results of my study will be published in journal articles and one-page written summaries.

If you would like to receive a copy of the final research report, you may visit the study office at the Saskatoon Westside Community Clinic. Also, an electronic copy of the final research report will be posted on the public website of the Saskatoon Westside Community Clinic.

**What are the possible benefits of the study?**
There are no direct benefits to you for participating in this study. There are potential indirect benefits to the community. I hope my study will help me discover facts that health care workers and policy makers should know.

**What are the possible risks of the study?**
There are no physical risks to you (e.g., bodily contact) for this study.

You might feel uncomfortable or upset when I share with you the draft interview guide that I initially developed for the individual APLWHA interviews because you might find some of the questions on this interview guide sensitive (e.g., living with HIV and not having medication). But if you do not want to talk during the Indigenous sharing circle, you do not have to. You can also leave the Indigenous sharing circle at any time. I will be careful not to push you to tell me something you do not want to share. If you do get uncomfortable or upset, I can set you up with someone to talk to.

All the information you provide my study will be kept strictly confidential to the best of my ability. However, if you decide to take part in this Indigenous sharing circle, I cannot guarantee confidentiality. There is no guarantee that the other study participants, who are also taking part in the same Indigenous sharing circle as you, will keep your information private. I will ask that
all participants respect each other’s privacy. The consequences of other study participants breaching confidentiality are possible social risks to you such as loss of your privacy and/or tarnishing of your reputation.

Food will be provided at the Indigenous sharing circle. If you have any known food allergies, can you let please let me know in advance.

**How private is your information?**
No one will have access to the data I collect from you except the research team (i.e., me, my supervisor, my thesis committee members and the data transcriber). I will use a participant-specific number to identify the transcript and other notes. They will not have your real name or your fake name. We will hold your information in strict confidence.

Your identity and all information are private and will not be released unless I have to report it. If you give me reason to believe that you are suicidal, I will have to report it to a health authority, and if you tell me about abuse to a child, I will have to report it to the police.

**Can I cover you for your time?**
I can cover you for $20.00 per hour for your time helping me with my study. I can cover a total of $20.00 for travel expenses. If you have childcare expenses, I can cover you for up to $40.00. Cash will be given to you at the time of the interview.

At the end of the Indigenous sharing circle, I will give you a traditional Indigenous tobacco bundle and feast (meal & beverage).

**Am I doing this study alone?**
I am doing this study for my degree at the University of Toronto because I want to know how to better help APLWHA. For my project, I am working with SHARE, the Saskatoon HIV/AIDS Research Endeavour. My study is supported by the Canadian Institutes of Health Research, by the University of Toronto, and by the University of Saskatchewan.

**Can you ask someone else about my study?**
The University of Toronto has rules about interviewing people. My study follows these ethical standards. If you have any questions about taking part my study, please contact the Office of Research Ethics, University of Toronto, (416) 946-3273, ethics.review@utoronto.ca

This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office, ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

**What does it mean if you sign the consent form of my study?**
If you sign the form, you will be volunteering to take part in my study. You can ask questions about the study at any point. You can also take yourself out of the study at any time. It will not be reported anywhere. If you withdraw from the study, you can ask me to delete the information you gave me.

**Can you refuse to take part in my study?**
You do not have to take part in this study. If you do not want to take part, that is not a problem. It will not be reported anywhere.

If you withdraw from the study, you will have the right to request that any information that you provided for the study be deleted from the data. Although other participants will have heard the information you provided, I will still delete your data from the transcription and my notes.

You will have the right to withdraw your data from the study up until the time the audio recordings from the sharing circle have been transcribed, which will be one week after the circle sharing occurs. The reason for this one week deadline is because the audio recording of the sharing circle will be transcribed within one week after the sharing circle is done, and once the audio recordings are transcribed, the audio recording will be immediately destroyed and there will be no way of determining who said what, simply based on the transcriptions.

Consent:
If you sign this form it means you understand:

- why I am doing the study,
- what I am asking you to do in the study,
- what the risks are to you if you go in the study,
- how the information you give in the study will be used,
- your participation in the study is completely voluntary,
- you can ask questions about the study at any time, and
- you may withdraw from the study at any time.

By signing this form, you agree to take part in this study. I will give you a copy of this form to take with you.

Fake Name of Study Participant:_______________________________________________

Signature of Study Participant:_______________________________________________

Date Consent Form Signed:_______________________________________________

Thank you,
Mr. Earl Nowgesic, BScN, MHSc, PhD Candidate
Researcher (Principal Investigator), The Indigenous Red Ribbon Storytelling Study
Prince Albert: (306) 797-0123
Saskatoon: (306) 880-0886
Toronto: (416) 838-6998
Dalla Lana School of Public Health, University of Toronto
155 College Street, Room 547, Toronto, Ontario M5T 3M7
Appendix Fii: Participant Consent Form to be Individually Interviewed for the Indigenous Red Ribbon Storytelling Study

[INSTRUCTIONS]: The researcher will give a copy of this form to each potential study participant and read it over with them.

My name is Earl Nowgesic. I am inviting you to a one-to-one interview for my study called the Indigenous Red Ribbon Storytelling Study. If you agree to help me by being interviewed, you need to sign this consent form using a fake name. We will use your fake name from now on.

The information in this consent form is intended to inform you on key aspects of my study and will assist you in providing voluntary and informed consent to participate in the study. Let me explain my study and how you can help. Please ask me questions at any point.

Why am I running the Indigenous Red Ribbon Storytelling Study?
I am a PhD student at the University of Toronto. I am studying public health. This research project is for my PhD degree. I want to find answers to these three questions:
1. How do HIV+ Aboriginal people in Saskatoon and Prince Albert find out about HIV medication?
2. How do they choose to start taking HIV medication?
3. How hard is it to stick to HIV medication?

I think there are many answers. Some people make a personal choice to take HIV medication. Some people consider the lives of people around them when making a choice. Sometimes people do not feel they have a choice. And sometimes others make the decision for them. But I know that I do not have all the answers. That is why I want to hear your story.

When my study is finished, I hope to give advice to health and social services in Saskatoon and Prince Albert in order to help Aboriginal people who want to take HIV medication. I also hope to develop ideas for policies that will help support Aboriginal persons living with HIV/AIDS (also called APLWHA).

Why am I asking you to be in my study?
I am looking for APLWHA who have lived in Saskatoon or Prince Albert for the last 12 months. Your story will help my study because you know what it is like to live with HIV/AIDS.

What do you have to do in my study?
If you volunteer, you will take part in a one-to-one interview to share your story about HIV medication. The interview will take place between February and March 2013 or July and August 2013. It will be in a safe, private location. It might be at the Westside Community Clinic. It can be at your home if you would like as long as a female colleague of mine (i.e., traditional ceremonial Indigenous helper) is able to come with me. We will use your fake name when we talk. The interview will last 1-2 hours. I will tape-record the interview. At any time
during the interview, I will turn off the tape-recorder if you ask me to. We can smudge before and after the interview, using a traditional, ceremonial Indigenous helper.

**How will I use your story?**
After your interview, I will pay a private data transcriber to type out every word of the tape-recording. I will use a number instead of your fake name to identify the transcript and my notes. They will not have your real name anywhere. I will use your story and the stories of others to figure out answers to my research question. The transcript of our interview will not be published.

I will keep all the information you give me private. I will store it in a safe place for up to seven years and then destroy it. The tape recordings will be erased as soon as they are transcribed. Only my research team will know where the information is stored and locked.

My final report will include a summary of all interviews. I might use parts of your story in workshops and conferences. If I ever quote your words directly, I will not mention any personal details about you. In addition to your story being used in oral and poster presentations during conferences and workshops as well as being published in my detailed PhD study report, the results of my study will be published in journal articles and one-page written summaries.

If you would like to receive a copy of the final research report, you may visit the study office at the Saskatoon Westside Community Clinic. Also, an electronic copy of the final research report will be posted on the public website of the Saskatoon Westside Community Clinic.

**Will I share the results of your study with you?**
If you want to see it, I will show you the transcript of our interview after it is typed. If you want something erased, I will do it. I will also share my final report with you if you want to see it.

**What are the pros and cons for you to take part in my study?**
There are no direct benefits to you for participating in this study. There are potential indirect benefits to the community. I hope my study will help me discover facts that health care workers and policy makers should know. Your story might help other women and men who are thinking about taking HIV medication. You might learn something about yourself that you did not know before the interview.

There are no physical risks to you. For example, you will not be asked to take any medication.

You might feel uncomfortable or upset when you share your story with me. But if you do not want to answer a question, you do not have to. And you can stop the interview at any time. I will be careful not to push you to tell me something you do not want to share. If you do get uncomfortable or upset, I can set you up with someone to talk to.

**How private is your information?**
No one will have access to the data I collect from you except the research team (i.e., me, my supervisor, my thesis committee members and a data transcriber). I will use a participant-specific number to identify your transcript and other notes. They will not have your real name or your fake name anywhere. We will hold your information in strict confidence.
Your identity and all information are private and will not be released unless I have to report it. If you give me reason to believe that you are suicidal, I will have to report it to a health authority, and if you tell me about abuse to a child, I will have to report it to the police.

**Can I cover you for your time?**
I can cover you for $20.00 per hour for your time helping me with my study. I can cover a total of $20.00 for travel expenses. If you have childcare expenses, I can cover you for up to $40.00. Cash will be given to you at the time of the interview.

I will give you a traditional Indigenous tobacco bundle.

**Am I doing this study alone?**
I am doing this study for my degree at the University of Toronto because I want to know how to better help APLWHA. For my project, I am working with SHARE, the Saskatoon HIV/AIDS Research Endeavour. My study is supported by the Canadian Institutes of Health Research, by the University of Toronto, and the University of Saskatchewan.

**Can you ask someone else about my study?**
The University of Toronto has rules about interviewing people. My study follows these ethical standards. If you have any questions about taking part in my study, please contact the Office of Research Ethics, University of Toronto, (416) 946-3273, ethics.review@utoronto.ca

This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office, ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

**What does it mean if you sign the consent form of my study?**
If you sign the form, you will be volunteering to take part in my study. You can ask questions about the study at any point. You can also take yourself out of the study at any time. It will not be reported anywhere.

If you withdraw from the study, you can ask me to delete the information you gave me. Your right to withdraw your data from the study will apply until the time your data is summarized with the data from the other study participants, in September 2013. After this date, the data from all study participants will be summarized together and it will not be possible to withdraw your data because there will be no way of knowing which data belongs to what participant.

**Can you refuse to take part in my study?**
You do not have to take part in this study. If you do not want to take part, that is not a problem. It will not be reported anywhere.

**Consent:**
If you sign this form it means you understand:
- why I am doing the study,
- what I am asking you to do in the study,
- what the risks are to you if you go in the study,
- how the information you give in the study will be used,
• your participation in the study is completely voluntary,
• you can ask questions about the study at any time, and
• you may withdraw from the study at any time.

By signing this form, you agree to take part in this study. I will give you a copy of this form to take with you.

I would like to review the interview transcript of my audio recording:  
☐ Yes  ☐ No

Fake Name of Study Participant:  __________________________________________________

Signature of Study Participant:  _________________________________________________

Date:  _________________________________________________

Thank you,
Mr. Earl Nowgesic, BScN, MHSc, PhD Candidate
Researcher (Principal Investigator), The Indigenous Red Ribbon Storytelling Study
Prince Albert: (306) 797-0123
Saskatoon: (306) 880-0886
Toronto: (416) 838-6998
Dalla Lana School of Public Health
University of Toronto
155 College Street, Room 547
Toronto, Ontario
M5T 3M7
Appendix Fiii: Participant Consent Form to be Observed in the Indigenous Red Ribbon Storytelling Study

[INSTRUCTIONS]: The researcher will give a copy of this form to each potential study participant and read it over with them.

My name is Earl Nowgesic. I am inviting you to take part in the participant observation section of my study called the Indigenous Red Ribbon Storytelling Study. If you agree to help me by being observed, you need to sign this consent form using a fake name. We will use your fake name from now on.

The information in this consent form is intended to inform you on key aspects of my study and will assist you in providing voluntary and informed consent to participate in the study. Let me explain my study and how you can help. Please ask me questions at any point.

Why am I running the Indigenous Red Ribbon Storytelling Study?
I am a PhD student at the University of Toronto. I am studying public health. This research project is for my PhD degree. I want to find answers to these three questions:

1. How do HIV+ Aboriginal people in Saskatoon and Prince Albert find out about HIV medication?
2. How do they choose to start taking HIV medication?
3. How hard is it to stick to HIV medication?

I think there are many answers. Some people make a personal choice to take HIV medication. Some people consider the lives of people around them when making a choice. Sometimes people do not feel they have a choice. And sometimes others make the decision for them. But I know that I do not have all the answers. That is why I want to hear your story.

When my study is finished, I hope to give advice to health and social services in Saskatoon and Prince Albert in order to help Aboriginal people who want to take HIV medication. I also hope to develop ideas for policies that will help support Aboriginal persons living with HIV/AIDS (also called APLWHA).

Why am I asking you to be in my study?
I am looking for APLWHA who have lived in Saskatoon or Prince Albert for the last 12 months. Your story will help my study because you know what it is like to live with HIV/AIDS.

What do you have to do in my study?
If you volunteer, I will observe you for up to one hour, one time only, during your health appointment with a health service provider.
I will observe how you respond to the physical and social setting of your health services appointment. I do not intend to evaluate the health service provider or you in any way.

I will be writing my recordings of the observations in a notepad. At any time during the observation period, I will stop writing/recording if you ask me to.

**How will I use your story?**

After your health appointment with a health service provider, I will type out my notes. I will use a number instead of your fake name to identify you in my notes. My notes will not have your real name anywhere. I will use your story and the stories of others to figure out answers to my research question.

I will keep all the information you give me private. I will store it in a safe place for up to seven years and then destroy it. Only my research team will know where the information is stored and locked.

My final report will include a summary of all observations I do. I might use parts of your story in workshops and conferences. If I ever quote your words directly, I will not mention any personal details about you. In addition to your story being used in oral and poster presentations during conferences and workshops as well as being published in my detailed PhD study report, the results of my study will be published in journal articles and one-page written summaries.

If you would like to receive a copy of the final research report, you may visit the study office at the Saskatoon Westside Community Clinic. Also, an electronic copy of the final research report will be posted on the public website of the Saskatoon Westside Community Clinic.

**Will the results of the study be shared with you?**

If you would like to know what was learned from this study, please let me know and we can make arrangements to get you a copy of a summary of the research results.

**What are the possible benefits of the study?**

There are no direct benefits to you for participating in this study. There are potential indirect benefits to the community. I hope my study will help me discover facts that health care workers and policy makers should know. My study might help other women and men who are thinking about taking HIV medication.

**What are the possible risks of the study?**

There are no physical risks to you.

During the observation period, you might feel uncomfortable having me in the room while you have your appointment with your health service provider. You do not have to be observed for any part of the appointment you don’t want to be, and you may ask me to leave at any time.

**How private is your information?**

No one will have access to the data I collect from you except the research team (i.e., me, my supervisor, my thesis committee members and a data transcriber). I will use a participant-specific number to identify my notes about your appointment. My notes will not have your real name or your fake name anywhere. We will hold your information in strict confidence.
Can I cover you for your time?
I can cover you for $20.00 per hour for your time helping me with my study. I can cover a total of $20.00 for travel expenses. If you have childcare expenses, I can cover you for up to $40.00. Cash will be given to you at the time of the interview.

I will give you a traditional Indigenous tobacco bundle.

Am I doing this study alone?
I am doing this study for my degree at the University of Toronto because I want to know how to better help APLWHA. For my project, I am working with SHARE, the Saskatoon HIV/AIDS Research Endeavour. My study is supported by the Canadian Institutes of Health Research, by the University of Toronto, and by the University of Saskatchewan.

Can you ask someone else about my study?
The University of Toronto has rules about interviewing people. My study follows these ethical standards. If you have any questions about taking part my study, please contact the Office of Research Ethics, University of Toronto at ethics.review@utoronto.ca or (416) 946-3273.

This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office at ethics.office@usask.ca or (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

What does it mean if you sign the consent form of my study?
If you sign the form, you will be volunteering to take part in my study. You can ask questions about the study at any point. You can also take yourself out of the study at any time. It will not be reported anywhere. If you withdraw from the study, you can ask me to delete the information you gave me.

Your right to withdraw your data from the study will apply until the time your data is summarized with the data from the other study participants in September 2013. After this date, the data from all study participants will be summarized together and it will not be possible to withdraw your data because there will be no way of knowing which data belongs to what participant.

Can you refuse to take part in my study?
You do not have to take part in this study. If you do not want to take part, that is not a problem. It will not be reported anywhere.

Consent:
If you sign this form it means you understand:
• why I am doing the study,
• what I am asking you to do in the study,
• what the risks are to you if you go in the study,
• how the information you give in the study will be used,
• your participation in the study is completely voluntary,
• you can ask questions about the study at any time, and
• you may withdraw from the study at any time.

By signing this form, you are consenting to your participation in this study.

Fake Name of Study Participant: __________________________________________

Signature of Study Participant: __________________________________________

Date Consent Signed: ________________________________________________

Thank you,
Mr. Earl Nowgesic, BScN, MHSc, PhD Candidate
Researcher (Principal Investigator), The Indigenous Red Ribbon Storytelling Study
Prince Albert: (306) 797-0123
Saskatoon: (306) 880-0886
Toronto: (416) 838-6998
Dalla Lana School of Public Health
University of Toronto
155 College Street, Room 547
Toronto, Ontario
M5T 3M7
Appendix Fiv: Consent Form to Participate in Indigenous Sharing Circle #2 of the Indigenous Red Ribbon Storytelling Study

[INSTRUCTIONS]: The researcher will give a copy of this form to each potential study participant and read it to them.

My name is Earl Nowgesic. I am inviting you to an Indigenous Sharing Circle #2 for my study called the “Indigenous Red Ribbon Storytelling Study.” If you agree to help me by being a part of the sharing circle, you need to sign this consent form using a fake name. We will use your fake name from now on.

The information provided in this consent form is intended to inform you on key aspects of the study and will assist you in providing voluntary and informed consent to participate in the study. Let me explain my study and how you can help. Please ask me questions at any point.

Why am I running the Indigenous Red Ribbon Storytelling Study?
I am a PhD student at the University of Toronto. I am studying public health. This research project is for my PhD degree. I want to find answers to these three questions:

1. How do HIV+ Aboriginal people in Saskatoon and Prince Albert find out about HIV medication?
2. How do they choose to start taking HIV medication?
3. How hard is it to stick to HIV medication?

I think there are many answers. Some people make a personal choice to take HIV medication. Some people consider the lives of people around them when making a choice. Sometimes people do not feel they have a choice. And sometimes others make the decision for them. But I know that I do not have all the answers. That is why I want to hear your story.

When my study is finished, I hope to give advice to health and social services in Saskatoon and Prince Albert in order to help Aboriginal people who want to take HIV medication. I also hope to develop ideas for policies that will help support Aboriginal persons living with HIV/AIDS (also called APLWHA).

Why am I asking you to be in my study?
I am looking for key informants (i.e., health service providers, government officials, community leaders as well as APLWHA) who have lived in Saskatoon or Prince Albert for the last 12 months. Your involvement in my study will help me to review the preliminary results of my study and help me to develop recommendations to improve the lives of APLWHA.

What do you have to do in my study?
If you volunteer, you will take part in an Indigenous sharing circle, which is a form of focus group interview. There will be up to 9 people in the sharing circle including a traditional
ceremonial Indigenous helper who will open and close the circle. The sharing circle will take place sometime in September 2013. It will be held at the Westside Community Clinic in Saskatoon. All volunteers will use fake names when we talk. The interview will last 1-2 hours. I will tape-record the interview. You can smudge before and after the interview, using a traditional ceremonial Indigenous helper.

How will I use your feedback?
After the Indigenous sharing circle, I will pay a private data transcriber to type out every word of the tape-recording. I will use numbers instead of fake names to identify speakers in the transcript as well as in my own notes. They will not have your real name anywhere. Your feedback on the preliminary results of my study is important to me. Your feedback will also help me to develop recommendations on how to support the lives of APLWHA.

I will keep all the information you give me private. I will store it in a safe place for up to seven years and then destroy it. The tape recordings will be erased as soon as they are transcribed. Only my research team will know where the information is stored and locked.

My final report will include a summary of the Indigenous sharing circle. I might use parts of your feedback in workshops and conferences. If I ever quote your words directly, I will not mention any personal details about you. In addition to your story being used in oral and poster presentations during conferences and workshops as well as being published in my detailed PhD study report, the results of my study will be published in journal articles and one-page written summaries.

If you would like to receive a copy of the final research report, you may visit the study office at the Saskatoon Westside Community Clinic. Also, an electronic copy of the final research report will be posted on the public website of the Saskatoon Westside Community Clinic.

What are the possible benefits of the study?
There are no direct benefits to you for participating in this study. There are potential benefits to the community. I hope my study will help me discover facts that health care workers and policy makers should know.

What are the possible risks of the study?
There are no physical risks to you (e.g., bodily contact) for this study.

You might feel uncomfortable or upset when I share with you the preliminary results of my study because you might find some of the information sensitive (e.g., living with HIV and not having medication). But if you do not want to talk during the Indigenous sharing circle, you do not have to. You can also leave the Indigenous sharing circle at any time. I will be careful not to push you to tell me something you do not want to share. If you do get uncomfortable or upset, I can set you up with someone to talk to.

All the information you provide my study will be kept strictly confidential to the best of my ability. However, if you decide to take part in this Indigenous sharing circle, I cannot guarantee confidentiality. There is no guarantee that the other study participants, who are also taking part in the same Indigenous sharing circle as you, will keep your information private. I will ask that all participants respect each other’s privacy. The consequences of other study participants...
breaching confidentiality are possible social risks to you such as loss of your privacy and/or
tarnishing of your reputation.

Food will be provided at the Indigenous sharing circle. If you have any known food allergies,
can you let please let me know in advance.

**How private is your information?**
No one will have access to the data I collect from you except the research team (i.e., me, my
supervisor, my thesis committee members and the data transcriber). I will use a participant-
specific number to identify the transcript and other notes. It will not have your real name or
your fake name. We will hold your information in strict confidence.

Your identity and all information are private and will not be released unless I have to report it.
If you give me reason to believe that you are suicidal, I will have to report it to a health
authority, and if you tell me about abuse to a child, I will have to report it to the police.

**Can I cover you for your time?**
I can cover you for $20.00 per hour for your time helping me with my study. I can cover a total
of $20.00 for travel expenses. If you have childcare expenses, I can cover you for up to $40.00.
Cash will be given to you at the time of the interview.

At the end of the Indigenous sharing circle, I will give you a traditional Indigenous tobacco
bundle and feast (meal & beverage).

**Am I doing this study alone?**
I am doing this study for my degree at the University of Toronto because I want to know how to
better help APLWHA. For my project, I am working with SHARE, the Saskatoon HIV/AIDS
Research Endeavour. My study is supported by the Canadian Institutes of Health Research, by
the University of Toronto, and by the University of Saskatchewan.

**Can you ask someone else about my study?**
The University of Toronto has rules about interviewing people. My study follows these ethical
standards. If you have any questions about taking part my study, please contact the Office of
Research Ethics, University of Toronto at ethics.review@utoronto.ca or (416) 946-3273.

This research project has been approved on ethical grounds by the University of Saskatchewan
Research Ethics Board. Any questions regarding your rights as a participant may be addressed
to that committee through the Research Ethics Office at ethics.office@usask.ca or (306) 966-
2975. Out of town participants may call toll free (888) 966-2975.

**What does it mean if you sign the consent form of my study?**
If you sign the form, you will be volunteering to take part in my study. You can ask questions
about the study at any point. You can also take yourself out of the study at any time. It will not
be reported anywhere. If you withdraw from the study, you can ask me to delete the
information you gave me.

**Can you refuse to take part in my study?**
You do not have to take part in this study. If you do not want to take part, that is not a problem. It will not be reported anywhere.

If you withdraw from the study, you will have the right to request that any information that you provided for the study be deleted from the data. Although other participants will have heard the information you provided, I will still delete your data from the transcription and my notes.

You will have the right to withdraw your data from the study up until the time the audio recordings from the sharing circle have been transcribed, which will be one week after the circle sharing occurs. The reason for this one week deadline is because the audio recording of the sharing circle will be transcribed within one week after the sharing circle is done, and once the audio recordings are transcribed, the audio recording will be immediately destroyed and there will be no way of determining who said what, simply based on the transcriptions.

**Consent:**
If you sign this form it means you understand:
- why I am doing the study,
- what I am asking you to do in the study,
- what the risks are to you if you go in the study,
- how the information you give in the study will be used,
- your participation in the study is completely voluntary,
- you can ask questions about the study at any time, and
- you may withdraw from the study at any time.

By signing this form, you agree to take part in this study. I will give you a copy of this form to take with you.

Fake Name of Study Participant: ________________________________________________

Signature of Study Participant: ________________________________________________

Date Consent Form Signed: ________________________________________________

Thank you,
Mr. Earl Nowgesic, BScN, MHSc, PhD Candidate
Researcher (Principal Investigator), The Indigenous Red Ribbon Storytelling Study
Prince Albert: (306) 797-0123
Saskatoon: (306) 880-0886
Toronto: (416) 838-6998
Dalla Lana School of Public Health, University of Toronto
155 College Street, Room 547, Toronto, Ontario M5T 3M7
Appendix G: Interview Guides

Three different interview guides were used in this study. They are as follows:
Appendix Gi: Interview guide for Indigenous Sharing Circle #1;
Appendix Gii: Interview guide for individual interviews; and
Appendix Giii: Interview guide for Indigenous Sharing Circle #2.

Interview guides Gi to Giii are found in the following pages.
Appendix Gi: Interview Guide for Indigenous Sharing Circle #1

Objective: By means of an Indigenous sharing circle, to engage communities in the design of a qualitative study (i.e., individual interview guide) to investigate ARV therapy among APLWHA.

Research Questions:
1. What are the core values of key informants (e.g., health service providers, government officials and community leaders as well as APLWHA) regarding the actual and/or potential use (i.e., access, acceptance and adherence) of ARV therapy among APLWHA?
2. What are the core values of key informants regarding possible factors (i.e., personal, interpersonal and socio-structural vulnerabilities and resilience) affecting the use of ARV therapy among APLWHA?

[TO START THE DISCUSSION:]
Thank you for participating in my study. You can leave the sharing circle at any time. Also, if you don’t want to answer any question, please just say pass.

I will be tape-recording this interview, because it will let me focus on what you are saying instead of me just taking notes. It is critical that everyone here today understands the importance of respecting each other’s confidentiality. So what is said in this room should stay in the room.

During the next 1 to 2 hours, I would like to ask some questions about your perspective as a key informant and APLWHA using or not using ARV therapy. Then I would like us to get your feedback on a draft interview guide that I plan to use in my study to conduct individual interviews with APLWHA. In this regard, I will be asking you for your feedback based upon your own experiences working with or having first-hand experience of being an APLWHA.

Research Question #1 of 2: What are the core values of key informants (e.g., health service providers, government officials and community leaders as well as APLWHA) regarding the actual and/or potential use (i.e., access, acceptance and adherence) of ARV therapy among APLWHA?

<table>
<thead>
<tr>
<th>Interview Questions</th>
<th>Probes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you please tell me what led you to take part in this study?</td>
<td>• How did you become aware of this study?</td>
</tr>
<tr>
<td></td>
<td>• What made you decide to take part in this study?</td>
</tr>
<tr>
<td>Can you tell me about your experience working with an APLWHA or being an APLWHA?</td>
<td>• insights</td>
</tr>
<tr>
<td></td>
<td>• understanding cultural issues</td>
</tr>
<tr>
<td></td>
<td>• challenges</td>
</tr>
<tr>
<td>Can you tell me about your workplace in terms of supporting APLWHA?</td>
<td>• programs and services</td>
</tr>
<tr>
<td></td>
<td>• cultural practices</td>
</tr>
<tr>
<td></td>
<td>• policies</td>
</tr>
<tr>
<td></td>
<td>• challenges</td>
</tr>
<tr>
<td>From your experience, how you would describe APLWHA in the Saskatoon and Prince Alberta areas?</td>
<td>• Characteristics</td>
</tr>
<tr>
<td>Please tell me what things could affect the use of ARV therapy among APLWHA.</td>
<td>• waiting to see a doctor</td>
</tr>
<tr>
<td></td>
<td>• waiting for HIV viral load (VL) testing, time between HIV diagnosis and VL testing</td>
</tr>
<tr>
<td></td>
<td>• developing ARV drug resistance</td>
</tr>
</tbody>
</table>
- fear of being rejected or stigmatized by health care personnel due HIV status, ethnicity, and drug & alcohol use
- employment, housing, access to food
- gaining access to children
- avoiding abusive situations and living with substance use issues
- sexual abuse
- childhood abuse
- self-harm
- social inequities
- health disparities
- sex trade
- colonialism
- dysfunctional behaviour of parents

| How and why are APLWHA either using (and/or not using) ARV therapy? | • Does late presentation to HIV care affect delays in accepting, accessing, & adhering to ARV therapy?  
• How do culture, values, and beliefs affect ARV therapy? What characteristics of culture, values, and beliefs affect ARV therapy?  
• How does colonialism affect ARV therapy? What characteristics of colonialism affect ARV therapy?  
• How does discrimination & stigma affect ARV therapy? What characteristics of discrimination & stigma affect ARV therapy?  
• How does empowerment affect ARV therapy? What characteristics of empowerment affect ARV therapy? |

Research Question #2 of 2: What are the core values of key informants regarding possible factors (i.e., personal, interpersonal and socio-structural vulnerabilities and resilience) affecting the use of ARV therapy among APLWHA?

<table>
<thead>
<tr>
<th>Interview Questions</th>
<th>Probes</th>
</tr>
</thead>
</table>
| Tell me about the relationship between different factors affecting ARV therapy. | Individual-level factors  
• secrecy, stigma  
• individualization of therapy, client-provider relationship  
• regimen complexity and treatment advances  
• side effects of ARVs either early in treatment or late in treatment; drug-drug interactions & differential adherence to individual drugs |
<table>
<thead>
<tr>
<th>What are your thoughts, feedback and feelings about the draft interview guide that I plan to use for the individual interviews of APLWA?</th>
<th>Are there particular questions that you like? Why? Are there any questions which seem unclear? Are there any new questions that should be added?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is there anything else you would like to say about the topics we’ve discussed today?</td>
<td></td>
</tr>
</tbody>
</table>

[TO END THE DISCUSSION:]  
This concludes our sharing circle. Thank you for your participation. Your participation was invaluable to help me develop my interview guide for when I conduct my individual interviews with APLWA.

To remind everyone again, it is critical that everyone here today understands the importance of respecting each other’s confidentiality. What is said in this room should stay in the room.

Today or after today, if you should have any questions about the study, please contact me.

Before you leave the session today, please help yourself to some food & beverage.
Appendix Gii: Interview Guide for Individual Interviews

Objective:
By means of individual interviews, to understand (i.e., explore, describe and explain) factors affecting ARV therapy use from the perspective of APLWHA in the Saskatoon and Prince Albert areas of Saskatchewan, Canada.

Research Questions:
1. How do APLWHA construct and understand their experiences of ARV therapy?
2. What are the personal, interpersonal and socio-structural vulnerabilities and resiliencies affecting access to, acceptance of and adherence to ARV therapy among APLWHA?

[TO START THE DISCUSSION:] Thank you for participating in my study. You can leave the sharing circle at any time. Also, if you don’t want to answer any question, please just say pass.

I will be tape-recording this interview, because it will let me focus on what you are saying instead of me just taking notes. Only I will know who you are. I will use a fake name for you throughout this interview and when I transcribe the interview tape.

During the next 1 to 2 hours, I would like talk with you about your experience, and what you think about HIV antiretroviral therapy (or ARV therapy). I only have a few questions to ask you, so please feel free to talk as much as you want.

There are no ‘right’ or ‘wrong’ answers. This interview is about you and your story. My purpose today is to find out what you think about ARV therapy.

Research Question #1 of 2: How do APLWHA construct and understand their experiences of ARV therapy?

<table>
<thead>
<tr>
<th>Interview Questions</th>
<th>Probes</th>
</tr>
</thead>
</table>
| Can you please tell me what led you to take part in this study? | • How did you become aware of this study?  
• What made you decide to take part in this study?  

| In general, can you please tell me about how other people’s thoughts & feelings affect you in using (or not using) ARV therapy? | • judgmental  
• discriminating  
• free choice to participate in ARV therapy  
• self-initiation  
• autonomous self-regulation  
• autonomy support  
• physician autonomy support  
• client’s perception of undue pressure & obedience to medical authority |
| In general, tell me about how your own thoughts & feelings affect you in using (or not using) ARV therapy. | • cultural identity  
• abuse (sexual, physical & emotional)  
• negative mood such as depression, anxiety & feelings of shame, guilt & embarrassment around being HIV positive  
• positive attitude, personal strengths such as disclosing HIV status  
• your perception of your health |
<table>
<thead>
<tr>
<th>In general, tell me about how other people’s actions affect you in using (or not using) ARV therapy.</th>
</tr>
</thead>
</table>
| • **confidentiality**  
• **discrimination**  
• **fear of being judged**  
• **cultural oppression**  
• **abuse (sexual, physical & emotional)**  
• perception of free choice to participate in ARV therapy |
| • realistic perception of current health  
• client’s personal importance of behaviour towards their health; pessimism about future  
• your knowledge about ARVs  
• treatment knowledge, such as purpose of ARVs  
• confidence in efficacy of ARVs  
• beliefs in the effectiveness of ARVs based upon the media or personal experiences of friends  
• expectations of adherence efficacy  
• your ability to adhere to ARV therapy regimes  
• number of medications  
• **anticipated side effects of ARVs & actual side effects** (e.g., nausea, vomiting, diarrhea & lipodystrophy)  
• self-regulatory efficacy & self-efficacy in general  
• not being able to make medical appointments  
• your satisfaction with health care personnel  
• self-esteem due to limited finances possibly leading to negative impacts on social relationships  
• perception of your social support  
• **childcare, having childcare responsibilities**  
• perception of quality of care within a jail  
• perception of free choice to participate in ARV therapy  
• self-initiation  
• **autonomous self-regulation**  
• perceived autonomy support  
• client’s perception of undue pressure & obedience to medical authority  
• treatment decision-making, such as not being involved in treatment planning  
• client’s perception of physician autonomy support  
• client co-plan for ARV therapy with & trust in physician  
• **holistic care** (e.g., health services integration) |
<table>
<thead>
<tr>
<th>In general, tell me about how your own actions affect you in using (or not using) ARV therapy.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• self-initiation</td>
<td>• non-disclosure of HIV positive status</td>
</tr>
<tr>
<td>• autonomous self-regulation</td>
<td>• alcohol &amp; drug use (e.g., IDU)</td>
</tr>
<tr>
<td>• perceived autonomy support</td>
<td>• childcare, having childcare responsibilities</td>
</tr>
<tr>
<td>• client’s perception of undue pressure &amp; obedience to medical authority</td>
<td>• formal education</td>
</tr>
<tr>
<td>• client’s perception of physician autonomy support</td>
<td>• place of residence (e.g., on or off reserve)</td>
</tr>
<tr>
<td>• client co-planning ARV therapy with &amp; trust in physician</td>
<td>• not living alone</td>
</tr>
<tr>
<td>• holistic care (e.g., health services integration)</td>
<td>• taking part in cultural activities</td>
</tr>
<tr>
<td>• self-initiation</td>
<td>• autonomous self-regulation</td>
</tr>
</tbody>
</table>

In general, tell me about any other things that affect you with using (or not using) ARV therapy.

• your knowledge of any health consequences of non-adherence
• supervised treatment interruptions
• self-management support
• holistic care (e.g., health services integration)
• education, employment, income
• housing and transportation
• incarceration
• social & cultural values
• AIDS service organizations
• Aboriginal organizations & culturally appropriate health care services
• non-Aboriginal organizations
• social supports
• use of a community pharmacy; home delivery; & delivery at a discreet location
• extended hours of health & social services
• abuse (sexual, physical & emotional)
• methadone maintenance

**Research Question #2 of 2:** What are the personal, interpersonal and socio-structural vulnerabilities and resiliencies affecting access to, acceptance of and adherence to ARV therapy among APLWHA?

<table>
<thead>
<tr>
<th>Interview Questions</th>
<th>Probes</th>
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<tbody>
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</tr>
</tbody>
</table>
| Tell me about what affects you with accessing (or not accessing) ARVs. | • acceptance of one’s HIV positive status  
• primary care physician  
• pregnancy  
• health insurance  
• realistic perception of current health  
• formal education, employment, income, transportation, pharmacare  
• place of residence (e.g., on or off reserve)  
• legacy of the Aboriginal Residential School System  
• cultural oppression  
• abuse (sexual, physical & emotional)  
• Aboriginal traditional healing ceremonies and cultural identity & values  
• self-esteem  
• social supports  
• First Nation traditional healing strategies, culturally appropriate health care services, cultural safety  
• Elder services  
• holistic care (e.g., health services integration) |
| --- |
| Please tell me about what affects you with accepting (or not accepting) ARVs. | • acceptance of one’s HIV-positive status  
• self-esteem  
• anticipated side effects of ARVs  
• confidence in efficacy of ARVs  
• self-efficacy  
• pessimism of the future  
• non-disclosure of HIV positive status  
• discrimination, fear of being judged, confidentiality,& perceived stigma  
• psychological distress, & depression  
• abuse (sexual, physical & emotional)  
• alcohol & drug use (e.g., IDU)  
• formal education  
• literacy  
• realistic perception of current health  
• client’s personal importance of behaviour towards their health  
• perception of free choice to participate in ARV therapy  
• self-initiation  
• autonomous self-regulation  
• perceived autonomy support  
• client’s perception of physician autonomy support  
• client co-planning ARV therapy with & trust in physician |
<table>
<thead>
<tr>
<th><strong>Tell me about any barriers (or facilitators) that are directly related to your access to &amp; acceptance of ARV therapy.</strong></th>
<th><strong>Tell me about any barriers (or facilitators) that are indirectly related to your access to &amp; acceptance of ARV therapy.</strong></th>
</tr>
</thead>
</table>
| - client’s perception of undue pressure & obedience to medical authority  
  - place of residence  
  - not living alone  
  - social supports  
  - childcare, having childcare responsibilities  
  - legacy of the Aboriginal Residential School System  
  - cultural oppression  
  - Aboriginal traditional healing ceremonies and cultural identity & values  
  - holistic care (e.g., health services integration) | - education of ARV therapy in general  
  - directions on how to take the ARVs  
  - difficulty remembering to take ARVs  
  - inconvenient time to take ARVs and scheduling adherence around meals, work schedules & activities of daily living  
  - cultural safety  
  - fear of discrimination & stigma  
  - abuse (sexual, physical & emotional)  
  - drug & alcohol use, & IDU  
  - health insurance  
  - Pharmacare  
  - primary care physician  
  - health clinic, health care staff  
  - uncomfortable & feeling vulnerable sitting in a waiting room of an HIV clinic  
  - picking up prescription  
  - waiting for blood to be drawn  
  - holistic care (e.g., health services integration) |
| **Tell me about any barriers (or facilitators) that are indirectly related to your access to & acceptance of ARV therapy.** | - acceptance of one’s HIV positive status  
  - fear of disclosing one’s HIV status  
  - lack of privacy, fear of discrimination & stigma  
  - history of residential school and trauma  
  - abuse (sexual, physical & emotional)  
  - self-esteem  
  - social supports, finances, welfare, and transportation  
  - housing  
  - place of residence (e.g., on or off reserve)  
  - culturally appropriate health services  
  - holistic care (e.g., health services integration) |
In general, tell me about how your own lifestyle affects you in using (or not using) ARV therapy.

- HIV viral load, CD4 count
- who you are as a person
- age, sex, & gender
- pregnancy and before & after fetus was born
- childcare
- drug & alcohol use, & IDU
- HCV & HBV infection, diabetes, & TB

Tell me about your current ARV therapy.

- How about the complexity of the ARV regime (e.g., number of pills, scheduling, and side effects)?
- How about your lifestyle in general?
- What is it like taking ARV therapy based on where you are living (e.g., on or off reserve, rural or urban, & jail)?
- What are the health care providers like for you?
- What characteristics of health services make it easier or harder for you to access, accept, and/or adhere to ARV therapy?
- holistic care (e.g., health services integration)

Tell me about what affects you with your adherence to ARVs.

- HIV viral load, CD4 count
- under care of physician with experience in HIV drug therapy
- therapeutic guidelines for HIV treatment
- ARV regime complexity
- adverse effects of ARVs
- quality of life
- coping
- HCV and HBV infection, diabetes, & TB
- mental illness, psychological distress, social supports
- abuse (sexual, physical & emotional)
- alcohol & drug use, & IDU
- First Nation traditional healing strategies, culturally appropriate health care services, & cultural safety
- Elder services
- holistic care (e.g., health services integration)
- legacy of the Aboriginal Residential School System
- cultural oppression, Aboriginal traditional healing ceremonies, cultural identity & values
- self-esteem
- discrimination
- young age
- gender; parents with demanding childcare responsibilities
- income (direct & indirect costs)
- **place of residence** (e.g., on or off reserve)
- incarceration
- unstable housing, migration

Is there anything else you would like to say about the topics we’ve discussed today?
Appendix Giii: Interview Guide for Indigenous Sharing Circle #2

Objective: By means of an Indigenous sharing circle, to corroborate the preliminary results of my study while creating opportunities and the will for communities to engage in social action to improve the lives of APLWHA.

Research Questions:
1. What do APLWHA think about the explanation of access to, acceptance of, and adherence to ARV therapy among APLWHA based upon the preliminary results of my study?
2. What social action is necessary to improve the lives of APLWHA from the perspective of key informants (e.g., health service providers, government officials and community leaders as well as APLWHA)?

[TO START THE DISCUSSION:] Thank you for participating in my study. You can leave the sharing circle at any time. Also, if you don’t want to answer any question, please just say pass.

I will be tape-recording this interview, because it will let me focus on what you are saying instead of me just taking notes. It is critical that everyone here today understands the importance of respecting each other’s confidentiality. So what is said in this room should stay in the room.

During the next 1 to 2 hours, I would like to share with you some preliminary results of my study and then get your feedback on them based on your own experiences either living with HIV or working with APLWHA. Also based on the preliminary study results of my study, I would like to ask you all to develop some recommendations for policy makers and health service providers on how to improve the lives of APLWHA in terms of antiretroviral therapy or ARV therapy.

Research Question #1 of 2: What do APLWHA think about the explanation of access to, acceptance of, and adherence to ARV therapy among APLWHA based upon the preliminary results of my study?

<table>
<thead>
<tr>
<th>Interview Questions</th>
<th>Probes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you please tell me what led you to take part in this study?</td>
<td>• How did you become aware of this study?</td>
</tr>
<tr>
<td></td>
<td>• What made you decide to take part in this</td>
</tr>
<tr>
<td></td>
<td>study?</td>
</tr>
<tr>
<td>What are your thoughts and feedback about the preliminary results of my study?</td>
<td></td>
</tr>
</tbody>
</table>

Research Question #2 of 2: What social action is necessary to improve the lives of APLWHA from the perspective of key informants (e.g., health service providers, government officials and community leaders as well as APLWHA)?

<table>
<thead>
<tr>
<th>Interview Questions</th>
<th>Probes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Based on the preliminary results of my study, what is your vision of the ideal</td>
<td>• community pharmacy, home delivery, delivery at a discreet</td>
</tr>
<tr>
<td>health care system for APLWHA living in the Saskatoon and Prince Albert areas?</td>
<td>location</td>
</tr>
<tr>
<td></td>
<td>• extended hours of community and social agencies</td>
</tr>
<tr>
<td>What things can be done to improve ARV therapy among APLWHA living in the Saskatoon</td>
<td></td>
</tr>
<tr>
<td>and Prince Albert areas?</td>
<td></td>
</tr>
</tbody>
</table>
| What can be done to create supportive environments for APLWHA living in the Saskatoon and Prince Albert areas? | • culturally-appropriate health services  
• cultural awareness sessions for service agencies  
• human resources policies in general  
• cultural policies (e.g., role of Elders, and spiritual leaders) |
<table>
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<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>How can ARV therapy offered in the Saskatoon and Prince Albert areas be improved for APLWHA?</td>
<td>• How can access to, acceptance of, and adherence to ARV therapy among APLWHA be improved in the Saskatoon and Prince Albert areas?</td>
</tr>
<tr>
<td>What are some interventions or incentives for APLWHA in terms of accessing, accepting and adhering to ARV therapy?</td>
<td>• What are the key factors that are important to accessing, accepting or adhering to ARV therapy?</td>
</tr>
<tr>
<td>Is there anything else you would like to say about the topics we’ve discussed?</td>
<td></td>
</tr>
</tbody>
</table>

[TO END THE DISCUSSION:]  
This concludes our sharing circle. Thank you for your participation. Your participation was invaluable to help me review the preliminary results of my study and to help me develop recommendations to improve the lives of APLWHA.

To remind everyone again, it is critical that everyone here today understands the importance of respecting each other’s confidentiality. What is said in this room should stay in the room.

Today or after today, if you should have any questions about the study, please contact me.

Before you leave the session today, please help yourself to some food & beverage.
Appendix H: Surveys

Three different surveys were used in this study. They are as follows:
Appendix Hi: Survey for Indigenous Sharing Circle #1;
Appendix Hii: Survey for individual interviews; and
Appendix Hiii: Survey for Indigenous Sharing Circle #2.

Surveys Hi to Hiii are found in the following pages.
Appendix Hi: Survey on Socio-Demographic and Health Information of Key Informants
(Indigenous Sharing Circle #1)

[TO CLARIFY: Now I just have some final questions, so I can learn more about the participants in my study. Can you please complete the following self-administered survey and return it to me before you leave this session today?].

[INSTRUCTIONS TO STUDY PARTICIPANTS]: Please do not write your name on this form. The information collected from you will be used for research purposes only.

Personal Information (Using a paper & pencil questionnaire, these questions are to be self-administered at the end of the Indigenous sharing circle)

1. Do you live in Saskatoon or Prince Albert?
   - [ ] Yes
   - [ ] No. If no, please specify how far you live from Saskatoon or Prince Albert.
     - _______ Km from [ ] Saskatoon
     - _______ Km from [ ] Prince Albert

2. Do you live on- or off-reserve?
   - [ ] On-reserve
   - [ ] Off-reserve

3. What is your current role in terms of working with APLWHA?
   - [ ] Health service provider
   - [ ] Government official
   - [ ] Community leader
   - [ ] Other, please specify ________________________________
   - [ ] Not Applicable

4. How long have you working in your current role?
   - [ ] Less than 5 years
5. What is your age?

- ☐ 5 to 9 years
- ☐ 10 to 14 years
- ☐ 15 to 19 years
- ☐ 20 years and greater
- ☐ Not Applicable

6. What is your highest level of education?

- ☐ Elementary School
- ☐ Grade 12
- ☐ Trade School
- ☐ College Diploma
- ☐ Professional Designation
- ☐ University Undergraduate Degree
- ☐ University Graduate Degree
- ☐ Other, please specify ________________________________
7. What is your employment status?

- [ ] Full-Time Employment
- [ ] Part-Time Employment
- [ ] Self-Employed
- [ ] Homemaker
- [ ] Unemployed
- [ ] Student
- [ ] Disability
- [ ] Retired

8. What is your total household income?

- [ ] Less than $20,000
- [ ] $20,000 to $69,999
- [ ] Greater than $70,000

9. What is your gender?

- [ ] Male
- [ ] Female
- [ ] Transgendered (Male to Female)
- [ ] Transgendered (Female to Male)

10. What is your ethnic background?

- [ ] First Nation
☐ Métis

☐ Inuk

☐ Other, please specify___________________________________________

☐ Don’t Know

11. What is your HIV Status?

☐ Positive

☐ Negative

☐ Don’t Know
Appendix Hii: Survey of Socio-Demographic and Health Information of APLWHA (Individual Interview)

Note: These questions are to be administered by the interviewer.

[TO CLARIFY:] Now I just have some final questions, so I can learn more about the participants in my study.

<table>
<thead>
<tr>
<th>Ethnicity and Place of Residence</th>
<th>EPR</th>
</tr>
</thead>
</table>
| EPR1. What is your Aboriginal/Indigenous background? | Status First Nation…………..1  
Non-Status First Nation………….2  
Métis ..................................3  
Inuk………………………………..4  
Aboriginal (unspecified)………..5 |
| EPR2. Do you live in Saskatoon? | Yes………………………..1  
No……………………………..2 |
| EPR3. Do you live in Prince Albert? | Yes………………………..1  
No……………………………..2 |
| EPR4. How far do you live from Saskatoon? | ______kilometers  
______Hours |
| EPR5. How far do you live from Prince Albert? | ______kilometers  
______Hours |
| EPR6. Do you live on or off reserve? | On…………………………..1  
Off……………………………2 |
| EPR7. How would you describe your current living accommodation? | Live on the street………….1  
Couch surf……………………..2  
Stay with friends……………….3  
Stay with family………………..4  
Hotel/Motel……………………..5  
Live in your own apartment…..6  
Live in your own house………..7 |

HIV Infection

HIV
| HIV1. In what year did you test positive for HIV? | ________________ |
| HIV2. Do you know what a viral load count is?   | Yes……………………………1  
|                                                | No……………………………2  |
| HIV3. What was your last viral load count?     | ________________ |
| HIV4. Do you know what a CD4 count is?         | Yes……………………………1  
|                                                | No……………………………2  |
| HIV5. What was your last CD4 count?            | ________________ |

### Antiretroviral Therapy

| ARV1. Did a health care provider (like a doctor) ever suggest to you that you consider taking antiretroviral (ARV) medication for HIV infection? | Yes……………………………1  
|                                                                 | No……………………………2  |
| ARV2. Did you ever take ARV medication?            | Yes……………………………1  
|                                                                 | No……………………………2  |
| ARV3. Have you ever stopped taking ARV medication? | Yes……………………………1  
|                                                                 | No……………………………2  |
| ARV4. How many times a day do you take ARV medication? | ____________times per day  |
| ARV5. How many pills of ARV medication do you take every day? | ____________pills per day  |

### Co-Morbidity

| CM1. Do you have any other medical conditions? | Yes……………………………1  
|                                               | No……………………………2  |
| CM2. What other medical conditions do you have? | Diabetes……………………………1  
|                                               | Hepatitis C Virus………………2  |
| **CM3. Do you inject street drugs?** | **Yes.**                           | 1 |
|                                      | **No.**                            | 2 |

<table>
<thead>
<tr>
<th><strong>Demographic Information</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DI1. What is your age?</strong></td>
<td>18-19</td>
</tr>
<tr>
<td></td>
<td>20-29</td>
</tr>
<tr>
<td></td>
<td>30-39</td>
</tr>
<tr>
<td></td>
<td>40-49</td>
</tr>
<tr>
<td></td>
<td>50+</td>
</tr>
<tr>
<td><strong>DI2. What is your highest level of education?</strong></td>
<td>Elementary school...</td>
</tr>
<tr>
<td></td>
<td>Grade 12</td>
</tr>
<tr>
<td></td>
<td>Trades school</td>
</tr>
<tr>
<td></td>
<td>College diploma</td>
</tr>
<tr>
<td></td>
<td>Professional designation</td>
</tr>
<tr>
<td></td>
<td>University undergrad. degree...</td>
</tr>
<tr>
<td></td>
<td>University grad. degree...</td>
</tr>
<tr>
<td></td>
<td>Other</td>
</tr>
<tr>
<td></td>
<td>(If other, specify)</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<p>| <strong>DI3. What is your employment status?</strong> | Full-time employment... | 1 |
|                                          | Part-time employment...         | 2 |</p>
<table>
<thead>
<tr>
<th>Self-employed</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unemployed</td>
<td>4</td>
</tr>
<tr>
<td>A homemaker</td>
<td>5</td>
</tr>
<tr>
<td>A student</td>
<td>6</td>
</tr>
<tr>
<td>On disability</td>
<td>7</td>
</tr>
<tr>
<td>On social assistance</td>
<td>8</td>
</tr>
<tr>
<td>Retired</td>
<td>9</td>
</tr>
<tr>
<td>A homemaker</td>
<td>10</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>DI4. What is your total household income?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $20,000</td>
</tr>
<tr>
<td>$20,000 to $69,999</td>
</tr>
<tr>
<td>Greater than $70,000</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>DI5. What is your gender?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Transgender (Male to Female)</td>
</tr>
<tr>
<td>Transgender (Female to Male)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>DI7. What is your sexual orientation?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Straight (Heterosexual)</td>
</tr>
<tr>
<td>Gay</td>
</tr>
<tr>
<td>Lesbian</td>
</tr>
<tr>
<td>Bi (Bisexual)</td>
</tr>
<tr>
<td>Transgender</td>
</tr>
<tr>
<td>Two-Spirit</td>
</tr>
</tbody>
</table>

**[CONCLUSION:]** Those are all the questions I have. Do you have anything you would like to add? Some of the things that we talked about today might have been stressful for you. If you would like, I could recommend someone that you can talk to about these issues. Also if you
would like, I can give you information about various programs and services that might be able help you. Finally, thank you for taking the time to participate in my study.
Appendix Hiii: Survey of Socio-Demographic and Health Information of Key Informants  
(Indigenous Sharing Circle #2)

[TO CLARIFY: Now I just have some final questions, so I can learn more about the participants in my study. Can you please complete the following self-administered survey and return it to me before you leave this session today?]

[INSTRUCTIONS TO STUDY PARTICIPANTS]: Please do not write your name on this form. The information collected from you will be used for research purposes only.

Personal Information (Using a paper & pencil questionnaire, these questions are to be self-administered at the end of the Indigenous sharing circle)

1. Do you live in Saskatoon or Prince Albert?
   - [ ] Yes
   - [ ] No. If no, please specify how far you live from Saskatoon or Prince Albert.
     - [ ] ________ Km from [ ] Saskatoon
     - [ ] ________ Km from [ ] Prince Albert

2. Do you live on- or off-reserve?
   - [ ] On-reserve
   - [ ] Off-reserve

3. What is your current role in terms of working with APLWHA?
   - [ ] Health service provider
   - [ ] Government official
   - [ ] Community leader
   - [ ] Other, please specify ________________________________
   - [ ] Not Applicable

4. How long have you working in your current role?
   - [ ] Less than 5 years
5. What is your age?

- [ ] 5 to 9 years
- [ ] 10 to 14 years
- [ ] 15 to 19 years
- [ ] 20 years and greater
- [ ] Not Applicable

6. What is your highest level of education?

- [ ] Elementary School
- [ ] Grade 12
- [ ] Trade School
- [ ] College Diploma
- [ ] Professional Designation
- [ ] University Undergraduate Degree
- [ ] University Graduate Degree
- [ ] Other, please specify_________________________________________
7. What is your employment status?

- [ ] Full-Time Employment
- [ ] Part-Time Employment
- [ ] Self-Employed
- [ ] Homemaker
- [ ] Unemployed
- [ ] Student
- [ ] Disability
- [ ] Retired

8. What is your total household income?

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- [ ] Greater than $70,000

9. What is your gender?

- [ ] Male
- [ ] Female
- [ ] Transgendered (Male to Female)
- [ ] Transgendered (Female to Male)

10. What is your ethnic background?

- [ ] First Nation
11. What is your HIV Status?
   - Positive
   - Negative
   - Don’t Know

12. Did a health care provider ever suggest to you that you consider taking antiretroviral (ARV) medication for HIV infection?
   - Yes
   - No
   - Not Applicable

13. Have you ever taken ARV medication?
   - Yes
   - No
   - Not Applicable
Appendix I: Observation Guide

Objective: By means of participant observation, to contextualize individual interview data in terms of how the physical and social setting of health services contribute to the behaviour of APLWHA in order to further understand ARV therapy among APLWHA.

Research Questions:
1. What are the observed activities, processes and events affecting APLWHA within a particular health services setting?
2. How do the observed interactions and relationships between APLWHA and their health services setting contribute to an understanding of the actual and/or potential use (i.e., access, acceptance and adherence) of ARV therapy among APLWHA?

The following questions will be used to collect data during the participant observation. They were developed based on guidelines from various authorities with expertise in the area of field observations (Bogdewic, 1999; Mulhall, 2003; Spradley, 1980):

Structural and Organizational Features
1. What is the description of the physical environment (e.g., space, objects, and people)?
2. How is the physical environment used (e.g., acts, activities, events, over time, and related to goals)?
3. How does the structure of the environment affect processes (e.g., related to goals, and associated with feelings)?

APLWHA
1. Who are the people involved (e.g., according to goals)?
2. How would the participants be characterize (e.g., dress, use of objects, according to time, and feelings evoked)?
3. What is the behaviour of the participants (e.g., use of activities and according to events)?
4. How do the participants interact with one another (e.g. role, membership, leadership, and location)?
5. How did this interaction begin?
6. How did the participants enter the group?
7. What is the body language of the participants?
8. How do the participants move?
9. Do the participants use their social and physical space differently?

Goal
1. What is the APLWHA trying to accomplish (e.g., according to time)?
2. How are goals accomplished (e.g., use of objects, involvement of activities, events, location, and related to time)?
3. What are the consequences of the goals (e.g., on people, and feelings)?

Activities
1. What are the acts that people perform (e.g., use of objects, and based on location)?
2. What is the process of activities (e.g., timing)?
3. What appears to be routine?
4. How does one activity or element relate to another activity or element (e.g., goals, and involve feelings)?
5. What norms are influencing the daily activity?

Special Events
1. What related activities do people conduct (e.g., location, use of objects, over time, and sequencing)?
2. What special events are taking place (e.g., multidisciplinary team meeting)?
3. How did the event begin?
4. How do events occur (e.g., involve actors, timing, relate to goals, and involve feelings)?
5. What is the relationship between acts and events?
6. Are there different perspectives as to what is taking place at the event?

**Time**
1. What is the time sequence (e.g., use of objects, acts, and location)?
2. How did this activity or event begin?
3. How long does the activity or event last?
4. What is the consequence of time (e.g., on objects, and on feelings)?
5. Does the timing in which the activity occurs seem appropriate?

**Dialogue**
1. What are the discussions of the participants?
2. What is the tone of the participants’ communication?

**Feeling**
1. What emotions are felt and communicated (e.g., according to objects, and people)?
2. How are feelings evoked (e.g., use of objects, acts, by location, and according to time)?
3. What are the consequences of feelings (e.g., acts, events, and goals)?

**Daily Diary**
1. What is the chronological daily diary of events before entering the field?
2. What is the chronological daily diary of events in the field?

**My Own Personal/Reflective Diary**
1. What are my thoughts about entering into the field?
2. What are my thoughts about being in the field?
3. What life experiences do I have that may affect what I decide to observe?
4. What life experiences do I have that may affect how I process what I observe?
Appendix J: Confidentiality and Non-Disclosure Agreements

There were two confidentiality and non-disclosure agreements noted as follows:
Appendix Ji: Globalme Localizations, Inc.; and
Appendix Jii: Pollon Qualitative Research

These agreements are noted in the following pages.
Appendix Ji: Globalme Localizations, Inc.

Confidentiality and Non-Disclosure Agreement

THIS CONFIDENTIALITY AND NON-DISCLOSURE AGREEMENT is made this 5th day of February, 2013.

BETWEEN:
Ernie Akkas
Globalme Localizations, Inc.
Vancouver, British Columbia
(referred to as the “Data Transcriber”)
AND
Earl Nowgesic
PhD Candidate
Dalla Lana School of Public Health
Faculty of Medicine
University of Toronto
(referred to here as the “Principal Investigator”)

The named Principal Investigator and the Data Transcriber agree to conduct the research method of data transcription in accordance with the principles and conditions outlined in this agreement.

Confidential Information
The confidential, proprietary and trade secret information of the disclosing party (“Confidential Information”) to be disclosed hereunder is (i) information in tangible form that bears a “confidential,” “proprietary,” “secret,” or similar legend, and (ii) discussions relating to that information whether those discussions occur prior to, concurrent with, or following disclosure of the information. The disclosing party shall make reasonable efforts to mark its confidential information in tangible form with any of the aforementioned legends prior to disclosure.

Obligations of Receiving Party
The receiving party will not disclose any of the disclosing party’s Confidential Information to third parties. The receiving party may disclose the information to its employees and subcontractors in order to be able to perform the work.

Term
This confidentiality and non-disclosure agreement will be in effect throughout the entire data transcription process.

No Obligation of Disclosure; Termination
Neither party has any obligation to disclose Confidential Information to the other. Either party may terminate this Agreement at any time without cause upon written notice to the other party, provided that each party’s obligations with respect to Confidential Information disclosed during the term of this Agreement will survive any such termination. Either party may, at any time: (a) cease giving Confidential Information to the other party without any liability, and/or (b) request in writing the return or destruction of all or part of its Confidential Information previously disclosed, and all copies thereof, and the receiving party will promptly comply with such request, and certify in writing its compliance.

Ernie Akkas
February 5, 2013
Date

Earl Nowgesic
February 5, 2013
Date
CONFIDENTIALITY AGREEMENT

This Agreement is made July 12, 2013 and is between:

Earl Nowgesic  
Doctoral Candidate, University of Toronto,  
earl.nowgesic@mail.utoronto.ca

Thereafter referred to as “E.N.,”

AND

Dr. Dawn Pollon  
Research Consultant and Data Analyst  
dawn@pollonqualitative research.ca  
1298 Traddell Ave.  
Victoria, BC  
V8P 2C9

Thereafter referred to as “Dr. Pollon.”

WHEREAS, E.N. possesses certain valuable and confidential information, data and expertise (collectively the "INFORMATION") relating to E.N.’s study of Access to, acceptance of and adherence to HIV antiretroviral therapy among Aboriginal people in Saskatchewan,

WHEREAS, such INFORMATION is considered by E.N. to be confidential, and

WHEREAS, E.N. is willing, subject to the terms and conditions hereof, to disclose such Information, to Dr. Pollon for the purpose of enabling her to evaluate such INFORMATION,

NOW THEREFORE, the Parties hereto agree as follows:

1. Promptly after execution of this Agreement, E.N. shall disclose to Dr. Pollon all relevant INFORMATION within its possession or control as deemed necessary by E.N., to facilitate the investigation and analysis of data. Dr. Pollon shall accept and hold such INFORMATION in confidence in accordance with the provisions of Section 2 below.
2. Without the prior written consent of E.N., Dr. Pollon shall neither willfully and knowingly (i) disclose to any third party or permit any third party to have access to any of the INFORMATION disclosed by E.N., nor (ii) use such INFORMATION for any purpose other than that stated in Paragraph 1 hereof. Dr. Pollon agrees to take all reasonable measures to keep this INFORMATION in a safe place where only she has access to. This includes print and electronic versions of any material pertaining to E.N. and his research project.

3. Except as provided in Section 1 hereof, no license or other right to use the INFORMATION is granted hereby.

4. The disclosure of INFORMATION by E.N. to Dr. Pollon shall not result in any obligation on the part of either party to enter into any future agreement relating to the INFORMATION or to undertake any other obligation not set forth in written agreement signed by the parties hereto.

5. INFORMATION furnished by E.N. to Dr. Pollon under the Agreement and data, analysis and reports produced by Dr. Pollon under the term of this agreement shall remain E.N.'s property and any documents furnished containing such INFORMATION shall be promptly returned to E.N. upon completion of the requested analysis.

6. Neither party shall be entitled to assign its rights hereunder without the express written consent of the other party.

7. This Agreement cannot be altered or otherwise amended except pursuant to an instrument in writing signed by each of the parties hereto and making specific reference to this Agreement.

By typing your name (below) to this agreement (original, facsimile, or electronic version), and returning this agreement with the words “I agree that this contract is binding” in the body of your email, your actions shall bind both parties.

This agreement entered into on this __12__ day of July, 2013.

Per: ____________________________

Earl Nowgesic

Per: ____________________________

Dr. Dawn Pollon
Appendix K: Ethics Certificates

There were two different ethics certificates noted as follows:
Appendix Ki: University of Toronto ethical approval; and
Appendix Kii: University of Saskatchewan ethical approval

These consent forms are noted in the following pages.
Appendix Ki: University of Toronto ethical approval

PROTOCOL REFERENCE # 28349

December 2, 2014

Dr. Ted Myers
DALLA LANA SCHOOL OF PUBLIC HEALTH

Mr. Earl Nowgesic
DALLA LANA SCHOOL OF PUBLIC HEALTH

Dear Dr. Myers and Mr. Earl Nowgesic,

Re: Your research protocol entitled, "Access to, acceptance of and adherence to HIV antiretroviral therapy among Aboriginal people in Saskatchewan"

ETHICS APPROVAL

Original Approval Date: December 14, 2012
Expiry Date: December 13, 2015
Continuing Review Level: 2
Renewal: Data Analysis Only

We are writing to advise you that you have been granted annual renewal of ethics approval to the above-referenced research protocol through the Research Ethics Board (REB) delegated process. Please note that all protocols involving ongoing data collection or interaction with human participants are subject to re-evaluation after 5 years. Ongoing research under this protocol must be renewed prior to the expiry date.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your protocol. Note that annual renewals for protocols cannot be accepted more than 30 days prior to the date of expiry as per our guidelines.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events should be reported to the Office of Research Ethics as soon as possible. If your research is funded by a third party, please contact the assigned Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your research.

Yours sincerely,

Raj Maharaj
REB Co-Chair

Darrell Tan, M.D., Ph.D.
REB Co-Chair

Dario Kuzmanovic
REB Manager
Appendix Kii: University of Saskatchewan ethical approval

Certificate of Re-Approval

PRINCIPAL INVESTIGATOR
Tod Myers

DEPARTMENT
University of Toronto

BEH# 12-364

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT
West Side Community Clinic
631 20th Street West
Saskatoon
SK
S7M 0X8

AIDS Saskatoon
1143 Ave. F North
Saskatoon
SK
S7K 4E3

Prince Albert Parkland Health Region
1200 24th Street West
Prince Albert
SK
S6V 5T4

STUDENT RESEARCHER(S)
Erin Nowgolec

FUNDER(S)
Canadian Institutes of Health Research (CIHR)

TITLE
Access to, Acceptance of and Adherence to HIV Antiretroviral Therapy Among Aboriginal People in Saskatchewan

RE-APPROVED ON
10-Nov-2014

EXPIRY DATE
09-Nov-2015

Delegated Review: ☒ Full Board Meeting: ☐

CERTIFICATION
The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS
In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.usask.ca/research/ethics_review/

Jamie Campbell, Ph.D., Vice Chair
University of Saskatchewan
Behavioural Research Ethics Board

Please send all correspondence to:
Research Ethics Office
University of Saskatchewan
Box 1900 RPO University
S6V 5T4

Saskatoon, SK Canada S7N 5A8
Appendix L: Operational Approval Certificates

There are three different operational consent certificates noted as follows:
Appendix Li: Prince Albert Parkland Health Region;
Appendix Lii: Saskatoon Health Region via University of Saskatchewan; and
Appendix Liii: Community Health Services (Saskatoon) Association Ltd.

These consent forms are noted in the following pages.
Appendix Li: Prince Albert Parkland Health Region

January 7, 2013

Earl Nowgesic, BScN, MHSc, PhD Candidate
PhD Student Researcher
Dalla Lana School of Public Health
University of Toronto
1309-500 Sherbourne Street
Toronto, Ontario M4X 1L1

Dear Earl,

This letter is to inform you that the Ethics Committee has met and has accepted your application to administer your study here in the health region. The committee expressed no concerns regarding your study and appreciates all of the information you have provided us. The decision was formalized on January 3, 2013.

We ask that you continue to keep the committee informed of any changes and the progress of your study on “Access to, acceptance of and adherence to HIV antiretroviral therapy among Aboriginal people in SK”. If you need anything further please feel free to contact kmacleod@paphr.sk.ca (306)765-6620.

Please be aware that while the Ethics committee is giving approval, administrative approval for participation needs to be obtained at the site by the participants. The committee has expressed an interest in the results of your study. Fulfilling this request is voluntary, and we would keep any information you provide to us confidential and secure. Any additional effort on your part is appreciated. Good luck with your study!

Thank you,

Kerri MacLeod
Ethics Coordinator
Prince Albert Parkland Health Region
Regional Ethics Committee

---------
PAPHR Ethics Committee
1521-15th Ave. West
Prince Albert, SK
Phone: (306) 765-6620 - kmacleod@paphr.sk.ca
Appendix Lii: Saskatoon Health Region via University of Saskatchewan

DATE: January 15, 2013
TO: Dr. Ted Myers
    Dalla Lana School of Public Health
    University of Toronto
    Earl Nowgesic, PhD Candidate
    Dalla Lana School of Public Health
    University of Toronto

FROM: Martha E. (Beth) Horsburgh
      Associate Vice-President Research – Health (University of Saskatchewan)/
      Vice-President Research & Innovation (Saskatoon Health Region)

RE: RESEARCH ETHICS BOARD (REB) #: BEH-12-364
    PROJECT NAME: Access to, Acceptance of and Adherence to HIV Antiretroviral
    Therapy among Aboriginal People in Saskatchewan
    PROTOCOL #: N/A

We have received the notification regarding the change in Principal Investigator for this project. Saskatoon Health Region is pleased to provide you with amended operational approval of the above-mentioned research project as acknowledgement for this change.

Kindly inform us when the data collection phase of the research project is completed. We would also appreciate receiving a copy of any publications related to this research. As well, any publications or presentations that result from this research should include a statement acknowledging the assistance of Saskatoon Health Region.

We wish you every success with your project. If you have any questions, please feel welcome to contact Shawna Weeks at 655-1442 or email shawna.weeks@saskatoonhealthregion.ca

Yours truly,

[Signature]

Martha E. (Beth) Horsburgh
Associate Vice-President Research – Health (University of Saskatchewan)/
Vice-President Research & Innovation (Saskatoon Health Region)

cc: Heather Miazga, Manager, Positive Living Program
    Heather Trischuk, Manager, Mental Health and Addictions Services

Catalyzing Health Research and Innovation Together
Appendix Liii: Community Health Services (Saskatoon) Association Ltd.

Research Project Approval

Project Name: Access to, acceptance of and adherence to HIV antiretroviral therapy among Aboriginal people in Saskatchewan

Saskatoon Community Clinic is pleased to provide you with operational approval of the above-mentioned research project.

Please advise me when the data collection phase of the research is completed. I would also appreciate receiving a summary of the results for this research project. As well, any publications or presentations that result from this research should include a statement acknowledging the assistance of Saskatoon Community Clinic.

I would like to wish you every success with your project. If you have any questions, please contact me at 664-4241.

Yours truly,

Tim Archer
Executive Director
### Appendix M: Study Timeframe

<table>
<thead>
<tr>
<th>ID</th>
<th>Task Name</th>
<th>Start</th>
<th>Finish</th>
<th>2012</th>
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<th>2014</th>
<th>2015</th>
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<td>1</td>
<td>Community engagement</td>
<td>2012-01-02</td>
<td>2015-03-31</td>
<td>Q3</td>
<td>Q1</td>
<td>Q2</td>
<td>Q4</td>
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<td>2</td>
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<td>2012-04-02</td>
<td>2012-09-28</td>
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<td>2012-12-31</td>
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