

**Increasing the Accessibility and Acceptability of HIV Counseling and
Testing among Aboriginal Women in Ottawa**

Lindsay Wilson

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School of Epidemiology, Public Health, and Preventive Medicine

Faculty of Medicine

University of Ottawa

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Abstract

Background: In Canada, Aboriginal women are disproportionately impacted by HIV and are tested later in disease progression, resulting in poorer health outcomes and increasing the risk of onward transmission.

Methods: Using purposive sampling, 13 self-identified Aboriginal women participated in in-depth, qualitative interviews exploring women's experiences with HIV testing and their ideas for improving the process. Thematic analysis was conducted in conjunction with constant comparison to identify emergent themes and to direct future interviews and analyses.

Results: Women identified several barriers to HIV testing converging on the subjects of insufficient knowledge of HIV and HIV transmission, lack of perceived relevance of HIV testing, unwillingness or inability to confront the need for testing, and judgment from self and others regarding engagement in HIV-related risk-behaviours. The women also described their acceptable and unacceptable testing experiences, presented recommendations for increasing HIV testing uptake, and suggested ways to create the ideal testing experience. The findings demonstrate a clear need for stronger engagement of Aboriginal women surrounding their HIV-related testing needs and increased access to educational opportunities, culturally appropriate care, and initiatives aimed at reducing societal stigma around HIV.

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desperate to finish this project, I am unwilling to do so at this time. Suffice it to say that each one of my family members has helped me to get to this point in their own way, whether by listening to me talk endlessly about my work and pretending to be interested, by playing hours of games with me when I needed a break, by agreeing to come on a post-thesis trip with me, or by having an awesome baby for me to play with during my trips home. I would especially like to single out my mother for being such an inspiration. I can never thank her enough.

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Chapter 1: Introduction

1.1 Context

1.1.1 HIV among Canada's Aboriginal People

Across Canada, Aboriginal* people are disproportionately affected by HIV, both in terms of the proportion of people infected with HIV¹⁻⁶ and in terms of how they are impacted by the disease⁷. Latest data from the Public Health Agency of Canada indicate that despite the fact that Aboriginal people represent about 4% of the total Canadian population, they comprised nearly 9% of prevalent cases and almost 11% of incident cases of HIV in 2014⁸. Compared to the general population, the incidence rate of HIV was 2.7 times higher among Aboriginal people⁸.

In Ottawa, the situation is similarly uneven. Although the incidence of HIV in Ottawa has shown a gradual decline in recent years, there are still between 60-70 new reported cases of HIV each year⁹, and Aboriginal people are considerably more likely to be affected than members of the general population¹⁰. Among people who inject drugs, Aboriginal people are nearly twice as likely to be infected with HIV, with 2008 surveillance data indicating that 17.2% of Aboriginal people in Ottawa who inject drugs were infected with HIV compared to 9.3% of non-Aboriginal participants¹¹.

These discrepancies in terms of the impact of HIV are due in large part to structural inequalities; Aboriginal people are much more likely to experience challenges such as poverty, discrimination, and lack of access to healthcare^{1,2,12}, all of which are risk factors for

* The term "Aboriginal" is used in this paper to refer to individuals who identify as part of Canada's First Nations, Inuit, or Métis populations. Although the term "Indigenous" is more broadly used around the world, in Canada "Aboriginal" is generally used to refer to Indigenous groups recognized under the Indian Act and referenced in the Canadian Constitution^{80,81}. Given the political and legal significance of the term, "Aboriginal" will be used throughout this paper.

HIV infection¹³. Furthermore, legacies of colonialism and historical trauma such as the residential school system and the forced removal of many Aboriginal children from their families have had dramatic, ongoing effects on Aboriginal people's lives and culture. For many, these struggles have resulted in issues of mental health, addiction, and violence, all of which are disproportionately high among Aboriginal people and increase their risk of HIV infection¹²⁻¹⁵. In particular, Aboriginal people are dramatically overrepresented among people who inject drugs^{3,13,16-18}, and injection drug use continues to be the most common route of HIV infection among Aboriginal people¹⁹.

Experiencing trauma is also associated with poorer outcomes following HIV infection; these experiences are often associated with “decreased antiretroviral (ART) adherence... distrust of medical professionals... and depression”²⁰. Given the extremely high rates of traumatic life events in Aboriginal communities, Aboriginal people may be at higher risk of displaying these traits²⁰. Additionally, Aboriginal people often have less access to highly-active antiretroviral therapy (HAART)¹⁴ than their non-Aboriginal counterparts, and are more likely to die without accessing treatment⁷. Among those who do access treatment, Aboriginal people are more likely to interrupt their treatment due to factors such as insufficient access to treatment and care, issues of child care when seeking medical appointments, and high levels of unstable housing, all of which make adhering to treatment more challenging⁷.

1.1.2 HIV among Aboriginal Women

Aboriginal women are particularly susceptible to the disproportionate impacts of HIV. While women represented about 20% of new reported HIV cases in Canada between 1998 and 2006, women accounted for nearly half (48.1%) of new reported cases among

Aboriginal people³. Again, structural factors have been documented to play a substantial role in this difference. Compared to non-Aboriginal women, Aboriginal women are more likely to experience an array of different HIV-related risk factors, including intimate partner violence, poverty, and substance use^{12,13,21}. Aboriginal women are also drastically overrepresented in the sex trade, “with estimates in 2000 suggesting that close to 70% of women working in the lowest paying tracks in Vancouver were young, Aboriginal women”²².

Additionally, many situations that place people at risk of contracting HIV disproportionately affect women. For instance, in a 2008 study of 543 Aboriginal youth in Vancouver who use drugs, participants responded to a questionnaire containing questions regarding sexual risk, experience of trauma, and drug use²³. The results of the study suggested that many young Aboriginal women were unable to negotiate safer sexual practices such as condom use due to “an imbalance of power in relationships and contextual factors such as the fear of anger, violence, or abandonment from their male partners... violence in relationships greatly reduces women’s ability to make safe sex choices with their regular partners, and compounds existing factors, including antecedent sexual abuse, unstable housing, and poverty”²³. Additional research indicates that in cases of injection drug use, women are generally more likely to require help injecting; a 2003 Vancouver study interviewing 661 people who inject drugs suggested that women most commonly report requiring help as a result of having no viable veins, injecting in the jugular vein, or due to shaky hands from nervousness or withdrawal²⁴. The need for help is particularly problematic as it is a behaviour that may put individuals at higher risk of needle- and other injection equipment-sharing, which is in turn associated with HIV transmission^{3,23,25,26}.

After contracting the virus, Aboriginal women who are living with HIV may face additional challenges. Aboriginal women tend to have less access to HAART and are more likely than members of the general population to die of AIDS without ever accessing treatment^{21,27}. Mental health also tends to be negatively impacted by a positive diagnosis of HIV. People living with HIV are at considerably higher risk of depression and anxiety than individuals in the general public, and this risk is compounded by issues such as substance use and intimate partner violence, both of which are more common among Aboriginal women²⁸. Furthermore, Aboriginal women face a substantial amount of stigma, with McCall and colleagues noting that “dominant, colonial representations of Aboriginal women as irresponsible or as burdens on the system... remain deeply embedded in the Canadian social consciousness”²¹.

1.1.3 Need for Earlier HIV Testing

In addition to the challenges associated with the relatively high number of cases of HIV within the Aboriginal population, there is also a significant lack of testing in the community. In Canada, it is estimated that approximately one-quarter of all individuals currently infected with HIV are unaware of their status^{19,29,30}, which translates to over 16,000 people^{8,29}. Data from a 2014 systematic review on testing practices among different subgroups in Canada suggested that in one study of Aboriginal people living off-reserve, only 13% had been tested for HIV in the previous 12 months³¹. Moreover, among Aboriginal people who have been tested, testing may not occur often enough to detect infection in its early stages¹¹. These substantial problems of low testing uptake and resultant late diagnosis present a variety of consequences at both the individual and societal level.

For the individual, earlier testing and diagnosis is associated with earlier entry into what is known as the “HIV treatment cascade”³² wherein learning of one’s positive HIV status can act as a point of entry to medical care, support, and treatment³³. Early entry into the treatment cascade is essential as numerous studies have indicated that people who begin HAART earlier in the disease course have better long-term health outcomes^{13,14,30,34-40}. Those who begin treatment later, however, face an increased risk of opportunistic infections^{30,33,34}, poorer overall treatment outcomes^{30,34,35,38,39}, less chance of immune recovery³⁰, and reduced life expectancy^{14,30,35,36,40}.

Testing has also been documented to hold a variety of benefits for people who receive a negative test result. Testing negative can help to relieve stress and anxiety about the possibility of being infected⁴¹. Additionally, pre- and post-test counselling that accompany HIV testing offer opportunities to engage with people who test negative around harm reduction techniques to help them remain negative⁴²⁻⁴⁴. In a 2011 study, focus groups involving 142 young African Americans demonstrated that participants who tested negative “often revealed a perspective that HIV testing provided an opportunity to assess and modify one’s behavior, namely, a reduction in the number of sexual partners and increase in the use of condoms”⁴¹.

From a public health perspective, promoting early testing has numerous benefits. In terms of financial costs, patients who present at a later stage of disease progression cost the healthcare system thousands of additional dollars compared to those who present earlier^{30,40,45}. Later disease stages of HIV tend to be more complex and require more resources to treat³⁴. Additionally, individuals who are unaware of their HIV status are less likely to be taking measures to prevent onward transmission of the virus; many individuals who know they are HIV-positive have been documented to change their behaviour to ensure

that they do not pass the virus on to anyone else^{33,34,39,40,45}. Furthermore, antiretroviral therapy decreases patients' viral load, thereby making it less likely that an individual who is receiving treatment will pass the virus on^{33,43,45,46}, with data indicating that transmission risks double with every ten-fold increase in one's viral load⁴⁵. Those who are unaware of their positive status also miss out on prevention programming and counselling that would teach them how to prevent onward transmission^{45,47}. This problem worsens over time as "the longer patients are unaware of their HIV infection, or have untreated infection, the more opportunities there are for transmission"³⁰.

In light of the substantial benefits associated with early diagnosis, it is essential to promote earlier testing, especially among groups known to test later. Aboriginal women, in addition to the unique challenges that they face in terms of HIV susceptibility and treatment, have been documented to exhibit low rates of testing uptake and to test late in the development of their infection if they choose to get tested at all¹³. Bucharski and colleagues noted that a much higher proportion of Aboriginal women than non-Aboriginal women who test positive are tested late in the infection's development¹³. Among pregnant women, this late testing is associated with Aboriginal women not receiving HAART until late in their pregnancy, increasing the risk of vertical transmission from mother-to-child¹³.

1.1.4 HIV Testing Options

A variety of testing options exist to determine whether or not an individual is living with HIV. In Ontario, testing can be accessed free-of-charge in a variety of locations, including community health centres and sexual health clinics⁴³. In a standard test, the patient undergoes a venous blood draw, and the sample is tested in the public health laboratory^{43,44}. Blood samples that receive a preliminary positive result for HIV antibodies are screened

again to confirm the result^{43,44}. Standard testing can take up to two weeks to provide results, which are then sent back to the provider to inform the patient of the result⁴³. By contrast, point-of-care (POC) testing is a screening test that can be performed on-site via a finger-prick and offers results within a few minutes^{43,48}. Patients who receive a preliminary positive result must provide an additional venous blood sample for standard testing⁴³, and patients who receive this result are counselled in order to ensure they are prepared for the possibility of a positive test result^{42,44}. This rapid testing has been documented to increase the proportion of patients who receive their test results^{48,49}, as offering the test and the results within one encounter may help to mitigate concerns that prevent patients from returning for their results such as time constraints, apathy, and fear^{4,49}. Results from a 2012 questionnaire administered by Schwandt and colleagues indicated that among 100 female patients in a Canadian urban primary care centre, 81% stated that they would prefer a point-of-care test to standard testing⁴⁹. There are currently 50 sites across Ontario that offer point-of-care testing^{43,50}, but as these sites are predominantly in urban areas, access to these services may be limited for people living in rural and remote areas.

Regardless of the method a patient chooses – and depending on the availability and accessibility of alternatives to standard testing – HIV counselling and testing guidelines in Ontario indicate that testing must be accompanied by pre-test counselling (which involves such elements as explaining testing options, preparing the patient for a positive result, and harm reduction information) and post-test counselling (which includes an explanation of the result, emotional support, treatment information, and additional information about harm reduction)^{13,43,44,50}. These counselling sessions are an important component of the testing process, as “a test by itself may not change behaviour and reduce the risks”⁵¹.

As with point-of-care testing, in Ontario there are currently 50 sites across the province that provide anonymous testing, primarily in public health units and community health centres⁴³. Patients with access to these sites can choose to be tested anonymously, where the patient's identity is neither requested nor recorded^{43,44,52}. For patients who either lack access to or opt not to undergo anonymous testing, two other options exist: non-nominal testing, where the patient's identity is known to the tester but the test is done using a code; or nominal testing, where the patient's name is connected with the test^{43,44,52}. HIV is a reportable disease in Ontario, meaning that positive test results must be reported to public health⁴³. Importantly, if a non-nominal test receives a positive result, the test becomes nominal, and the patient's name and result are reported to the local medical officer of health⁴³. In the case of anonymous testing, the patient's result is reported but the patient's name is not⁴³; however, upon seeking treatment, the patient's name is recorded. Patients who test positive will also be required to provide the names and contact information of past and current sexual and drug partners (known as "contact tracing") so that these individuals can be informed that they may have been exposed to HIV and should be tested as well^{44,53}.

The ability to access anonymous testing is extremely important in an era of HIV criminalization, where "the potential for criminal prosecution for HIV exposure, nondisclosure, and transmission has further amplified concerns about anonymity, confidentiality, and control over health decisions"⁵². It is also especially beneficial for people who are concerned about their privacy or fear potential repercussions as a result of being diagnosed with HIV, including stigma and discrimination⁵². This importance is further reinforced by data from the Ontario AIDS Bureau that indicates that the greatest proportion of positive test results emanate from anonymous testing services, suggesting that individuals

who believe they are most at-risk of contracting HIV may be more likely to choose anonymous testing⁴³.

1.2 The Study

1.2.1 Significance of the Study

Recognizing the importance of increasing testing uptake among Aboriginal women, the impetus for this research originated within and is firmly situated in the needs of the Aboriginal community. In 2011, the Ontario Women's Study (OWS) was undertaken by the HIV and Hepatitis C Prevention Research Team at the University of Ottawa to explore the unique HIV prevention needs of 14 diverse groups of women documented to be at higher risk of HIV infection. As a component of this study, in a focus group that sought to identify priorities for Aboriginal women regarding HIV prevention, participants reported that HIV in general and HIV prevention in particular were rarely discussed in the Aboriginal community due to strong taboos around the subjects⁵⁴. Additionally, there was a perception from the women that other issues such as addiction, poverty and violence are given higher priority than HIV prevention in the Aboriginal community⁵⁴. With so many pressing social issues that require attention, the women reported that HIV awareness had become a lesser priority. The need for more prevention programming and other resources for increasing awareness of HIV in general and HIV testing in particular were emphasized⁵⁴.

Following the completion of OWS, a two-day symposium entitled, *Let's Talk About Us: What Women in Ontario Have to Say about HIV*⁵⁵ (Agenda in Appendix A) was held in April 2013 and led by the HIV and Hepatitis C Prevention Research Team. This symposium brought together a wide variety of decision-makers, program managers, front-line workers, and women with lived experience to disseminate the results of OWS. The desire within the

Aboriginal community to see testing rates improve among Aboriginal women was reiterated during the event, and increasing Aboriginal women's access to HIV testing was identified as a major research priority⁵⁵.

In light of these findings, the need for more information about the best ways to increase Aboriginal women's access to testing was apparent. The findings from the focus group and the recommendations from the symposium were localized to the Ottawa context. A community consultation, *Increasing Women's Access to HIV Testing*, was held at the Wabano Centre for Aboriginal Health in August 2013 (Agenda in Appendix B). Participants from organizations across Ottawa were invited to share their current activities aimed at increasing Aboriginal women's access to HIV testing and small group discussions were held to discuss what steps still needed to be taken. From this consultation, it was determined that research was needed in order to capture the local perspectives of Aboriginal women themselves about how to improve their access to HIV testing. Some individuals attending this session expressed interest in becoming involved in any research undertaken to explore HIV testing with Aboriginal women, and these individuals ultimately served as recruiters for this thesis work.

More broadly, there has been a lack of research to date on barriers that keep Aboriginal women from seeking HIV testing. McCall and colleagues note that "with the exception of a handful of programs, Aboriginal women remain virtually invisible in HIV/AIDS research, policy and services"²¹. There is a clear need to draw Aboriginal women into discussions about their own perceived healthcare needs.

Additionally, much of the research that has been previously conducted in Canada is primarily focused on communities in British Columbia^{5,17,23,25,56,57}. By contrast, this research sought to recognize the HIV testing-related challenges that Aboriginal women themselves

have identified through firsthand experiences, and aimed to focus on the obstacles that could be pinpointed in Ottawa. By learning how to improve the testing experience for Aboriginal women, more effective approaches to early testing could be recommended and prioritized in accordance with local community desires.

1.2.2 Objective

In light of the documented personal and public health benefits associated with early HIV testing, continuing trends of disproportionately high rates of HIV among Aboriginal women across the country¹⁹ and in Ottawa, and a stated desire from the Aboriginal community to improve their access to testing, this project sought to explore the barriers to HIV testing identified by Aboriginal women living in Ottawa and the ways in which the process could be improved. By ensuring that the voices of Aboriginal women themselves were heard, recommendations based in the needs and perspectives of the community could be generated for increasing Aboriginal women's HIV testing uptake and making the testing experience more accessible and acceptable.

1.2.3 Research Questions

In order to achieve the objective, two research questions were developed to guide the project:

1. Among self-identified Aboriginal women living in Ottawa who have been tested for HIV, how can the testing experience be improved in order to encourage further testing in the future?
2. According to self-identified Aboriginal women living in Ottawa who have not been tested for HIV, what are the perceived barriers that prevent these women from seeking HIV testing and counseling and how can they be eliminated?

These questions were designed to capture the perspectives and opinions of two distinct groups of women: those who had been previously tested and those who had not. Women who had been previously tested would be asked about their experiences and how the testing experience could be improved in order to encourage Aboriginal women who have been tested to seek testing again. Women who had not undergone testing would be asked to provide insights into why they had never been tested and what could be done to encourage more Aboriginal women to undergo testing.

Chapter 2: Literature Review

A modified scoping literature review was performed to locate studies that explored Aboriginal women's testing experiences and previously identified barriers to testing. The findings of the literature review were used to inform the thematic guide that steered the interviews. Using these findings, relevant themes were identified and questions for participants were developed to capture the women's perspectives on HIV testing. A scoping review was used for this process as scoping reviews synthesize a variety of different studies "with the aim of informing practice, programs, and policy and providing direction to future research priorities"⁵⁸. As this review was intended to inform the thematic guide and the direction the study would take, a scoping review was considered ideal.

Two databases were used to identify relevant literature: MedLine and Scholar's Portal. Key words used included "HIV", "testing", "Aboriginal", and "women". An additional search was performed in MedLine using MeSH terms and keywords: "Aboriginal", "Indians, North American", "First Nation*", "HIV", "AIDS", "HIV test*", "HIV screen*", and "women", but this was found to be less effective in generating relevant articles than the search using only keywords, as many articles had not been tagged with MeSH terms. The articles selected for the literature review were restricted to those written in English and included only those published in 2000 or later. The titles of the resulting articles were scanned for appropriateness, and the abstracts of those that were deemed applicable were read. Those articles most relevant were read in full, and included in the review where appropriate. Articles that were included made reference to Aboriginal people and barriers to HIV testing, perspectives on HIV testing, and/or experiences with HIV testing. Occasionally, articles were included that did not refer to Aboriginal women specifically, but did describe

factors affecting the decision to undertake HIV testing among minority groups. These were included if the barriers described were also mentioned in articles that did refer to Aboriginal women (e.g. fear, stigma), as they occasionally provided new insights into the issues. Many of the articles included were collected on May 27, 2014, while another search was performed on May 29, 2015. The bibliographies of the articles included were also assessed to determine whether any additional papers should be included that had not been captured through the database search.

Using these methods, major barriers to HIV testing were identified in the literature. These barriers fall under three main categories: society-level structural factors of stigma, discrimination, and racism; personal factors, including fear, lack of perceived personal risk, and privacy concerns; and healthcare system factors such as unequal access to care, insufficient healthcare services and a lack of culturally-appropriate services.

2.1 Structural Factors

2.1.1 Stigma Surrounding Engagement in HIV-Related Risk-behaviours

HIV is a heavily stigmatized disease, which may partially account for low uptake of testing to confirm its presence^{49,59}; Majumdar and colleagues note that, “stigma and negative social attitudes toward HIV [are] major barriers to implementing a successful prevention plan”². This stigma may be associated with the fact that many risk factors associated with contracting HIV are connected with behaviours that are perceived as taboo, or are generally stigmatized in society, such as sex work or injection drug use¹⁴. Many women have reported concerns about being rejected or labelled in a negative way as a result of testing positive for HIV¹³.

Women often experience many factors which may place them at heightened risk of being stigmatized if they are diagnosed with HIV. In 2014, Borwein and colleagues administered a survey about “socio-demographic, behavioral, psychosocial, and health care utilization characteristics” to 249 “harder-to-reach” women living with HIV in British Columbia⁵⁷. Their results indicated that women who have experienced violence were also more likely to experience stigma as a result of being HIV-positive⁵⁷. Violence, and many of the factors associated with experiencing violence, such as poverty, alcoholism, and drug use, are all considerably more common among Aboriginal women than in the general population¹²⁻¹⁵, which may put them at increased risk of HIV-related stigma. A 2013 study involving 72 Aboriginal people living with HIV and reporting feelings of depression illustrated the potential impacts of this stigma¹⁴. The results of semi-structured interviews with participants revealed that this “stigma meant that participants who often felt marginalized by dominant Canadian society also felt alienated from their home communities, families, and friends. This increased their sense of isolation, their feelings of betrayal and anger, their depression, and for some, led to increased substance use”¹⁴.

Engaging in HIV-related risk-behaviours that are perceived as taboo can also lead to Aboriginal women experiencing what McCall and colleagues refer to as “multiple stigmas”²¹. As many Aboriginal women living with HIV are also involved in the sex trade or are dealing with addiction, they are often stigmatized for their engagement in these behaviours while simultaneously being stigmatized racially²¹. In a telling observation from 2009 regarding societal attitudes toward HIV among Aboriginal women, McCall and colleagues reported that all of the eight Aboriginal women interviewed in their study stated that “the stigma, rejection and health problems they were experiencing as a result of their HIV infection were, if not deserved, at the very least not unexpected”²¹.

The sense of being stigmatized or judged has been documented to be a very powerful deterrent to HIV testing. Healthcare workers who have not been trained in cultural sensitivity may be especially prone to causing Aboriginal people to feel misunderstood, discriminated against, and stigmatized⁴. In a 2010 study surveying 210 Aboriginal youth, Worthington and colleagues noted the importance of being non-judgmental when offering HIV testing to Aboriginal youth: “youth who sense judgment have been known to conceal the truth or simply walk out”⁴. This trend was also seen among the seven Aboriginal women interviewed by Bucharski and colleagues in 2006¹³. Being questioned by a tester about their HIV-related risk-behaviours without knowing why the questions were necessary resulted in the women “distancing (and even leaving the testing situation), concealing the truth, or not going for testing”¹³. All of these troubling findings regarding stigma present problems not only for individuals who are already living with HIV, but also for those who have not yet been diagnosed, as populations who encounter stigma regarding testing are less likely to test at all^{1,49}.

2.1.2 Discrimination/Racism from Healthcare Providers

In addition to the stigma associated with HIV, Aboriginal people have also reported not testing due to concerns about discrimination and racism due to their cultural identity^{1,3,13,21}. From a healthcare perspective, among HIV-positive Aboriginal women who also inject drugs, the combined effect of these two traits has been documented to put this group at risk of receiving sub-optimal care when it comes to HIV treatment⁶⁰, which may in turn influence one’s desire to be tested in the first place. This is especially troubling given that people who inject drugs are already known to have much less access to HAART and care than other groups, despite the fact that HAART is available free-of-charge in Canada⁶⁰.

Healthcare workers have been documented to be less likely to prescribe the most effective anti-retroviral therapies to people living with HIV who also use drugs, due to concerns about the individual's ability to adhere to the treatment regime, despite a lack of evidence that these concerns were warranted⁷.

Moreover, research has indicated that some Aboriginal people have experienced racialization or profiling from healthcare providers, who may have assumed that a patient was impoverished or dealing with addiction simply because of the individual's race⁶¹. Various studies have suggested that this can lead to patients' symptoms being ignored or invalidated, or the development of assumptions that a patient is going to be difficult^{13,61}. In a 2010 study, 82 Aboriginal patients in a Canadian emergency department were interviewed and participant observation was performed to assess the role of race and "racialization" in healthcare encounters⁶¹. Tang and Browne described instances of Aboriginal patients having their illness misinterpreted as a sign that they were drunk, with one man being escorted out of the hospital by security⁶¹. These experiences of stereotyping and racism may lead Aboriginal people to avoid encounters with the healthcare system^{13,61} and may serve as an important factor in low testing uptake. It has been recommended that cultural sensitivity and cultural safety toward Aboriginal people become a higher priority among healthcare workers in order to eliminate instances of stigma and discrimination toward Aboriginal patients^{4,21}.

2.2 Personal Factors

2.2.1 Fear of Consequences of a Positive Result

Numerous studies have indicated that many women do not seek testing for HIV due to fear of receiving a positive diagnosis^{13,21,45,46}. Following interviews with 41 Americans who received a late-stage HIV diagnosis, Schwarcz and colleagues reported that fear of a

positive diagnosis was the most commonly cited barrier to testing, especially among people who recognized that they had engaged in an HIV-related risk-behaviour, such as injecting drugs⁴⁵. Despite advances in HIV treatment, HIV continues to be perceived by many people as a death sentence^{13,45}. Cain and colleagues have suggested that due to the disproportionate social challenges faced by many Aboriginal people, this perception may not have been entirely unfounded: “With less access to treatment and the additional treatment challenges that can come from inadequate housing and substance use, diagnosis represented more of a realistic life threat for many participants than for other Canadians living with HIV”¹⁴.

In addition to a fear of the fatality of HIV, many women have also expressed fear of being judged or rejected by physicians and by their communities^{13,14,21,45}. In a 2011 study of nine Aboriginal people, Majumdar and colleagues noted that the possibility of rejection or stigma from one’s family or community often resulted in people living with HIV leaving their communities². Individuals have also been documented to fear being rejected from community agencies where they access services, or judgement from healthcare providers²¹, particularly if they were required to disclose their engagement in HIV-related risk-behaviours prior to testing¹³.

2.2.2 Low Self-Assessed Personal Risk of Contracting HIV

Within the general population, believing that one is not at real risk of HIV infection is a major barrier to testing, particularly among older patients and among women⁴⁷. The belief that an individual is not at risk of HIV infection is often misplaced and relies on assumptions or misinformation by healthcare providers. In a risk-based testing scenario, healthcare providers must assess a patient’s risk, which relies on providers making assumptions about patients and patients disclosing potentially stigmatizing behaviours⁶². Patients may be

ashamed of having engaged in these behaviours or fear being judged, and may thus opt not to provide an accurate assessment of their risk¹³. Additionally, some patients may unintentionally assess their own risk inaccurately due to a belief that they have not engaged in risk-behaviours or due to misunderstandings about how HIV is transmitted. As a result, patients who do not believe that they are at risk of HIV are often overlooked in testing, as providers often do not offer testing to individuals they perceive to be low-risk^{34,47}. Thus, among these patients, diagnosis tends to occur during hospitalization at a later stage of the infection, when treatment is less effective⁴⁷. Conversely, among individuals with a known risk-factor, such as men who have sex with men and people who inject drugs, late diagnosis tends to be comparatively low³⁴.

Misconceptions about personal risk occur among patients as well as providers. Data from the Public Health Agency of Canada's 2010 *Population-Specific HIV/AIDS Status Report: Aboriginal Peoples* indicated that a common reason given by Aboriginal youth for not seeking testing was the belief that their sexual partners were not infected³, which, of course, may not always be the case. The belief that one has not engaged in any high-risk activities, whether the belief is accurate or not, can thus contribute to the assumption that testing is unnecessary.

2.2.3 Concerns about Privacy/Confidentiality of HIV Test and Results

Due to the stigma often experienced by individuals who test positive for HIV, concerns about privacy and confidentiality have also been identified as barriers to testing for many Aboriginal women, especially for those in small communities^{3,13}. Bucharski and colleagues noted that many of the seven Aboriginal women interviewed in their study expressed a preference for a non-Aboriginal tester, and for testing to be conducted in a multi-

purpose building so that anonymity could be improved¹³. Individuals who were concerned that confidentiality could not be assured often sought testing and treatment outside of their own communities, as concealing the fact that they were seeking these services was very difficult³. Given the difficulty of hiding one's positive status from others combined with the documented preference of many Aboriginal people not to have their HIV status known by others³, confidentiality concerns may represent a sizeable barrier to testing.

2.3 Healthcare System Factors

2.3.1 Lack of Access to Healthcare among Aboriginal People

Aboriginal people often experience a substantial lack of access to health care and services, which may contribute to their low testing uptake; populations with less overall access to healthcare have been documented to be less likely to access HIV testing⁴⁹.

Aboriginal people face generally worse health outcomes and interactions with the healthcare system than the Canadian population at large⁶¹, and their experiences with HIV-related care are no different. Aboriginal women in particular have expressed concerns about accessing drug therapy and finding child-care to allow them to attend medical appointments⁷.

For Aboriginal people who are able to access care, the quality of the healthcare they receive may be less effective than the care received by non-Aboriginal people. Aboriginal patients are less likely to have access to physicians experienced in treating people living with HIV and to health services overall^{1,21}. In their survey of 892 Canadians living with HIV (146 of whom were Aboriginal), Miller and colleagues noted that Aboriginal people living with HIV were less likely to have access to a physician who was experienced in treating HIV-positive patients, and this inexperience led to providers prescribing less potent and effective HAART⁷. This is particularly problematic for Aboriginal patients who are co-infected with

HIV and Hepatitis C (HCV), as the hepatotoxicity associated with many HAART regimens could require a physician who is particularly experienced in prescribing appropriate regimens for patients living concurrently with HCV⁷. As issues of co-infection have been reported to be particularly problematic among people who inject drugs⁶³, and as injection drug use is the main route of HIV transmission for Aboriginal people³, improved access to an experienced physician is crucial.

2.3.2 Lack of Culturally-Appropriate HIV Testing Services

Finally, accessing culturally-appropriate healthcare services was identified as a major barrier to testing for many Aboriginal people^{2,13}. Health information about HIV that is presented in a culturally-appropriate way tends to be more effective in encouraging people to make healthy choices^{2,15}. Information that is not culturally-appropriate tends to be viewed as less relevant and is therefore less useful in helping people avoid HIV-related risk-behaviours¹⁵. In interviews with seven Aboriginal women, Bucharski and colleagues found that Aboriginal women deemed cultural sensitivity important to an ideal testing scenario, identifying such elements as “(a) sensitivity to and knowledge of the issues that Aboriginal women may experience; (b) inclusion of traditional teachings, practices and Aboriginal spirituality; [and] (c) an inviting physical environment”¹³. Aboriginal youth also reported a desire for more spirituality and culture in order to improve the testing process⁴. Seeking support from an Elder was also identified as an important factor for many Aboriginal women and youth^{4,13}.

Aboriginal women generally reported a desire for more Aboriginal workers at testing sites; it was preferred that the majority of the personnel, except possibly the tester, be Aboriginal, depending on the size of the community¹³. This desire was not unanimous,

however, as some women thought an Aboriginal tester would facilitate greater understanding and empathy with the women's experiences, but others felt that in a small community an Aboriginal tester would compromise confidentiality¹³. Seeing other staff members who were Aboriginal, however, was generally viewed as a positive feature of the ideal testing site, as “[p]erceiving a shared experience of the context of Aboriginal women’s life experiences was thought to enhance the comfort level of the women seeking testing”¹³.

2.4 Contribution of Literature Review to Thematic Guide

From the results of the literature, a thematic guide (Appendix C) containing a variety of potential interview questions was developed. In line with the barriers identified in the literature, the guide contained questions about community and personal attitudes regarding HIV, personal knowledge of HIV (and of testing in particular), access to healthcare and testing services, and awareness of available services. In order to capture perspectives about more general topics that may not have been captured in the literature, questions were also developed about factors that could promote testing uptake, attributes that would contribute to a better testing experience, and what factors would comprise the ideal testing experience.

Chapter 3: Methods

3.1 Qualitative Methods

3.1.1 Rationale

The community desire for this project was emphasized during the meetings conducted by the HIV and Hepatitis C Prevention Research Team discussed above. In order to most accurately capture the voices and experiences of Aboriginal women regarding HIV testing, a qualitative approach was chosen for this project. This was considered ideal because qualitative methods are essential “for understanding individuals’ and groups’ subjective experiences of health and disease; social, cultural and political factors in health and disease; and interactions among participants in health care settings”⁶⁴. In other words, the women’s individual perceptions about HIV testing as it relates to their lives would be most accurately recorded by using qualitative methods. Additionally, as Aboriginal women’s voices are often left out of research, a qualitative approach was thought to be the best approach for ensuring that participants’ voices were heard and their experiences were recorded in their own words. Participatory processes such as these can help to involve people of “traditionally unequal power and status in research and demonstrates an orientation towards bringing about change in a practice setting”⁶⁴.

3.1.2 Semi-Structured Interviews

In-depth semi-structured interviews were chosen as the main method of data collection. Semi-structured interviews focus on open-ended questions that have been developed ahead of time, but can also incorporate questions that arise organically during the interview, allowing for the exploration of previously identified themes while still permitting

discussion of new ideas that develop^{65,66}. This approach offered opportunities to ask the women about experiences that were in line with research but also minimized the risk of missing experiences that fell outside of previously identified barriers. These “digressions can be very productive as they follow the interviewee’s interest and knowledge”⁶⁵. Individual interviews were chosen over focus groups due to common concerns among many Aboriginal women regarding HIV and confidentiality¹³. Interviews lasted approximately 30-45 minutes depending on the length of the responses given by the participant and the new themes that arose during the interview.

3.1.3 Thematic Guide

As previously stated, a thematic guide was developed to steer the interviews. Following this guide, all of the women were asked about a variety of subjects including their first experience with testing, their reasons for not undergoing additional testing, and their perceptions of how testing could be improved. New themes that arose naturally during the interview were discussed, and, where appropriate, questions regarding these themes were added to the thematic guide for future interviews.

In line with the study research questions, the thematic guide included questions directed toward women who had not been tested for HIV and women who had previously undergone testing. Among women who had not undergone testing, the questions sought to understand why these women had not been tested and what could be done to encourage more Aboriginal women to get tested. Among women who had been tested, the questions were designed to explore their experiences with testing and what they felt could be done to improve the testing experience for Aboriginal women more broadly. All of the women were asked about how they felt HIV and testing were perceived in the Aboriginal community,

their plans to test in the future, their ideal testing experience, and their access to resources such as a family physician and information about HIV and testing. In this way, previously identified barriers to testing were examined, but the questions remained flexible enough to allow for further exploration of any new themes that came up during the interview.

In order to ensure that the interviews were as culturally sensitive as possible, extensive consultation with other members of the HIV/Hepatitis C Prevention Research Team occurred. These team members had experience in interviewing and community-based research, and were able to provide valuable insights into how to appropriately engage with the women involved in the study. Furthermore, the thematic guide was first used during interviews with service providers involved in harm reduction service delivery. These women participated in the first three interviews, and were given the opportunity to provide feedback on the thematic guide, including whether questions should be added or removed or whether any major changes should be made to the interviews. The guide was generally well-received, and no major changes arose from the feedback these women provided.

3.1.4 Interview Location

To ensure that the women felt as comfortable as possible and were willing to fully engage in the interview, each woman was given the opportunity to select the community health centre or service centre she wished to use as the interview location. In this way, the participants were able to choose a location with which they were familiar and in which they felt comfortable and welcome. Furthermore, this approach also benefited from the fact that the women often knew the staff at the organization; if any instances had arisen in which a counsellor was needed, the counsellor onsite was a worker familiar to the women.

3.2 Ethics

3.2.1 Ethics Approval

Ethics approval for this project, the thematic guide (Appendix C), the Participant Information and Consent Form (Appendix D), and the recruitment cards (Appendix E) was obtained from the Ottawa Health Science Network Research Ethics Board (OHSN-REB). The letter of approval can be found in Appendix F. Given the iterative nature of the data collection process, the thematic guide was approved with a variety of sample questions on the understanding that questions would vary between interviews.

3.2.2 Privacy and Confidentiality

At the beginning of each interview, the Participant Information and Consent Form was read aloud to each woman. The women were given a copy of the consent form with which to follow along and then to take with them if they wished. The women were informed about possible risks and benefits that could arise from participating in the study and of procedures that would be taken to ensure their confidentiality. Information on accessing local agencies offering HIV counselling and testing services was offered to the women and participants who seemed distressed were given the opportunity to speak with a counsellor or outreach worker. As the consent form was read, questions were encouraged by the interviewer and answered immediately. Once all questions were answered and consent was given, the interviewer signed and dated the consent form on the participant's behalf in order to protect their confidentiality. All of the women agreed to have the interview audio-recorded, and were instructed about how to shut off the recorder at any time.

In order to protect the privacy of the women and the confidentiality of the information they provided, all collected information was stored in locked filing cabinets in a

locked office at the University of Ottawa, and all electronic files were encrypted and password-protected. Additionally, transcripts and data were de-identified and anonymized. Only the primary investigator and the interviewer had access to the transcripts. After the recordings had been transcribed, the encrypted audio files were securely deleted.

3.3 Recruitment Process

3.3.1 Sample Size

Sample size for a qualitative project such as this is not dependent on such factors as statistical power and representativeness, but instead depends on the depth and content of an interview⁶⁶⁻⁶⁸. As Crouch and McKenzie argue, the purpose of an exploratory qualitative study is to “indicate rather than conclude. More strictly put, such studies formulate propositions rather than set out to verify them – or at least, convincingly demonstrate them (through reliance on, for example, ‘representativeness’ and the persuasive weight of large samples)”⁶⁹. Estimates of how many participants are needed in qualitative research vary, but typically range from approximately 12 to 30 participants⁷⁰. Given these guidelines, ethics approval for 40 interviews was obtained to ensure that even if all 30 interviews were conducted, more could be included in case of equipment failure or other issues that necessitated additional sampling such as non-completion or limited information from certain participants.

Interviews were conducted over five months (from February to June, 2015), until theoretical saturation was achieved. Theoretical saturation refers to the point in the analysis at which no new results appear and additional sampling would be redundant^{64,71}. In other words, “the researcher has continued sampling and analyzing data until no new data appear and all concepts in the theory are well-developed. Concepts and linkages between the

concepts that form the theory have been verified, and no additional data are needed”⁷¹. Thus, interviews were conducted until themes that emerged from participant responses had already been explored in previous analyses, and it was felt that there was no new information to be gained from further interviews. For this study, theoretical saturation among the demographics sampled was confirmed after 13 interviews. To confirm saturation, after three interviews had been analysed with no new themes arising, a final confirmatory interview was conducted. When this too provided no new themes, saturation was established.

3.3.2 Eligibility

Women who were eligible to participate were those who:

- Self-identified as Aboriginal
- Were at least 18 years old
- Were currently living in Ottawa
- Were capable of giving informed consent to participate
- Could communicate in and demonstrate a good understanding of English

3.3.3 Recruitment

Interviews were arranged in collaboration with two resource centres in Ottawa: the Drug Users Advocacy League (DUAL) and Minwaashin Lodge. In their own words, DUAL “is an independent group of drug consumers, ex-consumers and their allies who fight for the rights of those that use drugs, and our community, in the Ottawa area”⁷². Given that the most common route of transmission of HIV in the Aboriginal community is through injection drug use¹⁹, the inclusion of DUAL in the recruitment process ensured that the perspectives of those women potentially most at risk of HIV infection were included in the study.

Minwaashin Lodge is a support centre for Aboriginal women in Ottawa. The centre “provides a range of programs and services to First Nations, Inuit and Métis women and children (regardless of status) who are survivors of domestic and other forms of violence, and who may also be suffering the effects of the residential school system”⁷³.

Service providers from each of these organizations assisted with recruiting eligible women. The recruiters were directly involved in working with the women they recruited, making them well-suited to decide who would be a good candidate for the study. Recruitment was conducted using a purposive sampling strategy. Purposive sampling involves deliberately selecting participants who will provide rich information and depth about the subject being considered⁷⁴. The women who were chosen by the recruiting agencies were selected because they had “direct and personal knowledge of some event... that they are able and willing to communicate to others”⁷⁴. As the data were analysed from initial interviews, new respondents were recruited in order to address emerging themes and questions introduced by the earlier participants^{64,65,75}.

The women were assured that their participation or non-participation would have no impact on their access to services or resources at any organization they access. The women were also compensated \$30 for their time spent away from their other activities. This amount was approved by the Research Ethics Board.

3.4 Analysis

3.4.1 Thematic Analysis

Analysis occurred concurrently with data collection. As the interviews were conducted, the responses were transcribed and analysed, and emerging themes were identified using thematic analysis. This process involves “classifying, comparing, grouping

and refining groupings of text segments to create and then clarify the definition of categories, or themes, within the data... thematic analytic procedures focus on developing categories, derived inductively from the data itself, rather than from a priori theory, to enable systematic description”⁶⁴. In other words, the data were examined with the goal of identifying concepts or themes that helped to describe the data.

The thematic analysis was performed through extensive coding of the interviews. This involves labelling elements of the interviews with the theme(s) to which they belong^{64,65}. Segments of the interviews that are coded in similar ways are explored in the hopes of identifying patterns, similarities or differences while also considering the connections between the data⁶⁴. Through this process, a wide variety of themes were identified and explored within the interviews, falling under the broad categories of barriers to testing, previous testing experiences, and recommendations for testing improvement.

3.4.2 Constant Comparison

In addition to the thematic analysis element of the analysis, concurrent constant comparison was also performed on the transcribed interviews, meaning that themes identified in each interview were compared to themes that had come up in previous interviews. This process involves continuously identifying similarities and differences between the experiences and perspectives provided in each interview for the duration of the study^{76,77}. Its aim is “the identification of key elements influencing the phenomenon and the categorization of the relationships of those elements”⁷⁷. In particular, the themes were continuously assessed to determine whether they were unique to women from certain demographics (such as age or engagement in a specific HIV-related risk-behaviour) or whether they appeared consistently throughout a variety of interviews. This process allows

for the acknowledgement of themes that can help to inform the recruitment and collection processes⁶⁵.

By constantly comparing the responses of the most recent participants to the responses gathered in earlier interviews, it could be determined whether questions needed to be changed, added or removed. Additionally, women from different age groups and those who had engaged in various HIV-related risk-behaviours could be compared to one another in order to identify any major similarities or differences. This process also encouraged recruitment of women from different demographic subgroups with whom to compare existing findings.

Chapter 4: Results

In line with the thematic guide, the women's narratives converged on the subjects of barriers to testing, previous experiences with testing, and recommendations for how to improve the counselling and testing process. In this section, barriers are presented in terms of four main categories: insufficient knowledge regarding HIV and testing; lack of perceived personal relevance of HIV testing; unwillingness or inability to confront need for HIV testing; and judgment from self and others regarding engagement in HIV-related risk-behaviours. Experiences with testing are considered in terms of attributes that contributed to an acceptable or unacceptable testing experience. Lastly, recommendations are presented in terms of how to improve the testing experience, how to increase testing uptake, and how to create the ideal testing experience.

The themes that emerged from the interviews are illustrated by presenting the women's direct quotations. Interpretation and implications of these themes will be explored in more detail in the discussion section. In all of the narratives quoted, the women's names have been changed in order to ensure confidentiality. The women were told during the interview that they could choose the name by which they wished to be known. Those who preferred not to choose a name were assigned one.

4.1 Characteristics of the Women Interviewed

In all, 13 women were interviewed, representing a diverse cross-section of Aboriginal women in Ottawa. A brief description of each participant is provided in Appendix G. The women included four harm reduction service providers; four women who formerly or currently used injection drugs; one woman who used drugs by methods other than injection; two current sex trade workers; and two women who had a history of both injecting drug use

and involvement in the sex trade. Of these women, one disclosed that she was currently living with HIV. The women were not asked to provide their exact age in order to protect their privacy, but they did provide their age range (i.e. 30s, 40s, etc.). Using these approximate ages, the mean age of the women interviewed was around 40 years, ranging from 20s to 60s. All of the women recruited had been tested for HIV at least once.

Two women were exceptions to the purposive sampling strategy. These women were daughters of a previous participant and had been told about the interview by their mother. Despite the fact that these women were not specifically recommended by a service provider, it was determined that they would be invited to participate due to their ability to provide an inter-generational perspective on HIV testing.

4.2 Barriers to Testing – Insufficient Knowledge Regarding HIV and HIV Testing

Many of the barriers the women described stemmed from the issue of insufficient knowledge about HIV and HIV testing. They noted that misunderstandings about issues such as HIV transmission and the availability of testing services contribute to low testing uptake, as many Aboriginal women do not have the information they need to consider undergoing testing.

4.2.1 Misconceptions about HIV Transmission and Impact

Before women can seriously consider becoming tested for HIV, an understanding of how HIV is transmitted and who is at risk is required. Several of the women demonstrated a lack of awareness about HIV in terms of how it is transmitted and how it could impact their lives if they were to become infected. These misconceptions are important factors in the decision to undergo HIV testing, as they may influence people's perceptions of their own risk.

Regarding HIV transmission, Gina suggested that many people have concerns about transmission via casual contact, stating that she has occasionally worried about sharing a glass with someone living with HIV:

You know like, "Don't drink after me, don't touch me," you know.

I, I've even seen myself do that ... Yeah, I find out a friend of mine had it, I go, "Hmm, well I ain't drinking that after him." ... And "I'm not touching that."

Lisa described experiencing these misunderstandings firsthand, suggesting that fear of transmission through casual contact influences the way she is treated by others, including healthcare providers:

Uh, there's something, they just don't know how to deal with it, like in, they figure it's contagious but it's not contagious like, you know. It has to be through blood. And they don't realize that. I had one doctor who did that to me when I was in [name of location]. When I seen the doctor I said, "I'm HIV," he jumped back. He jumped back on me like, I was like, well, I don't know what you call it, well, as if I was well, contagious, like. And I went and seen the doctor again, and I went and seen a different doctor.

In addition to misunderstandings about how HIV is transmitted, the impact of HIV on one's life was not clearly understood. Irene demonstrated conflicting feelings about the consequences of living with HIV. She argued that people are no longer convinced that HIV is a death sentence so they do not feel the need to test, but almost immediately followed up by saying that if she was HIV positive, she would feel that death was imminent:

I don't find people talk about AIDS as much anymore as they used to, cause it used to be a big hype. Now it's not because there are people, we're starting to find out that it does, it's a killer uh, but it doesn't kill you right away if you can take care of yourself ... If it was like the plague, I'm sorry to say (laughs), you know what I mean? People would be talking about it all the time ... But because now we know it's not as deadly - in the beginning, everybody was like, "Oh my god, if you get AIDS you're gonna die right away, ba da da." ... But now that we know there's uh, ways to treat it and to

deal with it and if you change your lifestyle you can live forever. Well, not forever, but you know what I mean.

Well, it's sca- it's a scary topic. Man, if I knew I had AIDS, I would cry, I'd go drinking, I'd probably think it's my last day on earth.

Stephanie felt that the misconceptions that exist can contribute to people incorrectly assessing their risk, which can play a role in their decision to test:

Or they don't really understand their risk in a, in a realistic way. If you only know kind of these myths and, and you know, um, inaccurate information, you may not, might not access care when you actually are at risk.

Lisa's case is a poignant example of this, as insufficient knowledge about transmission contributed to her inaccurately assessing her own risk. She described feeling a lack of concern about her HIV risk prior to becoming infected even though she was sharing injection equipment with her sexual partners. She felt that because she was only sharing with partners, she was not really putting herself at risk:

I thought I'd never get it. That's the problem. Cause I looked after myself. I didn't share my needles with nobody, unless it was my partner ... And they're the ones who were sharing needles with everybody else. And that's why I reacted so hard.

Yeah, cause I didn't really know that much about it. Like, I knew you get it through blood and (pause) I was actually being dumb about it. Cause I figured, "Oh, I won't get it, cause I'm careful." Which I was careful, but I wasn't careful enough.

4.2.2 Secondary Position of HIV in Relation to Hepatitis C (HCV)

Some women suggested that the lack of HIV testing uptake among Aboriginal women can be partially explained by the fact that many people have a greater amount of awareness and knowledge about the risk of contracting Hepatitis C (HCV) than they do about HIV transmission. While the women felt that most people know a great deal about

HCV and its routes of transmission, they felt that HIV was not as well understood. As a result, people may think about the possibility of contracting HCV when engaging in potentially high-risk-behaviours but may not think about the risk of HIV, which may in turn keep them from testing. Christina suggested that the lack of dialogue about HIV may be keeping women from practicing harm reduction behaviours as well:

I think Hep C, to be honest, is focused on more right now than HIV. It's kind of uh, the hot topic of things you can contract (laughs). So I find that a lot of the women are worried about getting Hep C; I rarely hear a thing about HIV ... So yeah, I mean, they're working, they're working, they're sex trade workers and a lot of the time it's unprotected, so it's being passed on.

Irene believed that most people do not care about HIV because it does not affect their everyday life. She felt that if it was more immediate, people would talk about it more. The high prevalence and regular dialogue about HCV help to keep HCV on people's minds while the same cannot be said for HIV:

People talk more now about Hep C than they do about AIDS ... Because everybody's got Hep C ...And not everybody has AIDS. It's like, if you don't think it's happening to you, nobody cares.

Or say we share needles with somebody or they drop their needle or somebody picked [it] up, you know what I mean? People would think about it. But people would actually think about Hep C more than they would about AIDS... It's true! It really is, cause when I got Hep, it was a bigger thing than if I had, if I would have got AIDS.

4.2.3 Lack of Awareness/Visibility of Available Services

In addition to misunderstandings about HIV itself, the women felt that information was also lacking around HIV testing. They suggested that many women are unaware of what services exist and what services are locally available to them. They argued that organizations do not currently promote their testing services enough, with Alison stating that in the past testing was advertised much more prominently than it is today:

I feel like I haven't really seen much lately. Like, I remember years ago, I remember seeing posters like, "Get tested!" Or whatever, you know? Just, it would make you think. Like, "Oh, look at that poster." They were like, everywhere. I feel like they were everywhere! Now I don't really see that.

Jamie agreed with this, stating that information about testing is readily available for people if they know where to look for it, but that it needs to be more immediately available:

I think that if you look for it it's easy to get, but it's not like, right there, like in your face type thing. Yeah, I think it needs to be more like, outwardly open. Yeah but I know, like, the information is there, it's not really hard to find. But I guess making it just more, like, in front of you.

A few of the women were unaware of alternative methods of testing outside of a standard test at a doctor's office. In particular, several people were unaware that point-of-care testing even existed, let alone where they could access this service. Gina expressed a desire for a faster testing option, but did not believe that such a thing would ever exist:

There is nothing better. You go, get the needle, you get your blood tested, that's it ... What other way is there? ... You can't do it like you do in diabetes. You know, like, uh, testing for your, your, your sugar and all that. You have to go get the blood taken now, there is no other way of doing it ... Unless they come out with a machine that looks at you and says, "Oh yeah, you're HIV." Yeah, you know? It'll never, never happen.

Now if they did come out with something to prick your finger and say, "Okay, uh, you, you, you're HIV." If it was that quick? It'd be nice. It would be nice, but um, like I said, they'll never come out with it like that.

Troublingly, Mary noted that she personally would not know what to do if she were to receive a positive diagnosis as she was unaware of what resources exist:

Yeah, (pause) but too, I don't know the resources to go to. Like, had my test come out positive, I wouldn't know where to go from there. So, and to this day, I wouldn't know where to go from there either. Um, I'd probably go through the doctor and um, follow the steps that way. And then I would branch out and look for groups or

whatever on my own, kind of thing. But um, so it's a hard question for me cause I don't know what resources are there right now.

4.3 Barriers to Testing – Lack of Perceived Personal Relevance of HIV Testing

An important barrier identified by many of the women as contributing to low testing uptake was the idea that many Aboriginal women do not feel that they are at risk of contracting HIV and therefore do not need to be tested. This perception is closely linked to the issue of insufficient knowledge about HIV transmission, and seems to stem from the women believing that they are not susceptible to the virus or the notion that they are not engaging in behaviours that are associated with HIV transmission. As a result, even women who are aware of HIV and how it is transmitted may not consider prevention programming or testing services to be personally relevant or necessary.

4.3.1 Self-Assessment of Risk

The women reported that many Aboriginal women do not truly believe they are at risk of contracting HIV and therefore do not feel the need to test. Hannah, for instance, reported hearing stories of individuals who believed HIV could not be contracted by Aboriginal people, as it was a “white man’s disease”, or something that could only be contracted by people who are gay:

And I know it's not a white man's disease, but as far as the Elders and as far as the other people think, [it] is ... Oh yes. “I don't have it, what are you talking about? That's a white, that's a gay, that's a gay thing, that's a lesbian thing. No, it's not me!” ... Next thing you know, you give birth to a baby and it's got HIV. Why? Because you thought it was just a white man's disease.

Similarly, Stephanie indicated that she has worked with women who thought that HIV could only be contracted in Africa and denied their own susceptibility:

I think a lot of people like, they come to the city, they've never even heard of anybody having HIV. It's such a foreign, like, "Oh, only people in Africa have HIV." Like it's such a foreign concept to some people who have grown up in an isolated community where there, there's no such thing as HIV there. And then they come into a city and they're exposed to so much more, whether that's drugs, whether that's sex, whether, whatever behaviour that they're being exposed to or they've never, ever heard of this before.

Despite the denial of risk seen in many people, the women felt that there are substantial rates of engagement in potentially high-risk HIV-related behaviours in the Aboriginal community. They reported participating in or knowing others who regularly participate in behaviours that are associated with HIV transmission despite knowing that these behaviours are potentially risky. Furthermore, the women acknowledged that they were taking chances but still identified themselves as being at low risk of HIV infection. This perception seemed to reduce the women's likelihood of feeling that they needed to be tested. Mary, for example, reported that she would seek HIV testing if she felt she was at risk, but felt confident that it was unnecessary, despite her engagement in injection drug use:

If I feel the need, then I would be tested again, yes. Um, at this time in my life, I don't feel that need. Um, however, there would be uh, something that has um, a reason in my life that uh, I would be a little bit more cautious of that would probably bring me to testing, and that would be needles ... Um, if I poked myself or something, you know, that sort of thing ... But no, I don't uh, in my foreseeable future, I don't see any testing.

4.3.2 Role of Addiction on Prioritization of Healthcare

While the women reported that many Aboriginal women who have engaged in an HIV-related risk-behaviour may not recognize that testing has relevance to their lives, some women spoke about the more direct role some of these risk-behaviours can have in keeping people from considering undergoing an HIV test. For example, addiction may take priority over healthcare or block out thoughts of anything other than the addiction. Alison described

working with individuals whose addictions keep them from being contactable, causing them to miss appointments for healthcare or other services:

Um, just lifestyle. Um, you know, if uh, addictions, you know? ...Often it's really hard for us to even connect with a client. Let's say we have something planned, you know, "I'm picking you up for eleven, we're going to [name of agency]," for example, right? ... Um, well they may have, you know, it might have been nine o'clock when they got back home or wherever they're staying ... You know, so I'll call them five, ten times, they're not answering.

Jamie, Christina and Lisa suggested that people who are dealing with addictions may not be thinking about anything else, which can interfere with their uptake of services:

Jamie: *I think it's important [HIV testing], but I feel like because of addictions people don't really care about their health issues. ... If there's any. They kind of ignore that because the addiction kind of blocks it out.*

Christina: *Um, I don't think it's [HIV testing] as accessible as it could be, to my clients especially, and I don't think it's something that they choose to do. A lot of them are addicted. And it's not their number one priority.*

I mean, it's HIV and it's known, so it's not that there's a lack of knowledge on what it is. There probably is a lack of knowledge on how it would affect them long-term. You know what I mean? But, especially if you're dealing with women who, who have addiction issues, they're not thinking long-term. They're thinking day-by-day, right? ... I don't think that it's something people think about. Or really care, to be honest.

Lisa: *You know? If there's abuse and everything in your past, a lot of your abuse and how you've been brought up has a lot of factor to do, to it too. And especially if you're a hard-core alcoholic, drug addict. You just don't, you're drowning yourself in that, in the drugs, so you don't um, feel nothing.*

Christina went on to say that many women do not think seriously about testing until after their addictions are behind them:

I do believe that when, like, in some cases, of women who become clean and got off the streets and stuff, it often, it becomes important to them. In that process ... And that's just, I think it's nothing's important when you are fighting addiction.

4.4 Barriers to Testing – Unwillingness or Inability to Confront Need for Testing

In contrast to the perspectives the women discussed in the previous section that portrayed HIV as not being personally salient, some women described a number of barriers that can prevent Aboriginal women from seeking testing even when they may know that they should be tested. The women presented a number of factors that can influence a person's decision to test, including fear of the consequences of a positive HIV test result or a refusal to acknowledge HIV.

4.4.1 Fear of Consequences of a Positive HIV Test Result

A major barrier to testing reported by the women was fear of receiving a positive HIV test result and the consequences of an HIV diagnosis, particularly for women who felt that they had an elevated risk of receiving a positive result. The women reported being very afraid during and after the HIV test. Christina stated that she felt particularly afraid during her test because she was worried she had been exposed to HIV:

Um, I was young, but, and obviously nervous. Um, I mean, if it's – if it's something that you're doing because of the situation that's happened, that's obviously nerve-racking. A little bit traumatising. But um, yeah, so I was definitely nervous.

Irene noted that her fear began as soon as the testing process began, wondering throughout the test whether she might receive a positive result:

It's scary! Scary as soon as they take the blood from you! Right away, you start - at the beginning when they're starting to take your blood, and they're putting the alcohol swab, you don't really think anything of it. But once it's in that tube, you're

like, “Fuck, do I have it?” ... And you think of all the things, you think back of all the things you did, did he wear a condom, did this happen, did that happen. You’re thinking about it for that (laughs) next ten seconds until it shows up on the little thing. You’re shitting your pants!

The time women spent awaiting their test results was portrayed as very difficult and long wait times between the test and the result seemed to compound the women’s fear. Gina reported worrying that her test would be positive and wondering what she would do if that was the case:

First time, I was terrified, especially waiting for the outcome, and I’m going, “Oh god.” There goes one nail (mimes biting her nails), there goes the other nail, there goes the hand. And I’m going, “Ohh, what if I got it, what if I got it, what am I gonna do?”

Several women described feeling nervous and afraid during the long wait time after undergoing their tests. Irene, Alison, and Gina all mentioned how nerve-wracking it was to wait for their results:

Irene: *Yeah! Cause back then, when you first got tested, you had to wait two weeks to get your results so those two weeks you’re like, shitting yourself almost, you know what I mean? ... I walked on eggshells from the time they took my blood til the time they called me ... There’s nothing that can stop your panic! Because if you’ve got AIDS man, that’s it, that’s death. There’s no way, that’s how everybody thought about it, there’s no way around it.*

Alison: *[D]efinitely I was nervous ... They wouldn’t tell me over the phone, so I was like, I had anxiety, I was freaking out.*

Gina: *It’s not like [name of community health centre], here, like, they’re awesome here. You know, it’s boom! ... Here, no, you don’t got it, you know, so ... I had to wait a whole month like until I go back to my doctor to find out, so ... Well, I didn’t like it too much, like I would have enjoyed a phone call saying, “Hi, uh, (laughs), you can relieve yourself now!” (laughs) ... You know? You know, “You don’t have to pee your pants or nothing no more!” (laughs)*

Mandy suggested that the fear associated with testing comes from a fear of rejection or abandonment from family members in the event that the test came back positive.

***Mandy:** I think it's weighing, it weighs in on both, even if you're not positive. It's the testing, like, and you're sitting there, "What am I gonna do if I am?" And you know, even though you find out you're negative, it's just the pros and cons you're thinking, "Oh, this, my life is gonna be over, and I'm gonna lose my family and nobody's gonna wanna talk to me and all this."*

***Interviewer:** Mm. So even just the test itself is scary. Even if you don't think you're positive.*

***Mandy:** Yeah. If there's not enough info on it and you're not going to see a doctor that's understanding and, you know what I mean?*

Ellen shared this concern, stating that she was afraid a positive test would lead to the people in her life abandoning her:

I just, I don't know. I would be scared... I don't want people to walk away from me, not talk to me cause I'm sick.

Mary expressed fear of rejection and judgment from people more broadly, worrying that they would look down on her for being HIV-positive:

Okay, uh, I'd be petrified to get tested because if someone found out that I had (pause), yeah, they'd probably look and stick their nose at me or whatever ...And I would be afraid of that. I'm somebody, I'm trying to fix it, somebody who uh, has grown up all my life looking for approval of people. So if I found out that I had AIDS and I had to tell people, yeah, I'd be petrified of that.

In addition to worries about losing the support of others, much of the fear the women experienced seemed to be due to the perception of HIV as a death sentence. Stephanie described working with a number of Aboriginal people who believed that a positive diagnosis would mean the end of their life:

Oh. I've been through the process with a couple of people where there was a lot of fear. A lot of, um, I think people still believe, and again, like I said, I don't think a lot of, of the smaller Aboriginal communities, or people who haven't lived in an urban

setting have been exposed to this at all. So it's very scary, it's very dark, it's like a death sentence. People think it's like, you know, "I have cancer." I'm gonna, you know, people really feel like it is a disease that will, you know, eat you alive and spit you out. And you have six months to live and like, all of these really crazy kind of ideas.

Gina agreed with this sentiment, comparing an HIV diagnosis to being diagnosed with cancer:

"Oh, you're, you got it so bad that you got x amount of days to live." Almost like cancer!

Irene suggested that fear of HIV as a death sentence was a major reason for people's unwillingness to talk about or test for HIV:

Well, it's sca- it's a scary topic. Man, if I knew I had AIDS, I would cry, I'd go drinking, I'd probably think it's my last day on earth... Cause nobody wants to walk around knowing they have it. Like, AIDS, I, it's, it's a death sentence.

4.4.1.1 Avoidance of HIV Testing to Protect against Fear

One way in which the women described protecting against this fear was through avoidance. The women frequently stated that dialogue around HIV and HIV testing were generally avoided by many people in the Aboriginal community because when it comes to one's HIV status, most people "just don't want to know". This avoidance seemed to act as a coping mechanism for many of the women, as the reasons given for avoiding the test closely mirrored the reasons given for being afraid to test. Rather than face the frightening consequences of a positive HIV test result many Aboriginal women would prefer not to think about it at all. Some of the women suggested that this avoidance stems from a belief the individual may already be positive or have put herself at risk of infection, but would rather not to know for sure:

Ellen: *Cause they, they, they know they have HIV. But, uh, I know a lot that don't want to [test] because they know they have HIV ... They don't want to know the truth. They don't wanna know!*

Zelda: *They're hoping that they don't, well they don't want to know. That they have it. Maybe they've uh, um, put themselves in a position where they might get it so maybe it's best not to even know about it.*

Interviewer: *Mm-hmm. Why do you think they might not want to know?*

Zelda: *Well, who wants to know that they have a virus that could possibly kill you? ... They don't want to know about it. They don't want to find out that they have it.*

Gina: *Half of them are too scared. ... Half of them are too scared, they don't wanna know the outcome of some of their, what they've done in their life and that.*

The women offered a variety of reasons why some people would prefer not to know their HIV status, or in some cases, even to think or talk about it. Alison described her belief that many Aboriginal people avoid testing due to concerns about the consequences once they disclose their status to others:

A lot of people don't want to know their status, right? ... I guess if they... they just, they don't want to know, cause if they, you know, found out that they were positive, they would feel like they need to tell people and just, uncomfortable situations, you know?

Mandy supported this idea, stating that many Aboriginal women already experience so much stigma and discrimination in their lives that having to disclose that they were HIV-positive as well would just create more problems for them:

I think there's already enough discrimination on Aboriginal people so I think that it would add to it, so again, the unknown and people being terrified of what's gonna happen if they find out they are. ... Where are they gonna go and you know what I mean? They're already treated bad in society and once they have HIV it's, you know, gonna be worse ... you know?

Irene offered another perspective, suggesting that people choose not to find out their HIV status because if they knew they were positive, they would feel like their lives were over. Due to this perception of HIV as a death sentence, for many women, not knowing might be preferable to feeling that they only had a short time left to live:

[I]t's the thought of knowing. Who wants to know if they have, they have AIDS, who wants to know if they have cancer? You know what I mean? It's one thing, I'd rather go through my whole life knowing that I don't have it or turning a blind eye thinking I don't have it because once you think you've, once you know you have it, you're, the rest of your life is on a timeline. "I gotta get all this done!" You write a big bucket list, but if you didn't know you had it, you wouldn't be doing it all and you'd still be living your life normally, so now you're trying to cram your whole life into a small period of time.

She reiterated this thought a few more times during the interview; for her, it would be better not to know she was positive than to have to cope with the knowledge that she had a terminal illness:

And do you really want to live all your life taking all those pills? So that's why people don't talk about it. They'd rather know, they'd rather NOT know they have it ... If I have it, okay fine, I have it, I'll live the rest of my life. But, who wants, nobody wants to know they have it. So that's why nobody gets tested. That's like the ultimate, uh, gun to your head, man.

Seriously, that's just like, that's the worst thing, man, is knowing that is, that's the end, man, you're a walking corpse. That's how we look at it. Nobody ever wants to know that. It's just like me, I'd never want to know I have cancer, but I'd rather know I have cancer than AIDS because that's like, you know, let's say I went to a doctor and he said I had AIDS, I'd be thinking, I'd be remorseful... "Oh, I could have did this, I should have did this, I should have did that." So now you spend the last, let's say you got four months, you spend the last four months, "I should've, I should've, I should've." Then you try to squish it all together! I'd rather not know I have it and live my next four months the way I am now and knowing that my life is content and I don't have any remorse.

There was also a general sense that the only acceptable places to discuss HIV are organizations such as community health centres. Stephanie and Zelda suggested that when HIV is discussed outside of these organizations, it is not discussed in a very open way, which can interfere with establishing dialogue around HIV testing:

***Stephanie:** I think because of the stigma. I think places like [name of Ottawa community health centre], because it's the mandate that we serve, it's something we're always talking about, always engaging with people around, um, you know, safe injections, safe inhalation services, safe sex, kind of um, doing all of that harm reduction stuff to try and limit people um, having new infections of either Hep C or HIV but I think a lot of other places, it's just, it's, there's still so much stigma attached to it that it's not even a subject that's broached very often. Or if it is, it's in a very secretive kind of way.*

***Zelda:** Uh, I don't know about discussed. Unless there's somewhere like this place [community health centre]... You know that it's, it's kind of brought up to them. But you know, on the street... Maybe between other, between other uh, people, you know, you know that there's condoms out there and there's safe ways but that's about the only discussion I can think of... It's very hard to talk about.*

Some women also felt that the lack of dialogue around HIV was a problem, acknowledging that there are currently not enough opportunities to talk about it. Given the strong preference to avoid knowing one's status, the women generally felt that it was difficult even to bring up HIV or HIV testing with other people:

***Lisa:** Yeah, yeah, it's not exactly comfortable talking about, "Oh [inaudible] let's talk about HIV subject now!" Sometimes we do, but not often.*

***Mary:** I think the more people talk about things, the more it's going to be known. The more people um, are not hushed, the more it's gonna be known and uh, addressed. Like I think it's just swept under the rug and people just don't wanna... pay attention to it, I guess ... When people are afraid of something, right, they don't wanna talk about it.*

Hannah: It's just (long pause), it's like it's all hush-hush... You know? Don't mention HIV, don't mention Hep C, don't mention this. It's all hush-hush. It's like, guys, it's out there! It's there! It's hitting you in the head, saying, "Hello, we're here!" This is what's happening with our women and our youth, some of the children that are being born with HIV, Native children. Like, hello!

4.5 Barriers to HIV Testing – Judgment from Self and Others Regarding Engagement in HIV-Related Risk-Behaviours

4.5.1 Internal Shame due to Engagement in HIV-Related Risk-Behaviours

As previously discussed, many of the behaviours and practices associated with HIV infection tend to be stigmatized. The women suggested throughout the interviews that many Aboriginal women feel ashamed of having engaged in these HIV-related risk-behaviours, which can influence their willingness to disclose these behaviours in an HIV testing scenario. Alison described not wanting to disclose engagement in potentially stigmatizing behaviours to her doctor when she was tested because of concerns about being judged:

I would lie to my family doctor and tell her I was with someone ... I didn't want her to know that, you know, I was with random people.

Mandy agreed with this sentiment, stating that many women avoid testing because they do not want to disclose behaviours that may be very personal:

Depending on what clinic you go to, I think a lot of people are just like, why would they want to get tested, they're this age, and that age, and, and then a lot of people are like, stigma because they're [doctors] involved in their sex life or their personal life and some people don't wanna say that. And I get that.

Hannah corroborated Mandy's statement, but suggested that the reason many Aboriginal women would be ashamed to admit that they had engaged in high-risk activities was because there might be a perception that they had let down their culture. She felt that these beliefs contributed to substance use as women could be using substances in order to "punish themselves":

It's difficult for a Native woman to try to get back on track. Because they feel that they've... Native, Native people have such a (pause) high expectation of themselves. You know? They're proud to be Native... You know? And they walk and they talk and they're Native. So when something happens where there's a Native out on the streets, there's a Native drunk, it's more or less that they're punishing themselves more and more because of the fact that they feel that they've let down their parents or their tribe or, you know? And there's nothing there for them, to catch them and say, "Here, let's give you a little lift."

Stephanie supported the idea of perceived punishment, but felt that rather than punishing themselves, some women believed contracting HIV was their punishment for participating in risk-behaviours:

Cause there's a lot of shame around it and, you know, if you have never met anybody in your entire life who has HIV or Hep C, or whatever, you know, infectious disease that they might have, there's a lot of internalized stigma too that, you know, you've done something very wrong and this is your punishment for it.

She also felt that this sense of shame contributes to an unwillingness to disclose one's status:

No, I think there's so much shame attached to the illness, still in our community that people would not want anybody to know that they've come in contact with HIV.

4.5.2 Lack of Self-Worth

A few women described feeling that some Aboriginal women do not undergo HIV testing due to a lack of concern about their own lives. They suggested that many women in the Aboriginal community may not care if they contract HIV due to a low sense of self-worth. This lack of concern for their own health and lives can influence women's desire to seek testing, as they may feel that it does not truly matter whether they have HIV or not.

Irene suggested that this lack of self-esteem is especially prevalent in the Aboriginal community:

Yeah because Aboriginal people, Aboriginal, I don't think, this is gonna sound really stupid but I don't think Aboriginal people care as much ... And we don't care. It's true, people - I find Native people so, uh, I don't how to explain it ...they don't care about their lives too much.

Lisa supported this idea, stating that apathy about one's life can keep people from participating in harm reduction and testing behaviours:

Um, like I said, you've got some people that do care. And then there's some people that just don't care ... Why they don't care is um, cause I, I can't, I don't know what they're thinking in their lives, but maybe in their lives they think they're not worthwhile or something, you know? Cause that's how some people think. "I'm not worthwhile so what the hell does it matter if I get it and die?"

4.5.3 Racialized Stigma Directed toward Aboriginal Women

Given the taboos that exist around HIV, some women suggested that many Aboriginal women avoid accessing HIV testing due to concerns about stigma or judgment from healthcare providers and society at large surrounding HIV. Stephanie felt that stigma in the Aboriginal community may be stronger than that experienced outside of the Aboriginal community:

Um, some of the stigma that's attached to HIV, especially in the Aboriginal community, I think there's a lot more stigma than in mainstream culture.

Furthermore, the women felt that much of the stigma and discrimination directed toward Aboriginal women is racially-based. Jamie suggested that fear of racism from healthcare providers could contribute to a lack of testing uptake among Aboriginal women who seek healthcare from a mainstream institution:

Um, like, I've never really had anything like, personally, like personal experience, but um, like I've heard, um, like I do work with Aboriginal women so I've heard like, a couple of different stories of them experiencing like, um, like that they may have felt judged because of their race.

Hannah argued that society generally views Aboriginal women who are involved in the sex trade or who are dealing with addictions with more judgment than they would women from other groups:

And, but it's strange because when you see an Aboriginal woman out there, as a trades worker ... you just go, "Well, whatever." ... You know what I mean? Like, they're expected to be out there. You know?

And it's like, if you see a white woman on the, on the street, a trades worker, it's kind of like, "Oh, you should know better. Oh my god, didn't your family raise you right?" But you see an Aboriginal woman? Nobody chastises her, nobody says, "Didn't your family raise you right?"

It's like, they see a Native woman drunk; "Oh, that's normal."

She referred to her own experience with her family, noting that her mother and other women sometimes deny being from an Aboriginal background in order to avoid racism:

[M]y mom didn't want, didn't want people knowing that she was Native, because it puts a stigma on them. You know what I mean?

And it's hard because we're stereotyped so much that women don't want to admit they're Aboriginal unless they fully see it. Do you know what I mean?

4.5.3.1 Privacy/Confidentiality Concerns Compounded by Stigma

In light of the considerable amount of racialized stigma the women experienced, many women expressed concern that privacy could not be guaranteed if they expressed interest in testing and worried about the confidentiality of test results. Alison stated that knowing her test results would be kept confidential was one of her biggest concerns when it comes to testing:

Well, the confidentiality and the uh, the anonymity, that would be one of my biggest concerns ... Like, that's really important, I think, to a lot of people. I would want to ensure that, you know, the information, if it came back positive, wouldn't be going ANYWHERE.

Stephanie echoed these concerns, stating that if she were to seek testing she would not feel comfortable accessing services in Ottawa because the Aboriginal community is so small:

I think there's a lot of stigma. I know for myself, um, if I did need to get that done, I wouldn't be comfortable accessing some of the Aboriginal health services in Ottawa ... Because we have such a small community, um, I'd be worried about my confidentiality.

I would be concerned about my confidentiality, and because some of the practitioners that I would see at, at the clinic, let's for example, the Aboriginal health centre here, I would see them other places around the city when, and would be, just concerned about the stigma that would now be attached to me and my confidentiality itself ...The other thing I would be concerned about it because a lot of Aboriginal people here also know some of the service providers who are working at different agencies and I would be concerned about you know, someone being able to just type in my name and pull up and see, "Fear and concern about HIV." Or that I had blood-work sent off, or that I had um, and that would be just out there, and who knows where that information could be shared, so ...You know, having a close-knit community is a really positive thing but also in other ways it can be ver-, it can be limiting people from accessing care there.

4.5.3.2 Stigma as a Contributor to Unwillingness to Disclose HIV Status

In line with the women's concerns about people learning that they had sought HIV testing, many of the women felt that stigma played a role in whether or not one was willing to disclose her positive HIV status to others. Several of the women described feeling uncertain about whether they would voluntarily disclose their HIV status if they were to learn they were HIV positive. Lisa, who is living with HIV, explained that she readily disclosed her status to potential sexual partners, but was wary about telling people with whom she was not close due to concerns about stigma:

So yeah, I find, I do tell people if I'm going to have a partner or something, I tell them I'm HIV before we start. And after that it's up to them, so ...Uh, no, I don't think it's really none of their business if it's not, if I'm not involved with them in uh, in a ... real close relationship, there's no need to. And it's like I'm gonna go, some people still go, "Ahh!" at you, you know?

Ellen stated unequivocally that if she learned she was HIV-positive, she would be unwilling to disclose her status to others because of how she would be treated. She stated that she did not believe anyone would support her if she told them she was living with HIV.

***Interviewer:** Yeah. So if you were to find out that you were HIV positive, how do you think people would respond to that?*

***Ellen:** I would never tell them.*

***Interviewer:** You wouldn't tell?*

***Ellen:** And I wouldn't touch nobody. You think I'm gonna tell them?! ... No way.*

***Interviewer:** Do you feel like you would be supported?*

***Ellen:** No.*

Zelda was uncertain about who she could disclose to if she learned she was HIV-positive as she felt that she would have very few people in her life to whom she could disclose:

***Interviewer:** [C]an you tell me what you think your experience would be like if you found out you were positive?*

***Zelda:** It would be terrible. It would be terrible. I wouldn't want it. That's about all I have to say about that! (laughs)*

***Interviewer:** Would you tell anyone?*

***Zelda:** Hmm. Very few.*

She went on to say that she may be supported by others living in a similar situation to her own, but felt that her family would not be supportive, making her less likely to tell them:

I don't know if I'd want - I don't know who I'd turn to for support. It would be very hard to tell my family, my mother.

Oh yeah, it would be viewed negatively in my family, my family doesn't look uh, to me for much right now because you know, I've been um, you know, using you know, drugs, you know, on and off. And I've just, I'm kind of an outcast, so ... They would

probably be one of the last people I would tell about it if I had it ... So they, no they wouldn't be a support. Not many people out there would support. Maybe, um, good friends that are in the same ... thing I'm in to.

Gina had similarly mixed emotions about disclosure. She was certain she could tell her partner if she learned she was living with HIV, but she felt that due to a culture of stigma, there would be many others who would not be supportive if she disclosed to them, suggesting that they would go on to tell many other people:

Well, for starters, I don't have sex now anyways cause I'm too old to have sex (laughs). But yeah, I would [disclose]. I would, yeah, I would turn around and tell somebody, yeah. Oh yeah. Uh, my mate? I would tell him ... You can't uh, you can't turn around and say, "Okay hun, like, uh, are you gonna be in my corner?" "No, I'm just gonna go and tell everybody, 'Oh, she's got AIDS, stay away from her!'" ... You know? Like, that's how people act nowadays.

4.6 Women's Experiences with HIV Testing: Acceptable Testing Experiences

4.6.1 Low Self-Assessed Risk of Receiving a Positive Result

The women reported several factors that helped them to feel comfortable during their HIV test. Among women who felt that their test had been acceptable, assessing their risk of a positive result was described an important contributor to this perception. Women who viewed the test as part of their standard care or who did not feel that they had been exposed to any high-risk situations generally reported feeling comfortable with the testing process. Jamie described feeling confident during the test because she was not genuinely worried about the possibility of a positive result:

Um, well, I mean, it wasn't like, anything uncomfortable for me, like, personally. Um, but like, I was comfortable and confident getting it done, just because I knew, I guess I didn't really have anything to worry about.

Stephanie mentioned similar feelings, stating that despite the fact that she was nervous, her perception that HIV testing was all just part of her routine care made her feel better:

Uh, I was nervous. Again, like just for the things that I was saying, like, my, I was worried about my confidentiality, but um, I could appreciate that it was when I was getting all of my annual blood work done and because I work in a clinic where uh, I am exposed to different illnesses, when I do get my blood work done I get it done very thoroughly. I get testing kind of across the board. So for me, it was just part of my annual physical, part of something um, you know, that I would be doing just the same as getting a Pap test or getting my full blood work done. For me it was just part of um, my care. My annual care.

4.6.2 Undergoing Test in a Comfortable Setting

The women considered the appropriateness of the setting in which the test was administered to be a key factor in creating a smooth testing experience. Women who reported a more acceptable experience generally felt comfortable with the setting. Alison reported feeling safe because she was with her family doctor, but felt that going to a clinic might be more nerve-wracking:

And it was my family doctor, right? So I mean, I felt safe. You know? I imagine it would probably be a little different if you were in a clinic. You know, anonymous. Street-involved.

Jamie also reported feeling comfortable during her test, but felt that it was because she was tested in a culturally appropriate setting:

I think maybe that was partly because it was at like, an Aboriginal health centre... I think (pause) I'm not really sure if it would have been different if I went to like, a mainstream healthcare centre... Possibly, yes... Not saying that all places are like that but there is places that could be like that. Racism, or judgmental.

4.6.3 Provider Characteristics Perceived as Beneficial to Testing Experience

Lastly, the attributes of the individual administering the test were described as very important to whether or not the women perceived the experience as acceptable. Jamie noted that her doctor did not make her feel like she was being judged which helped her to feel more at ease:

I felt like, um, they made me feel comfortable about it. They didn't make me feel like I was being judged or anything.

Several women reported that the tester clearly explained the process to them before they were tested, and this seemed to put them more at ease with the test itself. Christina and Jamie described being told exactly what was going to happen during the test:

Christina: *Yeah, I was absolutely informed. Um, that was a process back then, through counselling. Um, basically, the hospital kind of set that up, so... So yeah, I was well-informed of what was gonna happen.*

Jamie: *No, like, they were really, you know, they really explained like, the process like, okay, even during the testing like, "Oh, I'm doing this now. This is what I'm testing you for, and this is what I'm, you know." So they explained everything very well so I knew exactly what was going on.*

4.7 Women's Experiences with HIV Testing: Unacceptable Testing Experiences

4.7.1 High Self-Assessed Risk of Receiving a Positive Result

While women who believed they were not at risk of HIV infection were more likely to report an acceptable testing experience, women who assessed their risk of receiving a positive result as elevated reported poorer experiences with HIV testing. Christina described feeling nervous when she was tested because it followed a sexual assault. She believed that the whole testing experience is generally more traumatic if the patient believes they have been put at risk:

Um, I was young, but, and obviously nervous. Um, I mean, if it's – if it's something that you're doing because of the situation that's happened, that's obviously nerve-racking. A little bit traumatising. But um, yeah, so I was definitely nervous.

Lisa reported feeling certain that she was going to be diagnosed with HIV when she was tested because she had learned that one of her partners had received a positive diagnosis

and she had been sharing needles with him. Despite stating that she had known that she was going to test positive, she felt that she was not emotionally prepared for the diagnosis:

That experience when I was tested, I was, I knew I was gonna get it. Because I had one partner, I mean, I had two partners, one I was with for three years, and we split up for a couple months and I went out with another guy. And we, I got him tested and I was still... I didn't have HIV then. Like I was, I didn't have it. And I got him tested and he was HIV and then my partner and my ex-partner before that, um, told me, he came back to me and told me, said, "I'm HIV," so I knew I was gonna get it. Cause of sharing needles, eh? I was sharing needles with my partners. With nobody else but with my partners, but my partners were sharing needles with other people.

The test, I was, it was, I dunno, she just said, "You're HIV," and then, pfft. The nurse just left me, just like that. And I'm just sitting there, I'm sitting there with it, like, like, I knew I was going to get it, okay, I knew it in my head. Like my head was ready for it, but my, my emotions weren't. (chuckles)

She described reacting very negatively to the news that she had HIV.

And so I just kind of flipped out, and I tried to commit suicide, and I beat the shit out of my one partner, put him in the hospital. Like, I almost killed him. But yeah. I took it hard that way. Six months I went out, I went on a rampage. I didn't care about nothing. I was fuckin' violent and vicious, didn't, I'd rob you, take anything you want, what was yours, dope or whatever, fuck I'd just grab it, I don't care, I'm dying anyways. That was my thought. So yeah, so it's, it was hard.

4.7.2 Provider Characteristics Perceived as Detrimental to Testing Experience

As in the case of acceptable testing experiences, providers played an important role in the women's feelings about the testing experience. Many women spoke about the need for an understanding, non-judgmental tester and the absence of these characteristics tended to be associated with an unacceptable experience. Christina reported that her experience would have been much better if she had been treated with more kindness. She was nervous about being tested, and felt that the tester should have been sensitive to that:

I think it could have been more of a personal... maybe if someone, you know was a little more gentle (laughs) or empathetic, I don't know. Probably could have went a

little easier... I think it's traumatising or a nerve-wracking experience for anyone that's doing it, so I think just a lot of empathy, you know? Um, kindness. Simple things like that would make a difference in that process.

Mandy and Hannah agreed with this sentiment, suggesting that a better bedside manner from the tester would be helpful, as they had both been tested by people who they felt were not understanding:

Mandy: *Just his whole approach, like, maybe if he had of come out and like, introduced himself and be like, "This is what we're gonna do today, this is the plan, are you..." Include people in their medical decisions, just don't do it, you know what I mean? And I think that if he had of come out to me and introduced himself and be like, "This is what we're gonna do because it runs in your family," then maybe I would have been okay with it. But he was just ignorant, you know, and, so. That's another thing.*

Hannah: *[when asked what could have been improved during her test] Kind of, bedside manner is a major one.*

Mandy reported feeling that she was being judged by her provider, which contributed to her negative perception of the experience overall:

Um, (laughs) you know what the doctor said? He's like, "Oh, this is gonna start running in your family, eh?" And I'm like, "What the fuck did you just say to me?" And he goes, "Well your aunt has it, she gave it to her kid, and you're living with her, you're gonna get it." I'm like, "I didn't come for a lecture, I came to get tested." ...We argued, like, I almost knocked that doctor out that day. Like, I couldn't believe, you know, thinking, "Oh, you're gonna have it because you're living with her and it's gonna run in the family." I'm like, "Wow, what the hell?" I couldn't believe that.

Donna and Hannah both reported similar experiences wherein they perceived that their providers were not listening to their needs, resulting in pain and frustration with the test. Donna felt that she was ignored because she was recognized as someone who uses injection drugs, leading to her opinions being disregarded. She also noted that the tester was not successful in performing a blood draw until Donna was properly included in the process:

Oh, it hurt like hell! ... Oh, I was in such pain!

Oh yeah, one nurse came at me, she goes, "Okay, I'm gonna do your test." And I said to her, I said, "I'm a user, IV user." I said, "So, when they see needles, unless there's something going IN, they'll run!" (laughs) And she, she just didn't listen to me whatsoever. And she poked me about three or four times. And that's one nurse. Then another one came, eh, cause she was having problems. I had three of them on my arms. And I kept going, "Ow, ow, ow, ow." And then finally this older nurse came in and she goes, "What's going on?" I said, "They can't get anything, nobody's listening to me. I'm a user, I'm an IV user, I know where to go. Nobody's listening to me." So she says, "Okay, leave her be." My arms were blue!... And uh, nothing was coming out. And I told her, I said, "I'm a user." I said, "If you just listen to me for a half a second, I'll tell you where to go!" She goes, "Okay, I'll listen to you." So I showed her where to go, one of my old-faithfuls. And she got me right off the bat.

Donna noted that the nurse who was successful in performing the test was successful because she listened to Donna and did not disregard her because of her drug use.

She goes, "See? If you listen to people-" She says, "Don't forget." She said to the other nurses that just because we're users doesn't mean we don't know what we're talking about, we don't know our bodies.

In Hannah's case, the experience led to her leaving a future testing situation when she learned the same provider would be administering her test again:

(Indicates arms) Well, as you see, I'm not a user. Okay? I'd pass out. I look at the girl and I say, "Listen, don't use a full syringe. Use a butterfly needle. If you use a butterfly needle, you'll get me the first time. Use a regular needle, you're gonna have to be digging for gold." "Oh no, I'm good at this." Sure enough, she dug for gold! And my arm looked like I had been, literally, like this (indicates forearm), like I'd been using. It looked like I literally was using! I actually had a friend of mine say, "You're not on the needle, are you?" I said, "No, no, no, no." Oh yeah. Second time I went back, I went back about six months later. This time she wanted to tackle this arm [indicates other arm from first test]. I looked at her, I said, "You've got to be fucking joking me!" She says, "What?" I said, "No, no no. You did it to this arm the last time. You're not doing it to this arm this time." "Well I'm the only one that does it." I said, "Well then I'll go back to [name of another service centre] at another time. Bye." And I [left]. There's no way an Aboriginal, a woman wants to sit there

and get dug! When you're telling somebody, this is my body, I know how it works, I know what it reacts to. You stick a big fucking needle in my arm, my veins are gonna go, poof, gone! They're playing hide and go seek and you're not gonna find it. Use a butterfly needle, which is thinner, little longer, it's more, not so intrusive. You know what I mean? And my veins just go "Hallelujah!" You know? But you fucking poke me with a regular needle, man, you might as well be digging for fuckin' next year. Cause they're not coming out for nobody. (laughs)

4.7.3 Lack of Support and Information during Results Delivery

While the perception of support and kindness during the test was described as extremely important to the women, these attributes were also important when they were being given their test results. Christina described feeling "numb" while she received her results, and felt that everything that was going on her life made it difficult for her to process her results:

I mean, I was young, and there was a lot going on the very first time. Um, I think I was a little bit in shock with the whole situation, so a negative result was not, you know, as important as it would be (laughs) now for me. Back then it was kind of just a numbness. So yeah, I didn't have much reaction at all to that.

Lisa, who received a positive diagnosis, reported not being given any support or information when her results were delivered:

The nurse could have at least pulled me aside and talked to me. But she didn't, the nurse that uh, gave me the results, but she didn't, you know? She didn't even ask how I felt or anything and this and I was just left with that big open void.

Mandy felt that she was judged by her provider when he gave her the test results. She also reported not being given any information and having to ask a family member for information about what to do after her test:

Um, it was okay, but his demeanour, he's like, "Oh, you're one lucky girl, you don't have it." And I'm like, "What the fuck?"

And thank god, like, she [her aunt] knew about it so I went and talked to her, you know? Cause he didn't give me nothing. Nothing at all.

4.8 Recommendations for Improving the Testing Experience

4.8.1 Greater Choice in Terms of Venue and Type of Test

A very strong recommendation from women was the need for more venues to offer testing and greater choice in terms of the testing process itself; people should have many options regarding where to get tested. Alison felt that this should be done by offering point-of-care testing more widely:

Well, I think that more agencies should offer point-of-care. A lot of times, let's face it, um, you know, our clients, especially clients with addiction issues, don't always make it to the hospital ...for the people that don't make it there [the hospital], it's good to have it, you know, like, even with us [her agency], you know? Being able to offer it more, you know? Having more opportunities out there where they can be tested.

Jamie felt that having more places offering testing is essential because it is important to test people when they are ready to get tested. If they are required to wait, the opportunity may pass:

And I think that um, women who are having problems, like, getting tested, and I think it would be better for them to be able to just walk in somewhere and get it right then and there because if they call to book an appointment and say, you can't get an appointment [until] a week from now, then they might change their mind by then.

I think it's just um, the not having it like, accessible right away. But most places you go, you have to wait for an appointment. So I think that's a really big barrier, for sure.

Zelda also expressed a desire for faster testing, suggesting that patients should be able to test the day they are prepared to do so:

So if you were to ask me about any way to improve it I'd say you know, faster testing. You know, maybe do it on the spot.

Cause my doctor had to, had to get the requisition, or I had to go to him to get the requisition to do it, I don't think I should have to do that ... I should be able to go in and be tested on the spot and find out the same day.

Christina agreed with this sentiment, stating that more mobile testing options would be ideal, because testing could occur immediately and patients would not have to go out of their way to get tested:

I would almost treat it as a... van. ...I mean, on a good day, you could probably get someone in to, you know, into the whole vibe of maybe getting tested if it was to them. But they're, at this point, not often do I see very many people go out of their way to, to get tested.

Similarly, Zelda felt that patients should have more opportunities to access testing that does not require them to wait so long for their results. She suggested that a shorter wait in the future would make the experience better, indicating a need for greater availability of point-of-care testing:

I would have preferred maybe to hear about it faster. Instead of waiting like two, three weeks. Because you're like on pins and needles until then.

I think it shouldn't take that long, you know, to hear back... Because, like, why would you do it in the first place if you didn't wonder about it? ... I just wish it was faster. Result time.

Hannah suggested that there should be more opportunities for anonymous testing, particularly outside of regular business hours, as she felt the lack of options could lead to procrastination:

You know? Like, I would love to see a safe place for women to get tested besides the [name of mobile service] ... You know they can walk in, they give a number, they don't have to even give their name, give a number, and get tested.... You know? It's the same thing as the [name of mobile service] but... a lot of girls don't want to walk into a clinic, they want to do it when everybody's asleep, type of thing, you know?

And then half the time when you've got working girls, trade workers, you've got drugs. So if you know, they get tied up with a date, then they run to their dealer, then by the time they think of it... You know? "I'll do it tomorrow."

Stephanie felt that having more opportunities to undergo an anonymous test could help make patients feel more comfortable, stating that this option would have been helpful for her:

Um, being offered an anonymous test might have been nice... Cause I wasn't offered that. I didn't straight out ask for it, but it would have been nice to have a couple of different options to maybe help me feel more comfortable.

Jamie also felt that some patients may not know where they can go for testing apart from their family doctor's office, which could contribute to concerns about privacy:

Or maybe even not knowing where to go besides their doctor's office... Yeah, maybe making it more like, known, of like, you know, this clinic offers HIV testing at this clinic... Or maybe going to a clinic that's just for women. Yeah, or maybe like it's another barrier that they don't wanna go somewhere because maybe they're afraid of seeing somebody they know there. Stuff like that.

4.8.2 Need for More Culturally Appropriate Services

Another strong recommendation from the women was the need for more culturally appropriate HIV testing services. Nearly all of the women spoke about the lack of services just for Aboriginal people in Ottawa, and the particular lack of services just for Aboriginal women. Only Lisa felt that there were enough testing services available in the city, but she acknowledged that she felt this way because she was not looking for testing services since she had already been diagnosed with HIV:

I think there's enough services. For them if they want to know whatever it is. There's one, [name of community centre] ...they got their own nurse, they got their own office and nurses there too, so. I think there's enough... Like I said I think that, for me, I think that, because I have it, so there's no reason for me to uh, even bother looking anywhere. I just know how to look after myself.

Among the women who were looking for services, there was almost universal agreement that there are insufficient HIV testing services available for Aboriginal women:

***Donna:** They don't have enough places for Aboriginal women! ...You know, like we're all pushed into the background as far as I'm concerned... There's not enough places for, for Aboriginal girls to go to where they can be comfortable and talk to people.*

***Hannah:** But it's hard. It's hard when you're Native and you're in a city of white people and you have nobody but another drunk Native beside you to help you. There's nothing there for us. We have [name of community centre]. We have [name of community centre], that's the only thing we have.*

Hannah spoke a great deal about the need for more culturally appropriate services. She felt that there is a substantial disparity in the number of services available for non-Aboriginal women compared to the services offered to Aboriginal women:

...but really you don't have a lot out there just for Aboriginal women... You have a lot for Caucasians, to say, I'm not being prejudiced...but it's true. Caucasians, you've got shit loads of stuff out there for them. But strictly for Aboriginal women? ...You got [name of community centre] That's what you have.

I think there has to be some added services in there. Don't get me wrong, the services that we have, they're okay. But it's nothing compared to what a white woman has services for. You know what I mean?

She also stated that the absence of services keep Aboriginal women from getting help that they may need in order to protect themselves from potentially high-risk situations:

But there's nothing there for us to catch them. And that's the frustrating part is because there is nothing there.

Nobody is stopping to say, when they see a Native working girl, saying, "Hey, do you need a hand?"

She suggested that for some women, they may feel unwilling to access services that are not just for Aboriginal women, so there is a need for more services that they feel comfortable using:

Native women don't want to, you know, be waiting outside a white van in the middle of the night to get tested... But they also don't want to walk into a man's, a white man's clinic... And say, "Can you test me for HIV?"... And that's sad, we shouldn't have to, we shouldn't be, we shouldn't have to feel uncomfortable to be tested... But a lot of the girls are uncomfortable or, Aboriginal women, they are very uncomfortable when they're getting tested in the same line as you know, Caucasians... You know? And I really think that if there is a place suited to Aboriginal style, then I think you would see so much more activity.

She also indicated that this increased comfort could help women to speak more freely about their needs:

As I said, having more of a Native shelter, or Native, uh, not so much a shelter, just a Native drop-in that's just strictly for... See, here [community health centre], when it's just women? We talk about a variety of things. Everything and anything.... But I know some of the Native girls, they don't open up too much... Because of their culture... I think, I honestly think, that if they're, if they're taught better, if they're taught more, and there's more of an Aboriginal, I guess circle, you could call it? ... I think you'd see a heck of a lot more involvement.

Mandy agreed with Hannah that there are considerably fewer services offered for Aboriginal women than for non-Aboriginal women. She suggested that health services for Aboriginal women need to be more of a priority:

I think Aboriginal people should be first priority and I think, like, I'm not trying to be racist, um, like, Aboriginals should be a priority like, at the clinics, right now, if it's an Aboriginal clinic. Yeah, I get they help other people and that's okay. But first, focus on your own people and you know, let the other, like, the other people can wait, instead of waiting two years for a doctor, do you know what I mean? That Aboriginal family might need it, they might have HIV and nobody, they don't, you know? ...And I don't care, everybody's saying Ottawa's the place to go if you're a Native, yeah, it might be, but the services are shit. Really bad.

There's not enough, especially in Ottawa there's not. There's one, what, clinic? [Name of clinic]. And I've been on the waiting list to see a doctor now there for two years, so. Yeah. They need another centre like that. And they know, they're even saying that more Aboriginal people are coming to Ottawa. Well, what are you doing? We need a, we need doctors, you know what I mean?

The women also noted that they would like to see more Aboriginal personnel in locations that offer testing. They felt that having Aboriginal staff present could help patients feel understood and comfortable:

***Donna:** Yeah, more workers that are Aboriginal, you know? ... Yeah, the Aboriginals are more comfortable being with Aboriginals.*

***Hannah:** Um, I think they should have more counsellors... Um, more sex trade counsellors... And possibly more sex, alcohol... counsellors... Uh, because those, those ones there are, are the most, if you're not on the street and don't have the money, you don't do drugs... If you're not on the street, you don't buy booze, you're not an alcoholic. These are things that we need to do, and to base it on our heritage. Not, sorry to say this, white man's heritage. But our heritage.*

Jamie suggested that the services offered at Aboriginal testing sites should be tailored to the needs of the Aboriginal community. In particular, she felt that there should be more opportunities for counselling:

I think that maybe there should be some difference because like, HIV is more common in Aboriginal women. So is a lot of other things... Violence, addictions, suicide. It's a lot higher in Aboriginal women than non-, so I think that's why they should have like, some sort of different service. Um, maybe more counselling for them, is one of them.

Like, definitely it needs to involve more, like, education, for sure, on HIV, um, and like, counselling for sure afterwards.

The women identified a number of benefits that could result from offering more testing services for Aboriginal women. Many of the women reported that Aboriginal women are likely to feel more comfortable being tested somewhere they feel their culture is understood and where they are surrounded by members of their community. Alison mentioned that having somewhere to go for healthcare where patients can incorporate their traditions could make them feel more at ease than in traditional healthcare settings:

Yeah, I think um, having more, like, Aboriginal-based uh, like agencies and drop-ins... Having it more welcoming for, you know, First Nations, Métis, and Inuit women.

Well, I think that hospitals can be very like, they're not very personable, they're very like, blah. White walls, grey walls. Uh, not too many people like hospitals. I think like, drop-ins and other organizations, if we're talking about, you know, Aboriginal women, you're gonna feel more welcomed going into a place that is like, culture-based, you know? Someplace where you can go and smudge or whatever you may want, right?

Christina and Mandy supported this idea, stating that most Aboriginal women feel comfortable being in a setting that is just for Aboriginal people:

***Christina:** I find that most Aboriginal people um, feel comfortable in their own setting... It's a comfort for them. So, it still leaves the traditional aspect of things. You know? I think that would be quite beneficial for the Aboriginal population.*

I don't know a lot of people, Aboriginal people, who go outside of, I mean, there's a medical clinic right in [name of Aboriginal health centre], probably the majority of people I deal with or know personally have their doctors there. They go to programming there. Everything's done there. Not often do I see people unless it's to, to a rehabilitation centre, do they gear out of that [Aboriginal-specific centres]... So if you say there's a clinic downtown, the public health or whatever, not many people, in my community anyway, are gonna go there. They're gonna go where they're comfortable.

I think it would have to be much more um, how will you explain it... open-minded? Not so clinical, more, almost more spiritual to be honest. They go a lot off of, even body language, it's important, you know. I think a lot of Aboriginal women feel judged as it is. That's just uh, there's a block-up for sure, especially if there's someone outside the race doing it. So if you were more kind and more, you know, open, open-minded, then yeah, that would definitely help... If it's more of a clinical setting, and a clinical or medical (laughs) mentality, then you're probably gonna have a little more (laughs) resistance from, from the women.

***Mandy:** I think it feels more comfortable because you know where you are, you know what I mean? Whereas if you just go to a regular medical clinic, and, people might be staring at you or whatever, making you feel uncomfortable.*

Hannah stated that offering more culturally appropriate services would help women to feel that they are in safe spaces where they can be more open:

You give us Native girls a chance to go somewhere where it's safe, secure, with our, with our tribe. Or tribes. Let us feel comfortable with other Native people and say what we wanna say.

We need something that's, that the Aboriginal women know it's theirs... And feel safe and comfortable because there's other Aboriginal women there... That they can talk to, that they can communicate with, that they can understand, they can - you know? It's, it's hard for an Aboriginal woman to walk into a white man's centre and say, "I need help."

Stephanie supported this idea, stating that more choice is required so women who are more comfortable being in a culturally appropriate setting can have that option:

I think there's a lot of benefit to having culturally appropriate services. Um, I think with, with HIV testing it's about getting the person where they're most comfortable, and that, unfortunately, might not be in the community here. So I think it's not like a one-solution-fits-all type deal, I think having those people is so important. Um, but it's not gonna be kind of a one, one-solution-fits-all. ...More choice, absolutely! So that the person can go where they're gonna feel more, most comfortable.

Hannah noted that while Aboriginal women are technically allowed into women-only drop-in activities, these activities can be isolating for Aboriginal women if they do not see other women from their culture:

[Referring to women-only drop-ins] "Oh, well you're a woman, you can go too!" How the hell do I know? I don't know that I can go there. And you walk in and there's a bunch of fuckin' white people sittin' around the table, you're going, "Yeah, okay. (Pause) I'll just take my coffee and go." You know?

Consistent with Hannah's statement, Christina reiterated the importance of comfort, and stated that a major component of helping women feel more comfortable is making them feel understood. She felt that testing in a culturally appropriate setting could help women to feel that their experiences and culture are understood, which may in turn make the testing experience more acceptable:

I mean, any Aboriginal person, especially today, feels more comfortable if there's someone who knows, you know? The culture, and the history. They just feel more, you're gonna get a lot more receptive.

Donna and Mandy felt that if more services were not added, there would be negative consequences for Aboriginal women. Donna stated that as Aboriginal service centres have closed in the last few years, more women have returned to issues from which they were previously recovering, while Mandy argued that the closure of services would keep women from feeling they had anywhere to go for testing:

Donna: *They closed down [name of Aboriginal service centre] there. You know? And that was a good place! And they were all going there! You know, they were going there to get warm, to have a warm meal, and, and now all of a sudden, boom! It's closed. It's no good. It's not right. You know? Girls are going back to the streets, going back to the alcohol, and uh, they're fighting a losing battle in my eyes.*

Mandy: *They're closing so many centres and there's nothing there for them anymore. There's nowhere for them to go. So if they have HIV, they don't care, they're not gonna get tested. They're just gonna go out and go about their daily thing.*

Hannah agreed with these statements, stating that more Aboriginal women would be able to avoid potentially high-risk situations if there were more supports in place to help them:

Yeah, I think if there were more services, and more Aboriginal services, for the Aboriginal women, I think you would see a lot more being cut back on the streets... The trade workers? I really do. And I think you would see a lot more trying to stay off the street, trying to get their life together... But you can't, you can't do that if there's nothing out there for you.

4.8.3 Increased Opportunities for Testing Initiated by Healthcare Providers

In addition to offering Aboriginal women more venues in which they can be tested for HIV, many women also indicated that there is a need for more provider-initiated testing. While some women may be able to request a test themselves, other women may be unwilling or unable to initiate their own HIV test due to many of the barriers mentioned above. For these women, more occurrences of providers offering an HIV test rather than requiring the women to ask for a test may help to increase testing uptake. Alison illustrated this point, indicating that it can often be challenging for women to request testing:

Cause a lot of times people don't want to ask, right?

Jamie suggested that providers could be using medical appointments as opportunities to engage with patients about why HIV testing could be a good idea:

I would just keep referring like, back to like, an Aboriginal health centre... So they could, you know, like their, like a team that you know, like their health team could, you know, advertise it more. Offer it more, maybe at medical appointments. Ask you know, "Have you ever thought about..." "These are maybe the reasons why you should..."

Christina supported the idea that testing should be offered at regular medical appointments without patients having to ask for it. However, she also acknowledged that some of the women who are most at risk may not be getting regular medical care, so relying on a family physician to offer testing may not be appropriate for them:

[B]ut just a regular physical, I think, if it was included in that, then that would probably save a lot of people. You know, nobody wants to go in for an HIV test. If it was already included in your physical – but then, that's even making sure that people are getting regular medical attention, and that's not even the case... So I'm pretty sure a lot of people, if you're targeting Aboriginal people, that they don't regularly go to the doctor.

Stephanie felt that having providers offer testing to all patients could help to reduce the perceived taboo surrounding HIV. Offering patients an HIV test normalizes the testing

process, and may help to reduce the sense of shame around disclosing engagement in HIV-related risk-behaviours. By letting patients know that HIV is something that can be spoken about openly, patients may be more willing to engage with the provider about their testing needs:

[A]lso just engaging people, having conv-, open, honest conversations with people, like especially in the medical field and the social services field with Aboriginal people, just having a more open dialogue about HIV to maybe try and um, demonstrate to people that this is not a taboo subject, this is something we can talk about, just like we can talk about... syphilis, for say. You know? Like, you know, a doctor's not, you know, cautious to bring that up with somebody, you know, in terms of testing, but you bring up HIV and, you know, it makes people feel uncomfortable or people don't feel well-equipped to talk about it. So I think education for providers too, who are serving Aboriginal populations could be amped up quite a bit.

Similarly, she felt that it would be wise to have providers build their capacity in their ability to bring up the subject of HIV with patients in order to help reduce the mystery and fear around HIV. She felt that this could be useful in helping providers discuss HIV with all patients, including those who they do not immediately perceive to be at high risk of HIV infection:

And more just, being open and honest and talking about it more. And I, cause often, you know, when you're getting your regular bloodwork done, your annual physical, that should be something that's talked about or offered or at least spoken about to the patient. And not just if you disclose something that puts you at risk. It should be something that's kind of about your, your regular healthcare. Just like you do your bloodwork and your Pap smears and all this other stuff.

And again, just have, like, talking about it more so when it does come up it's not just like, such a big, scary subject that you have to broach with somebody, that it's something that you're comfortable talking about and you're able to engage people in talking about it.

I think again it's about engaging people around the topic. Having it be a subject that's talked about, kind of to a variety of different types of people and not just kind of people who use drugs, or women in the sex trade, those are the only people you're talking to HIV to - about HIV with. I think it's something that practitioners and doctors and nurses and social workers need to build their capacity on so that they feel comfortable talking about it. Cause I think that's where a lot of the, the work stops is because the professionals aren't feeling that they're capable so they're not bringing it up with patients on a regular basis or across the board, or offering these services to people who aren't presenting with that sole uh, concern.

4.9 Recommendations for Increasing Testing Uptake

4.9.1 HIV-Related Education Opportunities

The women felt very strongly that providing Aboriginal women with more education about HIV and testing was key to increasing testing uptake. Many women spoke about the need to provide Aboriginal women with information about what HIV is and how it would realistically affect their lives. Alison spoke about her own experience with learning that rates of HIV are higher among Aboriginal women than among non-Aboriginal women, and how this realization led her to believe that there is a need for more HIV-related education in the community:

And maybe like, more education on it, cause I think some people like, they may not, I know just recently I found out that like, HIV is more common in Aboriginal women than it is in non-. So I think maybe like, education? Educating people more on that?

Irene supported this idea, stating that because there is so little conversation about HIV, there is a consequent lack of information available in the Aboriginal community, so education needs to be offered:

Yeah, if it was just talked about more, like, in, in a different context. Like, nobody, okay, if there was more commercials about AIDS, then, or, how to prevent uh, getting it, or little workshops on it, I think it would be really helpful and it would be talked about more... But nobody thinks about it. Hey, nobody's ever done workshops for AIDS... How to help yourself if you have it. How you should get tested for it. So nobody talks about it.

Stephanie stated that she regularly hears misconceptions from Aboriginal women regarding transmission, and felt that more needs to be done to correct these beliefs::

Like, for example, you know, you can't share a straw, or you can't share a toothbrush with your family member, or you know, if someone's mother gets diagnosed then, you know, those are kind of questions or myths that uh, someone in the household might have and that they would need kind of answers and support around.

Kind of combats some of those myths that are out there, some of the misconceptions and misinformation that people have. Even around um, how do you contract HIV? A lot of people have really weird misconceptions like, if they kiss somebody, I'm at risk, so just kind of debunking some of those myths.

Christina felt that there was a need for more information about the realities of living with HIV. She suggested that many people in the Aboriginal community perceive HIV as a death sentence and that there is a need to change this perception so that people would be more willing to get tested:

You want to know what would be beneficial too? Letting people know that it's not the end of their life... If they were to contract HIV, cause I think a lot of people just, especially, especially people with a language barrier coming off of, you know, remote areas and stuff, think that it's just it. You have HIV and then you die. Right? So maybe more knowledge on the fact that there's medications, that you can still live a very long life.

You're looking at, you know, a younger population should know that for sure, because a lot of them are using needles and, and stuff. But then also, too, the women, the sex trade workers who are... you know, I just think that just knowing that it's not the end of the world would be, you know, maybe it would help someone wanna get tested, get on medication.

Mandy suggested that a potentially effective way to provide this information would be by having people engage with someone living with HIV as it would give people a clearer picture of what life with HIV actually looks like:

Mandy: *More counselling, um, availability, some understanding, maybe even have somebody that has HIV to go in and talk to them.*

Interviewer: *Mm-hmm. Mm-hmm. Do you think that would be helpful in changing attitudes?*

Mandy: *Might not be. But maybe they could see and, you know, get a feel of what's going on, you know? Instead of just judging.*

Stephanie argued that education about HIV should be offered more in tandem with information about harm reduction. She noted that particularly for Aboriginal women who are originally from small communities, harm reduction information may have been inadequate in the past, so more needs to be done to help them reduce their risk of infection:

I've heard from people that, uh, you know, uh, who've, who I've gone through the process with around testing, to say that, "Um, you know, I'm not going to allow my body to be a host for this disease." So, I think there's also just not a lot of education too, on reserves, like people who've grown up more isolated didn't really receive any kind of information about HIV or transmission or sharing of, of needles or crack pipes or whatever that may be. There's just not a lot of information given to those people. And then they come to a big city like Ottawa where we have a lot of, you know, we have higher rates of these diseases, and uh, it's their first time kind of coming in contact with, with that system.

She also believed that more time should be spent providing information about HIV when they access harm reduction services such as needle exchanges. She stated that giving clients insufficient time can frustrate people and keep them from asking questions or sharing information about their own potential risk-behaviours:

I think one other thing that could be addressed is some, some of the needle exchanges that are happening, that are happening at Aboriginal health centres where people are, are engaging in those services but are not being given enough time. I know, I've heard that, you know, some of the needle exchanges at the Aboriginal agencies, the, because it's not a priority for them, because it's, it's, it's being staffed by someone who's doing ten different other things at the time that people are waiting like an hour to be seen. They're not staying, they're leaving, and then when they are seen, they're so fed up from waiting that they're in and out within a few minutes. And they're not

getting that teaching and they're not getting the information about harm reduction, and safe use, and not sharing, and your risk, and they're not getting the right services. For the Aboriginal community. Other needle exchanges in the city, there's, they're staffed. You're not gonna wait an hour to be seen. You're gonna get that time with the person who's educated and knows what they're doing, who knows about harm reduction where - for example, at [name of Aboriginal agency], it's run by a lab technician who has no experience in harm reduction, in social work, in, in anything related to HIV or Hep C or infectious disease control... You make people wait for an hour, by the time you see them, they're so fed up they want in and out of there quickly, they don't wanna sit and talk to you about their HIV risk or sharing or any questions that they might have about sharing.

In addition to a need for more education about HIV generally, the women expressed a desire for more information about HIV testing. Christina felt that there needs to be more information available about how an HIV test is performed, as she thought a better understanding about the test could promote testing uptake:

Um, I think the process would have to be explained. If it was a positive result. Or even, to let them know that it is just a simple blood test and that it's not this invasive procedure that's gonna (laughs) you know what I mean? Maybe just the, the general knowledge that it's quick and easy. And it really doesn't take up much time.

Mandy agreed with this, stating that currently women are not given enough information about what HIV testing entails:

It makes women like, a lot of people, whether you're Aboriginal, you're a white Canadian, or you're just, anything. It's scary. You have a doctor sit down and be like, "Oh, we're doing this test on you." No information, nothing. Like, maybe have a couple info sessions and then have the testing at the end. You know what I mean? Like, a full day course where you know, there's other people there, like, different ranges, different races, and then at the end of it be like, "Okay, who's ready to get tested?" You know?

The women offered a variety of suggestions for how best to disseminate information about HIV and testing. Alison, Christina, and Lisa suggested that handing out pamphlets of information would be ideal as they would reach a variety of people:

Alison: [M]aybe like a little pamphlet of info? For them to read. Just stating like, facts, something simple and easy... Doctor's offices, walk-in clinics... Any healthcare centre.

Christina: I think um, putting different pamphlets in different community settings, even on the street, even handing them off to our programs, [name of organization], or [name of other organization], or just, different things that are targeting, especially women at risk for HIV. Um, so that we could hand it out. I mean, I think it's a better chance. Because a lot of people don't have the same accessibility that other people have.

Lisa: What can be done about it is uh, you know, let the, give out information about HIV like, you know? Like, written information, like, it's not contagious and it, if you touch somebody or something, then it's not contagious like, and write out a little uh, pamphlet, is, a little pamphlet is something saying, "Hey, you know, it's no different than cancer or something like that." I mean, I think it would be uh, an idea.

Stephanie agreed that written information could be effective when face-to-face sessions were not possible, but noted that it is important to bear in mind potential literacy issues that may come up among clients:

I think face-to-face is always the best. But not everybody has the resources or capacity to do that. Um, I think for Aboriginal people, like, when you're giving information it has to be put into a context that makes sense to the person, whether that's, culturally makes sense, language-wise makes sense, um, people who have no idea about HIV, who have never ever met somebody who has HIV or ever thought that they're at risk, um, you know making sure that the information and the language that's used is easy to understand for people. People we know, our community has very low literacy, so.

A number of women also suggested that HIV testing should be introduced in schools so that children are informed about it at an early age. Christina, Irene, and Stephanie spoke of the need to educate early, with Stephanie noting that attitudes need to be changed over several generations:

Christina: *So I don't know, maybe more sex education? It should be included... I mean, they start sex education in grade six, that's eleven. So maybe that would be a good... Knowledge is good no matter what. Knowledge is powerful.*

Irene: *But you gotta think about it. They're not taught these things. On the reserve, we weren't taught any of this stuff, man. We were lucky if we were able to go to school with shoes on our feet! You know, and then when they, they come, they move into the city, it's a big city, like, but they still don't care about AIDS! ... Um, but you have to make them aware at a young age. Because then when they grow up in life, they're gonna talk about it more because they're more aware about it.*

So I think actually, I think it should be talked about more in school, that's where it should be started ... is in school. The younger you're taught about it, the carefuler you'll be and uh, people will talk about it more freely but now it's like, "AIDS? Hush-hush, don't talk about it! We don't wanna know it's, it exists." ... But if it was brought up, it would, like in school, and in hospitals and in, just in centres like this [community health centre], it would be a lot more helpful.

Stephanie: *But I think that the shame is so deep that it's gonna take kind of, generations to overcome. Um, that. And it has to start kind of in schools with children, kind of starting a new generation where there's gonna be an understanding about it and not so much shame and guilt and fear and stigma.*

In addition to educating in schools, Christina also felt that HIV testing information should be brought up in every harm reduction context in order to ensure people were getting the information they needed:

Yeah, I believe that it should be put into certain programs. There's a lot of programs that most women go to. Even um, I think a lot of the rehabilitation, like rehab? Um, even detox, like even the, I don't know, I think it should be brought up in every program that they offer to do with any kind of harm reduction.

Mary believed that education was important, but described feeling unsure how to bring up HIV testing or harm reduction with other people in her life, suggesting concern that she would seem judgemental:

...but with people that I'm in contact with now, which is a very different lifestyle, which does consist of drugs and prostitution, I'm not sure how to (pause) go about having a conversation of being safe and whatnot.

Hannah described the consequences of not offering more educational opportunities about HIV. She stated that the lack of knowledge in the Aboriginal community contributes to stigma and fear and prevents communities from being able to address the issues associated with HIV:

I think uh, older people have to be educated... And that's the thing. The, the Native, the Native society is more or less cut off. Okay? Unless something is pushed... But a lot of the Native is cut off to what Aboriginal women, and even some Aboriginal men, go through... You know? They, they turn a blind eye. "You, you do that, you're out of the tribe." What? Because they're not educated. They're scared.

Cause they really, and a lot of the older Native Elders don't want to know about it... Cause they don't understand it... And the reason why they don't understand is cause they're not educated... And because they're not educated, they don't know what to do to help people in their tribe, to help people in their society, to help, you know? They don't know what to do!

4.9.2 Community Engagement around HIV Testing

Several of the women felt that an effective strategy for increasing testing uptake would be to engage Aboriginal women more in the process of HIV testing. Donna argued that Aboriginal women should have more opportunities to get engaged in community projects and activities aimed at helping Aboriginal women get tested, particularly as many women have lived experience that could make their insights more valuable.

But, I've heard that they have, uh, you know, yeah, they have meetings and stuff, they should be more uh, how would you say that... um, advertised! ...You know? Cause I know a lot, like there's myself, and there's another girl, [name of woman], both of us, our tongues are not in our pocket... We like to go to meetings. We would have lots to say over there... You know? To listen and we give our points of view, points of view, you know? And, believe it or not, there'd probably be a lot of working girls that would listen to what we have to say because we're both ex-working girls... And we

both are clean... So it's not like we have it, or you know, we're not infected with it, and they'd say, "Well, fuck, you know, they worked all those years ago and they're still clean."... "Well what did they do?"

Hannah felt that community engagement and cooperation was essential for alleviating the impact of HIV in the Aboriginal community:

I think it's just more or less reaching out to the older ones. At some, you're gonna find conflict there, you're gonna find stubbornness, you're gonna find, "No, we're not doing this, no, we can't, no, we don't want to." Because of the fact that we're Native. We're proud. You know? And you start bringing in HIV into the tribes, and they're just gonna, they're gonna turn their back and say, "Fuck off." But if you do it non-pushy, I guess I could say. If you're not, there's a way of dealing with Natives, and there's a way of dealing with white men. Natives, you push something on a Native, Native's gonna go, "Fuck you!" and they're gonna turn the other way. You bring something to the table that a Native will be able to understand and wrap their brain around it, you've got them.

If you work together, it's like a Rubik's cube. Okay? It's all messed up and you gotta try to put it all back into the same colour. Well, that's kind of like a Native. We're all fucked up. And yeah, we, we can be put back together, but it's not by tearing off the stickers, it's not by taking it apart. It's taking your time and molding it. And letting us grasp what you're trying to teach us and tell us. We can grasp it, we can understand it.

Hannah also pointed out that the high respect with which Elders are regarded could be used to encourage people to test by engaging Elders in the process:

I really think they could! I think the Elders would be such, such an improvement... Instead of chastising the young ones that are actually saying, "Come on, let's see if we can do this." ...More people, Aboriginal people have the highest, most respect for the Elders... It doesn't matter if you're drunker than a skunk; an Elder walks by and they say hi, you say hi back. No matter what! ... And I really, really, really think if more Elders are involved in the system of trying to get more Native women tested and treated and, you know? I think if the Elders were more involved, I really think you'd, you'd be surprised how well it would actually take.

No matter what you do, no matter if you're stoned, you're drunk, or you're laying on your back, Elders are the most important people to you... And even though we might forget about our heritage because we're ashamed of what we've done, we still have that little bit of Native still there saying, "He's the Elder." ... He has to be respected. He has to be acknowledged... You know? So I think if Elders were really involved and I think if more Natives were strictly involved, I think you'd see a really good turn-out.

She believed that the first step in this process was extending invitations to Aboriginal community members more often when sessions are being held to discuss HIV:

I think more education, more seminars... More invitations for the Aboriginal Elders to come... And to listen.

Yeah, because, I mean, how often, how often do you see um, a conference happening and you see Aboriginal Elders coming in? ... You don't! You don't see that! ... Why? Because 1. They weren't invited. 2. They don't know what to do.

But that hand is never reached out. And I swear if that hand is reached out and extended in friendship, and understanding, and willing to train and teach and learn, they're gonna be handing a hand right back... We're always ready to learn, we're always ready to understand. But nobody includes us into it... And unfortunately, our culture, our hand, that hand doesn't get extended too often. And that's, the open communication has to be there, there has to be a line of open communication there. Between the Native, Native society and the ones that are trying to help.

Mandy supported Hannah's suggestion, stating that more needs to be done to ensure that Aboriginal women feel welcome and able to access services to meet their HIV testing needs:

You know, even people like, casually, like I hear people casually joking, but it's, no, it's not a joke, but, you know, you don't sit in the clinic and be like, to your girlfriend, "Oh, I'm gonna get an HIV test." And, you know, you're being serious, but she thinks you're just pulling her leg, you know? People can't be taken serious with that and I think when most people find out they get scared because they don't know anything about it. And I think we need to be educated more. Like I said, if they wanna start testing Aboriginal people like, do an info session or like, go, you know, go, bring it to their ceremonies. But ask them if it's okay and at the end if they wanna get tested, go

for it. And if they don't, at least leave them your contact and be like, "Hey, I'm here if you wanna get tested in a month." You know? Make them feel like they're wanted. Because they, honestly, Native people don't feel wanted.

4.9.3 Increasing Access to HIV Testing Services

Several women spoke about the need for more accessible testing. Many women are unable to access testing, especially if they are not regularly seen by a physician. Jamie felt that this was especially true among women who were dealing with addictions who need to have more accessible testing options so that they can be tested any time they feel motivated to do so:

Maybe, I don't know, more outreach, like offering women like, testing, kind of where they're at? Like for, making it, I guess easier for them to go somewhere where they like, could get tested if they were under the influence of alcohol or drugs ... Instead of, you know, maybe they think like they need to be sober to go to a doctor's office ... But maybe like, having like, a ... mobile station where they could go ... Yeah, more options. More accessibility for them. And not just having to like, book an appointment and go to a doctor's office.

Similarly, Christina suggested that the best way to reach more people would be to provide more testing options that did not require people to go out of their way to access the services:

Making it more accessible. Like, without anyone having to, to go out of their way. I mean, if it's there, it's there. And sometimes even a ten-minute break of getting out of where they are, you know, where they're at, just for that ten minutes, is welcomed for them.

Mary felt that this could best be accomplished by having a place specifically for HIV testing, as it would allow more individuals to access testing even without access to a family doctor:

I think uh, the doctor's offices and the uh, the clinics. Um... or a specialized clinic, you know? "[Ottawa Region] AIDS Testing Area". You know, kind of thing? Um, because I'm sure there's a lot of people out there that don't have doctors. And perhaps want to be tested. So if there was something like that, then I think that would... And I believe that people would probably use that, too.

Stephanie suggested that in addition to more access to testing, people across life domains need better access to educational programming and support groups to learn more about risk and harm reduction:

Yeah, they used to have a lot more, in my experience, I notice that a lot of services have been decreased over the years. When I first started working in Ottawa there were a lot more um, you know, education groups, psycho-, you know, educational support groups, um, groups for people living with HIV, that were like, well-advertised, well-attended, um, you know, even I think like, starting prenatally when women are expecting, to talking about risk of HIV. You know, all across kind of all life domains. For example, seniors, there's a seniors group happening, maybe one day talking about you know, HIV education. Um, kind of just making it accessible for people kind of across the board.

4.9.4 Providing Emotional Support for Women Seeking Testing

The need to feel supported also emerged from the women's narratives, whether this support was from the person administering the test, from health centre staff, or from the people in their lives. The women recommended offering more support services around testing, and offering women counselling to make them feel more comfortable with the process. Stephanie suggested that providers should spend more time with patients discussing HIV testing and argued that more counselling should take place during the encounter:

I think probably spending more time with people. You know, getting someone in and out in fifteen minutes for HIV testing, I don't really think helps build confidence in somebody to, to access medical supports when they have that kind of need. And just really listening to what the person is saying. What their concerns are, what stigma they feel that they might face, or confidentiality concerns that they might have. Um, just spending the time with somebody to, to really go over it and find out whether there's any teaching in harm reduction that needs to happen or safe sex, or whatever that may be, but just to make sure that they take enough time with the person and not just kind of get them in and out as quickly as possible.

I think having a known support person for the community helps, like here we have um, [name of support worker and institution she is affiliated with], getting her

connected, like, knowing that she's the support person for people, like, getting, getting to know her before that's your situation. Do you know what I mean? So that you do know that there are support people out there, that there are programs that you can access for support. Um, but, you know, having those interactions and, and meeting that person kind of before, before you really need it. You know what I mean? So that you're getting to know that person, you're getting comfortable with that person, you're building rapport with that person.

She posited that the ideal testing experience would involve a great deal of support and information for the patient:

I think the best testing experience would be for them to be engaged with a support person who is well-informed about HIV, who, who knows the client themselves, who can support them throughout the entire process. Before, after, during. During that wait time, making sure the person feels supported and cared for and, and understood. And um, they don't feel isolated, and you know, they're just waiting for this bad news to come their way. You know? Um, yeah, and to have somebody who's engaged in the community giving information, running education groups, that like, they are the face of like, who you can go to if you have concerns about HIV in the community.

Mary corroborated Stephanie's statement that testing services should offer support and counselling for people being tested so they can discuss the process with someone before the test is administered, suggesting that this could help to make patients feel more comfortable:

Um, and as we're talking here, you know, even if they had like, somebody to talk to or a counsellor or something, of some sort, someone, to have that available, I think would be beneficial. I'm a chatter, so if I could talk through something with somebody and be able to walk out, you know, half an hour later and still feel, and feel a little bit better about the situation, put my mind at ease, I think that would be beneficial for people... Um, but I think as a whole, people look for reassurance... You know? Or comfort. Some compassion, right? Um (pause), I think counselling maybe, of some sort.

Support in undertaking an HIV test can also be at a more personal level. Lisa felt that having someone to accompany a person to an HIV test would be very helpful in encouraging people to test, citing her own experience of being tested alone:

Just tell 'em! (laughs) "Go get tested right now, I'll come with you!" You know? Take a person with you to go get tested and you know, have a, a buddy kind of thing,

you know? And go in and just get tested with somebody and somebody who understands, who's been there, to go, for them to go with and you know can help 'em afterwards when they come out. If they are tested positive, how to deal with it.

Okay, well for me, I dunno, I might change a little something about it. For me, the best thing, when I got tested was I just went in by myself, I think it's best you have somebody come with you. Like, you know, uh, a partner or friend to come with you so you have somebody sitting beside you that's close, that's a close friend and that. For your testing, if it's negative, that's great, if it's positive, at least you have somebody you can talk to. And then you can discuss it and instead of just going by yourself and walking out by yourself, that's the main thing.

But like I said, have somebody to come with you who you trust. And sit with you. And then you know, have somebody when you come out, like, have somebody with you when you come out. With, you know, if it's negative or positive. So you're not alone. Cause being alone is the worst thing, I found. Was nobody there.

In addition to support before and during the test, several women spoke about the need for more support after the test was over. Alison and Jamie emphasized the need for support services following receipt of the results, particularly if the result was positive:

***Alison:** And if it did come back positive, like how would the person deal with that? How would I deal with that? ...You know? I imagine they would have like, um, staff on site like, to support the person if it did come back positive... And then like, other resources, you know? Like offered for like, longer-term, not just like, for that day when you find out you're HIV positive.*

***Jamie:** Um, talking like, face-to-face, for sure, because like, you know, if it's a positive test, the person's definitely gonna need like, some counselling services or someone to talk to like, at that moment.*

Lisa shared her experience with receiving a positive result, noting that she was not able to recover from the news until she had someone listen to her:

Lisa: For about six months, nine months. And then finally somebody grabbed me aside and said, "Hey, I need to talk to you." (laughs) "Okay." So we talked and then I was okay after that.

Interviewer: Yeah. And what did they say that made you feel better?

Lisa: Listen, listened to me. She listened. And this is uh, just uh, understand my ... Problem... Yeah, she pulled me aside and she said, "This is not you. What's happening? What's going on?" And so I told her and then, then she understood and then, yeah.

Gina and Stephanie recommended offering people the opportunity to sit down with someone to talk to and who could support them long-term:

Gina: They need to be able to have, to be able to sit down with somebody and talk and then have somebody, somebody that's on their side... You know? Like have somebody say, "Yeah, I'll be your, your, your partner or whatever, whatever you're gettin' done, I'll be there through thick and thin!"... more of an outreach program or whatever. Having somebody that's gonna be in your corner for you... If uh, if uh, let's say, uh, they find out they got AIDS, you know, they're gonna need that person to be there, right to the END.

Stephanie: Yeah. I think some support services for sure. Like having a case manager or a social worker or support person that they can talk to and get engaged with because obviously there's a reason why they're asking for this test. They're at risk somehow or in some way and they might need support around that.

So I think that could help too, you know, having um, a specific worker that's uh, like a support person that's well-informed about HIV who could support somebody um, accessing uh, testing, support after testing, whether that be a negative or a positive result, just having some follow-up.

Stephanie also felt that follow-up support should be offered for people who received a negative result, especially for people who may be engaging in high-risk-behaviours:

Um, a lot more follow-up too, with people who, who may be engaging in high-risk activities that need education and support around those choices and that lifestyle choices that they're making.

The women emphasized the importance of having somewhere in the community where they could feel supported, especially when one's family and friends are not offering support. Donna described seeing many women whose families were not involved in their lives:

[M]ost parents if their daughters are on the street doing this, well, they've already kind of booted them out of the house type thing, you know? So who's there to take care of them? Nobody.

She spoke highly of the staff at a community health centre for providing much-needed support, both in terms of healthcare and in terms of social support:

You know, like they were really, really good to me. Yeah. So the way I figure it is, these girls here are good. They'll stick by you 100%. You know? ... And uh, you can tell them anything. You know? Which is good, which is, a lot of girls they don't have people to talk to.

Irene reiterated the important role community health centres play in helping women feel supported:

These guys give you lots of education, any kind you, they, you need, they pretty much have. You need a lot of community centres... I think that's the way to go, is community centres, to get the word out. Yeah. Because if we didn't have community centres, half of us girls would have nowhere to go... And I think community centres are the way to go. Like, stuff like this, the stuff we talk about here, you couldn't talk about in church, you couldn't talk about in front of your family... You know? Like, this is, I think, the only other place you could go is community centres, for any kind of support.

4.9.5 Increased Testing Promotion and Advertising

Some of the women spoke about the need to advertise testing or to offer it in unique ways to capture people's attention and encourage them to test. Gina suggested that HIV

testing should be advertised extensively in places that offer testing as well as in phone books and flyers:

It should be advertised! ...You know? In a phone book or uh, flyers, or um, on the pole [telephone pole] ... You know like, advertise, you have to advertise. Nobody really knows, you know?

Your health clinics. You know, uh, doctors, uh, you know, have, have flyers on the table...At your doctor's office, wherever... Medical centres, anywhere. Hospitals, on their desks, anywhere.

Donna suggested that there needed to be more outreach and opportunities for women to share their stories and accept help:

Someplace where somebody can actually come sit down with somebody, be behind closed doors and speak what they have to say... a lot of girls are shy to talk.

She also suggested that although there are places where women can go to talk about HIV and testing, many women did not take the necessary steps to actually get tested. More outreach is needed to encourage women to make use of the services that exist:

I'd rather hear people talk less about it and do more about it. You know? But uh, yeah, cause like now, it's more open than when, when I was younger...You know? But uh, they don't seem to reach for it... You know? It's the whole thing, they don't reach for it... They expect it to come right to them. But you can't have it come to you, you've gotta step forward first and then somebody will step forward to help you.

Irene thought that the only way to encourage more testing uptake was to make testing mandatory:

I think once you know you're, if somebody knows their pregnant, I think you should be tested... That's when it should start and just keep going from there. Or I think once you hit legal age you should be tested. You should, just like, uh, going to a court appearance, you know what I mean? You're 18 man, you gotta go in to get tested every six months now! That's how I think it would actually work.

Similarly, Mandy and Ellen thought that testing should be promoted by offering incentives for people who get tested:

***Mandy:** Or even that, like, community, like a medical centre like here where they have a community fair and, you know what I mean? Or something. And you get tested for HIV, maybe you'll win like a ticket or something. Who knows? You know what I mean? I'm sorry, but I think now we're gonna have to start bribing people to get tested. [...] Yeah. "Here, you're gonna get tested, here's like a five dollar gift card for Tim Horton's or something." And it's really sad that it's coming down to that, but it is.*

***Ellen:** If you give them money, they'll do fuckin' anything... Uh, the subject is avoided cause they don't want to hear the truth, like I said... But, uh, they'll do it for money.*

Stephanie felt that it was the responsibility of organizations to ensure that clients are more aware of the services that are available within those organizations. She felt that this could be done by making sure clients know that they are in a safe space where HIV can be discussed openly and by making all staff aware of the services that are available for clients as soon as they walk in:

Um, I think you could probably start with having um, just information available to people. Whether that's a handout, whether that's a poster, just to show this is something that's safe to talk about here. Yes, we see people with HIV, yes, we want to engage with you around HIV, yes we want to do testing. Just putting it out there so that people who are accessing care can know. They see a visual cue that, "Okay, yes, it's okay for me to talk about that here. Yes, it's gonna be a safe place for me to disclose that I'm living with HIV, or that um, you know, my partner is living with HIV, or whatever the case may be ... And also having kind of your front line staff, whether that be receptionist, or whoever, you know, aware of what services are out there for people who, you know, who do present with those kinds of needs.

And just making it a more safe, inclusive space for people ...Like I said, like, some, some, either some stickers on the door or, like here, we fly the Pride flag, just some kind of indicators so that when people walk through the door, they know it's a place of welcoming and a place where they're safe to uh, disclose or whatever they need to do.

4.9.6 Greater Funding for HIV Testing Services

A few women felt that in order for testing to become a greater priority, more funding needed to be allocated to testing services. Zelda argued that if alleviating the impact of HIV was viewed as important, then more should be offered in terms of testing resources:

I'd say the government, you know, doesn't want to put out the money for people with, not for people with HIV, I shouldn't say that, but, you know like about, if it was, if it's on the rise, why aren't they doing like, more to... you know, open up places, you know, that can do like, instant testing?

Stephanie agreed with this, stating that as more services are cut back, the less effective they can be in providing support for clients:

And some advocacy work. That needs to be done around you know funding, like that being cut for services for people who have lost their primary support person, who was supporting them around their HIV now, you know, some of those programs no longer exist. Or there's maybe one worker for the entire you know, um, Southeastern Ontario, whatever that may be. There's kind of, it's slowly, slowly, slowly getting cut back more and more and more.

4.10 Recommendations for Creating the Ideal Testing Experience

Near the end of each interview, women were asked to describe the perfect testing experience and what attributes would help to make it the ideal experience for them. The women spoke about a variety of elements they would like to see in an ideal HIV testing scenario in terms of the tester and the location at which the test was offered.

4.10.1 Characteristics of Ideal Tester

A common suggestion from the women was that patients have a choice when it comes to the person administering their HIV test. For instance, Alison and Jamie noted that some patients would prefer to deal with someone they already know while others would rather not know the tester personally:

Alison: *So I think maybe someone from an outside agency. And it really all depends, though. You know, cause if you have good rapport with a client and you trust them, they could be more likely to want to have that test done with you.*

Jamie: *Um, see, it's kind of a tricky question, because some people would be more comfortable with somebody that they know, and have like, a relationship with. And then some people are comfortable with somebody that they don't know and probably wouldn't see again. So it's very hard to say like, which one would be better... I think having the choice would be good.*

Some of the women stated that they would prefer the tester be someone that they know. Donna felt that knowing the tester could make patients feel more at ease because they know they are with someone they can trust:

Cause they have all kinds of nurses and doctors that everybody knows and, uh the doctors here, they don't look down... You know, they know all the working girls and most of them what their sicknesses are and, and the girls feel comfortable to talk... And that's what you need... Like if you, if somebody does find out that they have HIV, well, the best person to talk to is somebody that you know... And we, the girls, the girls that work here know everybody here, so.... I think this would be the best place.

Interviewer: *Mm-hmm. And so you mentioned that [the tester] should be somebody that you know, do you think that the best person to give you the test and give the results would be somebody that you know?*

Donna: *Yeah. Yeah, cause then you could talk about it... You know? And they, and they wouldn't uh, feel alienated and all that, you know?... Yeah, I think this would be the best place. Or little centres like this. Like, there's other centres. Well, the other girls that have, that go to these other centres, they know the workers there. So it's better to be with somebody that you know.*

Illustrating the importance of trust, Gina suggested that her family doctor would be her first choice to give her an HIV test, because she felt confident that she could trust him:

I trust him [her doctor] more than I trust anybody else... But I wouldn't, I dunno, my doctor at least, his, nobody looks at his forms but me... I'm the only one that looks at the papers other than him. You know?

Conversely, other women declared that they would definitely rather not know the person administering the test, suggesting they should be from outside the Aboriginal community. Zelda was one such participant, stating that she would rather not see the tester again after the test was over:

Oh, probably never met. Because they probably wouldn't see me again after that.

Mary agreed, indicating that she would prefer not to know the person administering the test:

Because now I'm putting myself back in that situation. And uh, um, I'm not so sure that I would wanna know the face that was doing the blood-work.

Regardless of whether they wanted to know the tester personally, several women emphasized the importance of having a tester that they felt comfortable with, with Alison and Christina describing the optimal provider characteristics:

Alison: Just, the person and the people that are there, or the person administering the test is like, uh, you know, a friendly, empathetic, caring person. Um, trying their best to make them feel welcome and comfortable.

Christina: I think it's traumatising or a nerve-wracking experience for anyone that's doing it, so I think just a lot of empathy, you know? Um, kindness. Simple things like that would make a difference in that process.

4.10.2 Characteristics of Ideal Location

The women had several suggestions about where the best place to offer an HIV test would be. Donna asserted that testing should be more readily available in places where the women already go for other services:

Should have more testing here... Because all the girls come here. But, um, here a lot of girls, they come here, they come from medical help and stuff, so, sure, put a notice up. Free HIV testing done today. Or whatever.

Zelda agreed that a community health centre would be a good location, suggesting that testing should be offered in a building that offers multiple services so that privacy can be protected:

I'd say a place like this. I don't know why they couldn't set something up like that here... So that when you do walk into it, and even if, like someone noticed you walking into a clinic that does, that um, you know does HIV testing, so you're not singled out... And this is a place where they offer everything, so nobody would know that you're coming just for that.

Hannah agreed, noting that the ideal location should be somewhat inconspicuous and a place where Aboriginal women feel comfortable:

I think we need to have a safe place for Aboriginal women that's not standing out saying, neon sign, "Aboriginal Centre! Here, come get an HIV test!" No. We need something that's, that the Aboriginal women know it's theirs... And feel safe and comfortable because there's other Aboriginal women there.

Conversely, Irene felt that it might be preferable to have a location available just for HIV and for HIV testing:

I really think we need a place like, I don't know, just for AIDS! ... I don't even know if there is a place out there, there probably is and I don't know about it... For if somebody has it they can go in and they can get fed or they can get their Boost or they can get whatever they need because here it's for crack, it's for all addictions here. But I think if you have it, sometimes you don't wanna go to a place where there's crackheads and this and that, you want a place where it's just for you. You're sick, you don't feel like smiling today, you need your Boost, you need this, and you just want to be left the fuck alone. I think they should have just, clinics just for AIDS only.

Mandy supported Irene's statement, expressing concern that some women might find the community health centre environment triggering if they are recovering from an addiction and the testing location specializes in harm reduction:

Like even, like, I don't like this clinic anymore [community health centre]. They used to be okay but in the last, I don't know, little bit, they're not as, they're more focused on harm reduction and that's the thing they need to separate too, because if you're a

recovering addict coming into a harm reduction clinic and you want to be tested and you're Aboriginal, you feel out of place and you're stuck. You're like, "Am I gonna make it out of here without using?" And stuff like that. And they need to look at that too.

The women frequently mentioned the importance of the site having employees that were comfortable treating and dealing with HIV and with people who may be at high risk contracting HIV, such as people who are street-involved or people who use drugs. Irene felt that a centre run by people with lived experience of street-involvement would lend credibility to the testing services:

I think if you get a street person (laughs) who is like, straight now, to run it, I think it would be a good centre... Because they've been there, they've done it, they got the postcard. But sometimes when you go into those places these are like, Aboriginals who are polished up and clean. And they look down on you! I think they look down on you. If you got somebody who's from the street or who used to be an alcoholic or used to do this, and example, someone, okay, an Aboriginal who had AIDS. And who opened up their centre. I think would be a big hit! ... Because he's been there, he's done that. And he's, "Look at me, I'm still alive." And he doesn't look down on you... Yeah! Because who wants to talk to somebody who has, who doesn't have life experience? I'm not gonna go to a centre where nobody has any life experience because they're just talking through their hat.

Lisa and Mandy felt that the knowledge and experience of the employees working in community health centres made the centres the best places to get tested for HIV:

Lisa: *Because there's a nurse. (laughs) There's nurses here, doctors here, yeah. They, they specialize, I think specialize in AIDS and HIV and uh, Hep C and, you know, a lot of drug addicts and alcoholics mainly. So they understand what the, what they're, what they're doing, what they're going through. So yeah, this I think is a good, good place.*

Mandy: *Well, I think because it's an actual clinic that deals with street people and everything it's a pretty good clinic. Like, they talk to you first before they get, you know, you do it, and they talk to you after, and then you can have a follow-up to come in, you know? ...And there's people in the community they'll send you to, you know?*

Chapter 5: Summary and Discussion

This final chapter summarizes and discusses the implications of the perspectives the women shared during their interviews. In order to properly portray the women's interpretations of their experiences, the limitations of the study will first be outlined. The experiences of the women and the barriers they identified will be discussed, and suggestions regarding best practices and potential future directions for HIV testing will be presented in the context of the recommendations made by the women themselves.

5.1 Limitations

The objective of this research was to examine the barriers to HIV testing identified by Aboriginal women in Ottawa and to explore and document, through the women's narratives, how this process could be improved. Self-identified Aboriginal women with or without experience of undergoing an HIV test and who were considered by their healthcare providers to be willing and able to discuss HIV testing were eligible to participate. As all of the participating women had undergone an HIV test, barriers to accessing an HIV test were based on these participants' narratives rather than on the narratives of women who had not been tested for HIV.

Despite the initial intention to explore reasons why women may opt not to get tested for HIV, all 13 women in the study had been tested for HIV at least once. As a result, the second research question ("According to self-identified Aboriginal women living in Ottawa who have not been tested for HIV, what are the barriers that prevent these women from seeking HIV testing and counseling and how can they be eliminated?") could not be fully answered. However, due to the fact that many women had only been tested once, they were

able to address reasons why they had not tested again and to speculate about why testing uptake was low in their community at large.

It is probable that the reason for this lack of inclusion of women who had never been tested was due to the recruitment strategy that was employed. Because service providers from community agencies were involved in the purposeful sampling of the women, the majority of participants were women who made use of these community agencies. Their exposure to more services and resources through their involvement in the agencies may have made them more likely to have been tested in the past. Additionally, when the recruiters were looking for women who felt that they had something to say about HIV testing, the women who had not been tested may not have felt that they had anything they wanted to share in an interview.

As age was hypothesized to potentially moderate the women's perspectives, women from a variety of different age groups were sought in order to assess the uniqueness or transcendence of barriers and experience across demographics. Although there were two women in their twenties involved in the study, the study predominantly included women in their forties or older. Recruiters specifically looked for younger women, but most were unwilling to participate. A personal request from Dr. Lynne Leonard, who is well-regarded within the Aboriginal community, to an Aboriginal youth organization seeking their involvement in recruitment was met with reluctance from the organization and was ultimately declined by management due to concerns about the Aboriginal community being over-researched. This issue also arose when trying to involve a worker involved with the Ontario Aboriginal HIV/AIDS Strategy. Given the historical precedent of ambiguous outcomes for Aboriginal people involved in research and failure to include Aboriginal people throughout the research process⁷⁸, this reticence is understandable.

In spite of this lack of younger women, it is believed that this limitation did not greatly affect the results of the study. Constant comparison of the women's narratives in terms of age did not indicate that age had any effect on the women's narratives. Instead, engagement in common HIV-related risk-behaviours appeared to be the unifying factor between the women's perspectives, regardless of age. Therefore, it does not appear that further sampling of younger women would have yielded different themes or results.

Lastly, only one woman disclosed that she was living with HIV. Despite extensive efforts on the part of the recruiters, they were unable to identify any other women who were willing to disclose this information and participate in an interview. This reluctance could stem in part from the societal barriers discussed earlier in the results section, including concerns about stigma and discrimination. Despite reassurances that the interview would be confidential, it is possible that potential participants living with HIV were not prepared to share this information in an interview setting. To reiterate Mandy's point, many Aboriginal women already face a great deal of stigma and discrimination, and the possibility of people knowing that they have HIV may have been too troubling:

They're already treated bad in society and once they have HIV it's, you know, gonna be worse ... you know?

As in the case of age, results of the constant comparison analysis suggest that HIV status did not modify the women's narratives. The narrative provided by the one woman living with HIV was very closely aligned with the other women interviewed, and in particular with other women who inject drugs. It is therefore believed that the impact of this limitation on the study was minimal.

5.2 Enhancement Strategies

5.2.1 Adjustment of Interview Questions

Several strategies were employed to ensure the women understood the questions in the interviews and were willing to engage with the interviewer. One way in which this was done was by actively altering questions that were deemed to be ineffective. Due to the iterative nature of the qualitative interview process, questions that are not effective can be removed and new questions can be used instead, either in the moment or between interviews⁶⁵. In this study for instance, questions around community attitudes toward HIV had to be altered. Initially, the women were asked how they would feel if they learned they were HIV-positive and what they imagined that experience would be like. This question tended to result in the women closing off and declining to speculate. Thus, in subsequent interviews, the women were instead asked to imagine what the experience of learning one's positive status would be like for anyone. The women were much more willing to respond to this question and also tended to speculate about what they thought their own experience would be like. Adjustments such as these allowed for much more productive interviews.

5.2.2 Reassurance about Non-Judgmental Interviewing

Many of the women had engaged in behaviours that are either illegal or considered taboo, including substance use and involvement in the sex trade. The sensitive nature of the information the women shared could have made the study susceptible to social desirability bias, wherein the women did not disclose their engagement in certain activities out of fear of judgment or other repercussions. In order to encourage the women to be as honest as possible, the women were repeatedly reminded that they were in a safe space that was free of judgment, that they could choose not to answer any questions and that they were in charge of

recording their narrative. They were also reassured about the ways in which their privacy and confidentiality would be protected. By fostering a safe and comfortable environment, it is believed that this issue was generally minimal.

5.3 Implications of Results

5.3.1 Misunderstandings about HIV, Transmission, and Personal Risk

Many of the personal barriers to testing identified by the women stem from misunderstandings about living with HIV, HIV transmission, and personal risk. Many of the women who spoke about avoidance regarding HIV testing demonstrated a lack of knowledge of treatment possibilities, referring to HIV as a “death sentence” in a number of cases. They preferred not to know whether or not they were infected due to a perception that if they tested positive, nothing could be done about it. This same belief was also brought up by women who mentioned fear as a barrier to testing, as many women felt that HIV was synonymous with death. These findings suggest a need for better awareness of HIV treatment and management possibilities in the long-term. Fatalistic attitudes about life with HIV can exacerbate other issues of discrimination and addiction³, both of which have been identified as contributors to low testing uptake.

In addition to misunderstandings about disease management for people living with HIV, many themes dealt with misunderstandings about how HIV is transmitted. Women who spoke on the theme of self-assessed risk demonstrated that there are people who do not consider themselves to be at risk at all, while other women acknowledged engaging in HIV-related risk-behaviours but did not perceive themselves to truly be at risk. Conversely, several women demonstrated misconceptions about contracting HIV via means that are not associated with HIV transmission, including sharing dishes or through casual contact.

Several of the women noted that incorrect beliefs about HIV transmission contribute to issues of stigma and discrimination. Furthermore, a few women spoke about issues of low self-worth leading some women to feel that HIV was their punishment for engaging in HIV-related risk-behaviours. All of these results indicate that more information is needed about how HIV is transmitted and, maybe just as importantly, how it is not transmitted. As seen in the array of recommendations the women offered, greater and more opportunities for education about HIV are strongly sought after by the women, who felt that Aboriginal women and their families could benefit from increased understanding of HIV and its impact.

5.3.2 Issues of Disclosure

Many of the women reported concerns about rejection, stigma, and discrimination from others if they were to learn they were living with HIV. These concerns were commonly seen in the literature review as well, with numerous studies reporting that fear of negative reactions from others contributed to low testing uptake^{13,14,45,46}. Several of the women described feelings of shame contributing to Aboriginal women's unwillingness to disclose a positive HIV status. These concerns led several women to report that they would be unlikely to disclose their positive status to anyone, and among those who stated that they would be willing to disclose their status, it was generally specified that they would only tell a few people.

The women who believed they would be unwilling to disclose their HIV status if they learned they were positive generally reported feeling that they would not receive support from anyone if they did share their status with others. A need for support throughout the disclosure process is indicated in order for Aboriginal women to feel more comfortable disclosing their status, with calls for either designated support staff on site or the

implementation of peer support workers. Additionally, support is needed after disclosure occurs; several of the women felt that their families and other people around them would not be supportive if the woman was known to have been diagnosed with HIV. Education and counselling may be beneficial for all family members of people living with HIV in order to reduce the risk of rejection or ostracism.

The need to feel safe and supported when disclosing one's HIV status is particularly important in an era of criminalization of HIV non-disclosure. Currently, Canadian law requires people living with HIV to disclose their HIV status to potential sexual partners when there is a "realistic possibility of HIV transmission"⁵³. Given the reluctance many of the women showed regarding disclosure, it is important that patients are given the support and counselling they need to feel ready to disclose. Interestingly, concerns about criminalization or prosecution were not brought up by any of the women when discussing reasons for not testing. Considering the women's statements around disclosure it is possible they were unaware of this law, but it seems more likely that their reluctance had more to do with possible stigma from family members and friends than from sexual partners. The women generally reported that they would tell their sexual partners, but would be reluctant to tell anyone else. This may indicate that the women recognize this law, but the possible stigma from others would keep them from disclosing beyond what the law requires.

Importantly, women who used and injected drugs were the only group to report issues around disclosure. These women felt that they would not be supported if they were to become infected with HIV, which would make it difficult for them to tell others about their positive HIV status. These concerns may stem from the marginalization of people who inject drugs in society, or may reflect the lack of knowledge about where to go for HIV-related

resources and support reported by these women. Disclosure support services that are tailored to the needs of women who use and inject drugs are clearly indicated for this group.

5.3.3 Lack of Awareness of Testing Options

One issue that appeared frequently throughout the interviews was a lack of awareness of the existence of testing options outside of a standard test. Some women expressed a desire for a testing option that offered results more quickly than a standard test, but were skeptical that such a test would ever be developed. Others repeatedly emphasized their concerns about privacy and confidentiality. Given the availability of point-of-care and anonymous testing at numerous community health centres in Ottawa, it is apparent that these options need to be more-widely promoted. The women also indicated a preference for more information about how the testing process works. As this was also identified as a predictor of an acceptable testing experience, testers should ensure that the process is thoroughly explained to clients before the test is performed. Many women felt that the options available to them could and should be explained by distributing pamphlets about HIV testing, but this is already a very common strategy employed by community health centres across Ottawa. This suggests that either the way in which the pamphlets are currently offered is ineffective or that this strategy needs to be reconsidered and replaced with another method of information dissemination. Offering information about testing while providing harm reduction information is one possibility that was suggested by a few of the women; this method could provide an opportunity to engage with women who use drugs about their HIV-related risk-behaviours in a relevant way. Similar engagement could be developed for individuals with testing needs unrelated to substance use.

The need for tailored programming for women who have engaged in different risk-behaviours may be necessary when dealing with this issue as well. Only people who used and injected drugs reported feeling uncertain about where to access services. Service providers also discussed this theme, but they did not report feeling uncertain about service availability themselves. Women involved in the sex trade did not mention this issue at all, suggesting that testing promotion among this group may already be appropriate. Conversely, the women who used and injected drugs felt that testing services needed to be made much more prominent. In light of the elevated risk of contracting HIV among this group, the women's lack of knowledge about HIV testing is extremely troubling.

5.3.4 Hepatitis C (HCV) Immediacy

Several women explained that they believed Aboriginal women were not particularly concerned about HIV because they were more aware of and had more knowledge about the risk of becoming infected with Hepatitis C (HCV). They stated that this worry stems from the fact that HCV is extremely prevalent among people who inject drugs, so they are exposed to the possibility of contracting HCV more frequently than HIV. Additionally, HCV “is estimated to be about 10 times more infectious than HIV, per unit of blood required, and therefore requires less exposure than HIV”⁷⁹ to be contracted. Thus, it is possible that while HIV, unlike HCV, cannot be cured through treatment, the higher likelihood of becoming infected with HCV takes precedence over the lower possibility of contracting HIV. However, given the common routes of transmission between HIV and HCV and the apparent understanding of how HCV is transmitted, there appears to be a need for an increased emphasis on the possibility of contracting HIV in situations where HCV infection is possible.

Harm reduction programming may need to offer further information to clients about HIV transmission and how to protect themselves.

5.3.5 Need for Increased Provider-Initiated HIV Testing Offers

Issues of shame and stigma arose throughout many of the interviews, with several women suggesting that these issues may make testing unappealing for women who are unwilling to disclose their engagement in HIV-related risk-behaviours to healthcare providers. In other words, requiring patients to ask their physicians or healthcare providers for an HIV test may be a major barrier to testing. Encouraging providers to routinely offer HIV testing to all patients regardless of their perceived risk could alleviate stigma for patients and make them more likely to undergo testing that they might not otherwise have been willing or able to request. Furthermore, routine offers of HIV testing may help to normalize the testing process, helping to reduce stigma and encourage testing uptake.

5.3.6 Role of HIV Stigmatization in Feelings of Self-Worth and Shame

Many of the women spoke about the issue of perceived judgment, whether from themselves or from others. This issue seemed to arise from the fact that their engagement in HIV-related risk-behaviours was stigmatized, but many women identified a racial component to this judgment as well. This stigma can lead to issues of low self-esteem and shame, indicating a clear need to promote the normalization of HIV testing and education programming designed to alleviate HIV stigma.

Of note is the fact that women involved in the sex trade were much more likely to report shame and racialized stigma as barriers to testing. Service providers also mentioned these issues, but were less likely to identify them as barriers they had experienced themselves, while women who used and injected drugs did not report these issues as barriers

to testing at all. Furthermore, women who were involved in the sex trade were much more likely to emphasize the importance of having a non-judgmental, compassionate healthcare provider administering their HIV tests. These barriers may be interconnected, as the women's experiences of shame may reflect an element of internalizing the stigma and judgement directed at them by others. Services for Aboriginal women involved in the sex trade may need to emphasize self-esteem building in order to counteract these challenges.

5.4 Policy Implications: Best Practices and Future Directions

The women identified a number of recommendations for increasing the accessibility and acceptability of HIV testing that could be implemented to promote future testing. It should be noted that the potential benefits of many of these recommendations may not be unique to Aboriginal women.

A major theme identified by the women was the need for more choice when it comes to HIV testing; the women indicated that testing needs to be offered in more locations, ideally with at least some culturally-appropriate elements. The option should exist to choose between a multi-purpose building intended to protect confidentiality or a more HIV-specific testing location. The women also felt that they needed to have options in terms of point-of-care testing and anonymous testing, generally stating that these needed to be offered more widely throughout the city. By offering these services and tailoring them to Aboriginal women specifically, the women may feel more comfortable and willing to discuss their HIV-related needs. The option to access more services just for Aboriginal women was identified as a major contributor to helping women feeling safe and understood.

Helping women and their families to feel more supported throughout the testing process was also emphasized as an important area that could be improved in the current

testing experience. Several women reported feeling that they were not supported during the test, and believed they would not be supported by others if they were to receive a positive result. Helping women feel supported by ensuring there is someone available to answer questions and explain the test and the results was viewed as a potentially very helpful solution. Offering education, counselling, and support services to family members was also considered important, as informing families about HIV could help to minimize the risk of women being stigmatized or rejected as a result of a positive diagnosis. Ensuring that women understand that HIV is not a punishment for engaging in HIV-related risk-behaviours and promoting individual self-worth is an essential component of this support process.

In line with the need for more support and counselling, the women expressed a desire for more opportunities for education and engagement. They felt that more workshops and sessions about HIV should be offered at community health centres and other organizations around the city. They felt that the opportunity to learn about HIV testing would contribute to greater testing uptake. They also believed that more should be done to engage Aboriginal people in the initiatives that are already offered so that women can have a more active role in their own healthcare decisions. Including Aboriginal people and particularly Elders could lend credibility to the sessions and could help to promote understanding about the issue of HIV in the Aboriginal community. Furthermore, several women emphasized the importance of involving people with lived experience in the testing process, both in terms of people who are and are not living with HIV, as they can offer unique insights derived from their own lives. Engaging more Aboriginal people throughout the testing process could be an extremely valuable way to promote both the accessibility and acceptability of HIV testing while also promoting a greater understanding of the issues.

Finally, the women felt that HIV testing needs to be shown to be a priority by governments and organizations. Currently, testing is viewed by many women as being hidden and poorly advertised. Nearly all of the women reported that they felt HIV testing was not advertised as extensively as it should be, and several indicated that they were uncertain about where to access HIV-related services and resources. They also noted the frequency with which organizations are being de-funded and shut down, reducing Aboriginal women's access to testing services and other harm reduction resources. If HIV testing is to become a real priority, an example must be set by policy-makers; the current trend of cutting services and resources must end.

5.5 Contribution of the Study and Next Steps

Many of the findings presented in this study served to confirm and expand the barriers to HIV testing identified in the literature. For example, issues such as fear of a positive result, stigma, negative experiences with healthcare providers, internal and external judgment, and a lack of access to testing have all been recognized in other research, and were confirmed among this sample of women. However, new barriers and recommendations that were not discussed in the literature were identified by the women.

5.5.1 Newly Identified Barriers to HIV Testing

The new barriers converged around issues of knowledge relating to HIV. The various misconceptions surrounding HIV (with the exception of the perception of HIV as a death sentence) and the secondary position of HIV in relation to HCV did not appear in the literature used to inform this study, suggesting that these themes are unique and merit further exploration. Additionally, the need for better promotion of testing services was not

mentioned in detail elsewhere, indicating a need for more consideration into how best to advertise these resources in the Ottawa context.

5.5.2 Newly Identified Recommendations for Increasing Testing Uptake in Ottawa

In terms of recommendations, many participants offered new insights into how to engage Aboriginal women around HIV testing, many of which centred on involving women with lived experience. Similarly, the women recommended including more peer support workers in HIV testing programming. Recommendations included having women with lived experience offering insights into how they protected themselves from HIV or recruiting peer workers to provide emotional support for women throughout the entire testing process. These unique suggestions could be helpful in encouraging community health centres and service providers to include Aboriginal women more in HIV testing planning and programming to make the process more acceptable to Aboriginal women.

5.5.3 Dissemination of Results

As this research originated in the Aboriginal community, the results will be shared with the community. A community consultation will be held with members of the Aboriginal community, program managers, healthcare providers, and researchers to share the new findings and recommendations that have arisen from this study and the apparent differential impacts of various barriers on different groups of Aboriginal women. This consultation is intended to disseminate the results of the study and get feedback from the Aboriginal women about the conclusions that have been drawn. The findings will also be presented during the HIV and Hepatitis C Prevention Research Team's "Testing Day" event in early 2015, where recent research around HIV testing among various groups will be shared in order to further refine and discuss the results.

In closing, reiterating Hannah's evocative metaphor serves to underscore the importance of cooperation and engagement between the Aboriginal and non-Aboriginal communities in ensuring that HIV counselling and testing become more accessible and acceptable for Aboriginal women:

If you work together, it's like a Rubik's cube. Okay? It's all messed up and you gotta try to put it all back into the same colour. Well, that's kind of like a Native. We're all fucked up. And yeah, we, we can be put back together, but it's not by tearing off the stickers, it's not by taking it apart. It's taking your time and molding it.

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APPENDIX A –Let’s Talk About Us: What Ontario Women Have to Say about HIV



Let’s Talk About Us: What Women in Ontario Have to Say About HIV April 29-30, 2013



Monday, April 29, 2013			
8:30	BREAKFAST: Served outside Governor General's Room (2 nd floor)		
9:00	Welcome, Introductions & Agenda Review		Lynne Leonard San Patten
9:30	Epidemiology	Epidemiological Overview of HIV Among Women in Ontario	Robert Remis
9:50	Women and HIV/AIDS Initiative (WHAII)	Programs Responding to Women and HIV in Ontario	Fiona Sillars Mohini Datta-Ray
10:20	Questions and Discussion	Questions for clarification of content	San Patten
10:30	BREAK: Served outside Governor General's Room (2 nd floor)		
10:45	OHTN Cohort Study	Women in HIV care in Ontario: Characteristics at diagnosis & patterns of ongoing care	Ann Burchell
11:15	Introduction to OWS	Overview of OWS background and methodology	Lynne Leonard Noulmook
11:25	OWS Highlights	Overview of OWS findings by specific populations	Sudhibhasilp, Wangari Tharao, Vijaya Chikermane
12:15	LUNCH: Served outside Governor General's Room (2 nd floor)		
1:00	Questions and Discussion	Questions for clarification of content from morning discussion	San Patten
1:15	Thematic Priorities	<p>Small group discussions</p> <p>Guiding Question: Based on what has been discussed, what are you/your organization doing about the issues raised, and what are the gaps/outstanding needs as you see them?</p>	Small group facilitators
2:00	Plenary Report Back	Thematic priorities identified by each small group	San Patten
2:30	BREAK: Served outside Governor General's Room (2 nd floor)		
2:45	Voting on Thematic Priorities	Vote for top six research priorities	San Patten
3:00	World Café Discussions	In-depth discussions of top six research themes	Small group facilitators
4:30	Plenary	Summary of day one and plans for day two	San Patten
5:00	Adjournment		



Let's Talk About Us: What Women in Ontario Have to Say About HIV


April 29-30, 2013




Tuesday, April 30, 2013			
8:30	BREAKFAST: Served outside Governor General's Room (2 nd floor)		
9:00	Welcome and Report Back	Reflections or questions and report back from World Café from Day 1	San Patten
9:45	Inspirational Mini TED Talks	Five community leaders will provide a success story to demonstrate promising practices in addressing HIV issues among women in Ontario	Vijaya Chikemere, Louise Binder, Marvelous Muchenje, Sophie Werthelmer, Trisha Steinberh
10:20	Population-Specific Discussions	In-depth discussion of most relevant issues for each sub-population	Small group facilitators
10:45	BREAK: Served outside Governor General's Room (2 nd floor)		
11:00	Action Planning	identification of working groups which span research priorities and populations: 1) Short Term Actions – within one year and with currently available resources 2) Long Term Actions – within the next five years	Small group facilitators
11:45	Next Steps	Plenary discussion of key partners, mechanism for follow-up, timelines and potential collaborators	San Patten
12:15	Evaluation	Head, Heart, Hand Exercise	San Patten
12:30	LUNCH: Served outside Governor General's Room (2 nd floor) CLOSING SPEAKER Adjournment		Darien Taylor
2:00 – 4:00	We have ensured that the Governor General's Suite is available for you after lunch if you would like to continue your networking and discussions.		

Travel safely!

APPENDIX B – Increasing Women’s Access to HIV Testing: Community Consultation



**Increasing Women’s Access to HIV Testing
Community Consultation**



**1 August 2013
Wabano Centre for Aboriginal Health**

Thursday 1 st August 2013			
9:00	REFRESHMENTS : Coffee and Tea available		
9:15	Welcome and Introductions		Lynne Leonard All
9:30	Background to Consultation	Data from Ontario Women’s Study	Lynne Leonard
10:00	Current Activity in Ottawa	<u>Programs Responding to Women and HIV in Ottawa</u> Guiding Question: Based on what has been discussed, what are you/your organization doing about the issues raised	All
10:40	Potential Activity in Ottawa	Research Proposal Questions for Clarification of content	Lynne Leonard
11:00 NETWORKING BRUNCH			
11:30	Small Group Discussions	Increasing Women’s Access to HIV Testing	All
12:15	Plenary Report Back	Increasing Women’s Access to HIV Testing	Small Group Facilitators
12:45	Closing Remarks	Next Steps	Lynne Leonard All
1:00 ADJOURNMENT			

APPENDIX C – Thematic Guide

Interview Guide

INTRODUCTION (ALL PARTICIPANTS)

Objective: Establish rapport and direction of interview

Sample Questions

So this interview is going to be about HIV.

- **How do you think HIV is viewed these days?**
- How is HIV viewed in your community?
- How do you feel about HIV?

- **On the subject of testing, can you tell me what you've seen or heard about testing?**
- Have you ever come across HIV testing in your life?
- Do you feel like most people get tested in your community?
- What about you?

HIV TEST (NON-TESTERS)

Objective: To identify the factors that contribute to the decision not to get tested

Sample Questions

- Have you ever thought about being tested?
 - What prompted your thoughts?
- Can you tell me some of the reasons you decided not to get tested?
- Are there any circumstances in which you would get tested?
- If you wanted to get tested, how would you go about it?
- Do others encourage you to get tested? How so?

- Do you feel like HIV testing is important in your community?
- Is HIV testing discussed in your community?
 - How is it discussed?

- Are the reasons that made you first decide not to get tested still of concern to you?

HIV TEST (THOSE WHO HAVE BEEN TESTED)

Objectives: To identify the factors that contribute to the decision to get tested

To identify perceived risks and benefits of testing

To identify barriers and facilitators to testing

To learn how the testing experience could be improved

Sample Questions

- Can you tell me what led you to get tested?
- Can you walk me through your first testing experience?
 - What happened when you went for the test?
 - Did the tester obtain your consent?
 - How did you feel during the test?
 - Did you have any concerns about being tested?
 - How do you think the testing experience could have been made better?
 - How were your results delivered to you?
 - How did you feel about the way you got your results?
- Can you tell me about the other times you were tested?
- Do you feel like HIV testing is important in your community?
 - Is HIV testing discussed in your community? How is it discussed?
- Do you think there are ways that the testing experience could be made better?

FUTURE TESTING (ALL PARTICIPANTS)

Sample Questions

- Do you think you will decide to get tested in the future?
- Do you have any concerns about getting tested in the future?
- Is there anything that would make it easier for you to get tested?
- Would it be easier if testing was offered routinely as part of your medical care?
- Have you ever heard of point-of-care testing?
 - Would POC testing make it easier for you to get tested?

Other Questions:

- If you ever wanted to get tested how would you go about it?
- How is HIV viewed in your community?
- How is HIV discussed in your community?

- Tell me about what you think the experience would be like for someone who found out they were HIV positive.
 - What would you do?
- If you were to test positive, is there anyone you would disclose to?
- Do you think you would have enough support to be able to disclose your status?

ACCESSABILITY OF HIV-RELATED INFORMATION AND SERVICES (ALL PARTICIPANTS)

Objectives: Assess use and availability/accessibility of appropriate services

Sample Questions

- What would your ideal testing experience look like? (responses, how would that work?)
 - Where would you like to go to have an HIV test?
 - Can you tell me why you would like to go there?
 - Who would be the best person to give you a test and the results?
 - Can you tell me why that person would be the best person?
 - Would culturally appropriate services need to be different from the services offered for non-Aboriginal people?
 - What would that look like?
- Do you have somewhere you can go or someone you can talk to get information about HIV testing?
- How do you feel about your ability to access these resources?
- Where do you go for your healthcare?

CONCLUSION

Sample Questions

- Is there anything else you'd like to share with me that you don't feel you had the opportunity to share earlier?
- Do you have any questions for me?
- Can you think of any questions that I should have asked?
- In order to ensure I'm capturing data from a range of different people, would you mind telling me your age range?

APPENDIX D – Participant Consent Form



PARTICIPANT INFORMED CONSENT FORM

Title of Study: Increasing Access to HIV Testing and Counseling among Aboriginal Women in Ottawa

Principal Investigator (PI): Dr. Lynne Leonard XXX-XXX-XXXX

Funding Agency: University of Ottawa, Department of Epidemiology and Community Medicine

Participation in this study is voluntary. This Participant Informed Consent Form will be read to you and you will receive a copy of the form before you decide if you would like to participate. Ask the interviewer as many questions as you like.

Why am I being given this form?

You are being asked to take part in this research study as you have identified yourself as an Aboriginal woman who lives in Ottawa.

Why is this study being done?

This study is being carried out because research suggests that Aboriginal women in Canada are more likely to get HIV, the virus linked to AIDS, than other groups of women, and learn of this infection later than other groups of women in Canada.

We estimate that 40 participants will be enrolled in the study.

How is the study designed?

In this study, we will be listening to what Aboriginal women have to say about HIV testing. We want to hear about your experience if you have had an HIV test or to hear about the reasons why you have chosen not to get tested. We also want to know how you feel about HIV testing and how you feel the HIV testing experience can be improved. We want to use the information you provide to help improve access to HIV testing in your community.

What is expected of me?

If you agree to take part in this study, you will have a 45-60 minute personal interview. If you agree, the interview will be audio recorded.

During the interview, you may:

- Choose not to answer any question;
- Choose to stop taking part in the interview at any time; and,
- Choose to stop the tape recorder at any time.

How long will I be involved in the study?

The study will take about a year to finish. Your involvement will end after the interview. We will be holding a community consultation once the study is complete. If you would like, you will be able to obtain a copy of the final report at this event.

What are the potential risks I may experience?

It is possible that talking about some of your experiences during the interview may be painful or bring up bad memories. You will have a chance to ask questions or discuss any concerns or worries that you have. Information about counseling services will be given to you if you want it. You do not have to answer any questions that you do not feel comfortable answering.

Can I expect to benefit from participating in this research study?

You may receive no direct benefit from participating in this study. However, your participation may allow the researchers to recommend changes to improve HIV testing services for women within the Aboriginal community.

Do I have to participate? What alternatives do I have? If I agree now, can I change my mind and withdraw later?

Your participation in this study is voluntary. The alternative to participating in this study is not to participate. You may decide not to be in this study, or to be in the study now, and then change your mind later without affecting the medical care, education, or other services to which you are entitled or are currently receiving at this or any other agency.

If you withdraw your consent, the study team will no longer collect any information from you for research purposes. Information collected before your withdrawal may still be used as all information is being collected anonymously (no link is being kept between the study data and participants).

Will I be paid for my participation or will there be any additional costs to me?

You will receive \$30 in cash to cover any costs and the time spent in taking part in the study.

How is my personal information being protected?

- No personal identifying information will be collected in this study. The interview will be private and you may choose any name you would like to be known by for the interview.
- The interview will be audio recorded to help the study team remember everything that is said. The audio recordings will be given a number but it will not be linked back to you. Only people directly involved in the study will have access to the audio recording. The audio recording will be written out, and then the audio recording will be deleted. The written version will not include any personal identifying information.
- As all data is being collected anonymously, you will not be identifiable in any publications or presentations resulting from this study.
- For audit purposes only, your original study records may be reviewed under the supervision of Dr. Lynne Leonard's staff by representatives from:
 - the Ottawa Health Science Network Research Ethics Board (OHSN-REB),
 - the Ottawa Hospital Research Institute
- Research records will be kept for 10 years. During this time, all electronic records will be password protected, and all hardcopy documents will be safely kept in a locked cabinet at the University of Ottawa. The audio recordings will be kept in a secure file at the University of Ottawa until they are written out, at which time they will be destroyed. At the end of the 10 years, all paper records will be shredded and all electronic records will be securely deleted.

Do the investigators have any conflicts of interest?

There are no conflicts of interest to declare related to this study.

What are my responsibilities as a study participant?

At any time during the interview, feel free to mention any questions or concerns you may have to the interviewer.

Who do I contact if I have any further questions?

Should you have any questions, please feel free to contact the Principal Investigator. Her name is Dr. Lynne Leonard. You can call her at XXX-XXX-XXXX.

The Ottawa Health Science Network Research Ethics Board (OHSN-REB) has reviewed the plans for this research study. If you have any concerns about your rights as a research participant you may call the Chairperson of the Ottawa Health Science Network Research Ethics Board at XXX-XXX-XXXX.

INFORMED CONSENT FORM

Improving the Accessibility of HIV Testing and Counseling among Aboriginal Women in Ottawa

For Interviewer:

I confirm that:

- I have read every page of this Information Sheet and Consent Form to the participant.
- The participant has had a chance to ask me any questions they have about the study.
- Their questions have been answered to their satisfaction and they have agreed to participate in this interview.
- I have provided the participant with a copy of the Informed Consent Form for their use.
- To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

Name of person obtaining consent

Signature of person obtaining consent

APPENDIX E – Recruitment Card

Are you...

...an Aboriginal woman?

...over the age of 18?

...currently living in Ottawa?

Join us for a one-hour interview to share how you think access to HIV testing and counseling can be improved – whether you've been tested or not.

To find out more or to schedule an interview, contact the research coordinator at [REDACTED]

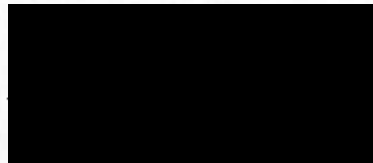
This study has been approved by the Ottawa Health Science Network Research Ethics Board

APPENDIX F – Letter of Approval from OHSN-REB



Ottawa Health Science Network Research Ethics Board/ Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa

December 19, 2014



Dear Dr. Leonard,

Re: Protocol # 20140899-01H Improving the Accessibility of HIV Testing and Counseling among Aboriginal Women in Ottawa

Protocol approval valid until - December 18, 2015

I am pleased to inform you that this protocol underwent delegated review by the Ottawa Health Science Network Research Ethics Board (OHSN-REB) and is approved for the recruitment of English speaking participants only. No changes, amendments or addenda may be made to the protocol or the consent form without the OHSN-REB's review and approval.

Approval is for the following:

- Protocol (version 1) dated December 15, 2014
- English Recruitment Cards (version 1) dated December 15, 2014
- English Interview Guide (version 1) dated September 28, 2014
- English Participant Informed Consent Form (version 2) dated December 17, 2014

Your request for a French exemption has been approved; the study may proceed in English only.

The REB no longer requires a 'valid until' date at the bottom of all approved informed consent forms. The consent forms currently approved for use by the REB are listed above.

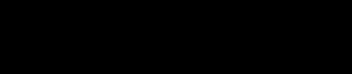
If the study is to continue beyond the expiry date noted above, a Renewal Form should be submitted to the REB approximately six weeks prior to the current expiry date. If the study has been completed by this date, a Termination Report should be submitted.

The Ottawa Health Science Network Research Ethics Board (OHSN-REB) was created by the merger of both the Ottawa Hospital Research Ethics Board (OHREB) and the Human Research Ethics Board (HREB) for meetings held at the University of Ottawa Heart Institute.

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DHSN-REB complies with the membership requirements and operates in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; the International Conference on Harmonization - Good Clinical Practice Consolidated Guideline and the provisions of the Personal Health Information Protection Act 2004.

Yours sincerely,



Raphael Saginur, M.D.
Chairperson
Ottawa Health Science Network Research Ethics Board

RS/kd

APPENDIX G – Participant Characteristics

Aboriginal Women Involved in the Study

Name	Age Range	Description
Alison	30s	Service provider
Jamie	20s	Service provider
Christina	30s	Service provider
Donna	60s	Former PWID** and former sex trade worker
Ellen	(age unknown)	Person who uses non-injection drugs
Zelda	50s	Current PWID
Gina	60s	Former PWID
Hannah	50s	Sex trade worker
Irene	40s	Sex trade worker and PWID
Stephanie	20s	Service provider
Mary	40s	Current PWID and sex trade worker
Lisa	50s	Current PWID, also living with HIV
Mandy	40s	Sex trade worker

**Person who injects drugs