



# Colonisation, suicide, and resilience: Storying with First Nations people living with HIV and AIDS

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## Abstract

The impact and trauma of colonisation persists among Indigenous Peoples in Canada, where they face a disparate burden of HIV diagnoses and suicide compared to the general population, yet still demonstrate tremendous resilience. In order to elucidate the issues facing First Nations people living with HIV and AIDS, 29 participants partook in traditional storytelling to share their experiences, resulting in 27 major themes. Participants shared the negative coping mechanisms, suicidal ideations, historical

traumas, and stigma experienced following their HIV diagnosis as well as their desire to re-engage and revitalize their connection to culture and community, demonstrating their unwavering resilience. Following the interviews, participants produced recommendations requesting funding for HIV and AIDS treatment and programming in First Nations communities, a government commitment to address issues surrounding poverty, stable housing, clean drinking water and perpetual trauma for northern Indigenous Peoples, and a need for accessible, culturally based treatment programs and services at HIV service organizations.

**Keywords:** Indigenous, suicide, colonisation, trauma, prevention, resilience

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## Introduction

Colonisation has suppressed Canada's Indigenous Peoples for hundreds of years and has played a significant role in the power structure of Canadian society, placing social, political, and economic inequalities upon Indigenous Peoples. These inequalities have caused unfavourable, intermediate, and proximal determinants (Reading & Wien, 2009), which have led Indigenous Peoples to suffer the worst social, economic, and health conditions in all of Canada (MacDonald & Altaran, 2007). Striking health disparities exist amongst Indigenous Peoples in Canada and have been well documented for decades (Kurtz et al., Indigenous Peoples in Canada experience ill health at rates far higher than in the non-Indigenous population across virtually every facet of health (National Collaborating Centre for Aboriginal Health, 2013). These gaps are paving the way for some of the shortest life expectancy rates of any one identifiable group within Canada (Government of Canada, 2017).

Along with these disparities, Indigenous communities are at the heart of an HIV and

AIDS epidemic in Canada, facing a 13% incidence increase in HIV infection between the years 2014 and 2016 (CATIE, 2019). The province of Saskatchewan has the highest rates of HIV infection in the country, mainly focused in First Nations communities (Woroniuk, 2017). Indigenous Peoples living with HIV on combination antiretroviral therapy have a lower life expectancy at age 20 compared to non-Indigenous Canadians (Patterson et al., 2015). Furthermore, the mortality rates of Indigenous Peoples living with HIV is higher than for other ethnicities in Canada (Benoit et al., 2017). Though the rates of HIV among Indigenous Peoples in the United States, Australia, and New Zealand are not substantially higher than non-Indigenous Peoples in said countries, colonization and inequitable social determinants place these populations at risk of a future HIV epidemic currently being seen in Canada (Negin et al., 2015). Perhaps one of the most pervasive impacts of colonialism still felt today is the disproportionate rate of suicide in Indigenous communities in Canada, particularly among Indigenous youth. Young Indigenous people living with HIV who use drugs in British Columbia are 12.9 times more likely to die compared to Canadians of the same age, with suicide being one of the leading causes of death (Jongbloed et al., 2017). This research shares the stories of 29 First Nations people living with HIV and AIDS in Ontario; how their lives have been shaped by colonial trauma, HIV, self-harm and suicide, and their undeniable will to keep living.

## Background

### Indigenous Peoples in Canada

Canada's Indigenous population is comprised of First Nations (status and non-status), Métis (registered and non-registered) and Inuit people and represents 4.9% of Canada's total population. Almost half (48%) of the 181,524

registered Indian<sup>1,2</sup> population in Ontario lives on 207 reserves<sup>3</sup> and there are 126 bands<sup>4</sup>, with over 23,000 speakers of Indigenous languages in the province (Government of Canada, 2018a).

### HIV and AIDS

The Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) disproportionately impact Indigenous Peoples in Canada. There is limited data on the true impact of HIV and AIDS on this population, given significant issues with HIV data collection and reporting. Of the estimated 63,100 people living with HIV in Canada at the end of 2016, 9.6% (6,055) were Indigenous, representing a 5% increase from the 2014 estimate (5,760). The estimated HIV prevalence rate for Indigenous Peoples in Canada in 2016 was 362 per 100,000 population: two times higher than in the general population (Public Health Agency of Canada, 2019). In 2017, Indigenous Peoples continued to be disproportionately represented, making up less than 5% of the population in Canada, but accounting for more than 20% of new HIV diagnoses (Haddad et al., 2018).

Indigenous women are more likely to be diagnosed with HIV than the general population, with up to 40% of new infections occurring in this group (Haddad et al., 2018). In 2017, Indigenous women in Canada accounted for 30.9% of new HIV cases in women compared with Indigenous men, who accounted for 16.3% of new cases in men (Haddad et al., 2018). In Ontario specifically, the percentage of new HIV diagnoses in Indigenous men increased from 1.4% in 2014-15 to 2.8% in 2016-17 while the percentage of new HIV diagnoses for Indigenous women increased from 5.2% in 2014-15 to 6.9% in 2016-17 (Ontario HIV Epidemiology Surveillance Initiative, 2019a). This may be attributed, in part, to the fact that the number of HIV tests increased across all health regions in

Ontario in 2016 and 2017 (Ontario HIV Epidemiology Surveillance Initiative, 2019b). Modes of exposure for women are mainly from sexual contact with men (at 59% of infections) and exposure through injection drug use (35% of infections). For men, the greatest risks are from injection drug use (32%), sexual contact with men (28%), and exposure through combined drug use and sexual contact with men (20%); only 16% reported transmission via sexual contact with women (Ontario HIV Treatment Network, 2014).

### Suicide in Indigenous Populations

Between 2011 and 2016, suicide rates in First Nations individuals were three times higher than in non-Indigenous people (Kumar & Tjepkema, 2019). In a study by Cain et al. (2011), of 72 Indigenous participants living with HIV interviewed across Canada, 35 described thoughts of killing themselves or attempts to die by suicide. Similarly, in a British Columbian cohort of 605 Indigenous participants, 53% considered taking their own life and 37% had attempted suicide (Moniruzzaman et al., 2009). Inuit Peoples, particularly Inuit youth, have some of the highest suicide rates in the country, dying from suicide at a rate of 40% compared to 8% across Canadians (Kral, 2016; Webster, 2016). It is currently estimated that suicide rates are 5 to 7 times higher for Indigenous youth compared to non-Indigenous youth, and 11 times higher in Inuit youth (Government of Canada, 2018b). About 1 in 20 to 1 in 10 off-reserve First Nations, Métis, and Inuit young adults reported having had suicidal thoughts in the previous 12 months and about 1 in 5 to 1 in 4 reported ever having had suicidal thoughts in their lifetime (Kumar & Nahwegabow, 2016).

Heightened suicide rates among Indigenous Peoples in Canada can be tied to historical trauma, poverty, family and community abuse or

<sup>1</sup> “*Indian* people are one of three cultural groups, along with Inuit and Métis, recognized as Aboriginal people under section 35 of the Constitution Act. There are legal reasons for the continued use of the term *Indian*. Such terminology is recognized in the Indian Act and is used by the Government of Canada when making reference to this particular group of Aboriginal people” (Government of Canada, 2012, Para. 10).

<sup>2</sup> “*Status Indian* is a person who is registered as an Indian under the Indian Act. The act sets out the

requirements for determining who is an Indian for the purposes of the Indian Act” (Government of Canada, 2012, Para. 11).

<sup>3</sup> “A *reserve* is a tract of land, the legal title to which is held by the Crown, set apart for the use and benefit of an Indian *band*” (Government of Canada, 2012, Para. 25).

<sup>4</sup> A “Band”, or “Indian Band,” is a governing unit of Indians in Canada instituted by the *Indian Act*, 1876.

violence, and a perpetual lack of access to education, health care, and social services (Webster, 2016). Indeed, McQuaid et al. (2017) found that exposure of one previous familial generation to Indian Residential Schools (IRS) was associated with increased risk for lifetime suicide ideation and attempts.

### Context of Colonisation in Canada

Canada is a settler colonial nation-state, one that is balanced upon white supremacy and heteropatriarchy (Arvin, Tuck, & Morrill, 2013). Health disparities faced by Indigenous Peoples in Canada have been directly linked to centuries of traumatic policy imposed upon them, resulting in a history of cultural genocide and colonisation. The impact of deliberate practices to remove the language and culture from Indigenous Peoples is still felt today. The reserve system, Indian residential schooling, the 60s scoop<sup>5</sup>, over-incarceration of Indigenous men and women, missing and murdered Indigenous women and girls, and the continued over-apprehension of Indigenous children by the state to be placed in foster care all contribute to the current health inequity of Indigenous Peoples. While we continue to see a proliferation of research on the health outcomes of Indigenous Peoples, colonisation is rarely discussed and situated in a historical context rather an ongoing process (Axelsson, Kukutai, & Kippen, 2016). Settler colonialism must also address the interaction of colonialism racism, gender, class, sexuality and desire, capitalism, and ableism (Snelgrove, Kaur Dhamoon, & Corntassel, 2014). Additionally, we must be critical of heteropatriarchy – Indigenous women have a disproportionate likelihood of being the victim of violence and report higher rates of HIV infection than Indigenous men (Browne et al., 2016). In total, colonial policies, attitudinal and systemic racism, and socio-economic disparities all present significant barriers to creating an ideal healthy environment and reducing HIV and suicide in Indigenous Peoples within Canada (Smylie et al., 2006).

<sup>5</sup>The 60s scoop in this context relates to a period from the 1940s-1970s in which thousands of children were apprehended by the state. Issues surrounding the

## Methods

This research was conducted alongside Indigenous Peoples living with HIV (IPLWH) and was directed by two community-based Indigenous HIV and AIDS service organisations. It was essential to be respectful of, to use positively, and to give agency to the knowledge conveyed to me by the participants through story. This research was approved by the Ryerson University Research Ethics Boards (REB 2015-343) and informed consent was obtained for all participants.

Data were obtained through a traditional Indigenous method called storytelling. Storytelling honours oral tradition and places ceremony at the forefront where participants share their perspective(s) through telling their story (Hyett et al., 2018). We asked about the impact of HIV and AIDS on the participants' lives and explored mitigating factors related to their HIV status that may have led them away from their northern/isolated community to urban centres. 29 diverse First Nations people with HIV and AIDS participated (see Table 1 for participant gender/sexuality breakdown). Participants were offered tobacco, a critical part of storytelling, and were provided a \$50 cash honorarium. The questions were open-ended and allowed the participants to answer as specifically or as broadly as they felt comfortable. The storytelling method allowed participants' answers to be re-crafted into a flowing story of their life's journey. After transcription, data were de-identified by assigning participants pseudonyms and given to six undergraduate students to re-story the transcripts by removing the interviewer's questions and comments. The data were then re-formatted and edited by the researcher into a set of uniform first-person stories.

After interviews, transcripts were uploaded into the software program QSR NVivo 2017 and coded. This process was chosen at the request of the community partners, as to better understand (in a quantifiable way) the issues facing First Nations people living with HIV and AIDS. This

continued apprehension of Indigenous children in what is known as the 'millennium scoop' will be addressed later in this section.

process uncovered 27 major themes, some of which are discussed below.

Table 1. Participant Demographics

	Straight	2-Spirited	Gay	“Not Straight”	Total
Female	11	1	0	0	12
Male	11	2	0	0	13
2-Spirited <sup>6</sup>	0	2	1	1	4
<b>Total</b>	<b>22</b>	<b>5</b>	<b>1</b>	<b>1</b>	<b>29</b>

The average age of participants was 48 years. The average monthly income of a participant was \$1,362 CAN, with all participants identifying as being the recipient of supports from the Ontario Disability Support Program. Education varied between participants, with 38% (n=11) not attaining higher than grade 9, 10% (n=3) completing grade 10 or 11, 17% (n=5) completing high school, 10% (n=3) completing some college, and 24% (n=7) completing a college or university degree. All participants who identified as two-spirited (n=4) had a college/university level education.

## Results

### Coping with Diagnosis

Eight participants recalled a negative, life-debilitating, or life-ending prognosis from their physicians when given their HIV diagnosis. Many recalled: “He says, ‘I’m sorry to tell you this, but you’ve got HIV, you’re dying’”. Additionally, Skywalker said: “Well, I was diagnosed I was told to get my affairs in order because within five years I was going to get sick”. All eight participants thought they were going to die because of their HIV status, and experienced some form of negative emotion, including feelings of isolation. Negative responses include feeling shocked, traumatized, scared, depressed, lonely, blaming themselves or, wanting to die.

In several instances, participants felt many emotions at once. Brant stated: “I was still in shock, I couldn’t sleep, I was hardly eating. I had quit my job because I thought well there’s no

hope. I lost hope. And still today there’s lost hope”. Likewise, Yvonne said: “I felt hurt, angry, alone. It was like I didn’t have anybody; I couldn’t turn to anybody; I didn’t know how to tell anybody. Really scary. I was up and down crying all the time. I was angry, pissed off at the world. Mad at everybody”. Others (n=9) blamed or questioned their own actions and how they contributed to becoming HIV-positive. Rick stated, “I was very shocked, and I just didn’t understand what I had done wrong, I just couldn’t figure it out”.

### Suicide

Eight participants discussed wanting to die after being diagnosed. Nora stated: “My experience started off rough. I didn’t know what was wrong with me. I thought of suicide. I thought about all kinds of stuff. I continued to use drugs for a couple of years.” Similarly, Yvonne recalled: “I finally got all of my test results, and they were positive. I became angry and I wanted to die, that day. I drank myself silly for the longest time, I just drank every day for a long time.” Irene said “I remember the doctor telling me that it was positive, and I just remember feeling lonely. It seemed like right from my head to my toes, I just felt empty and scared. I thought about suicide.” No participant mentioned having access to immediate and ongoing services for their new diagnosis or proper mental health care, and this lack of resources contributed to their inability to cope with the news. This lack of immediate support appeared to exacerbate an already emotional and demanding time. Brant detailed “always trying to attempt suicide [...] you know

<sup>6</sup> The term 2-Spirited means many different things, to different people. In this context, it was used by participants to describe both their gender identity

(found in the vertical columns) as well as their sexuality (found in the horizontal columns).

this happened like 20 times [...] trying to jump off bridges and slice my wrists and hang myself. I had a tough journey living with HIV and not having enough resources”. Six of these participants were women and discussed the impact their death would have on their children and family. Children were a significant protective factor against suicide.

Eighteen participants discussed turning to negative coping mechanisms, such as alcohol or drugs to numb their feelings, after learning they were HIV-positive. Singing Medicine Water says: “in my eyes HIV was a death sentence, so I kind of fell off the rails mentally. I got into addictions with drugs a lot more. I got into the drug addictions, I lost everything.” Eleven participants noted that they were ‘going to die anyway’ and therefore no longer cared about the impact of self-harming behaviour. Elizabeth stated: “I still wanted to get high. I came so close to dying by overdosing. Having HIV still didn’t stop me from using. I’m always thinking that I’m going to die anyway. This is something that justified me using, even with the HIV. I’m going to die anyway, so who’s going to care?” Similarly, Brant said: “My partner recently died in 2016. Because he wasn’t taking care of himself... when I found out I was HIV positive, I gave up. I was partying thinking I was going to die right away. So, I partied. I thought if I’m going to die, I’m going to have fun before I do.” While these behaviours were not discussed in the context of suicide, there is an underlying connection between extreme binge drinking or drug use and carelessness towards the negative outcomes that could ensue.

### **Trauma and Stigma**

All participants (N=29) described some form of trauma faced personally or by their loved ones. Nine participants either directly attended an IRS or had a parent who attended an IRS. Their stories contained themes such as bad parenting, alcohol, and drug abuse. Ray of Sun noted that IRS made her family angry and harsh: “My grandmother went through. My father too. It made my family harsh. I guess angry or something”. Eight participants were taken from their families and communities when young and suffered with addiction throughout their lives. Mikey stated: “I was taken from my community. I was taken when I was 10 or 11. Ever since then I was involved in Children’s Aid Society and after

that I went to the streets”. Eight participants experienced significant violence, typically in the form of domestic violence (n=6), which was linked to their drug addiction and relapse. Singing Medicine Water stated: “Once I got into the drug addictions, I lost everything. My self-worth, went through domestic violence with my partner, and restraining orders”.

A prominent theme we observed was stigma. Twenty-five participants described 67 instances of stigma in the form of rejection or threats towards them, noting that stigma was exacerbated by a lack of education about HIV transmission and risk. Four of those participants described violent acts committed against them as a result of their status. Eight participants noted that they experienced homelessness at some point in their lives, as described by Little Wolf: “When I became positive, I told my mom and dad, they kicked me out. They didn’t want me in the house because they were scared to touch me, scared to use a dish, scared to go anywhere near me”. Six participants experienced long-term homelessness and living on the streets or squatting.

### **Need for Culture**

Culture emerged in the majority of stories, with discussions around the importance of culture for health and healing, the loss of culture, and the desire for participants to re-engage with their culture. Mukada Mukaa explained the impact of culture on understanding HIV, “We have a different way of educating people around teachings. I even had to learn about certain medicines to take. I had to know who I was before I can help other people move forward. It’s time for people to start picking those teachings back up and sharing about HIV. Sharing about how they ended up being resilient.” This was echoed by Elizabeth: “I didn’t tell my elder that gave me my spirit name. I was ashamed to tell him. I did go to sweats and fasted in the bush by myself. Having all these agencies and support groups really helped me dealing with the HIV but the ceremonies even more.” Singing Medicine Water highlighted that being proud of who they are and their culture will make Indigenous Peoples more resilient, “Be proud of your culture. Never hide it. Embrace your culture, embrace your life. We put such a thumb on people. If you

love yourself, you'll make excellent choices in life. Know that they're not alone."

### **Resilience and Family**

The importance of children and family was scattered throughout many stories but especially prominent in women (n=9). A connection to children, family, and communities impacted participants' early coping, getting 'clean', and living a life of value beyond their HIV diagnosis. Ray of Sun said: "My family is a part of everything about me. They're very afraid. I just went through a little clean up and my parents brought me home. I stayed there for a month and that's how I could get through it all". Irene echoed: "I'm just happy to be where I am. And that all comes back from having a great community. Because if it wasn't HIV, it would be something else right? But my community backed me up and I think a lot more of our communities need to be like that because our people (IPLWH) are coming home to die and they need to be ready." Many found strength through family: "I was so sick I couldn't even move, and I don't know. It was my son that came and laid down beside me and I was so tired, and I knew he was scared, and my mom was scared. I could see it in their eyes. My cousins came in to support me then my mom came, and it was then that I knew I had to use all of my strength to get better."

Another theme identified was end of life dignity (n=5). Singing Medicine Water said: "death is pretty amazing experience. I am a caregiver it's my nature just to help people walk to the spirit world knowing that they had a great life. Forgiving people, themselves, anything that can make the transition easier for them, going out with an open heart knowing that you're good with God or good with yourself. To watch people, take their last breath is devastating but to know they took their last breath going out with good spirits is probably the best part. So, I really honour, honour life, but I honour death as well. And try not to make it so scary for people, especially if you're dying on your own. I hate to see people in hospice with no family, no friends, no caseworkers coming in to see if they're all right. I seem like the hospice queen." Four participants feared no one would be around when they died and that their spirit would not make it to the spirit world. Dominique said: "He (partner) wanted to move back to his First Nation

and die in the community he was born. He didn't want to die in a strange city, in a hospital room that was cold, he wanted to be surrounded by family. When he did go home to his community, they had a band council resolution drawn up against him and he ended up getting kicked out (because they didn't want an HIV-positive person in their community) and sent back to Vancouver. He had a really great support system of friends in Vancouver but those friends for him wasn't enough. I really believe that both his spirit and his friends were concerned about him and his ability to die in a good way." Depicting the importance of ceremony and celebration of life, Ray of Sun said: "They (IPLWH) want to start coming home to die and they should be allowed to do that."

### **Promising Practices Toward Suicide Prevention**

Participants (n=26) were asked to provide recommendations for improving access to services, treatment, or anything else that may assist IPLWH. More than half the recommendations included HIV-related education. Bee Dabum stated: "We need to also educate and give them the tools to not get infected." Many added: "it would benefit the culture and other communities to get the knowledge and access out here." There was a desire for cultural programming within HIV service organisations, exemplified by Nora: "More native. Strictly for native people," and Bee Dabum: "think there needs to be, if we could incorporate healing with more culture it doesn't just have to be about taking your HIV meds." Amaya was one of 16 participants hoping for cultural programming focused on the whole body (mental, emotional, spiritual, physical): "I would like to see our whole body included in our medical whatever treatment. And have it right there".

Thirteen participants recommended greater access to treatment and care for IPLWH. This is especially true in the north because, as Red Thunder Bird Man noted, the government needs to fund services beyond Toronto, and they should not be forced to go there for essential access and care. Little Wolf noted: "More clinics. More accessible HIV clinics. Easier testing, the testing that they have now, you can prick your finger and dot, more rapid testing for each clinic".

Funding was a concern for many participants ( $n=7$ ), who spoke of a lack of funding through Ontario Disability Supports Program (ODSP). For many, ODSP is their only source of income and is limited such that one cannot meet their basic needs.

## Discussion

When designing health and suicide prevention efforts, Western-based interventions focused on individual behavioural-change tend to be incongruous with Indigenous paradigms (Barker et al., 2017). Suicide prevention efforts must incorporate the basic facets of life that are beyond the reach of many Indigenous Peoples. Adhering to a medication schedule is negatively impacted by daily struggles to secure housing, food, income, and support (McCall et al., 2009). This is critical, as Indigenous Peoples have lower HIV suppression rates one year after antiretroviral therapy initiation compared to other populations, suggesting a need for targeted interventions to improve health outcomes during this crucial first year where suppression is normally achieved (Benoit et al., 2017b).

Paramount to meeting fundamental safety needs is the importance of language, spiritual, and cultural revitalization for Indigenous Peoples. There must be a greater emphasis on interconnectedness in healing and community wellness (Barker et al., 2017). Traditional teachings tell us that when individuals face harm, trauma, and addiction, it is not only necessary that the individual heals, but that balance is restored within the family and community too. In a study of 10 Indigenous women who had lost loved ones to suicide, participants said their belief in the Creator “pulled them through” and strengthened connections to their family and community (Goin & Mill, 2013). The loss of life, especially young life, is grieved and healed through participation in cultural ceremonies like sweat lodges, feasts, sun dances, and receiving help from ancestors and grandfathers through dreaming (Goin & Mill, 2013).

Learning about cultural traditions and ceremonies, seeking guidance from Elders, and rediscovering community roots have been cited as healing mechanisms for IPLWH, allowing them to reconnect and alleviate the isolation

faced as a result of their illness (Cain, Jackson, Prentice, Mill, et al., 2011). Connection to one’s Indigenous spirituality can aid in one accepting their HIV diagnosis (Cain, Jackson, Prentice, Collins, et al., 2013). Indeed, higher resilience in Indigenous youth has been associated with growing up in a family that often/always lived by their traditional culture and often/always spoke their traditional language at home (Pearce et al., 2015). Varcoe and Dick (2008) recommend comprehensive, locally developed community responses to disconnection and dislocation faced by Indigenous women living with HIV, aimed at cultural identity, healing, safe social support, and meaningful employment. Furthermore, practitioners must acknowledge that they, too, are the bearers of culture and should examine the impact of their behaviours, attitudes, and practices on their patients (McCall, Brown, & Reimer-Kirkham 2009).

Widespread research affirms that trauma can manifest as negative coping mechanisms, especially when exposed to the coping mechanisms at a young age during which the behaviours are normalized (Czyzewski, 2011). Negative coping mechanisms typically arise as drug and alcohol dependency in Indigenous populations: “As a result of a history of colonisation, isolation, poverty and language barriers, abuse of substances — especially alcohol and solvents — is more common in northern and remote communities. These communities are also more vulnerable to suicide, violence and poor performance in schools.” (Canadian Centre in Substance Use and Addition, 2018, p. 1). This was echoed by 23 participants, who discussed the impact of drugs on their lives and hopelessness resulting in feelings that their lives were not worth living.

Stigma is considered one of the most significant barriers to health and well-being for people who are living with HIV (Loufty et al., 2012). Upon diagnosis, many continue or even increase their indulgence in high-risk behaviours, putting themselves and others in danger (Harris & Larsen, 2008). HIV stigma is compounded by other inequalities, such as race, class, gender, and sexual orientation (Loufty et al., 2012). Indeed, the majority of participants described stigma they had experienced in the form of rejection and



threats, exacerbated by a lack of HIV education and awareness.

## Recommendations

The recommendations below are encompassing of the data collected in this research, with particular emphasis on the input of participants. Therefore, each of the recommendations starts with the word “we”, to re-iterate the importance of forming recommendations from the stories and experiences of Indigenous Peoples. Further, the recommendations were made in consultation with, and are endorsed by, two community organisations. Our aim was that these recommendations captured the voice of IPLWH and can be interpreted within a larger body of knowledge and literature. The following four recommendations are just a subset of the 29 made in our larger research study (Hillier, Winkler, & Lavallée, 2020).

1. We call on the federal government to provide sustainable and adequate funding for HIV/AIDS care, treatment, programming, and services in First Nations communities. This funding should be stable and long-term, in order to limit unnecessary work for individuals having to apply and re-apply for funding on an annual or semi-annual basis.
2. We call on the federal government to continue its commitment to addressing the significant issues affecting Indigenous Peoples across the north including poverty, lack of education, lack of adequate housing, lack of clean drinking water, youth suicide, and the continued intergenerational traumas they face. Without tackling these underlying issues, the incidence of negative coping mechanisms will continue to drive the incidence of HIV and AIDS within the Indigenous population.
3. We call on the federal government to provide a funding envelope that includes culturally-based healing for IPLWH that can be accessed by HIV service organisations.
4. We call on the provincial government to increase its funding of the ODSP for people living with HIV and AIDS to a comfortable, liveable amount. Many IPLWH struggle with homelessness as a result of their financial situation, which further exacerbates their ill health and related issues.

## Conclusion

Indigenous Peoples since time and memorial have been resilient in the face of trying adversity, including hundreds of years of systemic colonial policies and interventions aimed to eradicate them. Surviving these traumas has come with a steep cost to Indigenous Peoples as they continue to suffer the worst health outcomes in Canada, including a significantly greater likelihood of HIV infection. Inability to cope upon HIV diagnosis is one of the reasons IPLWH struggle with suicidal thoughts or behaviours. However, based on the findings of this research, family, community, and culture are protective factors that allow IPLWH to persevere through their hardships.

## References

- Axelsson, P., Kukutai, T., & Kippen, R. (2016). The field of Indigenous health and the role of colonisation and history. *Journal of Population Research*, 33(1), 1-7.
- Barker, B., Goodman, A., & DeBeck, K. (2017). Reclaiming Indigenous identities: Culture as strength against suicide among Indigenous youth in Canada. *Canadian Journal of Public Health*, 108(2), e208-e210.
- Benoit, A. C., Younger, J., Beaver, K., Jackson, R., Loutfy, M., Masching, R., Nobis, T., Nowgesic, E., O'Brien-Teengs, D., Whitebird, W., Zoccole, A., Hull, M., Jaworsky, D., Benson, E., Rachlis, A., Rourke, S. B., Burchell, A. N., Cooper, C., Hogg, R. S., . . . Zoccole, A. (2017). Increased mortality among indigenous persons in a multisite cohort of people living with HIV in Canada. *Canadian Journal of Public Health*, 108(2), e169-e175.
- Benoit, A. C., Younger, J., Beaver, K., Jackson, R., Loutfy, M., Masching, R., Nobis, T., Nowgesic, E., O'Brien-Teengs, D., Whitebird, W., Zoccole, A., Hull, M., Jaworsky, D., Rachlis, A., Rourke, S., Burchell, A. N., Cooper, C., Hogg, R., Klein, M. B., . . . the Canadian Observational Cohort Collaboration. (2017b). A comparison of virological suppression and rebound between Indigenous and non-Indigenous persons initiating combination antiretroviral therapy in a multisite cohort of individuals living with HIV in Canada. *Antiviral Therapy*, 22(4), 325-335.

- Browne, A.J., Varcoe, C., Lavoie, J. et al. (2016) Enhancing health care equity with Indigenous populations: evidence-based strategies from an ethnographic study. *BMC Health Serv Res* 16 (544) <https://doi.org/10.1186/s12913-016-1707-9>
- Canadian Centre on Substance Use and Addiction. (2018). *First Nations, Inuit and Métis*. Retrieved June 20, 2019, from <http://www.ccdus.ca/Eng/topics/First-Nations-Inuit-and-Metis/Pages/default.aspx>
- CATIE. (2019). *HIV in Canada: A primer for service providers*. <https://www.catie.ca/en/hiv-canada>
- Cain, R., Jackson, R., Prentice, T., Mill, J., Collins, E., & Barlow, K. (2011). Depression among Aboriginal people living with HIV in Canada. *Canadian Journal of Community Mental Health*, 30(1), 105-120.
- Cain, R., Jackson, R., Prentice, T., Collins, E., Mill, J., & Barlow, K. (2013). The experience of HIV diagnosis among Aboriginal people living with HIV/AIDS and depression. *Qualitative Health Research*, 23(6), 815-824. <https://doi.org/10.1177/1049732313482525>
- Czyzewski, K. (2011). Colonialism as a broader social determinant of health. *The International Indigenous Policy Journal*, 2(1), Article 5.
- Goin, L., & Mill, J. E. (2013). Resilience: A health promoting strategy for Aboriginal women following family suicide. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 11(3), 485-499.
- Government of Canada. (2012). First Nations and Inuit Branch: Mandate, Plans and Priorities. Retrieved January 21, 2016, <https://www.canada.ca/en/indigenous-services-canada/corporate/first-nations-inuit-health-branch/mandate-plans-priorities.html>.
- Government of Canada. (2017). *Life expectancy*. Retrieved January 22, 2017, <https://www150.statcan.gc.ca/n1/pub/89-645-x/2010001/life-expectancy-esperance-vie-eng.htm>.
- Government of Canada. (2018a). *Ontario Region*. Retrieved June 18, 2019, <http://www.aadnc-aandc.gc.ca/eng/1100100020284/1100100020288>.
- Government of Canada. (2018b). *Suicide Prevention*. June 18, 2019, <https://www.canada.ca/en/indigenous-services-canada/services/first-nations-inuit-health/health-promotion/suicide-prevention.html>
- Haddad, N., Li, J. S., Totten, S., & McGuire, M. (2018). HIV in Canada–Surveillance Report, 2017. *Canada Communicable Disease Report*, 44(12), 324-332.
- Harris, G. E., & Larsen, D. (2008). Understanding hope in the face of an HIV diagnosis and high-risk behaviors. *Journal of Health Psychology*, 13(3), 401-415. <https://doi.org/10.1177/1359105307088143>
- Hillier, S., Winkler, E., Lavallée, L.F. (2020) Decolonising the HIV Care Cascade: Policy and Funding Recommendations from Indigenous Peoples Living with HIV and AIDS. *International Journal of Indigenous Health*, 15(1), 47-59. <https://doi.org/10.32799/ijih.v15i1.33909>
- Hyett, S., Marjerrison, S., & Gabel, C. (2018). Improving health research among Indigenous Peoples in Canada. *CMAJ: Canadian Medical Association journal = journal de l'association médicale Canadienne*, 190(20), E616-E621.
- Jongbloed, K., Pearce, M. E., Pooyak, S., Zamar, D., Thomas, V., Demerais, L., Christiam, W. M., Sharma, R., Blair, A. H., & Yoshida, E. M. (2017). The Cedar Project: Mortality among young Indigenous people who use drugs in British Columbia. *CMAJ*, 189(44), E1352-E1359.
- Kral, M. J. (2016). Suicide and suicide prevention among Inuit in Canada. *The Canadian Journal of Psychiatry*, 61(11), 688-695.
- Kumar, M. B., & Nahwegahbow, A. (2016). *Past-year suicidal thoughts among off-reserve First Nations, Métis and Inuit adults aged 18 to 25: Prevalence and associated characteristics*. <https://www150.statcan.gc.ca/n1/pub/89-653-x/89-653-x2016011-eng.htm>
- Kumar M. B., & Tjepkema M. (2019). *Suicide among First Nations people, Métis and Inuit (2011-2016): Findings from the 2011 Canadian Census Health and Environment Cohort (CanCHEC)*. <https://www150.statcan.gc.ca/n1/pub/99-011-x/99-011-x2019001-eng.htm>

- Kurtz, D. L. M., Nyberg, J. C., Van Den Tillaart, S., & Mills, B. (2008). Silencing of voice: An act of structural violence. *Journal of Aboriginal Health*, 4(1), 53-64.
- Loufty, M. R., Logie, C. H., Zhang, Y., Blitz, S. L., Margolese, S. L., Tharao, W. E., Rouke, S. B., Rueda, S. & Raboud, J. M. (2012). Gender and ethnicity differences in HIV-related stigma experienced by people living with HIV in Ontario, Canada. *PLoS One*, 7(12), e48168-e48168. <https://doi.org/10.1371/journal.pone.0048168>
- MacDonald, N., & Altaran, A. (2007). Jordan's Principle, governments' paralysis. *CMAJ*, 177(4), 321.
- McCall, J., Browne, A. J., & Reimer-Kirkham, S. (2009). Struggling to survive: The difficult reality of Aboriginal women living with HIV/AIDS. *Qualitative Health Research*, 19(12), 1769-1782. <https://doi.org/10.1177/1049732309353907>
- McQuaid, R. J., Bombay, A., McInnis, O. A., Humeny, C., Matheson, K., & Anisman, H. (2017). Suicide ideation and attempts among First Nations peoples living on-reserve in Canada: The intergenerational and cumulative effects of Indian residential schools. *The Canadian Journal of Psychiatry*, 62(6), 422-430.
- Moniruzzaman, A., Pearce, M. E., Patel, S. H., Chavoshi, N., Teegee, M., Adam, W., Christian, W. M., Henderson, E., Craib, K. J., Schechter, M. T., Spittal P. M., & Cedar Project Partnership. (2009). The Cedar Project: Correlates of attempted suicide among young Aboriginal people who use injection and non-injection drugs in two Canadian cities. *International Journal of Circumpolar Health*, 68(3), 261-273.
- National Collaborating Centre for Aboriginal Health. (2013). *An overview of Aboriginal health in Canada*. <https://www.ccnsa-nccah.ca/docs/context/FS-OverviewAboriginalHealth-EN.pdf>
- Negin, J., Aspin, C., Gadsden, T., & Reading, C. (2015). HIV among Indigenous peoples: A review of the literature on HIV-related behaviour since the beginning of the epidemic. *AIDS and Behavior*, 19(9), 1720-1734.
- Ontario HIV Treatment Network. (2014). *The current state of the HIV epidemic among Indigenous people in Ontario*. <http://www.ohntn.on.ca/wp-content/uploads/2014/09/Indigenous-Report-2014Final.pdf>
- Ontario HIV Epidemiology and Surveillance Initiative (2019a). *New HIV diagnoses in Ontario, 2017*. <http://www.ohesi.ca/wp-content/uploads/2019/07/OHESI-2017-new-diagnoses.pdf>
- Ontario HIV Epidemiology and Surveillance Initiative (2019b). *HIV testing in Ontario, 2017*. <http://www.ohesi.ca/wp-content/uploads/2019/08/OHESI-testing-report-2017.pdf>
- Patterson, S., Cescon, A., Samji, H., Chan, K., Zhang, W., Raboud, J., Burchell, A. N., Cooper, C., Klein, M. B., Bourke, S. B., Loutfy, M. R., Machour, N., Montaner, J. S. G., Tsoukas, C., Hogg, R. S., & CANOC Collaboration. (2015). Life expectancy of HIV-positive individuals on combination antiretroviral therapy in Canada. *BMC Infectious Diseases*, 15(1), Article 274.
- Pearce, M. E., Jongbloed, K. A., Richardson, C. G., Henderson, E. W., Pooyak, S. D., Oviedo-Joekes, E., Wunuxtsin, M. C., Schechter, M. T., & Spittal, P. M. (2015). The Cedar Project: Resilience in the face of HIV vulnerability within a cohort study involving young Indigenous people who use drugs in three Canadian cities. *BMC Public Health*, 15(1), Article1095.
- Public Health Agency of Canada. *Summary: Estimates of HIV incidence, prevalence and Canada's progress on meeting the 90-90-90 HIV targets, 2016*. Retrieved January 20, 2017, <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/summary-estimates-hiv-incidence-prevalence-canadas-progress-90-90-90.html>
- Reading, C., & Wien, W. (2009). *Health inequalities and social determinants of Aboriginal Peoples' health*. <https://www.ccnsa-nccah.ca/docs/determinants/RPT-HealthInequalities-Reading-Wien-EN.pdf>
- Smylie, J., Williams, L., & Cooper, N. (2006). Culture-based literacy and Aboriginal Health. *Canadian Journal of Public Health*, 97(Suppl. 2), S21-S25.

Snelgrove, C., Kaur Dhamoon, R., & Corntassel, J. (2014). Unsettling settler colonialism: The discourse and politics of settlers, and solidarity with Indigenous nations. *Decolonization: Indigeneity, Education & Society*, 3(2), 1-32.

Varcoe, C., & Dick, S. (2008). The intersecting risks of violence and HIV for rural Aboriginal women in a Neo-colonial Canadian context. *Journal of Aboriginal Health*, 4(1)42-52.

Webster, P. C. (2016). Canada's Indigenous suicide crisis. *The Lancet*, 387(10037), 2494.

Woroniuk, A. (2017). *HIV: A conversation on a Saskatchewan epidemic*.  
<https://medicine.usask.ca/news/2017/hiv-a-conversation-on-a-saskatchewan-epidemic.php>

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