

# **HIV Prevention and Care among Rural and Remote Indigenous Communities in Canada: What is known and where are the Gaps?**

Literature Review prepared for Dignitas International's Indigenous Health Partners Program  
*HIV Prevention and Care Feasibility Study*

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## Executive Summary

Since 2004, Dignitas International (DI), a medical non-governmental organization, has been working in partnership with Malawi's Ministry of Health to support HIV treatment and care for more than 270,000 Malawians living with HIV in rural communities. With lessons learned from addressing operational challenges and gaps in Malawi and strengthening HIV care by reducing geographic barriers to access and incorporating community led models of care, DI launched its Indigenous Health Partners Program (IHPP) in 2014. A feasibility study conducted in partnership with various Indigenous communities and organizations in northern Ontario demonstrated that DI could play a meaningful role in supporting the delivery of innovative and culturally appropriate health solutions in Canada's most remote and underserved communities. This literature review is situated within a larger exploratory study to determine the potential for expanding DIHP to support HIV prevention and care for First Nations, Métis and Inuit peoples living in rural and remote settings in Canada.

Indigenous peoples in Canada are disproportionately impacted by HIV and represent a priority population for HIV prevention, treatment and support. Understanding HIV vulnerability among Indigenous people must begin with acknowledging the social determinants that are linked to historical and ongoing impacts of colonization and ongoing trauma. Identifying knowledge levels and access to HIV education and testing among Indigenous peoples living in rural and remote settings is critical given that levels of knowledge is associated testing and treatment initiation. The majority of HIV research has focused on urban populations, although knowledge and education are lower in rural and remote settings while access challenges are greater.

The specific objectives of this literature review were to: a) understand what the current state of HIV knowledge, attitudes and behaviors are among Indigenous peoples in Canada living in rural and remote settings; b) identify the key gaps in programming that have an impact on knowledge, attitudes and behaviors; and c) describe the current policy landscape, key principles and promising practices. The strategy for this review involved a broad search of the scientific and grey literature to identify literature on HIV among Indigenous populations with a focus on rural and remote regions. Relevant websites of governments and agencies involved in HIV with Indigenous populations in Canada were also reviewed, including the Canadian Aboriginal AIDS Network and the International Indigenous Working Group on HIV and AIDS, First Nations and Inuit Health Branch and the Public Health Agency of Canada.

While HIV is overrepresented among Indigenous communities with First Nations communities bearing the bulk of new infections, knowledge of and access to HIV testing is often lacking. Numerous gaps, all intersected by the impacts of colonialism and structural racism, affect knowledge and attitudes about HIV in rural and remote settings. These include a lack of healthcare providers, issues related to confidentiality in the context of stigma, the absence of culturally-appropriate and culturally sensitive sexual health education resources, and competing socio-economic priorities (e.g. housing). Challenges with a lack of complete data also compound the ability to fully measure the impact of HIV among Indigenous communities.

Much of the reviewed literature spoke to the resiliency of Indigenous peoples and the need for strength-based approaches. Promising principles include those that emphasize: the importance and role of culture, self-determination and reclamation; art-based strategies to share stories and build leadership; cultural safety and competency within healthcare settings; the need to address the social determinants of health. While this review provided a brief introduction to the various types of organizations working with Indigenous peoples at-risk of or affected by HIV in Canada, the second phase of this study will involve engaging with these organizations to identify promising practices in HIV prevent and care among Indigenous communities. This will help to identify opportunities for DI to support the delivery of HIV prevention and care among rural and remote Indigenous communities living in Canada.

## **List of Abbreviations Used**

AIDS= Acquired Immune Deficiency Syndromes

ART= Antiretroviral Therapy

ASHAC= Aboriginal Strategy on HIV/AIDS in Canada

ASO= AIDS Service Organization

BC= British Columbia

CAAN= Canadian Aboriginal AIDS Network

CIHAN= Canadian Inuit HIV AIDS Network

CATIE= Canadian AIDS Treatment Information Exchange

DI= Dignitas International

FNIHB= First Nations and Inuit Health Branch

HIV= Human Immunodeficiency Virus

IHP= Indigenous Health Program (at Dignitas International)

IIWGHA= International Indigenous Working Group on HIV and AIDS

NAHO= National Aboriginal Health Organization

NIHB= Non-Insured Health Benefits

OCAP= Ownership, Control, Access and Possession

PHAC= Public Health Agency of Canada

STBBI= Sexually Transmitted and Blood-Borne Infections

STI= Sexually Transmitted Infections

## **BACKGROUND**

### **Epidemiology of HIV among Indigenous Populations**

While HIV was first detected in Canada in 1982, the epidemic did not noticeably affect Indigenous populations until the 1990's (Archibald et al., 2003; Nowgesic et al., 2013). Today, Indigenous peoples represent a priority population for HIV prevention, care, treatment and support in Canada as they are 2.7 times more likely to get HIV than people of other ethnicities. In 2014, an estimated 75,000 Canadians were living with HIV (PHAC 2015). According to national 2014 estimates, there were 18.2 new HIV infections for every 100,000 Indigenous people in Canada. This compares to only 6.7 new HIV infections for every 100,000 people of other ethnicities (PHAC 2015). An estimated 6,850 Indigenous people were living with HIV at the end of 2014, accounting for 9% of HIV infections in Canada (PHAC 2015). More recent estimates suggest, however, that that Indigenous people represented approximately 21.2% of the 2,344 new HIV cases detected in 2016, when ethnicity was known with First Nations representing the highest affected group (19%) followed by Metis (1.6%), Inuit (0.3%) populations. Furthermore, between 2015 and 2016, First Nations peoples experienced the largest increase (29.9%) in case counts of all reported races/ethnicities and Indigenous sub-groups (Bourgeois et al., 2017).

Saskatchewan is currently experiencing a crisis due to a rise in HIV infections. In 2016, the HIV diagnosis rate was 15.1 per 100,000 population, more than double the overall Canadian rate (Bourgeois et al., 2017). This is followed by Manitoba which accounted for 5.4% of new cases in 2016. It has been estimated that approximately 71% of new cases in 2015 were among Indigenous peoples in Saskatchewan (Woodgate et al., 2017) and on some reserves, HIV incidence is as high as 95 cases per 100,000 population (Schafer et al., 2017; Leo et al., 2015).

Timely engagement in the HIV treatment and care cascade facilitates early initiation of antiretroviral therapy (ART), management of any secondary conditions, and overall improved survival. Indigenous people living with HIV, however, are more likely to be diagnosed late (Mill et al., 2008; Geduld et al., 2003; Jaworsky et al., 2012), demonstrate longer times between diagnosis and linkage to care (Plitt et al., 2009), have delayed ART initiation (King et al., 2001), and are less likely to have resistance drug testing (Eyawo et al., 2011). All these factors are associated with sub-optimal clinical outcomes including increased mortality (Schafer et al., 2017, Lima et al., 2006).

### **Drivers of HIV Infection among Indigenous Peoples in Canada**

The HIV epidemic among Indigenous peoples in Canada looks very different than among non-Indigenous peoples. For one thing, Indigenous populations are infected with HIV at a younger age (PHAC 2015; Bourgeois et al., 2017) and tend to have poorer socioeconomic status than non-Indigenous people living with HIV (Jaworsky et al., 2012; Lima et al., 2006; Heath et al., 1999). Understanding HIV vulnerability among Indigenous people must begin with an understanding of the social determinants that are linked to the historical impacts of colonization (Woodgate et al., 2017). Ongoing displacement, relocation breakdown of community and familial connections, the loss of language and cultural knowledge in addition to systemic stigma, structural racism and discrimination have led to an increased vulnerability of HIV (Interagency Coalition on AIDS and Development). Intergenerational trauma resulting from colonization is a determinant of health (Monchalin et al., 2016) and cultural genocide through assimilation in

residential schools and ownership of land (Wilson et al., 2016; Varcoe & Dick, 2008; McConney, 1999) has resulted in increased substance use and violence in many Indigenous communities.

Injection drug use is an important risk factor for HIV transmission within the Indigenous community. In 2014, an estimated 45% of new HIV infections among Indigenous people were attributed to injection drug use, while an estimated 40%, 10% and 4% were attributed to heterosexual contact, men who have sex with men, and men who have sex with men who also report injection drug use, respectively. Of HIV cases reported in 2016 attributed to drug use, 59.6% were among Indigenous people (Bourgeois et al., 2017).

Sexual and drug-related harms and sexual abuse, particularly among women, also increases risk of HIV infection (Woodgate 2017; Schafer et al., 2017; Varcoe & Dick, 2008). In one study, all Indigenous women had been affected by trauma and the impacts of residential schools and attributed their drug use to the abuse they experienced as children (Varcoe & Dick, 2008). Not surprisingly, the proportion of HIV cases among women that were Indigenous was 36.2% in 2016 (PHAC 2017). Importantly, Indigenous women continue to face disproportionate socioeconomic burdens and poverty and have rising rates of HIV compared to non-Indigenous women (OHESI, Jaworsky et. 2015). For youth, high rates of teen pregnancy and STIs (Healey 2015), inconsistent condom use, and feelings of invulnerability contribute to susceptibility of youth to HIV infection (Mill et al., 2008; Calzavara et al., 1998).

## **HIV in Rural and Remote Settings**

Where people live is associated with their health status, behaviors and health utilization (Sibley & Weiner, 2011). Importantly, populations living in rural settings tend to be under-served and have poorer health outcomes compared to their urban counterparts (MacKenzie et al., 2017; Canadian Population Health Initiative, 2006).

In the early stages of the HIV epidemic in North America, care was delivered almost exclusively in large urban areas but in the 1990's, HIV began to spread outside of major urban areas into smaller areas (Schur 2002). However, people living in rural areas and remote settings are still less likely to be tested for HIV compared to those from urban settings (Trepka 2014, Ohi et al., 2013; Schafer et al., 2017), and rural residence has been associated with late diagnosis (Trepka et al., 2014; Ohi et al., 2010). In BC, engagement in the HIV cascade of care varied by geographic region. Residents living in more rural regions were less likely to be linked to care, on ART, retained in care and have a suppressed viral load compared to individuals living in the Vancouver coastal health authority (Lourcenco et al., 2014).

Challenges unique to rural areas may include social isolation, long distances to health services, limited transportation and lack of HIV specific providers (Shafer et al., 2017). Indeed, women living with HIV participating in a national cohort study faced longer travel times and were more likely to receive care from a nurse compared to their urban counterparts (Beaver et al., 2015). In smaller communities, patient and community-level factors such as fear of HIV identity disclosure and privacy breaches may act as barriers to linkage and retention in care (Horstmann et al., 2010; Berg & Ross, 2014).

Identifying the levels of knowledge and access to HIV education and testing among Indigenous Peoples living in rural and remote settings is critical given that high risk behavior is lower among individuals who are aware of their HIV status (Mill et al., 2008; Marks et al., 2005). In addition,

the benefits of knowing one's status includes increased awareness of how to reduce risk of getting or transmitting HIV and the increased likelihood of ART initiation (BucharSKI 2006).

## **Rationale and Objectives of this Literature Review**

The majority of HIV research and program planning has focused on populations living in urban settings, although evidence suggests that knowledge and education is lower in rural and remote settings while access challenges are greater. Therefore, we sought to a) understand what the current state of HIV knowledge, attitudes and behaviors are among Indigenous peoples in Canada living in rural and remote settings; b) identify the key gaps in programming that have an impact on knowledge, attitudes and behaviors; and c) describe the current policy landscape, key principles and promising practices.

## **CONTEXT**

### **Indigenous Peoples in Canada**

While numerous Indigenous populations have been residing and flourishing in what is today called Canada for over 15,000 (Smylie & Firestone, 2015), the Canadian Constitution Act of 1982 specifies that Indigenous people consist of three groups: First Nations, Métis and Inuit communities. Status or registered Indians are legally recognized by the federal government for the purposes of the *Indian Act*. The Inuit are separate and have no legislation defining them although the Canadian government has assumed primary responsibility.

As of 2016, Indigenous populations totaled 1,673,785 people or 4.9% of the total population with 977,230 First Nations people, 587,545 Métis and 65,025 Inuit (2016 Canadian Census). It is worth mentioning here that these numbers are likely underestimated given numerous factors including non-participation, high numbers of mobile and homeless Indigenous individuals, and individuals who do not have the literacy skills required to complete a household census (Smylie & Firestone, 2015). For example, findings from the Our Health Counts Toronto noted that the census undercounted the size of Toronto's urban Indigenous population by a factor of approximately 2 to 4 (Rotondi et al., 2017). While Indigenous peoples in Canada are a heterogeneous population with varying cultural, economic and social characteristics (Interagency Coalition on AIDS and Development 2015), some commonalities exist such as connections to the land, cultural practices and traditions, the role of communities and families, and the importance of self-determination (LeFrance & Nichols, 2010).

The *Indian Act*, enacted in 1876 sought to assimilate Indigenous populations through institutions such as residential schools and land regulations. Its goal was to "define who Indians were and were not; manage Indians and their lands; and concentrate authority over Indian people" (Bourassa et al., 2015; Wotherspoon & Satzwich, 2000, pg. 30). Such policies limited employment and ownership options which affected the ability to find jobs and affordable housing (off reserves), and led to the loss of language and the breakdown of family and community structures (Varcoe & Dick, 2008). Historic and continuous forms of systemic oppression and colonialization continue to impact on every aspect of Indigenous life, including health (Wilson et al., 2016).

The residential school system which operated from 1874-1996 had a mandate to "kill the Indian in the child" (Truth and Reconciliation Commission, 2012). Over 150,000 Indigenous children

were forcibly removed from their families (Royal Commission on Aboriginal People, 1996) and in the church-run schools; they endured strict discipline, corporal punishment, physical, sexual and emotional abuse and were taught to feel shame about their culture, language and identities (Hylton 2002; Pearce et al., 2008). Surviving children often returned to their communities with the hard realities they learned and as a result, inflicted control, abuse and shame on their own children (Pearce et al., 2008). In the 1950's and 1960's, citing concerns of poverty and neglect, the "Sixties Scoop" saw the federal government again apprehend Indigenous children from their families and place them into the child welfare system (Hanson 2016; Woodgate et al., 2017). Even today, Indigenous children are overrepresented in the foster care system (Pearce et al., 2008). Intergenerational trauma is referred to as a "collective emotional and psychological injury over the lifespan and across generations" (Pearce et al., 2008, pg. 3; Yellow Horse Brave Heart, 2003). Essentially, unresolved trauma passed on from generation to generation. For example, a 2008 study noted an association between having at least one parent who attended residential school and involvement in the child welfare system (Pearce et al., 2008).

The removal of children, the heart, out of the community (Anderson 2011; Monchalin et al. 2016) led to further erosion of culture and cultural depression (Woodgate et al., 2017; Barlow et al., 2008), and women have also been targeted through colonial policy (Bourassa et al., 2015). As a result of the *Indian Act*, status women would lose their status if they married a non-status man. Furthermore, colonization suppressed conversations about sex and sexuality which would have otherwise been normalized conversations (Wilson et al., 2016).

The National Aboriginal Health Organization (NAHO) identified eight social determinants of health specific that are specific to Indigenous Populations in Canada. They include:

1. *Colonization*: Colonization breaks connections to the land, family and community, environmental degradation of traditional lands, and suppression of cultural and linguistic rights. Institutional racism, economic displacement, and the impacts of residential schools results in substance misuse, poverty, mental health issues.
2. *Globalization*: The UN reports that marginalization, discrimination and exclusion of Indigenous people as persistent social issues.
3. *Migration*: Many Indigenous populations are concentrated in rural and remote areas although travel to and from reserves to cities is common. This also includes movement away from home traditional lands.
4. *Cultural continuity*: Refers to the intergenerational connectedness of individuals, families and communities.
5. *Access to Health care*: In rural and remote areas, access is compounded with seasonal isolation. Health care priorities set by Canadian government may not match priorities set by Indigenous populations- including the role of traditional medicine, services and resources that are available in appropriate languages, and discrimination-free health care.
6. *Territory*: Relationships with the land and environment are a critical component of self-identification. Land rights are 'fundamental for the survival of indigenous communities'
7. *Poverty*: In Canada income for Indigenous populations is lower compared to non-Indigenous populations.
8. *Self-determination*: Conscious and deliberate objective to assert rights, and the need for meaningful engagement. This is also outlined in the UN declaration of the Rights of Indigenous People (Smylie, 2009). Denial of rights is harmful and self-determination can help enhance protective factors at the individual, family, community and system level that provide strength and resiliency.

Many of these determinants are further exacerbated by the lack of provincial and federal health care coordination (Schafer et al., 2017; Leo et al., 2015). At the national level, Indigenous Peoples are represented by: the Assembly of First Nations (AFN), the Congress of Aboriginal People (CAP), the Inuit Tapirrit Kanatami (ITK), the Métis National Council (MNO) and the Native Women's Association of Canada (NWAC). At the regional and community level, there are complex set of "jurisdictionally specific Indigenous governmental and service organizations" (Smylie & Firestone, 2015). Service jurisdiction is complex and the role of differing levels of government will vary depending on ethnic identity and geography (Smylie & Firestone, 2015). In contrast to non-registered First Nations and Inuit people living outside of communities in which their primary care and public health is delivered by the province/territory, delivery for registered First Nations and Inuit People living in First Nations or Inuit communities is funded by the First Nations and Inuit Health Branch (FNIHB) of Health Canada (Anderson & Smylie, 2009). Non-status First Nations, Métis people and urban Indigenous populations have traditionally been excluded from federal programming which currently are under the jurisdiction of the Public Health Agency of Canada. Many provincial public health departments argue that Indigenous health should be the responsibility of the federal government (Smylie & Firestone, 2015). Although the provinces and territories are primarily responsible for the provision of HIV/AIDS health and social services, approaches to Indigenous-specific HIV/AIDS care vary by jurisdiction (PHAC 2010). Indigenous communities, organizations and governments are simultaneously responsible for implementing on-reserve HIV/AIDS education, prevention, treatment, and care programs (PHAC 2010). In cases where there is an uncoordinated approach, this can lead to overlap in service provision or a lack in services, in addition to resource constraints.

Indigenous peoples in Canada have been over-researched. Historically the research has also been seen by many as "one-sided", with researchers benefiting through career enhancement, peer-reviewed manuscripts and funding support (First Nations Centre, 2007; Assembly of First Nations, 1998). Further, research was often conducted in ways that excluded the people it aimed to understand. In general, a non-Indigenous researcher would initiate a research project while the community and its members were simply the research subjects. However, the right of communities to control and govern the research process is tied to self-determination and to the preservation and development of their culture (First Nations Centre, 2007).

## **Ethical Research Principles Relevant to Indigenous Communities**

### *OCAP<sup>TM</sup>: Ownership, control, access and possession*

This term is linked to the agenda of self-determination because it serves to guide the re-appropriation of research activities and research outcomes pertaining to Indigenous people. It also provides jurisdictional framework for the research agenda and its relevance for methods and research ethics boards. The four principles are as follows: Ownership- Indigenous people will have the authority over the research process and any products extending beyond programs, the results of programs and any intellectual property. Control- Indigenous people are in charge of the process including leading decisions about research questions, methods, analysis and interpretation of findings. Access- Indigenous people have the right to access and use research findings- this involves translation of research instruments and results into Indigenous languages. Raw data will also to be made available. Possession- Actual holding with or without rightful ownership. In general, OCAP seeks to empower communities and maximize benefits to the community.

### Principles of Ethical Métis Research

The 6 principles that guide Métis-specific research include: 1. Reciprocal Relationships: Building relationships between researchers and communities; 2. “Respect For”: Individuals and the collective; 3. Safe and Inclusive Environments: Research should be safe for all; 4. Recognize diversity: Within and between Métis communities; 5. “Research Should”: Be relevant, benefit all and be accurate and accountable; 6. Métis Context: Understand history, values and knowledge.

### Inuit Qaujinajatuqangit (IQ):

This term is a system of beliefs and knowledge related to the Inuit culture that translates to “that which Inuit have always known to be true”. The Elders have identified a framework for IQ which is grounded in 4 laws or *maligait* that contribute to living a good life. These include: 1. Working for the common good; 2. Respecting all living things; 3. Maintaining harmony and balance; 4. Continually planning and preparing for the future. The six guiding principles that form the conceptual basis of IQ include: 1. *Pijitsirniq*-concept of serving; 2. *Aajiqatigiingniq*-concept of consensus decision-making; 3. *Pilimmaksarniq*-concept of skills and knowledge acquisition; 4. *Piliriqatigiingniq*-concept of collaborative relationships or working; 5. *Avatimik Kamattiarniq*-concept of environmental stewardship; 6. *Qanuqtuurunnarniq*- concept of being resourceful to stop problems.

### Tri-Council Policy Statement: Ethical Conduct for Research Involving Aboriginal People (Chapter 9)

These guidelines assist researchers and institutions in carrying out ethical and culturally competent research involving Indigenous communities. They call for increased partnerships, involving Indigenous peoples in the design of the project and providing information regarding the protective measures for ensuring and maintaining cultural safety. The most effective means of protecting traditional knowledge and having an equal voice at the research table may be to use Indigenous customs enforced by the community (Greaves, 1996). Research agreements should be required and dialogue must be a central feature of a new relationship.

## **METHODS**

### **Literature Review Search Strategy**

The search strategy for this review involved a search of the scientific literature through PubMed (1990-Present). Search terms included “HIV”, “AIDS”, “Canada”, “rural”, “remote”, “northern” “Indigenous”, “First Nations”, “Metis or Métis”, “Inuit”, “STBBI” or “STI” or “Sexually Transmitted”. While the term Indigenous is often/generally/usually preferred to Aboriginal, the latter term is still widely used and was therefore, included as a search term. Importantly there is no single definition of rural (Rural Health in Rural Hands), therefore we used a broad search to ensure that remote and northern settings were captured. A search of the grey literature was also conducted using similar search terms. In addition, a review of relevant websites from governments and agencies involved in HIV with Indigenous populations in Canada including the Canadian Aboriginal AIDS Network (CAAN) and the International Indigenous Working Group on HIV and AIDS (IIWGHA), First Nations and Inuit Health Branch (FNIHB), and the Public Health Agency of Canada (PHAC). References from reviewed materials were also searched.

There are a few limitations worth noting. First, all findings included in this review reflect information that the Research Associate was able to identify, namely findings that are publically available and currently published. Second, the type of search terms selected may also have limited the quantity and nature of the information retrieved.

## **RESULTS**

### **Key Findings**

Findings consistently demonstrated that people of Indigenous ancestry are overrepresented in the HIV epidemic in Canada. In general, the majority of literature related to HIV and Indigenous populations in Canada is focused on First Nations communities, particularly youth, and geographically focused on British Columbia, Alberta, and Saskatchewan. All studies and reports reviewed highlight the importance of recognizing the historically complex relationship Indigenous peoples in Canada have had with the Government and its impacts on health and social outcomes.

### **HIV-related Knowledge, Attitudes and Behaviors**

Knowledge of HIV is critical for protecting oneself from HIV and preventing ongoing HIV transmission (CATIE). In Canada, a 2012 national study noted that knowledge of HIV/AIDS is declining with 78% of surveyed Canadians citing that they were either not knowledgeable or only moderately knowledgeable about HIV and how it is transmitted. At the same time, 87% of surveyed Canadians felt that they were at low risk of contracting HIV (PHAC/CATIE survey).

Some studies noted that knowledge about HIV is limited in many Indigenous communities. In a study of street-involved youth in Vancouver, Indigenous ethnicity was negatively associated with higher levels of HIV knowledge (Johnston et al., 2011). A Saskatchewan study examining knowledge, attitudes and behaviors among sex trade workers, a large proportion of whom were Indigenous, found that knowledge about HIV, in particular, was varied. While awareness of HIV was high with 91.6% reporting that HIV was a problem in their communities, there were misconceptions about how HIV was transmitted. For example, a high proportion of participants believed that 'coughing and sneezing spread HIV' and that 'all pregnant women with HIV will have babies born with HIV'. These findings suggest that there are still a lot of misconceptions about HIV in some communities and settings.

In more isolated communities, many people may believe that HIV is not a problem (Patterson, 2007) although talking about sex and HIV is considered taboo (Crown et al., 1993). While there may be issues of substance misuse and unprotected sex occurring, there may also be denial about HIV. Related to this are misconceptions about sexual health. In one study women noted that sexual health education tended to focus on pregnancy prevention, while discussions related to risk of HIV and STIs were rare. In some settings, many still perceive HIV to be a "gay disease" largely confined to urban settings (Varcoe & Dick, 2008). Interestingly, others have argued that Indigenous youth may be more aware of HIV than other youth as they are more likely to recognize it as being a real problem in their communities (Larkin et al., 2007; Mill et al., 2008).

Regardless, knowledge of HIV affects one's decision to test and denial of HIV can make it difficult to promote the need for testing (Patterson, 2007). Importantly, testing for HIV is situated

within a multifaceted “web of social, cultural, and political factors...and general negative media and public attention to the disease as well as to those populations most likely to contract this disease” (Worthington & Myers, 2002, pg. 637). How individuals learn about HIV also matters. For example, a review of how HIV is portrayed in Indigenous media (1996-2000) found that the use of emotionally-charged, often negative terminology regarding HIV contributes to fear (Hoffman-Geotz et al., 2005; Clarke et al., 2005). Indigenous youth may, therefore, view HIV as a death sentence (Larkin et al., 2007; Mill et al., 2008; Mill et al., 2007).

A 2012 study revealed that approximately 37% of surveyed Canadians had reported receiving an HIV test (CATIE 2013). Results from the 2001 Aboriginal Peoples Survey of Indigenous people living off reserve demonstrated that approximately 41.7% had reported receiving an HIV test, with more women than men receiving an HIV test (Orchard et al., 2010). Of relevance, urban residency was associated with getting an HIV test. Similar findings were noted in a 2006 BC study where 60.4% of surveyed participants in rural BC had undergone an HIV test with participants living off reserves more likely to have undergone an HIV test (Wardman et al., 2006). Some literature suggests that Indigenous youth access to HIV testing is higher than the general population (Mill et al., 2008; Nguyen et al., 2000).

The decision to test is affected by many factors (Worthington & Myers, 2002). Barriers to testing can include denial, concerns about confidentiality, low self-esteem, high mobility, discrimination, and racism (Woodgate et al., 2017). In one study, most youth reported that their decision to test was influenced by a health professionals’ recommendation (Mill et al., 2008). In a 2008 study of youth from across Canada, the most common reasons for not testing was a self-perception of being at low risk (45.3%) and the perception of not having sex with an infected person (34.5%) (Mill et al., 2008). At the same time, even if an individual tests positive, they may not seek care immediately if they are scared or not wanting to think about their disease, are pre-occupied with drugs or alcohol, not wanting to live, or not knowing anything about HIV care (Mill et al., 2008). In one study, only 48% of Indigenous youth were assessed by a doctor within 1 year of their HIV diagnosis (Prentice et al., 2011). The lack of counselling during screening is also of concern, as findings from the Canadian Aboriginal AIDS Network (CAAN) indicates that approximately 23% of Indigenous people who sought HIV testing did not receive any information surrounding the disease and available treatment options (Mill et al., 2008).

The decision to test and engage with care may also be compounded by negative encounters with the healthcare system. Differing beliefs about health and illness may result in individuals feeling less likely to engage with biomedical services (Mill et al., 2007). Indigenous women living with HIV have highlighted the influence of historical trauma on their response to HIV testing and counseling (Mill et al., 2008; Bucharski et al., 2008); Women may be particularly afraid of disclosing abuse to formal services for fear of having their children taken away (Bourassa et al., 2015). While Indigenous women are at a heightened risk of HIV, in part due to exposures created from trauma (Reading et al., 2011), they are less likely to pursue early testing (Geduld et al., 2003). This has important implications as late diagnosis has been associated with numerous poor health outcomes and reduced survival (cite).

### **HIV-related Knowledge, Attitudes and Behaviors in Rural and Remote Settings**

Approximately half of the Indigenous populations in Canada live on reserves, which tend to be more remote and isolated from urban areas and health care resources (Statistics Canada 2013). While HIV first occurred in large urban cities, the epidemic has migrated into more rural

areas and in small settings in Canada (Schafer et al., 2017). Rates of HIV infection are increasing in nonurban centers, particularly in regions with previous low rates of HIV including the Prairie Provinces (Schafer et al., 2016). Indeed, the highest rate of HIV incidence in Canada is now occurring in Saskatchewan (PHAC 2017), a province with few urban centers and a mostly rural population (Schafer et al., 2017; PHAC 2014)

There is limited literature that compares rural and urban populations of people living with HIV in Canada. However, a recent study showed that there was a significant association between poorer quality of life and increasing degree of rurality (MacKenzie et al., 2017) among people living with HIV (Mackenzie). This highlights the vulnerability of the most remote and rural residents. Indeed, individuals living with HIV in rural areas have lower CD4 counts, a higher prevalence of Hepatitis C and are more likely to not have regular viral load measurements (MacKenzie et al., 2017).

Distances to care are more of a challenge in rural settings. Importantly physicians and nurses are concentrated in more urban areas and there is a general lack of specialists (Rural Health in Rural Hands, 2002). For people living on reserves, limited access to testing and the travel required to access specialized health services, including HIV prevention and care, can be challenging (Woodgate et al., 2017). In rural areas, even if care is available, it may not be located anywhere close to the individual's home (Trepka et al., 2014). According to one report, more than two-thirds of individuals living in northern and remote regions in Canada live more than 100 kilometers from a physician. In some places, people may have to travel up to 6 hours by plane to reach a hospital (Rural Health in Rural Hands, 2002). Existing clinics may have limited operating hours which don't take into consideration the long distances that clients may need to travel to access their services (Varcoe & Dick, 2008).

While there may be less perceived risk of HIV in smaller communities, there are serious concerns around confidentiality (Trepka et al., 2014). People living with HIV in rural settings face challenges regarding disclosing their HIV positive status in their communities for fear of stigma, isolation and sometimes violence and ostracism (Barlow et al., 2008, Patterson, 2007). As discussed above, in smaller communities, talking about HIV and sex is taboo. Talking about sex was historically not shamed in Indigenous culture, however, became a more difficult discussion as a result of the residential school system and the influence of the Church (Anderson K, 2001; Aboriginal Nurses Association of Canada and Planned Parenthood Federation of Canada, 2002). Without discussions on sexuality and sexual health, an individual may have less knowledge of HIV, may perceive their risk to be low and as a result, not get tested for HIV (Mill et al., 2008). In rural settings, health promotion programs including screening and diagnostic services are underdeveloped (Rural Health in Rural Hands, 2002) and there is a clear lack of testing on reserves. In Saskatchewan, for example, only 4/72 communities living on reserves had point-of-care testing (Schafer et al., 2017; Saskatchewan HIV Provincial leadership Team, 2015).

In general, there are less experienced providers based in rural and remote settings (Heckman 1998, MacKenzie 2017). There is also the perception that care is of better quality in urban settings, and that physician knowledge about HIV treatment is low in rural areas (Schur et al. 2002). Related to this is a lack of confidence in patients of local providers' HIV knowledge (Schafer et al., 2017; Heckman et al., 1998. For example, three-quarters of patients living in rural areas sought care in urban areas even though this resulted in longer travel times (Schur et al., 2002)

There is also limited access to addiction and mental health treatment in rural and remote areas, both critical for HIV prevention and support (Heckman et al., 1998; MacKenzie 2017). Findings from an Ontario-based study focused on women living with HIV, while participants living in the North (59% Indigenous) were more likely to be smokers and have ever injected drugs (64% vs. 14%), they faced longer travel times to access care (Beaver et al., 2015). At the same time, rural residents who must travel for care may be more likely to delay obtaining care if they do not have a personal means of transportation or have difficulty arranging transportation (Schafer et al., 2017). This may be amplified among Indigenous populations given the role of the Non Insured Health Benefits (NIHB) for First Nations and Inuit Peoples which requires application and approval for travel funds related to medical care; limited services and high numbers of people needing this financial support results in long wait times, therefore causing many people to give up (Varcoe & Dick, 2008). Furthermore, many people are often forced to relocate to urban areas to obtain better access to care, but then become disconnected from their social support networks (Varcoe & Dick, 2008). Women living with HIV in northern Ontario were more likely to move for HIV care compared to their urban counterparts (Beaver et al., 2015).

In northern and remote communities, there is also the additional challenge of finding services specific to Indigenous cultures that recognize and address the harmful effects of colonization (Bourassa et al., 2015; Schafer et al., 2017; Harris et al, 2010).

### **Special Comment on Stigma**

Stigma plays a central role in knowledge, attitudes and behaviors related to HIV. In remote communities, stigma stems from a lack of awareness and education (Patterson, 2007), however stigma and negative attitudes limit access to services, particularly for individuals concerned about privacy and confidentiality (Barlow et al., 2008). However, in low prevalence and rural areas, stigma can be amplified by the lack of transportation, access to specialized HIV services and limited social support (Zukoski & Thorburn, 2009), fewer medical experts, and isolated conditions (Zukoski & Thorburn, 2009; McKinney, 2002; Castaneda, 2000).

Studies of stigma suggest that context matters (Zukoski & Thorburn, 2009). HIV stigma and discrimination are often elevated in small communities which can be a barrier to getting an HIV test (Heckman et al., 1998; Barlow et al., 2008). As noted above, there are fewer social and public services in rural areas, and as a result, there are often safety and ethical issues given that many people often know each other (Varcoe & Dick, 2008; Heckman et al., 1998). There is a fear that information will be shared with other community members and for Indigenous people living with HIV, there is a fear of judgment and being unwelcome in their home communities (Barlow et al., 2009). In a study of PLWH in northern Ontario, higher levels of perceived HIV-related stigma were noted compared to those living in nonrural/southern Ontario (Jaworsky et al., 2012; Schafer et al., 2017). In their 2009 study, all participants experienced stigma in their communities (Jaworsky et al., 2012). As a result, individuals seeking an HIV test may choose not to test in the communities they live, either because there is no HIV testing or they knew the health worker administering the testing (Woodgate et al., 2017). Again, fear of stigma, may result in an individual choosing not to test or access services (Woodgate et al., 2017). Furthermore, people living with diagnosed HIV may skip doses for fear of disclosure (Golin et al. 2002).

Discriminatory attitudes from healthcare providers are commonly reported among Indigenous populations including among people living with HIV. Negative attitudes from healthcare providers and the perceptions that providers associate Indigenous identity with addictive

behavior (Barlow et al., 2008) can dissuade individuals from getting an HIV test (Barlow et al., 2008) or from seeking or returning to care (Golin et al., 2002). Indeed, experience of discrimination from healthcare providers can result in hesitancy in accessing services (Mill et al., 2007) or in some cases refusal of care altogether (Zukoski et al., 2009). Importantly, a 2012 Health Council Canada study documented widespread racism and stereotyping within the healthcare system and noted that Indigenous people do not seek treatment as a result (Bourassa et al., 2015). In a cross Canada Study of First Nations People, 15% reported that they had been treated unfairly or inappropriately because they were Indigenous (NAHO, 2004).

While community interventions specific to targeting and reducing stigma have been tested in urban centers, little work has been done in rural settings (Zukoski et al., 2009). Low prevalence and rural areas call for unique strategies that can address HIV and stigma (Zukoski et al., 2009). In rural HIV, training for medical staff is clearly needed (Yannessa et al., 2008). Training on cultural competency and cultural safety would also be welcome in smaller communities with high numbers of people of Indigenous descent (see below).

## **Where are the Gaps?**

### *General*

In general, most reviewed literature discussed the lack of culturally sensitive or appropriate health care (Matiation, 1999; Bucharski et al. 2006). In many situations programs and policies are externally influenced and developed by provincial and federal agencies. Programs and policies are therefore more likely to be focused on financial issues as opposed to the health needs of local individuals (Varcoe & Dick, 2008); additional support in improving service delivery and access issues is instead required. In rural areas, there has also been a general downsizing of social services, and existing services are often siloed and not able to address intersecting health needs including addiction, trauma and primary care (Varcoe & Dick, 2008; Rural Health in Rural Hands, 2002). From a leadership level, some communities may still be in denial that HIV exists (Patterson, 2007) and there may be no sustainable funding to support HIV related initiatives (Patterson, 2007)

### *Education*

In terms of education, rural and urban Indigenous youth have noted that sex education is inadequate (Restoule et al., 2010). When curriculum on sexual health is available it is not always followed as a result of high staff turnover, the logistical aspects of bringing in a trainer or other competing priorities (Crown et al., 1993). In one study, participants noted that “community efforts were often disconnected from one another, or limited to ‘pretend prevention’ – simplistic educational efforts that did not address the underlying issues” (Varcoe & Dick, 2008). Education for youth was also noted as starting too late (Restoule et al., 2010) and, going forward, should be paired with fun activities so that young people will attend and participate (Restoule et al., 2010). HIV education can also be a costly endeavor when it requires an external resource person to travel to remote widely scattered communities (Crown et al., 1993; Patterson, 2007).

### *Availability of Healthcare Providers*

It has been historically more challenging to treat HIV in rural areas given limited supply of healthcare providers and less developed infrastructure (Schur et al., 2002). Limited specialized support services and immense distances make service provision challenging (Crown et al.,

1993). Many communities will only have one community health representative who is responsible for managing all the health issues of the entire community (Patterson, 2007). There are also issues with high turnover and staff retention (Crown et al., 1993). It is important to understand the extent to which care for HIV is being sought in urban areas in order to support service delivery planning in rural communities (Schur et al., 2002).

### *Women-Specific Needs*

Indigenous women are less likely to pursue HIV testing (Geduld et al., 2003), in part due to the lack of culturally appropriate health care (Matiation, 1999; Bucharski et al., 2006). Gender, living in rural areas and poverty are all shaped by the intersecting risks of violence and exposure to HIV. Findings from one study noted that the way Indigenous women living with HIV are treated creates a form of 'triple jeopardy' discrimination (being a women, Indigenous and HIV positive) that contributes to their ongoing marginalization and isolation (Reading et al., 2011). Experiences of sexual abuse in women are much higher than men (Pearce et al., 2008). Women in rural areas may be also disconnected from HIV support programs and social networks, otherwise offered or available in more urban settings. If women are forced to travel for care, they may not have familial or social support (Varcoe & Dick, 2008). For Indigenous women, the lack of trust in their service providers is linked to historical and ongoing colonial relations that have fundamentally targeted women and disrupted their communities and cultures (Reading et al., 2011; Bourassa et al., 2015).

It is important to note that Indigenous men are overrepresented in HV diagnoses and also require specific programming to address their unique needs. This includes men who identify as two-spirited) for which there is a significant gap in the literature that specifically addresses their unique health and service needs (Zoccole, Myers and Day, 2005).

### *Language Barriers*

Language shapes the way people think about, understand and interact with their surroundings. For Indigenous people, language and oral traditions are tied to cultural expression. Health and well-being are connected with culture and "culture and language can act as buffers/protective factors against negative effects of risk" (Wilson et al., 2016; McIvor et al., 2009). According to the 2016 Canadian Census, more than 70 Indigenous languages were reported (Stats Can) with numerous languages spoken in the north (Crown et al., 1993). With the absence of a common language, it can be challenging to communicate about HIV to communities and across generations. In many languages, there is not comparable vocabulary for HIV concepts and in some cases, words or terms may have opposite meanings. The numerous languages spoken require multiple versions of resources and materials, although in many situations or settings this is a challenge as services and resources are not always available, particularly in rural and isolated communities.

### *Other Pressing Issues*

HIV prevention is a low priority in communities that are still reeling from the impacts of the residential school system and the *Indian Act* (Prentice et al., 2011). In many communities there are more immediate concerns like opioid overdose crisis, unemployment, family violence, alcohol abuse, youth suicides, inadequate housing, and access to safe drinking water (Rural Health in Rural Hands, 2002; Crown 1993; Webster 2013; Russell et al., 2016). As a result, HIV and STI testing and the provision of condoms remains a low priority (Prentice et al., 2011).

### *Confidentiality Concerns*

As noted above, concerns about confidentiality are commonplace in small rural and remote Indigenous communities. As a result of a lack of confidentiality, anonymity is difficult to maintain. Common complaints in rural, remote and isolated communities is that a relative or friend works at the health centre or band office (Patterson, 2007) and people at risk may be reluctant to seek testing if they fear their privacy will be breached. Women in one study commented that “confidentiality was a joke” given that they would often end up with family members or friends as service providers, information was shared outside of professional relationships or people would be observed as clinics were utilized (Varcoe & Dick, 2008). There are also concerns with the application process for medical travel and accommodation grants through FNIHB (Patterson, 2007).

### *Data Challenges*

In their 2015 article, Smylie & Firestone argue that there are two underlying roots to health information challenges for Indigenous populations: “the lack of relevant, consistent and inclusive Indigenous identity indicators in core population data sets; and the need for meaningful Indigenous leadership and participation in the governance and management of Indigenous health data (Smylie & Firestone, 2015). The full impact of HIV infection among Indigenous communities in Canada is not yet fully realized. Therefore, caution should be used when interpreting data drawing conclusions from the numbers reported. An adequate description of the HIV epidemic among Indigenous people in Canada requires accurate and complete access to ethnicity data (Minichello et al., 2013; Wynne & Curre, 2011; Smylie, 2006). Unfortunately, varying degrees of completeness and accuracy result in gaps in data on HIV and STIs among Indigenous populations (Minichello et al., 2013). These stem from multiple causes including delays in reporting, misclassification of ethnicity status (Bucharski et al., 2006) and interprovincial variation in ethnicity reporting (only available in Canada since 1998). Indeed, ethnicity data is not available for all provinces and territories and so only data from certain provinces and territories is used when examining HIV diagnoses data on Indigenous people (PHAC 2006; Smylie, 2006). Misclassification of Indigenous Peoples as non-Indigenous can also mask the epidemic in some areas but underestimating the true level of risk (Smylie & Firestone, 2015). As a result, data on STIs and HIV in Indigenous communities and populations is limited (Minichello et al., 2013; Smylie, 2006) and these gaps in surveillance data represent a challenge in developing appropriate health interventions, monitoring programs and other policies targeting Indigenous Populations (Interagency Coalition on AIDS and Development). Importantly, engagement of Indigenous peoples in the collection and analysis of data related to HIV is critical for ensuring completeness as well as appropriateness and relevance. At the same time, data on local and regional trends are also needed.

Finally, it is worth noting that there is no single definition of ‘rural’, so the proportion of participants living in rural areas will vary. For example, depending on which definition is used, approximately 21-30% of the Canadian population lived in rural settings in 2001 (Rural Health in Rural Hands, 2002).

### **Current Strategies, National organizations, AIDS service Organizations, and an Introduction to Promising Principles and Practices**

This section of the review will focus on highlighting relevant HIV strategies and key organizations working in the area of HIV with Indigenous communities. Key concepts important

for working with Indigenous communities in HIV, as well as some promising principles and practices, will also be introduced. Given that there was not a lot literature specifically examining gaps in service provision, we will explore existing services/programs that support HIV knowledge, prevention and care for Indigenous communities in Canada. This section will be developed more in the next Phase of this study through a more systematic review of service and program agency websites as well as discussions with service providers working in this sector.

### **Strategies:**

**Aboriginal Strategy on HIV/AIDS in Canada II** (for First Nations, Inuit and Métis Peoples from 2009 to 2014): **ASHAC** was initially proposed in 2003 after a literature review and consultation with more than 170 people. Key goals include the following: 1) Ensure that all the best possible efforts, in all areas, are placed to meet the needs of Aboriginal people living with HIV/AIDS; 2. Prevent further spread of HIV/AIDS among Aboriginal populations through education, awareness, diagnosis, care, treatment and support programs for those at risk of, living with and affected by HIV/AIDS guided by research data and evidence-based decisions; 3. Respond to the diversity within the Aboriginal population through culturally relevant and targeted initiatives including harm reduction approaches and group specific resources; and 4. Support Aboriginal people living with HIV/AIDS to improve quality of life by maintaining consistent services and promoting relational care. The nine key strategic areas include: A. Holistic Care, Treatment and Support; B. Aboriginal HIV/AIDS Research; C. Broad-based Harm Reduction Approaches; D. Capacity Building; E. Legal, Ethical and Human Rights Issues; F. Partnerships, Collaboration and Sustainability; and G. Prevention and Awareness.

**The National Aboriginal Youth Strategy on HIV and AIDS in Canada:** for First Nations, Inuit and Métis Youth from 2010 to 2015: This strategy was launched during the 2010 Aboriginal Awareness Week. It was developed with guidance from the National Aboriginal Youth Council on HIV and AIDS (comprised of youth aged 18 to 29 from all provinces/territories). The strategy recommends culturally relevant and youth sensitive strategies to address HIV among Indigenous youth. It promotes the right of youth to be educated and to use this knowledge to empower themselves and their peers to prevent HIV infection and encourage testing, treatment and care.

**The International Indigenous Strategic Plan on HIV and AIDS for Indigenous Peoples and Communities from 2011 to 2017:** This strategic plan facilitates discussion among Indigenous peoples living around the world and provides a structure for such communities to interact with their own governments, AIDS Service Organizations (ASOs) and other stakeholders in the response to HIV. There are 6 key objectives which were designed on input from members of the IIWGHA: 1. Increase the visibility of the impact of HIV and AIDS in Indigenous communities at the international level; 2. Improve meaningful inclusion of Indigenous Peoples and Indigenous people living with HIV in research, policy and program development at the regional, national and international level; 3. Work towards the accurate representation of Indigenous peoples in HIV and AIDS epidemiological data within their own regions and countries; 4. Provide capacity building and development to raise HIV and AIDS and Indigenous People as a health priority; 5. Promote Indigenous specific approaches to the social determinants of health; and 6. Conduct sustainability planning.

This strategic plan encourages the sharing of wise practices between members and for the Canadian Aboriginal AIDS Network to take on a leadership role in implementing the strategic objectives identified.

### ***National HIV Organizations focused on Indigenous Communities***

While there are numerous national organizations focused on Indigenous populations and health including the National Aboriginal Health Organization (NAHO), the Métis National Council, the Métis National Council of Women, The Assembly of First Nations, and Inuit Tapiriit Kanatami (National Representational Organization for Inuit in Canada), this section highlights national Indigenous organizations focused specifically on HIV.

**Canadian Aboriginal AIDS Network (CAAN):** CAAN, a national not-for-profit organization was established in 1997 and represents over 340 member organizations and individuals. It is governed by a national 13-member Board of Directors and provides a national forum for members to express needs and concerns. CAAN works to ensure access to HIV-related services through advocacy and provides relevant, accurate and up-to-date HIV/AIDS information. They represent a key national voice of a collection of individuals, organizations and provincial/ territorial associations, and provide leadership, support and advocacy for Indigenous people living with and affected by HIV. CAAN provides a National forum for Aboriginal Peoples to holistically address HIV and AIDS, Hepatitis C, other Sexually Transmitted and Blood Borne Infections, TB, Mental Health, aging and related co-morbidity issues; promotes a Social Determinants of Health Framework through advocacy; and provides accurate and up to date resources on these issues in a culturally relevant manner for Aboriginal Peoples wherever they reside. CAAN has produced numerous reports and research studies that help to identify wise practices.

**Canadian Inuit HIV AIDS Network (CIHAN):** Pauktuutit established the Canadian Inuit HIV/AIDS Network (CIHAN) to guide its HIV/AIDS programming in the Inuit regions and with particular Inuit groups. CIHAN functions as a consultative and advisory group to Pauktuutit's sexual health program on matters pertaining to sexual health, hepatitis C and HIV/AIDS prevention, care and treatment among Inuit. CIHAN is Pauktuutit's window on the regions and its pulse on Inuit communities. CIHAN members provide Pauktuutit with updates on their respective regions in the areas of sexual health, hepatitis C and HIV/AIDS. In this way, CIHAN helps to facilitate Pauktuutit's outreach to Inuit communities and groups and collaborates with the Canadian Aboriginal AIDS Network. CIHAN also functions as a mechanism to share information on HIV/AIDS across all regions. Pauktuutit and CIHAN project activities include raising awareness, producing and distributing newsletters, posters, CDs, and training videos, developing web-based information; training for front line health workers; supporting sexual health (including HIV and Hepatitis C) fairs and walks in Inuit communities; attending meetings to share information and encourage cooperation on sexual health; and serving as advocates for Inuit at the national and regional levels.

**AIDS Service Organizations (ASOs):** ASOs are community-based organizations that specifically focus on HIV. They run a range of community-based programming including treatment access support, housing and legal support, education, training and knowledge translation activities. They also participate in research programs, develop policies, organize conferences, and provide networking opportunities and conduct outreach programs. ASOs specific to Indigenous communities affected by HIV complement these services by providing a range of programs at provincial levels and incorporate cultural programming specific to Indigenous communities including integration of traditional ceremonies and medicines. However to date, like other ASOs, they tend to be focused mainly urban settings.

## ***Promising Principles and Practices:***

### *Reclaiming and Resiliency through Strength-Based Approaches*

Reclaiming is the ultimate form of decolonization (Wilson et al., 2016; Flicker et al., 2014) and is an assertion of sovereignty (LeFrance & Nichols, 2010). This approach can be a helpful way to start the discussion on HIV prevention (Wilson et al., 2016). As such, organizations and researchers working with Indigenous communities on issues related to HIV note that one of the priorities that research programs must make explicit is the need for strategies that focus on cultural reclamation, reconnection and reengagement and center on the knowledge, skills, talents, and resiliency of Indigenous people (Wilson et al., 2016; Barlow et al., 2008). Programs that support self-determination and therefore fuel the goals and aspirations of communities to “preserve, restore, and protect their cultures and ways of doing things” (LeFrance & Nichols, 2010) are key. Approaches that are strength-based; sex positive; culturally safe and incorporate Indigenous models of health promotion (Wilson et al., 2016) help to promote positive self-identity and highlight the resiliency of Indigenous communities (Mooney-Somers et al., 2012; Wilson). Indigenous community members know what is best for their communities and should be a central part in leading the development of sexual health delivery and needs assessment (Wilson et al., 2016).

### *The Importance of Culture*

It has been identified that recognizing the value Indigenous cultures are critical for addressing the HIV epidemic among Indigenous people (Nowgesic, 2011). Health and wellbeing should include aspects of the spiritual, physical, mental and emotional health (Reading et al., 2011; Medicine wheel). Culture, in one study, was “seen as a path toward new meaning in life, learning to take pride in being Aboriginal and generally improving self-esteem” (Barlow et al. 2008). Women in one study identified a range of activities that are helpful for managing their HIV and healing from sexual trauma including healing ceremonies, smudging, Elders and spiritual leaders, faith in the creator and powwows (Reading et al., 2011). Varcoe & Dick point the success of cultural and spiritual reawakening in communities and the role of powwows and traditional dancing (Varcoe & Dick, 2008). Elders are critical to an Indigenous evaluation framework (LeFrance & Nichols, 2010). For many youth, Elders act as stewards for imparting teaching and disseminating culture and traditional ways (Flicker et al., 2015). They can help teach the language (Wilson) which can serve as protective factor against HIV infection and lead to pride (Varcoe & Dick, 2008). In one study, youth viewed their cultures as “key to combatting HIV because traditional practices teach values like respect for and knowledge about one’s body, health sexuality, sexual pride and living a balanced life” (Wilson et al., 2016). Findings from Restoule et al., noted that youth in rural areas were more likely to suggest strategies to address HIV that involve their whole communities including Elders (Restoule et al., 2010). Knowledge can come from three ways: Traditional knowledge- handed down through generations and reinforces core beliefs and values (e.g., creation stories); 2) Empirical Knowledge: gained through observation over time; and 3) Revealed Knowledge which is acquired through dreams, visions and spiritual protocol (LeFrance & Nichols, 2010). Community is central and so the use of participatory approaches is helpful (LeFrance & Nichols, 2010).

### *Two-Eyed Seeing and Creation of Ethical Space*

The concept of two-eyed seeing allows us to see “from one eye with the strengths of Indigenous ways of knowing, and from the other eye with the strengths of western ways of knowing and to use both these eyes together” (Hatcher and Bartlett, 2010, pg. 16). This helps to take down

walls and boundaries to equalize existing power imbalances. It is a new way of creating knowledge. Related to this, is the concept of ethical space where all assumptions, biases, and misrepresentations about the 'other' are brought to bear in the interest of identifying moral and ethical principles in cross-cultural interaction (Ermine, 2007). Ethical space can help us to reconcile worldviews and create a space to step out of our allegiances, detach from our assumptions and biases about the world, and assume a position where dialogue can occur (Ermine, 2007).

### *Cultural Safety and Competency in Healthcare Settings*

While western medicine is based on a disease model, traditional medicine is based on wellness (Rural Health in Rural Hands, 2002) with the central belief that a "person needs to have a full circle walk just to keep them balanced" (Nowgesic, 2013). Evidence suggests that when Indigenous people living with HIV are able to participate in traditional practices, they are better able to come to terms with their HIV diagnosis and manage their addictions (Barlow et al., 2008). This relates as well, to the physical space of the clinic where local Indigenous culture can be included as art or as part of the infrastructure (Barlow et al., 2008).

The importance of how Indigenous people living with HIV construct and understand their experiences with HIV care are highlighted in the Indigenous Red Ribbon Storytelling Study (2013-2015). There were numerous recommendations based on the findings of the study specific to healthcare and healthcare providers including that providers should not judge Indigenous people living with HIV who also are living with a substance use disorder and instead should support treatment by ensuring that Indigenous cultural values, beliefs and customs are an integral part of health services. It was also recommended that clinics should ensure that they have all the various necessary types of service providers including an Elder-in-residence who can specialize in providing HIV support to Indigenous people living with HIV within the context of Indigenous traditions (Nowgesic, 2015). A culturally safe healthcare that is free from racism and discrimination is required (Bourassa et al., 2015).

Additionally, five wise practices identified in the CAAN Cultural Competency Study (2013) included: 1. Stronger community partnerships with Aboriginal organizations to increase access to services; 2. Information about basic Aboriginal-specific health issues for service providers, in particular about understanding constraints around such programs as NIHB which Métis are not eligible for; 3. Centralized access to Aboriginal resources; 4. Use and importance of a holistic approach- address emotional, mental, social, physical and spiritual needs and 5. Importance of respecting and providing treatment choices to people at ALL stages of the journey.

Related to this is *relational care* which requires healthcare providers to be willing to have a dialogue with their Indigenous patients about how to integrate both western medicines with traditional wellness practices into the care that they receive (Barlow et al., 2008). These relationships should be based on trust, rapport, respect, flexibility and openness and in many ways are reflective of the Seven Sacred Teachings: love, respect, courage, honesty, wisdom, humility and truth (Barlow et al., 2017).

Wise practices for providing relational care include: 1. Acknowledge individuals' experiences of colonialism; 2. Approach families as a unit, make information available to everyone (this was also echoed by various key collaborators); 3. Be deliberate and use sustained message to normalize HIV; 4. Make an effort to reduce the perception that because they are Indigenous, substance use or social assistance is presumed to be a part of the life; 5. Treat the person and not the disease; 6. Maintain knowledge of Indigenous-specific services to help individuals seek

a path towards wellness and reconnection with their identity; 7. Create a safe space for Indigenous people living with HIV to connect and support one another; 8. Take practical steps where traditional wellness practices and ceremonies can take place; 9. Express a genuine respect and trust for Indigenous clients, respect their resilient nature; and 10. Provide culturally relevant resources to clinics and agencies (Barlow et al., 2008)

### *Arts-Based Practices*

Using arts in ceremony, expression and function has been happening in Indigenous communities for millennia (Peltier, 2015). The use of arts-based practices fits well with the oral and visual culture of many Indigenous populations. There have been numerous studies which suggest that, particularly for women and youth, arts-based approaches can help to engage people living with HIV in leadership and activism (Flicker et al., 2014) and also to help tell their stories (Peltier, 2015). This is best highlighted in the Taking Action Project which uses art and art-based approaches to increase awareness and develop youth leaders in HIV health promotion (Flicker et al., 2014; Wilson et al., 2016) and the Visioning Health Project which creates the opportunity for Indigenous women living with HIV to tell their stories and generate new knowledge. Indeed, stories are often perceived as “holding medicine” and the act of sharing them is healing (Smylie, Olding and Ziegler, 2014).

### *Addressing the Social Determinants of Health*

Importantly, quality care cannot be provided in a silo; a holistic approach is required. For example, violence and HIV cannot be prevented or treated in isolation, or without significant economic and social change at all levels (Varcoe & Dick, 2008). The importance of developing economic and employment strategies that help address issues of economic dependence, violence and associated health risk are critical (Varcoe & Dick, 2008). Locally developed community responses that address cultural identity, healing, safe social support, poverty and meaningful employment can help to increase awareness of HIV and promote testing and care.

## **CONCLUSIONS AND NEXT STEPS**

This literature review has highlighted various factors that influence and impact knowledge, attitudes and behaviours towards HIV with a focus on Indigenous peoples living in rural and remote Canadian settings. Findings demonstrate that while HIV is overrepresented among Indigenous communities, knowledge of and access to HIV testing is often lacking. This is due to many factors which are all intersected by the impacts of colonialism, racist policies and structures that continue to target Indigenous peoples, and ongoing experiences of intergenerational trauma.

We have identified numerous gaps affecting knowledge and attitudes about HIV that are particularly common in rural and remote settings where many Indigenous peoples live. These gaps in knowledge, such as misconceptions about HIV and one’s personal risk, can affect behaviours such as accessing HIV testing when available. The limited number of healthcare providers including those with specialization in HIV in rural and remote settings creates concerns around trust (particularly for women) and confidentiality in the context of stigma, consequentially creating barriers to HIV testing and treatment. The lack of culturally-appropriate and culturally sensitive sexual health education resources also leads to lower levels of HIV knowledge. Furthermore, many Indigenous communities regularly face more demanding concerns such as poor housing, access to clean water and high rates of youth suicide, making

HIV awareness and testing less of a priority. At the same time, it is important to acknowledge that the HIV epidemic among Indigenous communities in Canada has not yet been fully realized due to incomplete and often fragmented data.

While gaps were discussed, much of the reviewed literature spoke to the incredible resiliency of Indigenous peoples and the need to approach HIV from a strength-based methodology. Programs that emphasize the importance and role of culture and reclamation have shown to be effective for increasing HIV knowledge and testing behaviours. For example, the incorporation of art and art-based strategies, particularly when working alongside women and youth, creates space for individuals to tell their stories and become active leaders and advocates within and for their communities. Improving cultural safety and cultural competency within the healthcare setting and recognizing that HIV care cannot exist in a silo allows for the broader social determinants of health to be addressed. It also allows for a more holistic approach to an individual's wellness and wellbeing. Related to this is Indigenous framework of two-eyed seeing, where one eye is used to see the strengths of Indigenous ways of knowing, and other eye to see the strengths of western ways of knowing. Using both eyes together helps to remove barriers and create an ethical space where different worldviews are reconciled; where individuals can detach from their personal assumptions about the world and allow for respectful and genuine dialogue to occur.

### ***Next Steps***

Several key organizations working with Indigenous peoples at-risk of or affected by HIV in Canada were briefly highlighted in this review. The second phase of this exploratory study will involve identifying a more comprehensive list of the national, provincial/territorial, regional and local organizations, agencies and individuals that are involved in the provision of HIV prevention, support and/or care for rural and remote Indigenous communities in Canada. We will engage with these organizations and individuals to learn more about their work, discuss key gaps and challenges, identify promising practices that have demonstrated success, and how an organization like DI might contribute to HIV prevention and care for Indigenous communities. Simultaneously, we will examine DI's organizational strengths and capacity to determine what lessons can be drawn from working in HIV prevention and care with rural and remote populations that may be applicable to undeserved and remote Indigenous communities in Canada.

The knowledge generated from this first phase of the study will be combined with findings gathered in the second phase of the study to form a feasibility report. The report will include recommendations for DI on how to proceed with appropriately and effectively supporting the delivery of HIV prevention and care among rural and remote Indigenous communities in Canada. As DI is interested in supporting Indigenous researchers, health system policymakers, managers and frontline staff to address challenges in HIV prevention and care that have a significant impact on Indigenous populations in Canada, this report will be shared with individuals and organizations participating in the community consultations, as well as potential partners and collaborators. This will help to identify ways we can build respectful and sustainable partnerships to help address the HIV-related priorities of Indigenous communities, and support the advancement of HIV services through new and collaborative programming. Our findings may also have relevance to other international non-governmental organizations developing programs in Canada focused on Indigenous HIV prevention and care, or other sexually transmitted or blood-borne infections.

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## **APPENDIX A:**

### **Situating this Literature Review within Dignitas International's Indigenous Health Program**

Since 2004, Dignitas International (DI), a medical non-governmental organization ([www.dignitasinternational.org](http://www.dignitasinternational.org)), has been working in partnership with Malawi's Ministry of Health to support HIV treatment and care for more than 200,000 Malawians living with HIV. In 2014 DI launched its Indigenous Health Program (IHP) following a feasibility study conducted in partnership with various Indigenous communities and organizations in northern Ontario. Results of the feasibility study demonstrated that DI could play a meaningful role in supporting the delivery of innovative and culturally appropriate health solutions in Canada's most remote and underserved communities. Following this DI collaboratively developed a community health worker project in partnership with the Sioux Lookout First Nations Health Authority that was designed to improve care and management of type 2 diabetes in remote First Nations communities in northern Ontario.

This review is situated within a larger exploratory study to determine the potential for expanding DIIHP to support HIV prevention and care for First Nations, Métis and Inuit peoples living in rural and remote settings in Canada. This review will help to uncover existing gaps in knowledge, attitudes and behaviours relating to HIV, and is the focus of the first phase of this study. This is a critical piece given the known impact of knowledge levels on attitudes and uptake of HIV prevention, support and care. The second phase of this study will involve developing a more comprehensive list of programs/services that work with Indigenous communities affected by HIV and engaging with them to identify promising practices. At the same time, we will engage with key DI staff and affiliates to identify DI's organizational strengths in HIV prevention treatment and support. The knowledge generated from this exploratory study will contribute to a shared learnings report which will include recommendations for DI on collaborative and genuine partnership opportunities that acknowledges the resilient nature of Indigenous peoples while providing support or delivery of HIV prevention and care.