

**HIV Testing in Nova Scotia: An Indigenous Perspective on Access and Acceptability**

By

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***Dedication.***

This paper is dedicated to the father of my children, John Joseph Abram, and his amazing family, friends and community. Sharing my life with you has made me the person I am today; a person with the knowledge and worldview that I feel blessed to have acquired. Through our three amazing, resilient, strong, unique and loving children Sara, Lisa and Quinton, I know that we are all stronger together, no matter where we come from. Thank-you for sharing a way of life and worldview that I would never have known if not seeing it through a mother's eyes.

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## **Abstract**

Understanding the relationship between race/ethnicity and Human Immunodeficiency Virus (HIV) provides insight into HIV testing behaviour (PHAC, 2014). Nationally, Indigenous peoples of Canada represent a higher rate of HIV infection than the national average (PHAC, 2014). The purpose of this study is to explore the perceptions of HIV testing within Indigenous populations of Nova Scotia. Individual interviews were conducted to explore barriers and facilitators affecting the accessibility and acceptability of HIV testing within the Indigenous population of Nova Scotia. Further, participants were invited to share their first voice knowledge about the perceptions of HIV testing within Indigenous communities; what is needed for HIV testing to be accessible and acceptable to Indigenous populations; what are the barriers and facilitators to getting tested; and how to improve the access and acceptability of HIV testing within Indigenous populations in Nova Scotia.

## **List of Abbreviations Used**

**Human Immunodeficiency Virus (HIV)** is a virus that gradually attacks the immune system, which is the body's natural defence against illness. The virus weakens the immune system and leaves a person's body susceptible to various forms of infections. If a person's body becomes infected with HIV, their body will find it harder to fight off infections and diseases (PHAC, 2016).

**Hepatitis C Virus (HCV)** is a liver disease caused by infection with the hepatitis C virus. It is often referred to as a "silent" disease because symptoms often do not appear until the liver is already severely damaged (Canadian Liver Foundation, 2016).

**Acquired Immune Deficiency Syndrome (AIDS)** is a syndrome caused by Human Immune Deficiency Virus (HIV). It begins when a person's immune system is too weak to fight off opportunistic infections. A diagnosis of AIDS occurs when a combination of CD4 cell counts and opportunistic infections due to a weakened immune system from HIV (PHAC,2010).

**APHA** is an Indigenous (Aboriginal) Person who is living with AIDS. APHA also includes Indigenous people who are HIV infected and are not living with AIDS. The acronym comes from 1) Aboriginal Person living with HIV/AIDS, or 2) Aboriginal Person Having AIDS. Hence, the reason the acronym includes both Indigenous persons living with HIV/AIDS (PHAC, 2010).

## **Glossary**

**Aboriginal** is a term that has been used to refer to First Nations, Metis and Inuit peoples in Canada (Joseph, 2016). However, it is important to note that the terms used to identify a population needs to reflect the identity of the population as defined by themselves (Joseph, 2017). Aboriginal is a colonial term that was adopted to replace “Indian” (Statistics Canada, 2015). This term is used within the document when it is either a direct quote or from a referenced source to support the research. In definition, the term Aboriginal is not synonymous with the term Indigenous (please see the term Indigenous below). The term Aboriginal does not reflect the true identities of the population involved, and this term also excludes the Innu population. The use of the term Aboriginal is diminishing, and depending on the context, the term Indigenous is becoming more widely used. The term Indigenous encompasses all peoples indigenous to the land referred to as Canada (Joseph, 2017).

**Cultural barrier** is a rule or expectation in any culture that prevents or impedes someone, from outside of that culture, from being included or participating equally. Culture refers to the various factors which establish a cultural practice such as the environment, religion, race, gender, and includes tradition, practices, values and beliefs (Quora, 2016).

**Indigenous** is the term used to describe people or things belonging to the country in which they are originally located, rather than migrating there or being brought there from another land (Webster, 2017). Implementing the term Indigenous by the Canadian government is regarded by some as a responsible and respectful change in the relationship between the federal government and Indigenous Peoples (Joseph, 2016).

Indigenous is used throughout this document to refer to the first people of the land, First

Nation, Metis, Inuit and Innu, and is applied when it is the author's own words referring to the identified populations.

**Medical Drive** refers to transportation funded by Non-Insured Health Benefits (NIHB), a Department of Health Canada and First Nations and Inuit Health, to provide transportation to and from various medical appointments for individuals residing on reserve (Health Canada, 2016). This service addresses the access to health services as a Social Determinant of Indigenous Peoples health (National Collaborating Centre for Aboriginal Health, 2010).

**Social Barriers** refers to the inequalities, in gender, ethnicity, race, religion, health or socioeconomic status, between individuals or groups that prevent them from achieving or accomplishing their goal. Social barriers include systemic and structural barriers that deny the opportunity to access resources and to advance the interests of Indigenous People. These barriers include social behaviours, resource distribution, policy and practice that results in social exclusion through fear, stigma, small community challenges, and geographical barriers (Standing Senate Committee on Social Affairs, Science and Technology, 2013).

**(W)holistic** better reflects the Mi'kmaq worldview which means all, inclusive, or the whole. Whereas in the English language the word holistic is often used in place of (w)holistic. The term holistic is about theology or religion or referring to a place where something used to be, i.e., a hole. The (w) in front of the word holistic is set in brackets to identify the word as something that does not have direct meaning in the English language but translated, has significant meaning for the values, beliefs, norms and tradition within the Indigenous populations (Canadian College of Homeopathic Medicine, 2011).



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## CHAPTER 1: INTRODUCTION

The rate of new HIV infections in Canada has been slowly declining over the past 7 years, with 2,044 new infections in 2014, 2,076 in 2013, 2,081 in 2012, 2,290 in 2011, 2,330 in 2010, 2,391 in 2009 and 2,620 new infections in 2008 (PHAC, 2014). Social and political engagement in the health management of HIV contributes to the reduction of new incidents of HIV. For example, research on drug therapy for HIV, programs and social supports to assist those living with HIV and the reduction of the stigma and social harm associated with testing HIV positive (PHAC, 2012). Since 1985, when Canada began collecting surveillance data on HIV infection there have been over 80,000 cases of new HIV infection in Canada alone (PHAC, 2014). The social and political engagement that started more than 30 years ago resulted in decades of public pressure on the government to make funds available specifically for HIV education, support, and treatment. Due to the lengthy period of social and political engagement, government policies that have stimulated programs, partnerships and strategies designed to reduce the stigma of HIV and AIDS, and increase access to HIV testing throughout Canada have been implemented and continue to evolve.

One of the key initiatives of the Public Health Agency of Canada (PHAC) HIV prevention strategy is to increase the number of people getting tested for HIV (PHAC, 2012). According to PHAC (2010), 25% of those infected with HIV in Canada do not know they are HIV infected. More recently, the PHAC (2014), HIV estimates indicate that of those infected with HIV, 21% are unaware of their HIV status. Moreover, according to CATIE (2015), at least one in five people living with HIV do not know they are HIV infected. Many Indigenous people are unaware of their HIV status, and receive a

diagnosis of HIV infection at later stages in the progression of the HIV infection, thus reducing individual health outcomes (Plitt et al., 2009). The subsequent diagnosis of HIV infection may also increase the possibility of onward HIV transmission within the Indigenous population, where there are higher rates of risk factors that can enable HIV transmission (O’Byrne, 2012). O’Byrne (2012) identifies the density of factors that permit HIV transmission within a population increases the rate of infection within that population, including individual susceptibility to HIV infection, sexual contact, group factors and population level factors.

Individual susceptibility includes personal knowledge and prevention information as well as biological factors. Sexual contact includes the person and their sexual partner’s sexual contacts. Group factors include the density of sexual partners within a specific group, and the population factors include perceptions of sexuality and safer sex practices including views on harm reduction, power and social norms (O’Byrne, 2012). The increase in concurrent sexual partners or the higher number of sexual partners within the specific population enhances the density of HIV and likelihood of HIV transmission (O’Byrne, 2012). Moreover, the perceptions of power, social norms, sex, sexuality, and access to harm reduction opportunities magnify the situation (O’Byrne, 2012). Early detection and treatment of HIV infection reduce the risk of onward transmission (Plitt et al., 2009). HIV testing is an important HIV prevention strategy where, individuals who know their HIV status actively engage in practices that prevent onward HIV transmission (O’Byrne, 2012). Further investigation of the barriers and facilitators to accessing HIV testing within the Indigenous population is needed to obtain a better understanding of HIV and HIV testing within the Indigenous population.

Population specific analysis indicates that Indigenous peoples experience HIV infection rates 2.7 times greater than other populations (CATIE, 2015). HIV testing is both an individual and population-based intervention, given that it is a primary and secondary prevention strategy which can contribute to a change in risk behaviour both at the individual and the population level. However, some challenges that impact HIV testing as a population-based intervention. As such, population-based HIV intervention strategies may utilise targeted HIV testing within specific populations with greater risk factors associated with HIV acquisition and transmission. Example of HIV targeted testing includes testing within the Intravenous Drug Users (IDU), sex workers, populations from HIV endemic countries and other populations burdened by HIV infection (O’Byrne, 2012). This population-based approach is referred to as the Impact Fraction Model and can be very effective and include interventions such as STI testing on university campuses that target students and the distribution of condoms within environments where gay men frequent (O’Byrne, 2012).

Disseminating a population-based intervention in the community requires respect for the population as well as the involvement of the people in the development and delivery processes of the intervention (Canadian HIV/AIDS Legal Network & CAAN, 1999). HIV is similar in transmission to other bloodborne infections (BBIs) and sexually transmitted infections (STIs, or STBBIs). However, the stigma and discrimination associated with HIV tend to be much greater and are unique to HIV. Therefore, population-based HIV strategies need to include individuals of the population to avoid perceived discrimination, infringement of human rights and privacy, to avoid harm to individuals of the population that are being targeted. Harm can result in reinforcing

feelings of fear, denial and discrimination, and thus compromising the strategy's ability to be a population-based intervention strategy and an individual health intervention (Canadian HIV/AIDS Legal Network & CAAN, 1999). HIV testing is the only means of accessing specialised health care, which also reduces the risk of transmission (O'Byrne, 2012). Further, HIV testing impacts the health of individuals and communities more broadly. The health management of HIV is impacted by HIV testing, as is the reduction of new incidents of HIV and improving access to HIV testing for those unaware of their HIV status. Additional impacts include: research on drug therapy for HIV; programs and social supports to assist those living with HIV; and, the reduction of the stigma and social harm that is associated with being HIV positive (PHAC, 2012).

To understand how HIV affects the diverse Indigenous communities across Canada, an accurate national rate of HIV infection which includes race/ethnicity data is needed. According to the information gathered from the PHAC (2014, 2011), epidemiological reports, Indigenous populations make up 9% of all people living with HIV in Canada. As Indigenous peoples represent approximately 4% of the Canadian population, Indigenous peoples are more than two times overrepresented among those living with HIV (CATIE, 2015). Further to the information obtained from PHAC (2011, 2014), the regions, communities and people of Canada are very diverse, and the national rate of HIV transmission may or may not be reflective of HIV transmission in the Atlantic region (CATIE, 2015). Understanding the actual rate of HIV infection from a national perspective is complex, contested and often misunderstood (PHAC, 2014).

While there has been a steady decline in the rate of HIV infection nationally, the rate of HIV infection among Indigenous women continues to rise where in the 2014

PHAC report, Indigenous women represent 30.6% of all new HIV infections compared to 11.6% among Indigenous men. As indicated in the 2014 PHAC report, a greater proportion of males were unaware of their HIV status than females, which suggests that Indigenous females are being tested for HIV more often and at early stages of infection compared to Indigenous males. Whether these tests were part of a prenatal HIV screening or as part of a general health care check-up is uncertain. It is noteworthy that the same PHAC report identifies Indigenous women's route of exposure to HIV as IDU (63.6%), and heterosexual contact (34.8%), while for Indigenous men, HIV exposure is IDU (54.6%), and heterosexual contact (21.5%).

According to the Canadian Aboriginal AIDS Network (2010) study, 20% of AIDS cases in Canada are found in Aboriginal populations. The average age of diagnosis is also much younger, in that 32% of those diagnosed with HIV are Aboriginal youth, age 15-29 years (CAAN, 2010). These statistics are based on nationally reported cases and do not accurately reflect the Indigenous populations across all regions of Canada.

The Atlantic Region includes four provinces with First Nation, Innu and Inuit communities as well as Metis Peoples living in these areas. In this document, Indigenous is used to refer to all or any one of these populations. However, the diversity of the Indigenous peoples of Canada are not identified for a provincial analysis by race/ethnicity within the national PHAC data in that race/ethnicity data were only available in approximately 58% of all HIV prevalence data in 2014 (PHAC, 2014). The lack of available data contributes to the challenges within the Atlantic Region in analysing data by province, race/ethnicity, age and sex. Also, there are significant differences between the western provinces and the Atlantic Provinces including HIV testing rates and

surveillance (PHAC, 2011).

There are limitations within the National Surveillance Data which pose challenges when attempting to identify possible HIV trends (PHAC, 2014). To determine trends in HIV surveillance and HIV testing rates in the Indigenous population of Nova Scotia more data is required to identify changes in behaviour, resources and supports and the overall access and acceptability of HIV testing. Additional data collection needs to include race/ethnicity, age, sex, exposure and jurisdiction. Being unable to identify provincial trends and changes further complicate the development of an effective national strategy for HIV testing which could be useful for all provinces, communities and populations, (CATIE, 2015). The need to deliver respectful and effective HIV testing strategies within target populations, including ethnicity and Indigenous status, the target population must be involved in the development and delivery of the testing strategy. Ensuring that there is not an opportunity to discriminate, exploit, contribute to fear and stigma while contributing to providing prevalence and incidence data on HIV and ethnicity. When a specific population is not included in national prevalence and incidence reports, it creates additional obstacles when trying to isolate the specific challenges, barriers, issues and facilitators to HIV testing in the Nova Scotia Indigenous Communities.

### **1.1 Research Question**

The research questions for this thesis have been developed to address the issues of access and acceptability of HIV testing within the Indigenous populations in Nova Scotia. There is very little if any research data specific to the Indigenous populations in Nova Scotia. Furthermore, the Aboriginal (Indigenous) AIDS Service Organization (ASO) has indicated the need for Indigenous specific data within Nova Scotia and the Atlantic region to develop effective HIV prevention strategies and education within the communities they

serve. The questions included in this research we developed in collaboration with Healing Our Nations (HON) and the researcher, the questions include; what are the perceived barriers associated with low rates of HIV testing among the Indigenous peoples in Nova Scotia? How do the Indigenous populations of Nova Scotia perceive HIV testing? What is needed for increased access to HIV testing prevention initiatives in Indigenous communities throughout Nova Scotia? Is there a difference in perceived barriers, perceptions and impacts of HIV testing between the on-reserve population and the off-reserve population of Indigenous peoples in Nova Scotia?

The ability to identify any differences between the on-reserve Indigenous peoples and the off-reserve Indigenous populations will provide insight into the impact of the environment and its effects on social and cultural norms within the indigenous peoples in the province. The investigation of differences and similarities among the on and off reserve Indigenous populations in Nova Scotia include; how the broader diverse ethnic/race community affect Indigenous peoples and their access and acceptability of HIV testing; what is the impact of living off-reserve and does it affect Indigenous peoples and their perception of HIV testing and their Indigenous identity?



## **CHAPTER 2: REVIEW OF RELATED LITERATURE**

### **2.1 International HIV Prevention Strategies: Individual and Population**

HIV testing is a fundamental component of international and national strategies (UNAIDS, 2017). The Impact Fraction Model provides structure for HIV prevention efforts, including testing, by directing efforts towards the populations most affected, and selecting the interventions which involve those most affected and can impact their health outcomes in the prevention of HIV/AIDS (O'Byrne, 2012). Evidence indicates that when a person knows their HIV status, there is a significant effect on risk behaviour and the reduction of transmission to others (O'Byrne, 2012). Given how HIV is transmitted, it can be challenging to separate primary prevention (e.g., prevent seroconversion) and secondary prevention strategies (e.g., early detection and treatment of lower viral load, increase health outcomes and reduce onward transmission). Primary and secondary prevention are interconnected as they benefit both the health of the individual living with HIV and the public (O'Byrne, 2012).

Furthermore, O'Byrne (2012), states that reducing HIV transmission at the population level includes viral load suppression and changing sexual health behaviours. Access to treatment is dependent upon HIV testing and access to Highly Active Antiretroviral Therapy (HAART) treatment which reduces the viral load, ultimately reducing the risk for HIV transmission (O'Byrne, 2012). There is evidence to suggest that a 95% or better adherence rate in taking antiretroviral Therapy (ARV) is an effective means of achieving an undetectable viral load and in reducing transmission (Combes et al., 2009). Reducing HIV transmission at the population level is largely related to HIV testing, knowledge of one's HIV status, and access to treatment and care among those

who test HIV positive. HIV testing uptake needs to increase to improve population level HIV prevention. In Canada, it is a criminal offence for a person who is HIV positive to engage in sexual activities that present a “realistic possibility” of transmitting HIV. Without prior disclosure of their HIV status, engaging in unprotected sexual activities can be considered a crime as put forth by the Supreme Court of Canada on October 5, 2012 (Canadian HIV/AIDS Legal Network, 2015).

The ruling by the Supreme Court of Canada aims to protect individuals from becoming infected through sexual contact with someone who is HIV positive and knows their HIV status. Unfortunately, this decision overlooks personal responsibility, and the right of persons who engage in consenting sexual contact to both protect themselves and to not engage in sexual activities that may place them at risk for HIV transmission. Despite this ruling, there is a lack of evidence supporting the use of criminal law as a means of preventing HIV transmission. What the criminalisation of HIV non-disclosure does accomplish is to further the discrimination towards people living with HIV by charging them with a criminal offence even in instances where there was no transmission of HIV (Canadian HIV/AIDS Legal Network, 2015). The Canadian HIV/AIDS Legal Network (2015), also states that this misguided use of the law is often applied in the interest of public health. Furthermore, the criminalisation of HIV non-disclosure may prevent people from accessing proven public health initiatives that can help reduce HIV transmission such as testing, counselling and support, and partner notification. The HIV non-disclosure law could lead to an abuse of human rights and further stigmatise people living with HIV. The nondisclosure law undermines the principle that everyone is responsible for his or her sexual health, and creates a false sense of security by assuming

that the law will protect them from HIV (Canadian HIV/AIDS Legal Network, 2014).

Additional strategies include targeting HIV prevention and testing interventions for vulnerable or ‘high risk’ populations. This strategy also allows for the opportunity for those most affected by HIV to be involved in the planning and design of the testing approach and process. O’Byrne (2012), identified that in Canada the uptake of HIV testing is poor even though testing is free. Additionally, in some provinces such as NS, there are no testing uptake data available. In 2011 the PHAC estimated that 25% of people living with HIV did not know their HIV status. To increase the uptake of HIV testing in Canada, PHAC has developed and released an HIV Screening and Testing Guide in 2013.

## **2.2 Human Rights, Regulations and Guidelines for HIV Testing**

Appropriate guidelines for HIV testing are necessary to protect individual rights to privacy and autonomy while balancing the interest of public health (Gahagan, 2010). The interdependence of individual and population interests creates a challenge in developing HIV testing guidelines that both respect the person and the population’s health.

The American College of Physicians has adopted guidelines that have influenced the World Health Organization (WHO) and United Nations AIDS (UNAIDS). Further research has been conducted by Global Health Initiatives (GHI) which impacted low-resource countries (Biesma et al., 2009). Since HIV/AIDS is a global health issue, both international and national strategies are needed to account for the socioeconomic diversity within and between countries (Biesma et al., 2009). However, this creates even further challenges when the strategy is dependent upon its effectiveness within individual communities and populations with varying resources, needs, strengths and challenges.

PHAC has stated that community conditions affect the health of individuals and this statement is supported by the Declaration of Commitment on HIV/AIDS made in 2001 by the United Nations General Assembly (UNGASS,) supporting an integrated approach to the prevention, treatment and support to individuals and communities affected by HIV/AIDS (Veinot, 2013). Most recently, the UNGASS has made a new Political Declaration which utilises the framework of the Sustainable Development of Goals, or also referred to as SMART (sustainable, measurable, achievable, realistic and time bound) goals. This UNGASS plan was a result of the United Nations General Assembly high-level meeting which has implemented “specific and time-bound targets and actions that must be achieved by 2020” (Holligndale UNAIDS, 2016).

The President of the Assembly, Mr Lykketoft, was quoted in a press release from the UNGA (June 8-10, 2016) stating: “We must pay greater attention to equality and inclusion, uphold human rights and speak out against stigma and discrimination.” This statement supports and reinforces the need for target population HIV testing strategies and the rights, and the need to reduce fear, exploitation, stigma and discrimination of targeted populations; ensuring that HIV prevention strategies include individual interventions as well as population-based interventions. The goal of the new Political Declaration is to end the AIDS epidemic by 2030 (UNGA, 2016).

Qaseem et al., (2009) identified the guidelines for the American College of Physicians and how they establish the standards of providing information of HIV testing, screening and counselling (pre- and post-test). These guidelines are designed to address the following issues: 20,000 people per year are infected with HIV by someone who does not know their HIV status; the opt-out pregnant women strategy reduces mother to child

transmission; risk based testing is cost effective; people aware of their status reduce risk behaviour; and, risk based screening has failed. Based on these findings, the American College of Physicians has adopted an opt-out approach to HIV testing, which means that HIV testing is part of a standard screening process and that the patient has the right to say no to HIV testing. To ensure that consent has been given, the screening process must include informing the patient that HIV testing is part of the standard screening process. Also, to the opt-out approach within the American College of Physicians guidelines, there was an increase in HIV testing by targeting high-risk groups such as service users of Sexually Transmitted Disease (STD) clinics, inmates, homeless populations, men who have sex with men (MSM), and those who use drugs. What is not clear is if the identified high-risk groups perceive themselves as having the ability to say no to HIV testing. According to O’Byrne (2012), and CAAN (1999), it is important to ensure that there is involvement in the development and delivery of targeted HIV testing interventions to reduce fear, stigma, discrimination and the ability to say no to HIV testing.

PHAC has recently released HIV testing guidelines which are in line with international HIV testing guidelines and based on those adopted by the Centre for Disease Control in the United States. The PHAC guidelines include offering HIV testing as part of the periodic routine medical care based on a simplified risk assessment, and an option to remain voluntary, based on informed consent with flexible pre, and post test counselling (PHAC, 2013). In addition, PHAC has included couple’s HIV testing, and integrated HIV testing services including those for tuberculosis (TB), sexually transmitted and blood borne infections (STBBI) and hepatitis C (HCV). Other services include antenatal care, sexual health and family planning, drug and alcohol treatment, newcomer and travel

health clinics, mental illness treatment and psychiatric services, as well as cancer or oncology clinics.

The screening and testing guide also addresses some of the barriers associated with HIV testing including guidelines for the pre- and post-test counselling, how to give results, retesting, referrals and partner notification. It is important to note that this is a guide and does not impose regulations or supersede any provincial/territorial legislation, policy or practice requirements or professional guidelines. The Canadian Medical Association has adopted the opt-out approach to HIV testing for pregnant women. PHAC (2016), recommends that all pregnant women be offered HIV testing, this includes pre- and post-test counselling. According to PHAC (2016), HIV testing of pregnant women is the woman's choice. However, some provinces and territories have adopted the opt-out HIV screening for prenatal care, as the College of American Physicians, meaning that pregnant women are informed of HIV testing as part of the prenatal screening process, and if the women do not refuse, consent is implied (PHAC, 2016). The recommendation of prenatal HIV screening is a guide and provides opportunities for provinces and territories to implement their guidelines on how HIV screening is offered to pregnant women either an opt-in or opt-out approach. Regardless, HIV screening as part of the routine prenatal screening process must obtain informed consent, meaning the woman must know she is being tested for HIV and receive pre- and post-test counselling (PHAC, 2016).

Implementing an opt-out approach to HIV testing could pose challenges that need to be considered within an HIV testing strategy (Rennie & Behts, 2006). In the ethics of routine HIV testing in low-income countries, it has been identified that there are

inequities in access to health care, and little access to opt-out HIV testing within the population most affected by HIV which typically include lower social and financial status (Rennie & Behts, 2006). This inequity challenges the human rights surrounding opt-out routine HIV testing where access and refusal for HIV testing should be available to all, regardless of social and financial status.

Merchant et al., (2012), identified that patients and clinicians hold different views on HIV testing methods. According to Merchant et al., (2012), clinicians are concerned with the use of general consent for testing. Service users have suggested that the opt-out approach would be less stigmatising, and that general consent and voluntary counselling are acceptable. This difference in perspectives may be due to the additional responsibility for the clinician, including protecting the rights of the service user (Merchant et al., 2012). The divergent views of HIV testing between physician and patient indicate a power imbalance between the clinician and the service user, where clinicians recognise the additional responsibility they hold, and service users view services differently.

### **2.3 Indigenous Diversity**

Characteristics associated with HIV testing and prevention within traditional Western or mainstream services do not necessarily reflect the needs of the Indigenous populations. As identified in Bartlett et al., (2007), and Worthington et al., (2010), there is diversity among the Indigenous peoples of Canada, and the social norms, values, and beliefs of Indigenous peoples are not congruent with those of the Western World. It is important to note that the Indigenous populations is not a homogenous group, and has diverse geography, resources, and languages (Bartlett et al., 2007).

For example, the characteristics of service desired by Indigenous youth differ

significantly from mainstream HIV testing and support services. Worthington et al., (2010) note that Indigenous youth would require an environment and service practices that reflect their home community, with less formality, a communal atmosphere, and an increased feeling of acceptance, to increase their comfort and accessibility to HIV testing. Similarly, Bucharski et al., (2006) identified that Indigenous women want to have family and peer support with them during testing, to mitigate the stigma associated with the environment and location of the testing. According to Bucharski et al., (2006), is directly related to the intergenerational impacts of stigma, and the cultural norm of nondisclosure to outsiders, that causes heightened shame, preventing access to many services. There are also differences between Indigenous on reserve and off reserve populations and their perceptions of mainstream services and their desired services. According to Orchard (2010), the off-reserve Indigenous populations have unique characteristics that are not congruent with those of the broader population. Low education and unemployment among the Indigenous off-reserve populations are associated with higher rates of HIV testing (Orchard, 2010). Further supporting Orchard's identification of the need to develop evidence-based, culturally meaningful HIV testing and explore other factors associated with HIV, testing and perceptions of the Indigenous populations.

To increase our knowledge and understanding of the trends and behaviours surrounding HIV testing in the Indigenous populations, there is a need for a consistent means of identifying ethnicity, and HIV risk factors for people who tested for HIV (Canadian HIV/AIDS Legal Network, 2012). Although race/ethnicity has been included in the HIV screening data since 2009, it is not complete. For example, ethnic identity is not routinely documented for an HIV test in Ontario due to human rights, legal



implications and confidentiality (Canadian HIV/AIDS Legal Network, 2012). Routinely seeking ethnic and other identifying information can be viewed as an infringement of human rights and poses potential confidentiality issues and further stigma and discrimination (Canadian HIV/AIDS Legal Network, 2012). Pope and Morin (2011) state that people living with HIV, or who are at risk of HIV infection are frequently defined by their risk factor or behaviour, such as gay and bisexual men and intravenous drug users. Although this process aids in identifying risk behaviour it also further stigmatises people living with HIV (Pope & Morin, 2011).

The issues surrounding confidentiality also hinders reporting of HIV/AIDS within the Indigenous populations where some reporting provinces do not consistently identify ethnic or Indigenous status due to a potential breach of confidentiality and possible loss of anonymity, specifically related to anonymous HIV testing (CATIE, 2015). In Ontario, anonymous HIV testing service providers do not have to send the results of a positive HIV test to Public Health. Therefore these results do not get reported for federal epidemiological analysis (HIV & AIDS Legal Clinic Ontario, 2016). Also, not all provinces request ethnic identity for their provincial public health services, and therefore can not submit data for federal epidemiological analysis due to additional costs associated with data collection, analysis and reporting (Mellom, 2011).

Additional challenges are stemming from the inconsistent collection of ethnicity/race data and HIV/AIDS data. This is a secondary level surveillance issue and focuses on communities and populations, and the loss of knowledge that can be obtained through specific demographic data. These data can be useful to individual communities and the development of an informed response to HIV/AIDS prevention, treatment and the

access and acceptability of HIV testing. The need to collect secondary level data is supported by the extensive documentation of intravenous drug use (IDU) and HIV infections collected by WHO and UNAIDS and the United Nations International Drug Control Programme (UNDCP). The IDU populations across the globe are distinct from other identified populations and report a significantly high rate of HIV infection associated with IDU behaviour. The issue is not to focus on IDU but rather the behaviour and other mitigating circumstances that contribute to IDU behaviour. As a result, the development and implementation of HIV prevention strategies specifically for IDU populations which include but are not limited to methadone programs, needle exchange, condom and bleach distribution, outreach, and social network interventions (Ball et al., 1998).

The findings by UNAIDS (2016) reflect the effectiveness of population specific strategies and programs for the prevention of HIV and access to treatment for HIV/AIDS. Understanding the population's specific characteristics, social determinants of health and social/cultural traditions, values and history are used to develop and implement a strategy that is population effective. Population specific strategies include ethnicity/race identification and reporting for data analysis for secondary strategies (community or population) that prevent the transmission of HIV and development of AIDS and the overrepresentation within specific populations.

The A-Track pilot survey done in Regina, Saskatchewan provides a good starting point to better understand the overrepresentation of the Indigenous populations in HIV transmission and infection rates. The pilot study identified several risk behaviours associated with HIV transmission and other blood borne infections are contributing

factors of the high rate of HIV infection within the Indigenous populations (PHAC, 2014). The finding of this study recognises the need for Indigenous-specific health and social support services, including HIV testing (PHAC, 2014). Although, the study cannot be assumed representative of all Indigenous peoples in Canada, as the study only included Indigenous peoples from community and health care sites in Regina. However, it is a good starting point, and reference for other jurisdictions to develop effective HIV testing and supports specific to the identified needs of the Indigenous populations (PHAC, 2014).

The lack of understanding of the rate of HIV and the relationship between access, acceptability and uptake of HIV testing within the Indigenous population is a contributing factor to the lack of knowledge as outlined in the literature. The lack of knowledge limits the direction of research and ultimately the interventions that may be implemented to address the problem and reduce the spread of HIV within the Indigenous populations (Duncan et al., 2011). The fact that that there is approximately 25% of the infected population who do not know their HIV status, increases the risk for transmission, and delays access to treatment for HIV, impacting health outcomes. It has been identified that when people know their HIV status, there is often a change in HIV risk behaviours, with the intent to protect others from possible HIV infection (O'Byrne, 2012). Knowing one's HIV status can help and contribute to the reduction of the spread of HIV and increase positive health outcomes (O'Byrne, 2012). The timing of HIV diagnosis about HIV infection also impacts further HIV transmission and individual health outcomes. Individuals from the Indigenous populations are receiving an HIV diagnosis at later stages of HIV progression (Plitt et al., 2009). Early detection of an HIV infection can help ensure access to treatment, and potentially reduce viral load. Early detection may

reduce the risk of onward HIV transmissions, and can increase long term positive individual health outcomes (Plitt et al., 2009).

## **2.4 Identified Barriers to HIV Testing**

HIV testing within Indigenous populations may include administrative, cultural, physical and policy barriers (Charu et al., 2009). In most situations, the process for informed consent usually requires a signature and understanding of the implications of being tested for HIV (Charu et al., 2009). This process may require additional time and understanding of the concept of informed consent. Language barriers may further contribute to the misunderstanding of informed consent and confidentiality, and contribute to feelings of isolation and alienation. Cultural norms may also impede where silence may be an accepted norm (Charu et al., 2009). In Canada, verbal consent may be obtained when a broad spectrum of tests is being offered such as prenatal or identifying infection or illness, and general consent to medical care is acceptable (PHAC, 2012). When considering HIV testing within an Indigenous community the issue of confidentiality becomes a priority (PHAC, 2012). The health services within the on-reserve Indigenous communities are managed and controlled by community members, and members of the health care staff team may even be related to service users, posing unique challenges to confidentiality and trust of health care and individual privacy within a collective society (Dobblesteyn, 2006).

The perceptions of a lack of risk or the need for HIV testing are also barriers within the Indigenous communities (Cain et al., 2013). Cain et al., (2013) state that there is little difference in how Indigenous people respond to an HIV diagnosis, compared to non-Indigenous peoples. However, they also say that the histories of Indigenous

participants tend to shape their perception of their diagnosis, where drugs and alcohol were a major concern for all those involved in the study. Their research also indicated that many people experience shock and depression associated with their HIV diagnosis and their life histories. The shock was related to their perceived lack of risk or need to be tested for HIV.

This lack of perceived risk contributes to the barriers associated with HIV testing within Indigenous populations. For example, diagnosis of HIV after the presentation of symptoms reduces positive health outcomes. Many participants in the Cain et al. (2013) study regarding depression and HIV experienced shame and guilt associated with their HIV diagnosis preventing them from getting support and treatment, potentially placing them at further risk for opportunistic infections and full-blown AIDS.

## **2.5 Canadian Context of HIV and the Indigenous Communities**

According to the Canadian HIV/AIDS Legal Network and the Canadian Aboriginal AIDS Network, as noted in the Canadian HIV/AIDS Policy and Law Newsletter (1999), the response to HIV/AIDS-related issues within Indigenous communities must begin with the acceptance of the historical role played by racism, discrimination and cultural oppression. The response must also include the broader systemic issues that continue to affect Indigenous communities while at the same time recognising that Indigenous populations in Canada include First Nation, Metis, Inuit and Innu peoples. Indigenous communities are defined by geographic factors such as on-reserve or off-reserve, as well as community and band membership where there is more likely to be more than one Indigenous identity. The role of Indigenous governance along with the need to incorporate HIV/AIDS issues specifically for Indigenous Peoples is also

noteworthy.

To provide effective resources and services in the prevention and treatment of HIV/AIDS among the Indigenous populations in Canada, service providers need to address the barriers and challenges to increase acceptability and accessibility to prevention services such as HIV testing, counselling and support. The obstacles and difficulties to access and acceptability of HIV testing within the Indigenous populations have been identified as administrative, cultural, physical and policy barriers (Charu et al., 2009). Further, Dobblesteyn (2006) identified confidentiality and trust as barriers to HIV testing in the Indigenous on-reserve communities. Cain et al., (2013), also identified the lack of perceived risk and historical realities of the Indigenous population as barriers to HIV testing. Unfortunately, there have not been many facilitators identified in the literature which could be opportunities to increase access and acceptability to HIV testing within Indigenous populations. Accurate reporting of ethnicity and uptake are important factors to understanding the true reflection of the impact of HIV/AIDS on the Indigenous populations in Canada. According to Hill (2003), underlying socioeconomic factors may increase the risk activities within Indigenous communities thereby contributing to the overrepresentation of HIV infection within the Indigenous populations of Canada.

Furthermore, the prevalence of HIV/AIDS among Indigenous peoples in Canada is not entirely understood. Hill (2003), states that nearly half of the cases of AIDS reported to PHAC do not identify ethnicity and that the number of Indigenous people living with HIV/AIDS is underestimated. According to PHAC (2013), the number of AIDS cases has decreased due to the introduction of highly Active antiretroviral therapy (HAART). The reduction is also observed by some provincial reporting incidences of

AIDS (PHAC, 2014). This reduction in reported AIDS cases also includes incidents of AIDS cases among the Indigenous populations, where 59.3% of all reported AIDS cases included information on race/ethnicity (PHAC, 2012). Of these, 49.0% of AIDS cases identified themselves as White, 34.3% as Indigenous, and 8.8% as Black” (PHAC Surveillance Report to December 31st, 2012). In 2014, half of AIDS cases were missing race/ethnicity data, and therefore incidents of AIDS cases within the Indigenous populations offers an incomplete picture (PHAC, 2014).

Although these numbers reflect a decrease in the prevalence of AIDS cases in the Indigenous population, there is still a vast over-representation of AIDS within this population. Given the overrepresentation of HIV infection and the socioeconomic issues contributing to health outcomes within the Indigenous population, it is not unreasonable to conclude that the number of Aboriginal (Indigenous) Persons Having HIV/AIDS (APHAs) is underestimated. Underestimation could also be used to argue that now is the time to invest more into HIV transmission prevention, as well as access to treatment to lessen the burden of HIV within the Indigenous populations. This is supported by WHO, UNGA, UNAIDS and UNGASS where in June 2016 it was stated that “Today is the day that we collectively say that we will end the AIDS epidemic by 2030” (UNGA Press Release, 2016, pp 1).

In recognition that each province/territory has its regulatory guidelines, the HIV Testing Guide sets a standard of care that aims to protect and respect individual rights as well as the public’s health. Gahagan (2010), has identified some challenges and implications of adopting the national guidelines without community involvement and local input. These challenges contribute to the barriers identified in providing health care

and HIV testing/treatment services to a large rural geographic area, creating geographic barriers to services. These barriers further compromise access and accessibility to HIV testing, support, and treatment. Gahagan (2010), further urges the need for community involvement and evidence based research to guide the implementation of a strategy that increases testing rates for high-risk populations, without compromising individual rights. HIV point of care testing (POCT) has been available in Canada since 2005, however, despite the acceptability of HIV POCT across Canada, lack of access in the Atlantic region remains problematic (Asghari et al., 2017). Specifically, HIV POCT is not available in any of the four Atlantic Provinces. The challenges with HIV POCT include the lack of access for rural and remote communities, including Indigenous communities, the lack of innovative non-traditional healthcare services such as HIV testing sites also creates barriers for Indigenous communities and other rural areas (Asghari et al., 2017). Developing national and international strategies must respect local factors and diversity by including perspectives on the needs of the individual populations and the broader structural barriers that exist. Respecting local factors and diversity also applies in Canada when one considers the provincial diversity, national statistics and the population distribution within provinces and across Canada.

In Nova Scotia, a total of 766 cases of HIV infection were reported between 1985 and 2011. The Indigenous population accounts for 3.2% of all cases from 2002 through 2011 (Surveillance Report on HIV/AIDS in NS: 1985 to 2011). Race/ethnicity data were available in approximately 58% of all HIV prevalence data in 2014 (PHAC, 2014). Therefore, the rate of reported HIV infection among the Nova Scotia Indigenous populations is not accurate. According to a representative of First Nations Inuit Health



Branch (FNIHB), HIV testing within the Indigenous population of Nova Scotia is either not identified or unknown (Morris, 2012). Without HIV testing and surveillance, we do not definitively know the HIV prevalence in the Nova Scotia Indigenous communities. For surveillance data to be useful, testing frequencies need to increase along with the self-identification of Indigenous ancestry.

Within the Indigenous communities of Nova Scotia, the current characteristics and factors related to HIV testing appear to impact the access to HIV testing and reporting. The inconsistent data collection on Race/Ethnicity within the Surveillance of HIV testing is a challenge (PHAC, 2014). There needs to be community involvement when developing HIV testing guidelines (Gahagan, 2010; Charu et al., 2009) identified barriers to HIV testing within the Indigenous population as administrative, cultural, physical and policy barriers; Dobbblesteyn (2006) identified confidentiality and trust as barriers to HIV testing in the Indigenous on-reserve communities; and Cain et al., (2013), identified the historical realities of the Indigenous population as barriers to HIV testing.

## **2.6 Purpose of Research**

The purpose of this qualitative, exploratory research study is to obtain community knowledge and understanding of the perceived barriers/opportunities associated with the access and acceptability of HIV testing within Indigenous populations of Nova Scotia. In this research, the Indigenous peoples include First Nations, Metis and Inuit from on and off reserve. It is also important to note that in the Atlantic Region there is one Aboriginal AIDS Service Organization (AASO) serving four provinces, every Indigenous community in the region, both on and off reserve; Healing Our Nations (HON). The Indigenous population served by the ASO includes First Nation, Innu, Inuit and Metis.

However, not all are captured in this pilot provincial qualitative study. It is intended that this research provide insight and first voice input for further investigation of HIV testing among the Indigenous communities throughout Nova Scotia, both on and off reserve, and guide further study throughout Atlantic Canada. The characteristics that contribute to the current HIV testing rates in the Indigenous populations of Nova Scotia will be investigated, identifying the on and off reserve characteristics contributing to HIV testing rates within the Indigenous peoples of Nova Scotia. Results will provide additional information about HIV testing among Canada's Indigenous peoples and augment the effectiveness of prevention initiatives in Nova Scotia.

### **CHAPTER 3: DESIGN AND METHODOLOGY**

The methods used for this study is a qualitative community-based research (CBR) approach. The CBR methodology recognises the value of community knowledge of the research topic: HIV testing and access, acceptability and uptake of the Indigenous populations in Nova Scotia. As well as the importance of this knowledge about the effectiveness of strategies and services being implemented, HIV testing is a primary prevention tool for the spread of HIV and impacts the health outcomes for individuals living with HIV (Bartlett et al., 2007). Recognizing current Indigenous health inequities such as socioeconomic status, addictions, violence, sexually transmitted infections and access and use of health care services, the use of a CBR approach will assist in balancing the researcher and community relationship, and implementing a collaborative and equitable relationship (Harris, 2006). To ensure a CBR approach is established and maintained throughout the research process, a Community-based Research Review Team (CRRT) was implemented as part of the method.

CBR is beneficial to both the researcher and community in reducing power imbalances within the research process and the data collected (PHAC, 2012). In addition, the CBR approach to research provides an opportunity to implement several Indigenous research methods. These methods recognise the ownership of knowledge founded in the Indigenous community and respect the traditional means in which information and knowledge are shared (Bartlett et al., 2007).

Moreover, a CBR approach supports the guidance and cultural safety established through the active involvement and direction of a culturally centred community-based organisation, such as HON. The involvement of HON provides access to the information

that is required to implement strategies and services that affect the uptake of HIV testing among the Indigenous population; the prevention of HIV among the Nova Scotia Indigenous peoples; and improve the health of Indigenous people living with HIV (Bartlett et al., 2007). Cultural safety is defined as more than cultural awareness, sensitivity and competency. It is an understanding and awareness that the cultural values and norms of others may be different from the researcher (Anishnawbe Health Toronto, 2012). Storytelling and the use of traditional sweet grass ceremonies, which wash away negative thoughts and feelings contributing to a safe environment for sharing, were utilised in partnership with the Healing Our Nations (HON) program staff (Cameron, Andersson, McDowell & Ledogar, 2010).

### **3.1 The Role of the Researcher**

Having resided on a reserve for the past 15 years and raising children to maintain their identity as Mi'kmaq First Nation, and accept their non-Indigenous mother as a member of their community, the balance of community roles, values, norms, and traditions with my children's identity has shaped my approach to this research. The Medicine Wheel teaches that the strength of the circle is found in the balance of the mental, emotional, physical and spiritual aspects of ourselves as people. Recognizing the value of balance in all facets of life; personal, family, community and society, like the social, ecological model, requires balance within and among all these systems. As a researcher, I have seen and experienced social, economic, familial, community and political inequities. As such, I have experienced the personal struggle in achieving and maintaining personal, family and community balance and supporting her children who identify as both Indigenous and non-Indigenous through their birth status and band

membership. My children have experienced social exclusion based on their Mi'kmaq status within the mainstream school system, and at the same time, undergone a form of community alienation due to their status within the on-reserve community. To identify as a member of the community and to be accepted for who I am, the researcher needed to come to terms with familial diversity and find internal balance.

This research initiative will draw from the social ecological perspective of health. Individual, interpersonal, organisational, community and public policy relationships we experience to contribute to the contextual understanding of health outcomes about the social, physical and cultural aspects of these relationships (Stokols, 1996). The identification of power and authority from a critical social science perspective affects these relationships and how individual reality is constructed (Adler, 1997). The balance between the ability to make choices and acting on those options, about the surrounding social environment, its norms, values, beliefs and consequences, elicits the constructed reality of that experience, contributing to an individual reality or world view (Hopf, 1998).

Within the researcher's personal, familial, community and professional roles there has been a relationship based on a continuum of power and oppression that has influenced both beliefs and behaviour through adaptation and behaviour-setting (McLaren & Hawe, 2004). The impact of power within relationships contributes to shaping the realities developed through the many roles and relationships experienced throughout the life journey (Hopf, 1998). In relation to the social ecological perspective of health and the relationships of varying social environments, the roles of power and authority influence what is accepted and what is omitted in services, programming, communication,

resources and interest (Hopf, 1998). It is the continuum of interpersonal, organisational, community and public policy relationships between the Indigenous communities and the social majority that impacts access and acceptability of services. When services are implemented, and the cultural context of the broader society is integrated within services, thus omitting the reality of those who are not identified within this mainstream group. This can result in a reality that is constructed through the power and authority of the external environment, in relation to the individual or collective community (Lieberman et al., 2013).

Individuals identify their unique understanding of their relational experiences (consciously or unconsciously), which is dependent on the interaction of others to create individual versions of truth (Hopf, 1998). One reality is not right and the other wrong but rather, each reality is accurate to its context, thus creating multiple truths. It is when we accept community truths through our behaviour that a collective reality is established. Through community norms defined by collective interactions of the members of each community, we can identify collective knowledge where individuals share common beliefs, values, and interpretations, stemming from a shared perspective of the various relational experiences (Alder, 1997). The personal reality and the collective reality are dependent on the interaction of others (Hopf, 1998). The interpretive framework for this study is one of a social constructivist, where our realities are based on relationships with others and the experiences we obtain from them. The collective social identities that we accept through our formation of groups and systems, and where we cannot separate self from those accepted collective social identities (Alder, 1997).

From this view, the reality is interdependent where the interaction between

research and the researcher is needed to identify the individual experience (Creswell, 2007). The need for multiple truths stems from a critical social view of power imbalances embedded within social experiences. The role of power and authority shape or influence the social constructivist view, and the need for multiple realities constructed through the interaction with others. The distribution of power alters how we perceive others, ourselves within groups and the realities experienced. Power is not the focus of our realities but influences our perceptions and experiences, which shape our realities (Hopf, 1998). The interactions and our interpretations of those interactions are affected by the distribution of power within relationships and contribute to our truths (Hopf, 1998).

Power or the lack of power changes how we perceive things, thus influencing our individual views of reality. As such, there are elements of critical interpretations where inequities and power imbalances are identified. The critical interpretations of our experiences and perceptions of events are the materials used to create our construction of what we perceive as the truth. Therefore, we all can construct various forms of truth based on our interpretations of inequities and power imbalances. The critical interpretations are the stage where the social construction occurs. It is the construction of truth that shapes how we see ourselves, those around us and the world in which we live. The foundation of the researcher's interpretive framework paradigm is social constructivism, with underpinnings of critical interpretations of the social, ecological model of health. It is the construction of truths established through the inequities of social relationships and the systems within which they function.

Furthermore, the role of relationships within the perceptions of individual truths limits the ability to identify and articulate participant perceptions and acknowledge and

account for researcher bias. Utilizing critical theory identifies the impact we have on each other, and therefore it is not possible to completely factor out the researcher role within the relationship of the researcher and the research itself (Hopf, 1998). The role of Western world views and research methods within the Indigenous context may lead to misinformation, inaccurate and potentially harmful interpretations and representations of the data (Cameron et al., 2010).

As a researcher, the relationship between participants, stakeholders and the data are subject to individual interpretation. Integrating a community-based research methodology within the research study strengthens the relationship between the researcher and the researched. The use of community-based research methods for this study will establish interaction between the researchers and the Indigenous communities, including a Community-based Research Review Team (CRRT). To address the issue of researcher bias and methodological rigour, the data collection, analysis and findings are subject to review by both the researcher and the researched community through a Community Research Review Team (Tobin and Begley, 2003).

### **3.2 Healing Our Nations (HON)**

The relationship between HON and the researchers, Tammy Barbour MA(c) and Dr Jacqueline Gahagan, has been established over several years of collaboration. This collaboration has continued throughout the research development stage, including the design and methodology of the project. Creating a research study that integrates the HON program profile and the rigour required in qualitative research methodology, allows the research to be community-based, and includes elements of Indigenous research methods such as storytelling and traditional sweet grass ceremonies, contributing to the research



environment and participant cultural safety within the data collection process. Furthermore, the current research project recognises that the ownership of knowledge belongs to the community, and is shared with the Researchers and HON, which is congruent with ownership, control, access and possession (OCAP™) principles when working with First Nation communities. Ensuring that the community has a means of influencing how knowledge is gathered, recorded, analysed and shared is also embedded within the methodology of the research through the establishment of the CRRT.

HON is a program sponsored by the Union of Nova Scotia Indians (UNSI). UNSI is the host organisation and provides administrative supports to the Indigenous Atlantic based HIV/AIDS education, prevention, and support and empowerment services delivered through the HON program. HON provides services and resources in a culturally appropriate/relevant approach to prevention within the Indigenous communities, both on and off reserve, including Indigenous people currently in correctional facilities. The mission statement for the HON program is representative of the (w)holistic delivery of the program. "We are here to teach and support our people in the prevention of HIV/AIDS and related issues such as; Healthy Sexuality, Sexually Transmitted Infections, Hepatitis ABC, and co-infections, in a manner that is respectful to our Aboriginal ways of life. We are guided on this mission by the people we help." (HON, 2012).

The structure, program and services of HON are based on traditional values of the Indigenous community, where the community is a collective society, and the (w)holistic world view is shared and integrated within the principles of community-based programming and services. The current research project is structured as a community-

based research study and reflects the core values of HON and the principles of CBR. According to Israel, Schultz, Parker and Becker (1998), the eight principles of community-based research are: (1) recognizes the community as a unit of identity; (2) builds on strengths and resources within the community; (3) facilitates collaborative partnerships in all phases of the research; (4) integrates knowledge and action for mutual benefit of all partners; (5) promotes a collaborative learning and empowering process that addresses social inequities; (6) involves cyclical and iterative process; (7) addresses health from both positive and ecological perspectives; and (8) disseminates findings and knowledge gained to all partners.

The current study, “HIV testing in Nova Scotia: An Indigenous perspective on access and acceptability” incorporates the eight principles of CBR. First, Indigenous people are identified as an identity, and each Indigenous community is also recognized as a unique with own resources, characteristics, norms, values and beliefs specific to the community. Second, the partnership with HON and its involvement with all of the Indigenous communities throughout Nova Scotia identifies each community along with its specific resources and strengths. Third, the partnership with HON and the recruitment process, along with the establishment of the CRRT and its involvement with data and analysis facilitates the collaboration between the researcher(s) and the community. Fourth, the data, analysis and findings are useful for all partners involved. Fifth, the process of identifying the research topic, methodology, data collection, analysis and findings have been accomplished through collaboration. Sixth, the process for data collection and analysis are both cyclical and iterative utilizing the CRRT and thematic analysis. Seventh, the research is designed to capture the relationship between people and

the environment (on and off reserve) as well as individual Indigenous communities are unique in their identity, strengths and resources. And eight, the findings of the research is shared with all partners and communities of Nova Scotia through the partnership with HON and their work with all of the Indigenous communities in Nova Scotia.

### **3.3 Community-based Research Review Team(CRRT)**

Usher (1997), identified the need to implement an element of self-reflection by researchers towards the research being done, to determine the cultural differences and how they are found within the choices made in the research. Recognizing the influence of the researcher within the research process is a significant aspect of this study, it is important to recognise the impact the researcher can have on the behaviour and choices of others within research (Martin-McDonald & McCarthy 2007). The continued collaboration and partnership between HON and the researchers will enhance self-reflection. A Community-based Research Review Committee (CRRT) was established for guiding the research process, to ensure that there was accountability for cultural differences found between disciplines, groups, communities and individuals.

The CRRT included a member of the Union of Nova Scotia Indians, Program Manager of HON, a representative of First Nation Inuit Health Branch (FNIHB), Researchers (Tammy Barbour, and Supervisor Jacqueline Gahagan, PhD) and a community representative. The CRRT was identified and established during the planning stage of the research; cleaned aggregate data was sent to the CRRT via encrypted email file for review and identification of potential cultural and community areas of knowledge, interest and understanding. The analysed data was also sent to the CRRT via encrypted email for final review and identification of cultural and community knowledge,

understanding and interest.

### **3.4 Rationale**

The need for interaction is integral to the CBR methodology (Lavallee, 2009). Strategies need to be developed to assist in the reduction of any influence and interpretations the researcher may bring to the study (Lavallee, 2009). A genuine practice of CBR requires fundamental equality and collaboration between the researcher and the community (Harris, 2006). The initiation of the research topic 'HIV testing in the Nova Scotia Indigenous Communities' was identified in partnership with (HON) and the Researcher. Moreover, the use of a qualitative methodology rather than a quantitative one will provide a deeper, richer breadth of knowledge. Establishing a richness of information on the topic will provide additional information for future research on the subject.

### **3.5 Ethics for Working with Indigenous Populations**

The current knowledge that exists about HIV testing within the Indigenous populations may not be reflective of the Indigenous communities in Nova Scotia, as reporting of HIV testing and race/ethnicity is incomplete with approximately 50% of reported HIV cases containing race/ethnicity data (PHAC, 2014). Race/ethnicity data were available in approximately 58% of all HIV prevalence data in 2014 (PHAC, 2014). The data from the province of Nova Scotia indicated 1.1% prevalence of new HIV cases in the 2014 Surveillance Report (PHAC, 2014). To obtain a better understanding of HIV within the Indigenous communities across Canada we need to ensure that the voice of Indigenous communities in Nova Scotia and the larger Atlantic Region are included in the literature and HIV testing data. Recognizing that the Indigenous communities within

Nova Scotia are unique and distinct and that the literature and HIV testing data does not include this unique and distinct population. It is the purpose of this research study to identify and understand the current barriers and facilitators to the access and acceptability of HIV testing within the Nova Scotia Indigenous population. Ensuring that the research framework, methods and interpretation of findings are reflective of the Indigenous community in Nova Scotia is the foundation for the research questions and is supported by the gaps in the literature, epistemology and interpretive framework as well as the methodology and theory.

The partnership between HON and the Researchers, Tammy Barbour MA(c) and Supervisor Dr Jacqueline Gahagan from Dalhousie University, helps ensure the integration of community values and interests within the research, contributing to trustworthiness and ethical consideration. The CRRT ensures trustworthiness of the research and findings. Credibility has been established through the strategies embedded in the research methodology that aim to establish reflective truths of the participants (Tobin and Begley, 2004). The role of the CRRT within the research design established trust, reciprocity and rigour of the research study.

In partnership with HON, the measures and structure of data collection were established to maintain cultural and community relevance, where the information originates from the community member's experiences, and is owned and shared by the community participants. The research study establishes reciprocity for the Researchers and the community through the partnership with HON and ensures that the purpose of the research includes additional knowledge that can be used to enhance programs and services.

### **3.6 Ethical Considerations**

This research project required the ethics approval of Mi'kmaq Ethics Watch and Dalhousie University. The ethical considerations of this research include the two dimensions of working within an Indigenous population and the concerns of the individual participants. Working with the Indigenous community in partnership with HON was an integral aspect of the ethical considerations and the integration of community-based research with some Indigenous methods. A Memorandum of Understanding between HON and the Researchers, Tammy Barbour, MA Candidate and Supervisor Dr Jacqueline Gahagan (Appendix II) was established and addresses involvement, participation, ownership of knowledge, use of knowledge, and dissemination of findings. The roles and responsibilities of both the community and the Researcher(s), were detailed, as identified in the Ownership, Control, Access and Possession (OCAP™) Principles, and applies to all research, data or information initiatives that involve First Nations. HON participated in the identification of issue and topic of this investigation and throughout the entire process. The information obtained from this research will be useful to HON and the participating communities, in relation to programming, partnerships, decision making and policies about HIV testing. The findings will be shared with HON and passed on to the communities in an accessible format; supporting the OCAP™ principles for research within Indigenous communities. This ownership of the knowledge and findings ultimately influences the communities' ability and willingness to affect change from within, resulting in community empowerment (Harris, 2006).

The questions and nature of this study require a nonintrusive approach and

cooperative integration within the Indigenous community and resources. Confidentiality was ensured for the individual interview by coding and removing identifying information when reporting findings (Appendix IV). Every effort was made to ensure the identity of all participants remained confidential and, to the extent possible, anonymous.

Involvement in this research poses a limited risk and has been designed to address confidentiality and access to support specifically. Access to support and counselling was provided to all participants to ensure those who experienced any hardship because of this study received support. Ethics approval was obtained from Mi'kmaq Ethics Watch and Dalhousie University prior to any data collection.

### **3.7 Methods**

The research methods for this study were developed to increase participation, ownership, reflective interpretation, shared learning and community engagement. A thorough search of the type, location and availability of HIV testing sites in Nova Scotia was conducted by a search of the Provincial Health Authorities websites, cross referencing with regional and provincial AIDS Service Organizations (ASOs,) and checking with the Indigenous Communities of Nova Scotia and their Health Centre services. Local and provincial organisations and their services were used to provide some details about each testing site, types of testing available, site locations, and the targeted population of the service provider. The identification and logging of the HIV testing resources available on-reserve were also completed in collaboration between HON and the Researchers.

#### **3.7.1 Data Collection Procedures**

Data were collected from the Indigenous communities in Nova Scotia, both on

and off reserve and included a total of six individual interviews with Indigenous participants; three males and three females; there were one male and one female off reserve participant and, two males and two female on-reserve participants. Data were collected initially by HON which included sex, age, and if they resided on or off reserve. Participants were then asked to provide a telephone number and email address for the researcher to contact them. Collecting the initial demographic data through HON was done to reduce the cost to the participants in the study for all Indigenous people throughout Nova Scotia by utilising HON's 1-800 number and increased interest from the community by initially contacting a recognised Indigenous organisation. Once the research contacted the participants, a location for the in-depth interview was identified by the participant.

The interview included a series of questions and probes to elicit a dialogue between the researcher and participant to obtain as much information about HIV testing in the community both on and off reserve. Each participant signed a letter of consent and received a \$20 honorarium for their time and knowledge. Once all the interviews were completed the raw data were cleaned to remove all identifying information including communities, individuals and organisations that may have been identified. The clean data were then aggregated to reduce the potential identification of individual participants. The cleaned and aggregated data was then sent to the CRRT for initial review of the data for its authenticity of the Nova Scotia Indigenous population and to reduce the possible breaches of confidentiality that may be unknown to the researcher. Once the cleaned aggregated data were approved by the CRRT, data analysis was initiated (Appendix I).



### **3.7.2 Participants**

There are thirteen designated First Nation Communities in Nova Scotia (on-reserve), and one (identified) urban Indigenous population in Nova Scotia (off-reserve). Working collaboratively with HON, the research study was designed so that all the communities could participate in this study. Selection criteria for participants included: Self-identification as Indigenous, age 18 or older, females and males, and a combination of on and off reserve, urban, Cape Breton and Nova Scotia mainland communities. Participants have been compensated with a \$20.00 honorarium for the time away from their other responsibilities. The honorarium recognises the value of participant time of approximately one hour, and the importance of the information they are willing to share with the Researchers. The in-depth interviews took place with Indigenous people who were ready to talk about HIV testing. The discussion included topics related to: when should people be tested; is HIV testing accepted in their community; where can people get tested, what types of testing are available; and what is the impact of getting tested for HIV individually and for the community.

### **3.7.3 Recruitment**

Participants were recruited through HON, with the use of posters, community announcements and word of mouth. The process for recruitment included participants contacting HON through their 1-800 number to reduce costs of participating to individuals who reside outside of the Halifax area. Once participants contacted HON, a brief questionnaire was done about their identity, age, sex and if they lived on or off reserve. The potential participant was then asked to provide a contact number and email for the researcher to initiate contact with them. Once contact between the researcher and

participant was made, the participant was asked to identify a place where they would feel comfortable talking about HIV testing, a date and time that would work for them. The researcher would confirm the date, time and place identified and would travel to meet with each participant somewhere in their community. Participation was voluntary and signed informed consent was obtained from each participant prior to data collection.

### **3.8 Measures**

Data collection involved in-depth interviews with Indigenous participants (Appendix III). By holding individual interviews, each participant was invited to provide detailed information, without the influence of outside or additional information. The data collected from each interview is then unique to that participant and can be compared to other participant data for similarities, commonalities and emergent themes. The individual interviews were semi-structured to allow flexibility for participants to provide as much information as they were able from their perspective. Participants were asked questions about their knowledge of HIV testing, HIV transmission and prevention, the importance of HIV testing, the barriers and challenges to HIV testing within the community, the impact of HIV in their community, locations for HIV testing, and thoughts on how to make HIV testing more accessible to the Indigenous populations (Appendix III). The data were transcribed by the Researcher and then aggregated and cleaned to ensure participant anonymity. The data were then shared with the CRRT through an encrypted electronic file.

### **3.9 Data Analysis Procedures**

The data were analysed using thematic analysis, to identify areas of a topic that reflected the aggregated knowledge, experience, understanding, values, beliefs and

perspectives of all the participants. The data analysis was done systematically using inductive thematic analysis to identify themes for discussion and create recommendations. According to Boyatzis (1998), thematic analysis is a flexible means to organise and simplify broad concepts woven throughout large amounts of qualitative data and provide access to culturally relevant themes and rigour in identifying patterns of meaning.

The CRRT reviewed the cleaned aggregated data via electronic file transfer to ensure reflective data analysis and methodological rigour. An inductive process was then used to establish the emergent themes based on the data. The process for coding the data began with several readings of the interview transcripts to obtain an overall sense of the topic. The transcripts were reviewed several more times to identify common or significant phrases (Creswell, 2013). Codes were then developed for each theme and applied to statements, words or phrases, establishing the content of each theme (Boyatzis, 1998). Coding started with the common language, then areas of focus and finally emergent themes. Thematic analysis was used to identify and describe ideas found in the data and identifying themes. The phrases, statements and themes were continuously reviewed to determine any further patterns within the data for a comprehensive presentation of the findings.

There were continuous comparisons of the themes that emerged and the content of the data. Patterns and themes that emerged from the data were then identified from the thematic analysis of the individual interviews. The analysed data was shared with the CRRT through an encrypted electronic file, and no concerns were identified with the initial analysis. The final analysis and findings were formatted for this document,

including significance and limitations. A report of findings will be developed specifically with and for HON, to build towards reflective recommendations for HIV testing education and awareness, community practice, HON education and support, and to increase their ability to inform policy affecting Indigenous Peoples.

## **CHAPTER 4: FINDINGS**

The results of this study offer important information about the availability of HIV testing throughout the province of Nova Scotia, the location of HIV testing and the types of HIV testing available. In addition, this study looked at the availability of HIV testing in the Nova Scotia Indigenous communities, both on and off reserve. Further, this research study included in-depth interviews with both male and female Indigenous participants from on and off reserve. Thematic analysis was used to analyse the aggregated data of six participants; four on-reserve, two males and two females; and two off-reserve, one male and one female. After reading the transcripts several times, common themes were identified, as well as, common language and patterns. Coding was used to identify emergent themes and categories of data. The findings from the analysed data resulted in the identification of four emergent themes, and are presented in this chapter.

### **4.1 Type and Location of HIV Testing Sites in Nova Scotia**

As part of this research study the current availability of HIV testing in Nova Scotia, types of HIV testing available and HIV testing locations were identified. In Nova Scotia, there are three types of HIV testing available; Nominal, Non-Nominal and Anonymous. According to the AIDS Coalition of Nova Scotia, the testing types can be defined as 1) Nominal: In a nominal test, the tester's name and identifying information are sent to the lab along with their blood sample. The test provider is legally obligated to report an HIV positive test result to public health officials 2) Non-nominal: The test provider uses a code when sending the blood sample to the laboratory for testing. Public Health officials are only notified of individual's identity if the results come back positive and 3) Anonymous: There is no collection of personal information about the tester. Only

epidemiological data (i.e. sex, age) is sent to public health officials if the results are positive (ACNS, 2015).

The only two locations in Nova Scotia where anonymous HIV testing can be accessed are the Halifax Sexual Health Centre and the AIDS Coalition of Cape Breton (Sydney). Capital Health HIV testing information identifies the Northern AIDS Connection (Truro) and Pride Health (Halifax). However, a further investigation within Capital Health revealed that currently, HIV testing is not available at these locations, due to staffing and funding issues (Capital Health HIV Testing Information, 2015). In Nova Scotia, an HIV test can also be obtained from a family doctor or walk-in clinic, but it is important to note that unless a non-nominal HIV test is requested, a nominal HIV test will be given (ACNS, 2015).

A fourth type, HIV Point-of Care Testing (HIV POCT) is not currently available in any of the four Atlantic Provinces (Gahagan, 2015). However, HIV POCT was pilot tested recently in Halifax, with funding support from the Nova Scotia Advisory Commission on AIDS. The pilot was launched to determine the acceptability and uptake of HIV POCT, as well as the prevalence of HIV among vulnerable, hard to access populations (Gahagan, 2015).

Currently, there are three ASOs and one Aboriginal AIDS Service Organization (AASOs) for all the Atlantic Region, which is HON. It is important to note that the AASO is an Atlantic Region organization and provides education, support, resources and referrals to all four Atlantic Provinces, both on and off reserve, including 33 designated Indigenous communities. The ASOs are in Halifax, Truro and Sydney, all providing education, support and referral.

#### **4.2 HIV Testing on and off reserve.**

In addition to identifying the availability of HIV testing off reserve, an overview of on reserve HIV testing was also completed in partnership with HON. HON indicated that each Indigenous community is autonomous and identifying each community's resources and access to HIV testing is not possible. However, it can be said that access to HIV testing on reserve is limited, and is further confounded by confidentiality and trust. Trust of the person doing HIV testing in the community is important, however maybe in conflict with the need and expectation of confidentiality when being tested for HIV. Where there is an increased probability of the tester being personally known to the individual or even a family member. HIV testing off reserve, in surrounding communities is also limited.

The surrounding towns with medical centres are small, so confidentiality and anonymity are problematic and thereby increasing the probability of stigma and discrimination in town for the Indigenous people accessing town health care and HIV testing. Without a car or some form of public transportation, the distance to get to a testing site is usually quite far in rural areas of Nova Scotia. Medical drives are on-reserve transportation provided by approved Indigenous community members, to provide transportation to other community members for medical treatment and appointments. Medical drives that include transportation for HIV care and testing are supported through FNIHB. For example, a community member can book a medical drive within the community to access HIV testing and care in the urban centre. However, the probability of knowing the medical driver is significant and could compromise confidentiality.

### **4.3 Individual Interviews**

The next phase of the research study was to conduct the in-depth interviews with both on and off reserve participants. The four emergent themes identified in the data were: 1) inconsistent access to HIV testing; 2) uneven distribution of knowledge about HIV; 3) identification of barriers associated with acceptability of HIV testing in the Indigenous communities in Nova Scotia; and, 4) normalisation of HIV testing. These four themes are presented as they related to the research questions about access and acceptability of HIV testing within the Indigenous communities of Nova Scotia and include perceived barriers and facilitators to HIV testing. The first three themes identify some of the barriers associated with access and acceptability to HIV testing and the fourth theme is presented as a facilitator to increase access and acceptability of HIV testing.

### **4.4 Barriers to HIV Testing**

#### **4.4.1 Theme One**

##### ***Inconsistent access to HIV testing.***

Inconsistent access to HIV testing among the Indigenous populations living in Nova Scotia was identified from the data. Access to HIV testing includes issues such as geographical barriers; primary care absence; the location of HIV testing services; in community testing; transportation; use of access; and, trust and familiarity.

The rural location of most Indigenous communities throughout Nova Scotia is a contributing factor when considering access to primary health care, emergency and HIV testing. Some small communities with less than 1,000 residents have minimal resources. Other communities with larger populations have access to additional resources that include community nurses and access to a doctor. This theme was defined by participant's observations that this is more than an on reserve and off reserve distinction.



In some communities, access to HIV testing is available in their community through their health centre, some only have access to a family doctor 20 minutes away, and other communities do not have access to a regular family doctor at all. In some cases, the nearest clinic or medical centre is more than 30 minutes away, and transportation for medical drives is not evenly distributed throughout the communities.

Participants identified the benefit of having HIV testing available on the reserve and indicated that this would increase access to HIV testing. It was identified that the nurses at the health centre could do HIV testing if it was allowed, and would address the major concern of transportation. Access to medical drives is also inconsistent, where the demand for medical drives is greater than the supply when considering that medical drives are available for blood work, medical appointments, treatment and other health issues including testing for HIV. Getting a drive from a friend or family member who has a car is not always possible, as indicated by the following on reserve participant, “...it is difficult to get a drive, and the medical drivers are booked up” (Female on reserve participant).

***Geographical barriers and transportation.***

When residing on reserve in Nova Scotia, there is often need to travel to the closest town or city where there are medical clinics and doctors to obtain an HIV test. The distance between reserves and towns in Nova Scotia usually requires some form of transportation to get to a physician’s office or a clinic. The FNIHB does support medical drives for HIV testing for on reserve residents, however, participants of this study indicated access to medical transportation was not consistent. As one on reserve participant stated; “It is kinda hard to get medical drives.... a lot of them say they are book up when they are not” (Male on reserve participant). Moreover, another female on

reserve participant said; *“No but a lot of people might not know...like it depends on the driver like you usually have to book in advance to get a drive.”* A third on reserve male participant responded; *“No...I have to walk everywhere”* when asked if there was any other type of transportation available. The inconsistencies of access to HIV testing on reserve contribute to further barriers to accessing HIV testing.

Participants consistently identified the geographical barriers associated with access to HIV testing; however, these barriers were unique to each community. As identified by one off reserve participant when asked where they would go to get tested for HIV they replied; *“Walk-in clinic in the city...or the doctor’s office in town”* (Female off reserve Participant). Although the city referenced by this participant is about an hour away, the ability to walk into a clinic and receive an HIV test was a benefit when access to HIV testing was unavailable locally. Further, the capacity to make an appointment with a doctor in town approximately 30 minutes away was also a comparable form of access but would require some planning to obtain transportation for the appointed time. In another situation, a female on reserve participant indicated that HIV testing could be found through their doctor in town approximately 20 minutes away; *“My doctor...mine is in (name of the town which is 20 minutes away)”*. In these situations, transportation is also an issue when considering the access to HIV Testing.

The rural and remote locations of the on reserve Indigenous communities in Nova Scotia directly impact the HIV testing resources that are available to each community. The availability of medical transportation (Medical Drives), funded by the FNIHB, is inconsistent from one reserve to another. The autonomy of each on reserve community is another important characteristic that impacts the knowledge and understanding of access

to HIV testing. In comparing participant responses, it became clear that access to on reserve HIV testing and transportation for off reserve testing were both inconsistent. Transportation for the off-reserve participants was not as much of an issue as they resided in an urban area with public transportation. However public transportation can be challenging to navigate when the person is not from the city.

***Location of HIV testing and in-community testing.***

There were different responses when asked if HIV testing was available in their community through the health centre; with some suggesting they would go into town to a doctor to get the test and others said they could request the test at the health centre. However, a person must go to the blood clinic or hospital to get their blood drawn. As stated by one female on reserve participant when asked if they knew where they could receive an HIV test, she stated; *“Hospital...I don’t think it is on the reserve anywhere.”* It was also suggested that they could get their blood drawn at the health centre in their community, but they were not sure. In contrast, another on-reserve participant stated:

*“Oh yeah for sure... In the on-reserve community, there is not a doctor, but there are nurses who can do HIV testing.”* When asked if HIV testing was available on the reserve, an off-reserve participant stated; *“On reserve, they won't do a test, and that is in many communities, not sure about which communities, but I do know that a lot of on-reserve people cannot go into their health centre and get an HIV test.”*

When participants were asked if they thought HIV testing was being accessed on the reserve, an on-reserve female participant said; *“they can go to the town, yeah...but it is not near by, at least 10, 20 mins away.”* A male on reserve participant indicated that they could, *“Probably draw their blood here...,”* when asked. The rural location of many

of reserve Indigenous communities in Nova Scotia and their distance from the nearest town or rural community were identified as barriers. Participants also identified the availability of HIV testing in their communities (on reserve) and the absence of a primary health care provider as a direct barrier to accessing HIV testing. There also appears to be inconsistencies with access to HIV testing on the reserve where some health centres can request an HIV test and others cannot. As one on reserve male participant indicated; *“On reserve, they will not do a test here....in the city it can be done in many places.”* Another on reserve female participant indicated that HIV testing was not available in their community when asked; *“No, I don't think you can get that done around here... I don't think it is on reserve anywhere.”* A third on reserve male participant replied; *“Yeah, and sometimes a doctor comes to the Health Centre”* when asked is HIV testing was available in their community.

The off-reserve location to HIV testing was also inconsistent with one off-reserve male indicating; *“I can access HIV testing at the clinic, doctor's office and I'm not sure if it is still available at the AIDS Coalition of Nova Scotia or not.”* While another off-reserve female indicated that she did not know where she could test for HIV, *“Um.... I'm not sure where to go to get tested....”*

***The absence of primary health care providers.***

Further, it was identified that the on-reserve communities in Nova Scotia do not all have a primary health care provider within their community. Although some communities have access to a primary health care provider, it is not consistent and could change from one appointment to another, reducing the ability to establish a relationship of trust and familiarity between the health care provider and the community member. On reserve access to a family physician is inconsistent where there may not be one regular

doctor that visits the community or is in the community on a regular basis. This was introduced by one on female reserve participant, stating that; *“First Nation communities have doctors that come to the communities...”* An on-reserve male participant was “not sure” if there was a doctor on duty at the health centre in their community, and another female on reserve participant stated that “there are no doctors but there are nurses...and they are not from the community.” The availability of a physician in the community is inconsistent both between communities and within a community as one male on reserve participant indicated; *“...I think they just got a doctor up there recently...”* The inconsistency within the community was identified by another male off-reserve participant who stated:

*“From what I see they access the doctors in the health centres on reserve and use them as their family doctor even though it could change...I mean a new doctor could start coming....and in the city or off reserve people don't necessarily see one doctor either so I'm not sure if it is really any different”.*

***Inconsistent Access to HIV testing.***

The inconsistent access to HIV testing was identified in the data by both the on reserve and off reserve Indigenous participants. Geographical barriers, transportation issues and the lack of primary health care providers in the community contribute to the inconsistencies between the on reserve Indigenous communities. Changing primary health care providers in the health centres on reserve limit the ability to form a relationship based on trust and familiarity between the health care provider and the community. This is also identified as a barrier for the off reserve Indigenous participants who indicated that accessing a city doctor is challenged by the lack of familiarity and trust in larger urban centres. Participants identified that even though there are more

choices in the larger urban centres, those choices are not always congruent with Indigenous experiences and personal values. A male off-reserve participant stated that:

*“In the city, there are doctors and people can go to walk-in clinics....it is easier to get a doctor in the city, but not everyone will see a city doctor. It is different living off reserve; people still like to know who they are around so...places like the Friendship Centre.”*

***Trust and familiarity.***

When people migrate to the larger urban centre, there is a desire to be surrounded with people you trust and are familiar. In one such place, the Friendship Centre, there is the presence of culture, custom and identity. When living in a city where there is lack of familiarity with the urban centre, there is a resistance to accessing health services, primary health care and HIV testing. It was stated the people do not see ‘city’ doctors’ due to issues of distrust, as the following off reserve participant remarked; *“For me, it is that I don’t know them and don’t...um...really trust them”* (Off reserve Male Participant). The concerns about familiarity and trust in accessing health care and HIV testing is a common thread among both the on and off reserve participants of this study.

Nova Scotia data is therefore consistent with data collected in other Canadian locations. Boucharski et al., (2006) identified the need for “sensitivity to the historical and current context of Indigenous women’s life experiences”.

HIV testing is technically available through any family doctor in Nova Scotia. However, the process for prenatal screening which includes HIV testing requires, in which case the doctor is to inform the patient that, as part of the prenatal screening they are being tested for HIV and that they have the right to ‘opt out’ (Nova Scotia Strategy on HIV/AIDS, 2003). As discovered during the interviews, this is not always the case as identified by

one participant who said of her experience with being tested for HIV when pregnant:

*“Well when I was pregnant I think I was tested for HIV, but the doctor didn't tell me I was getting tested.... he just handed me my blood work and included it ... I know now that they do that, but I didn't know I could say no, but I really didn't think about it, so it didn't bother me...at least I didn't have to spend time worrying about it because I didn't really know”* (Female on reserve participant).

Statements such as this identify another issue regarding access to HIV testing and the ethical issues around informed consent. In this situation, the patient did not know they were receiving a test for HIV and therefore could not give consent which is a requirement of the testing. This identifies more questions about HIV testing and the regulations/guidelines surrounding it, including pre, and post testing counselling, as well as the potential situation of discrimination and racism.

#### **4.4.2 Theme two**

The uneven distribution of knowledge about HIV and HIV testing was the second theme identified in the data. Valuable knowledge about HIV testing includes the risk of HIV transmission, the presence of HIV, HIV testing and identification of HIV status as a means of prevention. There appears to be limited knowledge about the types of HIV tests that are available in Nova Scotia. However, there was knowledge and awareness about the HIV POCT being piloted in Halifax to measure access and uptake of HIV testing.

#### ***Risk of HIV transmission.***

From the findings of this study, there was a general acceptance that HIV was in their community and that not everyone had access to the information needed to protect themselves and others from the transmission of HIV. It was also identified that the people who are most at risk for HIV transmission do not have access to information, supports or

knowledge of HIV transmission, testing or treatment. This finding could also be related to the stigma that is often associated with HIV within the Indigenous communities of NS. The identification of the presence of HIV in the community and the risk of HIV transmission within the community was consistent throughout the data and was a common theme of discourse. The potential for HIV transmission within the community, specific to behaviour, was presented as common knowledge by one female on reserve participant who stated; *“There is a lot of intravenous drug use, and they seem to be younger.”* The presence of IDU in the community was identified as a primary source of transmission, and IDU was a frequent occurrence as stated by one male on reserve participant;

*“...there are so many people that are injection drug users.....I know this reserve ...yeah there is a lot of drug use and sharing.”*

The connection between the presence of HIV in the community and the presence of intravenous drug use was identified, as was the need for more prevention and intervention initiatives including HIV testing. The participants of this study identified the relationship between the presence of HIV and IDU. Participants also identified the need for increased access to HIV testing in their communities both on and off reserve. One female on reserve participant stated the relationship and the risk through this statement; *“...there intravenous drug use in the community and there is HIV in our community too...but really high drug use.”* Harm reduction and safe injection is not something that is talked about in the community nor was it defined by the participants. However, the concern and recognition of the potentially increased infection of HIV within their community were genuine and concern for all participants. Efforts have been made to



introduce a needle exchange, through partnerships, and the use of natural helpers in a few communities.

The presence of the mobile methadone distribution identified by participants of this study and their awareness of the presence of HIV and the risk of transmission within their communities was identified as a potential facilitator or resource for increasing access and acceptability of HIV testing in their community. The participants of this study all identified HON as a resource, and were aware of the services they provided, including going into schools and health centres, but stated that it is still not enough. One female on reserve participant said:

*“...it should have been put in place a long time ago, and it would have made a difference...but there was nothing put in place then, and AIDS and HIV has increased since the 80s.”*

The idea of collaboration and partnerships was also identified in this study to increase resources and the effectiveness of HIV testing. As one on reserve female said;

*“I think they could help people be more educated and want to get tested...I think if (AASO) was there with the nurse that people would get tested because they built that relationship for years and years.”*

Collaboration between nurses and the AASO, HON was identified several times. Having the AASO present during HIV testing would increase trust between the community and health care service providers. The presence of a trusted organisation that is part of the community would impact the uptake of HIV testing within the Indigenous communities as stated by a male off reserve participant:

*“...for (AASO) and the nurses to work together in HIV testing, support, access to*

*treatment... it just seems like a really natural type of fit to actually create some sort of...real impact.”*

Statements such as this identify the desire and acceptance of the AASO working with Provincial health care service. HON was established in 1993 and has offered anonymous HIV testing in the office with little uptake. The HON office was located next to the Friendship Centre which may have contributed to the low uptake as well as who was doing the HIV testing. HON does not have the capacity to do HIV testing itself; rather a partnership was formed with the Halifax Sexual Health Centre (HSHC) who provided a nurse to come to the HON office and deliver the anonymous testing program.

***Types of HIV testing.***

Participants indicated that they could access condoms at the health centre and that a methadone bus comes around the community. They also reported that there were too many people living with HIV which could have been prevented with more education and knowledge about HIV transmission and bringing HIV testing into the community. Of the participants interviewed the only one knew of two types of HIV testing, nominal and non-nominal but all the participants were aware of the POCT testing being done in Halifax. Participants identified the need to have access to more knowledge and testing in their community to keep the community safe. One male on reserve participant stated, “Yes, HIV is in our community” when asked if HIV was a concern in the community. The denial of potential risk was also identified as a contributing factor to people not getting tested for HIV. The lack of knowledge or uneven distribution of knowledge about HIV transmission and HIV testing was identified by one off reserve male participant who identified the risks associated with the presence of HIV and opportunities for HIV transmission stated:

*“Where there is both the presence of HIV and behaviour that allows for the transmission of HIV, such as intravenous drug use and unprotected sex, there are going to be more cases.”*

***Impact of knowledge.***

Most identified the requirement to have more information, more access to resources, knowledge and more HIV testing available to all community members.

Another male supported this position on reserve participant who stated:

*“Yeah, there is a lot of like people who shoot up n stuff, and they don't get tested, I know there is HIV in the community; and people just think it will happen to someone else, but it is here and can happen.”*

Participants identified that there is a lack of, or uneven distribution of, education about HIV and HIV testing and that more education and knowledge would affect behaviour. This is especially true where knowing your HIV status and knowledge of how HIV is transmitted could decrease risk taking behaviour such as having unprotected sex, reducing the number of sex partners and sharing needles when using intravenous drugs. It was identified that there was a presence of Hepatitis C in the community and that HIV and HepC are both blood borne pathogens. It was also identified that people have a desire to protect themselves and others in the community. As stated by an on-reserve female participant:

*“People wouldn't be so I don't know, care free probably wouldn't take something or give it by their shared needles, or smoke weed Ya never know...I mean Hep C is in the community too, and that is spread the same way.”*

***Knowledge about HIV testing.***

Participants identified that Hepatitis C (HepC) was also present in the community

and didn't seem to have the same effect on people's perceptions as HIV. Throughout these interviews, there was a discussion about HIV and Hepatitis C and the desire and need to protect each other from these diseases. As stated by one female on reserve participant;

*"If more people got tested, then people would be a lot safer and not give it to others."*

During the interviews, participants identified others as having a lack of knowledge or education about HIV and HIV testing. This could be related to some of the stigmas that are associated with the transmission of HIV and people living with HIV/AIDS. However, some participants felt that there was a need for education for youth, as stated by a female off reserve participant:

*"Education might help, but get it to the people who need it, I don't know I think it is probably more important that the young people get the education now rather than later, bribe them with pizza and door prizes, so they attend".*

A common area of discourse during the interviews was that people didn't understand the various ways of transmitting HIV, the different types of HIV testing available and how testing can prevent the spread, and improve the health of individuals living with HIV.

This is supported by a statement made by an on-reserve male participant:

*"They probably don't fully understand all the ways that you can get HIV...some ways but are not fully educated".*

### ***The role of HIV testing as a prevention strategy.***

The uneven distribution of knowledge about HIV and HIV testing was identified throughout the interviews and included access to HIV testing and the various types of HIV testing. Each community has a Health Centre, but not all have a primary health care

provider or a consistent primary health care provider. Most communities cannot provide HIV testing of any type and rely heavily on HON coming to the communities to deliver HIV/AIDS/HepC/STBBI education sessions and supports. According to the participants of this study, this is not enough, and people want to keep themselves and others safe as stated by an on-reserve female participant:

*“Well, there is the lack of education ....” when asked about the HIV education that is available in the community.*

The interviews with participants had similar threads of perceptions and knowledge about HIV testing, what was happening in the community and what was needed to help keep their community safe. One female on reserve participant responded by saying that there is;

*“Not enough education...people weary about getting testing...uhh, I wouldn't say there is so much a stigma, I mean it's their own preference their scared to find out for sure and not having very much education in that area ....”*

The fear and stigma was not stated in all interviews but was linked to the discussion.

#### **4.4.3 Theme three**

The identification of barriers associated with access and acceptability of HIV testing in the Indigenous communities in Nova Scotia was the third theme identified. Participants identified social barriers more often than cultural barriers. The distinction between social and cultural barriers was made by the participants throughout the discourse. Social barriers include fear, stigma and homophobia, small community challenges, and confidentiality as consistent issues when accessing HIV testing whether the community is on reserve or off reserve. Indigenous traditions, values and beliefs were

not specifically identified as barriers when accessing HIV testing. However, the desire to have someone with you when you receive your test results was identified and could be in part due to cultural norms. Participants expressed concern for both the people using intravenous drugs and the younger population who may be experimenting with alcohol, drugs and sex.

***Fear, stigma and homophobia.***

The social barriers most frequently identified were fear and stigma, but upon further analysis of that data, a pattern emerged where the social stigma is directly related to the sexual activity that transmits HIV from one person to another. Specifically, the term ‘gay sex’ and ‘dirty’ were used to describe the behaviour. This was common among participants and indicates the presence of homophobia as a barrier to HIV testing, where the transmission of HIV is related to a specific sexual activity referred to as ‘gay sex’. The social stigma or homophobia that surrounds HIV as being a ‘gay disease’ or ‘dirty’ is a barrier to HIV testing. One male off reserve participant stated:

*“Being gay yeah know it was dirty and it was the source of HIV stigma. Where Hep C....is mainly IDU.... these people aren't sleeping together which is a sexual thing...drug use isn't seen as a bad thing, but sex is dirty.... when sex is more natural than drug use...but educating on both HIV and Hep C might reduce the gay stigma around HIV”.*

This statement also identifies the relationship between Hepatitis C (HCV) and HIV as blood borne pathogens, though they are viewed very differently within the community. Participants could identify that the transmission of HIV is potentially like HCV and yet concern or fear of HCV was not identified by participants. HIV was compared to HCV by participants who identified the similarities in transmission and yet there are differences

in acceptance within the Aboriginal community. As stated by a participant there is a perceived social difference between HIV and HCV from the community perspective and perhaps the reason why there is less concern about HCV and yet still a fear and need for knowledge about HIV as identified by one male on reserve participant:

*“I would imagine like AIDS like your pretty much gonna die, and you’re gonna die soon where Hepatitis is like manageable”.*

It was also identified the mode of transmission of HCV was commonly accepted as related to IDU which appeared to have less stigma. Where HCV was perceived to be more closely related to IDU than sex, it was not perceived to have the same stigma as HIV. It was identified that one of the main reasons people do not get tested for HIV was that receiving a positive test result would affect their relations with the community since the stigma surrounding HIV is still present and negatively affects familial and community relationships.

The stigma surrounding HIV being perceived to be a “gay disease” was also associated with feelings of ‘shame’ or being ‘dirty’ as identified within the data.

Interestingly, the concept of sexual activity was also present throughout the discourse and carried some form of the stigma associated with it, whether it was age, number of partners or sexual identity. As one female on reserve participant identified, multiple sex partners was a common occurrence among the younger people:

*“Yeah, cause all these teenagers are running around doing the nasty... yeah this one is with that one and that one and so on...and another”.*

According to the participants of this study, the topic of sex remains a social taboo, and the labelling of gay sex as “dirty” identifies the presence of homophobia.

***Cultural differences as a barrier.***

Although participants stated that there were social barriers such as stigma and homophobia, rather than cultural barriers related to the access and acceptability of HIV testing, the desire to have someone with you when you see the doctor was identified as a means of community support and access to better care. It was also stated that having someone with you when you receive the test results would be beneficial. As one male off reserve participant identified, it would be advantageous to have someone with you when you receive your HIV test result or any other health related information:

*“I think it is beneficial to people when they receive test results to be able to have somebody with them”.*

***Small community challenges and confidentiality.***

Receiving an HIV positive diagnosis is something that all participants identified, and emphasised that the loss of community acceptance and sense of belonging would leave people feeling rejection rather than acceptance. A male on reserve participant said:

*“Probably fear, some people would be afraid to get tested or find out that they could have it”.*

Another male on reserve participant talked about it being scary and the fear of others knowing and fearing how they would treat him...and not wanting to give it to someone else, as he stated, “...being diagnosed with HIV it is scary...” It was identified throughout the study that participants believed that HIV testing was needed in their community for several reasons, including the presence of HIV in their community, the casual sex that was a common practice among the youth, and the presence of intravenous drug use in their community. The presence of HIV, casual sex and IDU in a small community not only increase the risk of HIV transmission, but it also reduces anonymity. As with all the



participants of this study, members of a small community know what is happening all around them. This reduces confidentiality and could affect access and use of HIV testing.

Fear of receiving an HIV positive test result is a contributing factor in the acceptability and uptake of HIV testing among the Indigenous communities, where the fear appears to be related to the perceived idea that people will know they are HIV positive. This may be linked to the confidentiality issues that have been identified when accessing HIV testing but was not stated as the reason for their fear other than the belief that people would know they are infected. As one male off reserve participant said:

*“I hear it all the time that people don't want to get tested because they don't want people to know they are positive.”*

This is in direct contrast to the common belief that confidentiality is not an issue when it comes to HIV testing. One female on reserve participant stated; “... *the testing is all confidential, yeah know even at the health centre.*”

Although not clearly indicated as a breach of confidentiality, there seems to be a belief that once you test positive for HIV, people in the community know you are infected. This could stem from the stigma that is associated with HIV as being a “gay disease” or ‘shame’ and ‘dirty’. This may be associated with being an intravenous drug user where others assume that people who use intravenous drugs together all have HIV and/or HCV. Whether HIV is stigmatized due to the historical relationship with being a “gay disease” or intravenous drug use, the stigma affects HIV testing access and acceptability within the Indigenous communities of Nova Scotia.

## **4.5 Facilitators for HIV Testing**

### **4.5.1 Theme four.**

The normalisation of HIV testing was also a key theme identified throughout the data where participants suggested the need to shift HIV testing away from behaviour, sexuality, and risk, toward something that is a normal part of individual and community health. This could be accomplished by creating an environment that removes the stigma and fear around HIV testing and supports everyone getting tested, and having HIV testing visible throughout the community and not hidden. Although there is still resistance, a lack of knowledge or uneven distribution of knowledge, stigma and fear, there is also a desire to contribute to a safer community for everyone. There is a recognition that HIV testing contributes to everyone's health and well-being. Participants appeared to be informed about opportunities that were available in other places, or that were new and obvious in the community, such as the methadone bus on the reserve, and the option for HIV testing through this form of service. Shared ownership of community safety was identified as a value throughout the data and is unique to this research. Furthermore, it also indicates the need for further investigation and to look at how HIV testing is presented and delivered to the Indigenous communities. Further, there may be a need to ensure opportunities for Indigenous communities to define how HIV testing would best serve their community within the Nova Scotia strategy on HIV/AIDS.

#### ***Testing for everyone.***

When a female on-reserve participant was asked what would make HIV testing more acceptable, she responded without hesitation; *"Uhh...if everyone got tested"* The normalization of HIV testing removes the stigma associated with HIV. It instead makes it about being a person and member of the community. The desire to protect all members of

the community was a consistent element of all interviews and discourse. Another male off reserve participant ended the conversation with an opinion where he simply said; *“I just think everyone should get tested.”*

It was also identified that increasing HIV testing would reduce the spread of HIV in their community and affect how people felt about HIV. It was a common theme among participants that increasing the availability of HIV testing would lower the barriers that exist to HIV testing and would affect how people engage in risk behaviours. One male on reserve participant said:

*“Have somewhere on this reserve where people could go and go down there and just get tested without having to leave...it would be a lot easier...cause some people don't have the money or the time to go into the city to get tested and spend the day to go do this and that.”*

The increased access and uptake of HIV testing would increase positive health outcomes, and contribute to a more connected community with less stigma and fear. As a female on reserve participant thoughtfully suggested:

*“Yeah, I think it would make it like more normal... People would be more willing to get tested, and people would be a lot safer using needles and shit.”*

This was said during a discussion about increasing HIV testing within the community. Throughout the discussions with participants, it became clear that fear and stigma surrounding HIV existed, though it was also clear that there was a common desire for greater access to HIV testing so that the testing was known and visible within the community. Knowledge and visibility could contribute to the normalisation of HIV testing, and would be a form of reducing the stigma and fear. One female on reserve

participant identified that by normalising or making HIV testing accessible to everyone in the community it would reduce the fear and shame that is associated with being tested for HIV:

*“I think it would be accepted; I think if people were to realise that it is something for the good that can protect them”.*

The desire for safer communities appears to be the motivation for the normalisation of HIV testing. The desire to normalise HIV testing within their community was consistent and included creative ways of bringing HIV testing to their community. The participants of this study identified the need to increase access to testing by bringing it on reserve, making it part of regular medical care, and reducing the wait time for test results through HIV POCT.

The idea of normalising HIV testing so that it is available to everyone rather than targeting individuals or “at risk groups,” was common throughout the data and seen of increasing access and acceptability of HIV testing. Participants identified the benefit of “just everybody needs to get tested”, and one male off reserve participant specifically identified POCT as a means of testing, and introducing it like the methadone bus which has become a normal part of the community. Another female on reserve participant further supported this statement by saying; “

*If it was available in our community, I’ve seen like...we have buses with methadone that like go around, they could probably like do the same thing with testing.”*

***Bringing HIV testing to the community.***

Through the interviews with participants, it was identified that increasing access to HIV testing by bringing it to the community would help reduce the stigma and fear

associated with HIV testing. One off reserve female participant stated; *“If it were easier to get tested it would help, people would be more inclined.”* We know from the literature that people who know their HIV status, change their HIV risk behaviours to protect others. The participants of this study also identified the relationship between HIV testing, knowing one’s HIV status and reducing the onward spread of HIV. This was a key theme throughout the discourse, as it is a common thread within the fabric of their community, to protect each other and keep each other safe as stated by a female on reserve participant:

*“If more people got tested than people would be a lot safer and not be giving to it others.... if people know that they would be safer using drugs and shit’.*

***Community health outcomes.***

Through the increased access and acceptability of HIV testing, risk behaviour such as sharing of needles and unprotected sex would decrease, there by contributing to both individual and community. It was also identified that HIV testing would benefit individuals who tested HIV positive, as HIV positive the only means to accessing treatment. A male off reserve participant stated that the only way a person can access the treatment that is available for HIV is through HIV testing and that if HIV testing were more accessible and normalised within the community, it would increase positive health outcomes for everyone; *“...testing to access treatment.... Definitely”.*

The desire to normalise HIV testing within Indigenous communities addresses both access and acceptability. By increasing the availability of HIV testing in the community and delivering it via an accepted and trusted service provider, access to HIV testing would be positively affected. By integrating HIV testing into the community and providing resources to individual communities, would increase acceptability. Introducing HIV testing within the community was presented to increasing both access and

acceptability of HIV testing while increasing positive health outcomes for the whole community. As one male off reserve participant stated:

*“...then it is there if you need and you don't have to ask...more people would show up....and if you don't need it you can say no”.*

Reducing the barriers to accessing HIV testing is a key component to increase the uptake of HIV testing among the Indigenous populations in Nova Scotia. Establishing practices and protocols that are acceptable to the Indigenous community of Nova Scotia is another key component to increasing the uptake of HIV testing among the Indigenous populations in Nova Scotia and contributing to better health outcomes for the whole community, according to the participants of this study.

## CHAPTER 5: DISCUSSION

The inclusion of the Nova Scotia Indigenous communities and the on-reserve health centres within the development, direction and implementation of the Nova Scotia Strategy on HIV/AIDS is an essential element to addressing some of these real life systemic issues identified by the participants of this study. The analysis of the data identified key emergent themes as well as a common belief that “everyone should get tested for HIV”, that HIV was in his or her community, and that the significant presence of intravenous drug use and multiple sex partners increased the risk for the spread of HIV. Further, HIV testing increases access to treatment and positive individual and community health outcomes. Participants indicated that knowing one’s HIV status would decrease risk behaviour and increase the desire to protect others in the community. From the participants’ perspective, there appears to be a shared understanding of the benefits of HIV testing, including access to treatment and reduction of HIV transmission.

From the data, it appears that there is a real desire for HIV prevention interventions, as well as the prevention of other blood borne pathogens, as indicated by community members both on and off reserve. Throughout the individual interviews, the topic of confidentiality and the desire to have support when accessing HIV testing was explored. As identified by one on reserve female participant, the desire to have a friend or family member attend medical appointments, even confidential ones’ is something that would help. Most service providers would recognise the need for confidentiality and prefer to deliver test results in private. The practice of providing HIV testing in private and ensuring confidentiality may be a deterrent to some Indigenous people for several reasons identified during this research including the long history of colonisation, trust,

fear, stigma and potential discrimination. This may stem from a cultural norm that has been established over several decades of distrust and faith with the health care system among the Indigenous peoples of Canada. The ability to have a support person with you when accessing health services outside of your community is important so that Indigenous peoples will access health care. In the literature, this is identified as a cultural characteristic (BucharSKI et al., 2006).

These findings are congruent with the conclusions of this current study regarding barriers to the access of HIV testing among the on and off reserve Indigenous participants in Nova Scotia. It also appears that the participants of this study wish to normalise HIV testing to contribute to community safety. This is not consistent with the statements made about fear, stigma and lack of knowledge that exist within the community when asked about HIV and HIV testing. The identification of sexual activity as “doing the nasty” contributes to the stigma associated with sex, sexual activity and sexual identity. Sex and sexual activity appear to be judged more harshly than drug use. The association with the type of sex is further viewed negatively and is labelled “gay sex”. This type and level of stigma contributes to the fear of being tested for HIV and entrenches the shame surrounding HIV and HIV testing.

Participants identified that the HIV knowledge that does exist within the community is not evenly distributed which further confounds the findings. Those with the knowledge may not perceive themselves to be at risk of HIV transmission, further distancing themselves from individuals who may be at risk of HIV transmission. Orchard et al., (2010), identified the “need for improved HIV testing strategies to reach greater numbers of Indigenous peoples living off reserve” (pp. 324). The lack of or inconsistent



access to education are factors in the denial, or the false sense of safety relating to HIV transmission and testing; which seems to be related to the common desire to keep each other safe. As one on reserve participant stated; “...*It can't happen to them....*” when asked if HIV transmission was a concern in the community. Where there exists an uneven distribution of knowledge about HIV and HIV testing, the desire to normalise HIV testing could lead to disenfranchisement of individuals and entrench an in-group and out-group situation, dismantling the indicated desire to have safer communities for everyone. The data certainly indicates that there is a level of readiness within the Nova Scotia Indigenous communities, to increase HIV testing uptake and to respond to the increased needs, potential barriers and systemic challenges with regards to public health policy.

Readiness for HIV testing must be scanned to include all the barriers and facilitators to HIV testing, including types of HIV testing, testing resources, collaborations, access to treatment and support; the benefits of testing, privacy, choice and the desire to protect each other. As indicated in the data, the desire to protect themselves and others was stated several times, along with bringing in new resources, types of testing and collaboration between existing resources to enhance services and increase access. These are identified options for increasing HIV testing in their community contribute to the readiness of the community. However, it was also clearly indicated that there are stigma, fear and discrimination about how HIV is acquired. Although there is still fear and stigma within the community that was also identified several times throughout the interviews, the acceptance of HIV testing as being part of the community was identified as something that was needed to increase access and

acceptability of HIV testing. Gauging the readiness of Indigenous communities to normalise HIV testing and having it visible in their community needs to be measured before any action is taken. The two means of increased access to HIV testing suggested by participants were; 1) bringing HIV testing to the community, and 2) increasing transportation to go to the sites where HIV testing is available.

The two means of increasing access to HIV testing suggests the need to understand the community's readiness to increase HIV testing which would need to be determined by the individual Indigenous communities as each community is autonomous and unique, with diverse geographical characteristics, resources, and capacity. Part of the discussion with participants included how to increase the access and acceptability of HIV testing. It was identified that this is a personal choice and people were entitled to privacy, but that increased education and presence of HIV testing would increase the uptake of HIV testing in the Indigenous communities. The participant's statements about increasing AASO (HON) presence in the community and increasing the access to HIV testing as stated by a female on reserve participant support that argument. Participants recognised the need to have outside expertise and education in the community and the need to make the connection between the outside resource and their health centre visible to the community as a whole. Bringing in outside nurses for HIV testing and collaboration with community service providers would contribute the normalisation of HIV testing in the Indigenous communities and provide an opportunity for cultural diversity including having supports with you when you get a test for HIV and receiving the results of an HIV test. It was identified that collaboration between outside health care providers and community health services would contribute to increased knowledge about HIV and HIV

testing, reduce the fear and stigma surrounding HIV and HIV testing, increase access to HIV testing by making HIV testing an acceptable part of the community.

Through the collaboration between the Researcher and HON, the research topic and issue have been identified. The findings from the interviews identified the need and desire to have increased access to education, resources and supports around HIV and HIV testing in their community. The lack of information about HIV testing uptake within the Indigenous community in Nova Scotia creates challenges for HON. The development, implementation and delivering effective supports, education, partnerships and strategies that will contribute to the prevention of HIV and to more positive health outcomes for Indigenous (Aboriginal) People living with HIV/AIDS (APHAs). The knowledge being collected from the Indigenous communities in Nova Scotia will be instrumental in increasing the effectiveness of HON programming and services around the acceptability and uptake of HIV testing. The methods for this study have been implemented to ensure that the research initiative, process, activities and outcomes are useful to the stakeholders: HON, the Researcher and research community, policy makers, and the overall desire to prevent the spread of HIV and increase positive health outcomes for APHAs. Furthermore, the data analysis process has been a collaborative endeavour between the Researcher and HON to ensure that the interpretations are reflective of the community's culture, values and beliefs (Appendix III).

## **5.1 Recommendations**

The following section offer recommendations that have been developed based on the findings of this research and are designed for HON and the Indigenous communities they serve; partner organisations who work with HON the Indigenous communities

throughout Nova Scotia, as well as Health Promotion service providers and health care services. The recommendations were developed through the identification of barriers and facilitators to HIV testing within the Indigenous populations of Nova Scotia. The recommendations are for both HON and provincial service providers, policy makers and leaders. These recommendations also contribute to the UNGASS Political Declaration, (2016) which has implemented specific and time-bound targets and actions to be achieved by 2020, with the overall goal to end the AIDS epidemic by 2030.

### **5.5.1 HON**

1. Establish a strategy that includes every Indigenous community in Nova Scotia for a “Get Tested” Campaign. This should include a community needs assessment/environment scan of community services, resources, knowledge about HIV and HIV testing; including attitudes, beliefs, values, traditions, fear, stigma and discrimination. The development of a community strategy would also include the involvement of community health centres, community policy makers, elders, youth and other community leaders. HON would be the conduit of each communities’ strategy and provide guidance throughout the process sharing the information, knowledge and feedback from research, evaluations, community assessments/environmental scans. The development and implementation of the strategy will take significant time for each community, and will take HON several years to complete, however, the impact of this program would be in alignment with the UNAIDS 2016 strategy and timeline.
2. Extend services to existing and new partners working with HON to prepare partners both on and off reserve, Indigenous and non-Indigenous to increase knowledge and capacity. Through the continued capacity increase and strategy planning, partners

will be able to confidently and comfortably work with and support community directed and initiated programming. Organizations should include Health Promotion and Health care service providers in areas surrounding the Indigenous communities throughout Nova Scotia.

3. Connect with the Nova Scotia Advisory Commission on AIDS to initiate a conversation about the identification, development and implementation of an Indigenous HIV/AIDS testing Committee would include FNIHB, community health centres, HON and the Advisory Committee. As the Indigenous HIV testing committee develops, invite other community partners to provide their insight and expertise including Mobile Outreach Street Health (MOSH), Mainline, Mi'kmaq Native Friendship Centre, Native Council. The purpose of the Indigenous focussed strategy, and being included in the Nova Scotia Strategy on HIV/AIDS is to ensure that provincial policy, practices, programs and services reflect and include the Indigenous identified needs, goals, capacity. As well as, values, beliefs, barriers, facilitators and traditions that will support and assist in the success and increased uptake of HIV testing within the Nova Scotia Indigenous populations.

4. Develop innovative ways in which HON connects with, and works with Indigenous community leaders and policy makers. This is a key factor in ensuring that the unique characteristics, needs and strengths of the Indigenous population in Nova Scotia are part of the provincial strategy for HIV testing. Further, this will also assist in gauging each community's readiness for HIV testing and how it could impact individual communities and community members. Through the continued connection, dialogue and sharing of information/education with a community leader, a better understanding of

potential barriers and success to HIV testing in the Indigenous communities of Nova Scotia can be obtained. The development of a Nova Scotia specific community readiness environmental scan can be developed to measure readiness and identify areas of need.

5. Continue to develop innovative HIV/AIDS education programs specifically on HIV testing, its benefits, its challenges, individual and community benefits and, health outcomes, as well as discussion about community readiness for HIV testing and how this could be both beneficial and harmful to community members. Also, include discussion and information about the Social Determinants of Health, Indigenous history, and the Truth and Reconciliation (TRC) report. Integrating these specific topics within an HIV testing workshop will provide interesting discussion and feedback. It is important that this workshop is facilitated by HON staff where there is an existing relationship with each community and an established trust as and Indigenous service provider.

#### **5.1.2 Health Promotion and Health Care Providers.**

1. Health Promotion service providers need to increase their education and competency of Indigenous culture, needs, traditions, values and beliefs. This also includes the use of relevant language, terminology and identity. To participant and partner with Indigenous service providers and work in the Indigenous communities, there must be an increased understanding, value and competency of Health Promotion service providers to be effective within the Indigenous communities.

2. Increasing capacity and competency of Health Promotion and health care service providers will be greatly enhanced the partnering, networking and collaboration with HON and FNIHB. This will strengthen the success of any strategies, programs and services associated with HIV/AIDS and HIV testing within the Indigenous populations.

The likelihood of increasing uptake of programs and services will be affected by the access and acceptability of the programs and service among the Indigenous peoples.

3. Create partnerships with Indigenous Health Centres, Health Promotion and health services both on reserve and off reserve (including HON, Friendship Centres, Tribal Councils and Native Councils) throughout Nova Scotia. These partnerships will increase the access for Health Promotion, and health care professional to participate in the establishment of innovative Indigenous focused programs (utilising Harm Reduction approaches), HIV testing services, health promotion activities, education and the Social Determinants of Health that will both utilise the Indigenous worldview and the expertise of health professionals.

4. Conduct more CBR research into the deeper knowledge and understanding of the Social Determinants of Health with the Indigenous populations and their realities, histories and experiences. This deeper understanding will contribute to the development of Health Promotion and health care services that are specifically designed to incorporate the truth of Indigenous peoples' social determinants of health and the source of statistical overrepresentation of health outcomes.

## CHAPTER 6: CONCLUSION

Health Promotion and health care service providers need to become knowledgeable with respect to the TRC, its findings and recommendations as they pertain to health and wellness broadly and HIV specifically. The recognition of the UNGASS strategy and goal of eradicating the AIDS epidemic by 2030 combined with the TRC, the framework for developing and implementing Indigenous specific HIV testing programs, services, education and resources must be established in the Atlantic region. The value of integrating these documents to establish, for example, HIV testing policies and their philosophical frameworks, is crucial for the health and well-being of Indigenous populations in Nova Scotia.

Collaborations among the community nurses at the health centres, the AASOs and primary health care providers is reflective of the community's values and strengths and was a key element to the success of this research. Throughout the process, it was consistently identified that having AASOs working with the community health nurses would increase access and acceptability of HIV testing among the Nova Scotia Indigenous communities. The consistent recognition that outside expertise may be needed to increase the access and acceptability of HIV testing in the Indigenous communities, and there is valuable knowledge within the Indigenous community to benefit the development of a provincial HIV testing strategy. It was also identified that increased specialised transportation would be beneficial to include to augment access to acceptable forms of HIV testing. This has also been identified in previous research and literature on the Indigenous populations in other geographical areas of Canada (BucharSKI et al., 2006; Orchard, 2010; Worthington et al., 2010).



For Indigenous communities to be prepared to increase HIV testing in their community there needs to be additional programs, education and supports in place to respond to a positive HIV test, access to treatment, and to address individual and community fear and stigma. Examples of these programs may include: mobile HIV POCT, support for and recognition of leaders identifying HIV testing as an acceptable activity, ; building on the community knowledge and capacity delivered by HON, obtaining community information from all Indigenous populations in Nova Scotia and the Atlantic region, conducting additional research that targets stigma and discrimination within the Indigenous communities, and gaining a better understanding and perspective of ‘truth’ behind the presence of stigma and discrimination. The implementation of such interventions would contribute to the reduction of HIV transmission, provide the necessary education for the community to protect themselves and each other, and would provide more access to treatment at earlier stages in the progression of HIV/AIDS, resulting in better health outcomes for Indigenous peoples.

The uneven distribution of knowledge and education was identified throughout the study and was connected to the access to and acceptability of HIV testing. Education was also a contingent part of the social barriers that prevent people from accessing HIV testing. However, the desire to normalise HIV testing to remove fear and stigma is directly linked to both HIV education and increased access to HIV testing, requires further investigation of community characteristics, norms, traditions, values and beliefs. The barriers and facilitators that contribute to the readiness of each Indigenous community to increase access to and acceptability of HIV testing will require further investigation of the capacity, resources, self-identified need and ability to collaborate with

other health care services in their area, and work with provincial and regional health authorities in Nova Scotia.

Collaboration and the community readiness for increased access to and acceptability of HIV testing in the Indigenous communities of Nova Scotia remains an important health promotion issue. Moreover, as each community is autonomous and unique, additional efforts are needed to community readiness. This issue was introduced briefly in the data that included criminalisation and HIV POCT accuracy, which suggests some of the participants are very knowledgeable and up to date about HIV testing and some of the broader social issues that accompany it.

The focus of this study was access to, and acceptability of, HIV testing in the Nova Scotia Indigenous communities. The findings of this study address both barriers and facilitators associated with access and acceptability. These results include possible collaboration among health centres and ASOs/AASOs to increase the knowledge of HIV and HIV testing. Community leaders would need to understand the risk and recognise the presence of HIV and the risk of transmission that exists within their community and increase resources for access to knowledge, supports, resources and testing.

The findings of the research study are meant to help provide additional contextual information about access to and uptake of HIV testing among the Indigenous populations in Nova Scotia. Specifically, this information may assist in determining the unique characteristics associated with HIV testing uptake, access and acceptability in Nova Scotia Indigenous communities, and provide insight into the broader Canadian picture of HIV testing, and HIV testing within Indigenous populations. Many of the issues, challenges and barriers identified in the previous literature on HIV testing among the

Indigenous peoples, are both similar and distinct to the Atlantic region of Canada and establish a local context for HIV testing among the Indigenous communities in Nova Scotia. The differences among provincial services in Nova Scotia contribute to the uniqueness of access and acceptability of HIV testing among the Indigenous communities here and capture the specific challenges that are faced by the health care services, testing services and Indigenous communities in understanding HIV testing within this provincial context and within public health services. Both our demographic and geographic data, as well as the disparities in resource distribution within Nova Scotia, are also unique compared to other regions in Canada. These unique characteristics and HIV testing challenges and barriers add to the Canadian context of HIV testing and the Indigenous populations.

The dissemination of the research findings includes submission and presentation of the findings to HON for use in their programming and information sharing throughout the Indigenous communities in the Atlantic Region. In addition, the research and findings will be submitted to the Canadian Journal of Aboriginal Community-Based HIV/AIDS Research (CJACBR) which is published annually by the Canadian Aboriginal AIDS Network (CAAN). It will also be sent to the Aboriginal Health Research Networks Secretariat in Canada (formerly known as the National Aboriginal Health Organization (NAHO), to the re-named International Journal of Indigenous Health (IJIH) in 2016.

### **6.1 Significance and Limitations**

Several limitations of this study should be noted. Although the community partnership is part of the research methodology, and strength of the community-based research practice, there are specific limitations that arise from this structure. Although

recruitment for the study was done throughout the Indigenous communities, it is more likely that the actual participants resulted from them accessing or attending HON programs and services. Also, using a convenience sample may limit the applicability of information received.

This research adds to the dearth of information about HIV testing among Indigenous peoples in Nova Scotia; however, the findings are not generalizable. The findings support the development and implementation of effective and responsive HIV testing prevention initiatives, developed by HON and implemented throughout Nova Scotia. Specifically, these results indicate that HON is visible within the Nova Scotia Indigenous communities and that an increase in their presence is desired. Further, the collaboration between health care providers in the Indigenous communities of Nova Scotia and HON would be viewed as an asset for the increased uptake, access and acceptability of HIV testing within the Nova Scotia Indigenous communities. Specifically, this research provides a better understanding of the perceptions and beliefs surrounding HIV testing among the Indigenous peoples in Nova Scotia and warrants further investigation into the access, acceptability and uptake of HIV testing in the Indigenous communities. These findings are supported by the conclusions outlined in both Orchard (2010), where more research is needed to understand the dynamics and characteristics which can be linked to HIV testing among Indigenous peoples in Canada. PHAC (2012), also supports these findings, where pre- and post-test counselling should be flexible enough to meet the unique characteristics of each client.

In conclusion, there is a need to have a variety of Indigenous expertise in the identification, development, implementation and delivery of HIV testing programs and

services from both the Indigenous communities and the AASO (HON), as well as health care providers and health promotion services. This would include HIV testing and the recognition that the Aboriginal AIDS Service Organization in the region, HON take the lead for further investigation, identification, collaboration, development and delivery of HIV testing programs within the Nova Scotia Indigenous communities. Moreover, to further this investigation, to incorporate the full Atlantic Region to ensure that all Indigenous communities in the jurisdiction receive effectively, culturally safe, non-intrusive and relevant HIV testing resources, supports and access to services.

Further collaboration and investigation such as more CBR into HIV testing in the Indigenous communities in Nova Scotia are needed to provide effective testing services, programs and supports, enhance community HIV prevention initiatives and provide HON with community-based information to inform policy affecting Indigenous peoples in Nova Scotia. This is the first step towards obtaining insights about why people are being tested or not within the Nova Scotia Indigenous communities, and how Indigenous peoples in Nova Scotia view HIV testing regarding access and acceptability. Ultimately the information obtained from this research provides information for community groups to develop, design and implement effective and responsive supports and education initiatives about HIV testing and prevention, that will be acceptable and accessible to the Indigenous populations in Nova Scotia.

The research focus of this study included a qualitative, exploratory community-based research approach integrating Indigenous traditional ceremonies and methods of sharing information. This increase the dialogue between the research and participants, providing a richness of data. The partnership with HON increased the relationship

between the communities and the researcher as well as the OCAP principles: ownership, control, access and possession of the knowledge shared by the participants and communities. Exploring access and acceptability of HIV testing within the Indigenous population of Nova Scotia, and identifying the similarities and difference between the on and off reserve Indigenous populations has added to the understanding of HIV within Nova Scotia and the Indigenous peoples. The results of this study have successfully contributed to some initial steps for augmenting effective prevention initiatives in Nova Scotia.

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## Appendix I –Tables

Table1

Participants

	On Reserve	Off Reserve
Male	2	1
Female	2	1

## Appendix II - MOU

### Memorandum of Understanding

Between

Healing Our Nations  
31 Gloster Court  
Dartmouth, NS  
B3B 1X9

And

Tammy Barbour MA (c), Dr Jacqueline Gahagan (Supervisor) Dalhousie University  
*The Researchers*

(Collectively referred to herein as the “Parties”)

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#### BACKGROUND

1. Healing Our Nations supports and approves its participation in the HIV Testing in NS: An Aboriginal Perspective on Access and Acceptability in principle.
2. The Parties have entered a collaborative research project to work toward the following goals and objectives:
  1. Advance the knowledge and understanding about perceived barriers and opportunities associated with HIV testing among Aboriginal people residing in NS.
  2. Identify what the unique needs for HIV testing to be accessible and acceptable to the Aboriginal population in NS are.
  3. Identify realistic and effective health promotion initiatives for HIV testing information among the Aboriginal population in NS.
  4. To contribute the National information about HIV testing in the Aboriginal population in Canada.
  5. To provide information that can be augmented for the effectiveness and responsiveness of HIV prevention, education and support initiative in Atlantic Canada.
1. In support of these goals and objectives, the Parties will seek to combine traditional and innovative forms of research.

2. Healing Our Nations wishes to ensure that its people's customary stories and related teachings do not become the property of Dalhousie University or its supported or affiliated Researchers.

3. The Parties wish to carry out their goals and objectives in the context of the following principles:

- a) Respect for all parties involved.
- b) Transparency in all dealings with respect to the research project
- c) Observation of cultural customs and practices, with respect to traditional knowledge. Dalhousie University and its supported or affiliated Researchers should not personally acquire any royalties from publishing materials containing Aboriginal stories, myths, legends, folklore, oral traditions or other traditional knowledge; and
- d) Collaborative decision-making.

**THEREFORE, THE PARTIES HAVE THE FOLLOWING UNDERSTANDING:**

**Process**

1. A mutually agreed-on process will be followed to reach the goals and objectives outlined above. The process shall include:

- a) Development of an academic and community informed project research plan, with explicit reference being made to the plan as to how the project will contribute to the Parties' broader goals and objectives.
- b) Review and approval of the research plan by Healing Our Nations administration.

**Informed Consent**

1. The informed consent of individual community members must be secured in writing before they participate in research or recordings. The written permission of the individual community members to release the information to Healing Our Nations will be sought by the Researchers, including any restrictions the individual community members might wish to attach to the use of this information. Written informed consent is evidenced by the signature of the individual community member on the Participant Consent Form.

**Disposition of Research Materials**

2. Originals of all audio/visual recordings (in digital and/or analogue formats) and copies of all notes, transcripts, photographs, and other records of the research will be kept by Healing Our Nations. Copies of all audio/visual recordings and originals of notes, transcripts, photographs and other records will be kept by the Researchers.

3. The Parties will ensure that a final, permanent repository for the research materials, to be created by the Researchers, will be utilized. Additionally, the Researchers will make as a condition of the deposition that the repository will provide access to Healing Our Nations members. Further, the repository will adhere to any confidentiality or use restrictions made by the individual community members under section two of this memorandum.

### **Protection of Customary Intangible Property**

4. The Parties agree that the Researchers will respect customary Aboriginal property laws. To facilitate this, the Parties agree that the Researchers will endeavour to, where reasonably possible, **not record** known customary intangible properties, respecting private and confidential sacred matters (“Customary Intangible Property”)

5. The Parties recognize that Healing Our Nations representatives/elders may provide guidance and advice in identifying and delimiting Customary Intangible Property. (Customary Intangible Property including but not limited to smudging, traditional prayer, ceremonial artefacts)

### **Publication**

6. Subject to the terms of the arrangement set out in this Memorandum of Understanding, Healing Our Nations hereby grants the Researchers a licence to publish for scholarly and educational purposes the information collected during the research project.

7. The Researchers will ensure that two copies of all publications, conference papers and other educational and scholarly materials produced during the project be left with Healing Our Nations.

### **Ownership of Customary Intangible Property**

8. In publications resulting from this collaborative arrangement, no claim of copyright or exclusive rights by the Researcher or their publishers will be made on legends, myths, folklore or Customary Intangible Property that are the acknowledged intellectual property of Healing Our Nations and the communities and community members involved in the project.

9. Any publication done for scholarly and/or educational purposes will include the following provision: “The text of the stories, myths, legends, and folklore belong to the Aboriginal people, and therefore no claim of copyright or exclusive rights is made upon them.”

## **Confidentiality and Royalties**

10. The Parties agree that where Customary Intangible Property, referred to above in sections five and six of this Memorandum of Understanding, is shared with the Researchers, or mistakenly recorded by them, they will use all reasonable efforts to prevent the publication of, or public access to, this information.

11. The Parties will not acquire any royalties or monies tantamount to royalties for publishing materials that contain Aboriginal stories, myths, legends, folklore, or Customary Intangible Property. This does not constrain the Researchers from publishing the linguistic analysis.

## **Dispute Resolution**

12. In case of a dispute arising from the implementation of this Memorandum of Understanding, the Parties shall exhaust alternative dispute resolution models such as negotiation and mediation before employing other forms of dispute resolution such as arbitration or adjudication. Parties shall act in good faith to resolve the dispute.

13. In the case of a dispute arising regarding the proper management of Customary Intangible Property, the elders associated with Healing Our Nations shall specify the means of settling the dispute, such as meditation.

## **Notification**

14. Any notice of written communication required under this agreement may be given as follows:

Healing Our Nations  
31 Gloster Court  
Dartmouth, NS  
B3B 1X9

Tammy Barbour, MA(c)  
School of Health and Human Performance  
  
Dalhousie University  
Halifax, NS  
B3H 4R2  
(902)448-7055

Dr. Jacqueline Gahagan (Supervisor)  
School of Health and Human  
Performance  
Dalhousie University  
Halifax, NS  
B3H 4R2  
(902)494-1155

**Amendments**

15. Amendments to this Memorandum of Understanding must be in writing and signed by authorized representative of Healing Our Nations and the Researchers with Dalhousie University.

**Duration of Agreement**

16. The term of this Memorandum of Understanding is from September 1<sup>st</sup>, 2014 to August 31<sup>st</sup>, 2015, and may be renewed. The \parties will review this agreement monthly.

17. The Parties may terminate this Memorandum of \understanding in writing at any time subject to 30 days' notice.

**SIGNED BY THE PARTIES ON THE DATES SET OUT BELOW**

\_\_\_\_\_ Date: \_\_\_\_\_  
Signature Healing Our Nations Rep

\_\_\_\_\_ Date: \_\_\_\_\_  
Signature Researcher

## Appendix III - Interview Guide

### Individual Interview question guide

**Project Title:** “Access, acceptability and uptake of HIV testing in NS: A First Peoples perspective.”

**Project Dates:** 2013 - 2014

**Method:** **Semi-structured** face-to-face interview

**Topic:** **HIV, testing accessibility and acceptability with the Aboriginal communities of NS/PEI**

**Target Audience:** **Aboriginal community members** residing in the province of NS

**Principal Investigator(s):** Tammy Barbour, MA (candidate), Dalhousie University, School of Health and Human Performance (tammy.barbour@dal.ca); Jacqueline Gahagan PhD., Dalhousie University, School of Health and Human Performance (

**Instrument Title:** Individual Interview Guide

*Below is a general guide that we will use to lead our individual interviews. We may modify this guide as needed as the preceding interviews will inform subsequent interviews.*

*Before starting, conduct the informed consent process, and review compensation (each participant will receive \$20 honorarium for their time investment in the research).*

### **I. Introduction**

Welcome participant and introduce the Researcher and HON staff present.

Explain the general purpose of the interview discussion and why the participant was chosen.

Explain the presence and purpose of recording equipment.

Address the issue of confidentiality.



*This study is intended to identify issues, barriers, and challenges to accessing and the acceptability of HIV testing in the provinces of NS and PEI among the Aboriginal communities. Further, to provide first voice recommendations to increase the access and acceptability of HIV testing among the Aboriginal population of NS and PEI.*

*Aboriginal people represent approximately 3% of the Canadian population and are over represented in the rate of Human Immunodeficiency Virus (HIV) infections. Rates of HIV infection in the Aboriginal population is as high as 20% of all new infections in Canada (Canadian Aboriginal AIDS Network, 2010).*

*However, the rates of HIV infection among the Aboriginal population in Atlantic Canada are difficult to identify due to the small population size and issues of confidentiality. In addition, HIV infection rates in provinces with smaller populations are combined where, for example, NS (NS) and Prince Edward Island (PEI) combine positive HIV test results to help ensure confidentiality. This creates challenges in understanding the true impact of HIV within the Atlantic Region.*

*The purpose of this qualitative study is to obtain knowledge and understanding about HIV, testing and barriers/opportunities within NS's Aboriginal population. You have been chosen to participate in the interview because you self-identify as Aboriginal, you are 18 years of age, you live On/off reserve, you are m/f and your individual perception of the topic will be useful in the identification of recommendations to increase accessibility and acceptability of HIV testing among the Aboriginal population in NS and PEI.*

*Recording equipment will be used for data analysis only. Once the data has been transcribed and all potential identifiers are removed the recorded data will be digitally locked, encoded password protected and stored at Dalhousie University. Only the transcribed anonymous data will be used for analysis.*

*Your identity and participation in this study are confidential, meaning that your identity will not be shared or participation confirmed in association with this study and the information contained there in.*

## **II. Interview**

A semi-structured interview will be conducted. The topics produced by the interviews will generate recommendations to improve access and acceptability of HIV testing among the Aboriginal population in NS and PEI.

Individual interviews will be conducted to identify challenges, barriers and issues affecting accessibility and acceptability of HIV, the perceptions of HIV testing, the unique needs for testing to be accessible and acceptable, the barriers to getting tested; and what

would be beneficial for testing to be more accessible to the Indigenous communities of Nova Scotia and Prince Edward Island.

*What are your initial thoughts about HIV testing?*

This may bring forth their opinions, if so, follow this path until exhausted or until about 10-15 minutes go by and then steer them to the prepared themes.

*What types of HIV testing are available in your geographical area? How far away are they? What type of transportation is available? Are there challenges to get to the testing site? What types of resources are available to access testing? Is HIV testing needed in your community? Why or why not is HIV testing needed? Is HIV testing acceptable within your community? What would make HIV testing more acceptable to community members? What would make HIV testing more accessible for community members?*

*Ask him/her to comment on their experience, why, and how this experience has affected their perceptions.*

Follow the interviewee's lead as you explore the issue. Ask for examples of some kind. When you feel the area has been explored adequately, move on to the next item, probing for connections between items, and asking for additional items, not on the list, or rejection of items not deemed relevant. Once a domain has been adequately explored, move on to the next domain.

**End of Interview Core Questions: 45 minutes**

**As the time is drawing to a close, ask if they have any additional topics or information that they have not already shared.**

### **III. Closing**

*Closing remarks: That's all the questions I have. Thank you for participating in this discussion.*

### **IV. Issue their compensation**

**Appendix IV–Informed Consent**

**INDIVIDUAL INTERVIEW  
PARTICIPANT CONSENT FORM**

***HIV TESTING IN NOVA SCOTIA: AN INDIGENOUS PERSPECTIVE ON ACCESS  
AND ACCEPTABILITY***

**Contact Person:**

**Tammy Barbour, MA candidate  
School of Health and Human Performance  
Dalhousie University  
(902) 448-7055  
[tammy.barbour@dal.ca](mailto:tammy.barbour@dal.ca)**

**Supervisor:**

**Jacqueline Gahagan, PhD  
Head of Health and Human Performance  
Dalhousie University  
(902) 494-1155  
[jacqueline.gahagan@dal.ca](mailto:jacqueline.gahagan@dal.ca)**

## **INTRODUCTION**

We invite you to take part in a research study being conducted by Tammy Barbour, MA candidate and supervised by Dr Jacqueline Gahagan from the School of Health and Human Performance at Dalhousie University in collaboration with Healing Our Nations. Your participation in this study is entirely voluntary, and you may withdraw from the study at any time. The study is described below and tells you about the potential risks, or discomfort which you may experience. Participating in this study might not benefit you directly, but we hope to learn things that will benefit others, Healing Our Nations and influence policy and practice. Please feel free to discuss any questions you have about this study with the person conducting the interview or contact the Supervising Investigator, Dr Jacqueline Gahagan at (902) 494-1155

## **PURPOSE OF THE STUDY**

The purpose of this qualitative, exploratory research study is to obtain community knowledge and understanding of the perceived barriers/opportunities associated with the access and acceptability of HIV testing within the Indigenous populations of Nova Scotia to provide insight and first voice input for further investigation of HIV testing among the Indigenous communities throughout Atlantic Canada. The characteristics that contribute to the current HIV testing rates in the Aboriginal population of Nova Scotia will be investigated. Results will provide additional and contributing information about HIV testing among Canada's Aboriginal population while augmenting the effectiveness of prevention initiatives in NS.

## **STUDY DESIGN**

This research project is a Qualitative Community-based study developed in collaboration with Healing Our Nations. The study includes individual interviews with Indigenous peoples living on and off reserve in Nova Scotia. The interview will last about 60 minutes. Individual interviews will be asked to take part in a dialogue about HIV testing access and acceptability within the Indigenous communities of Nova Scotia including. Areas of investigation include; knowledge about HIV testing, knowledge about HIV transmission and prevention, the importance of HIV testing and the barriers and challenges to HIV testing within the community, the impact of HIV in their community, location of HIV testing, and what would make HIV testing more accessible to the Aboriginal community. Your participation in the interview is completely voluntary, and there is no further obligation to take part in the study. You are only consenting to take part in an interview.

### **WHO CAN PARTICIPATE IN THIS STUDY**

You are eligible to participate in this study if you self-identify as Indigenous living on or off reserve in the province of Nova Scotia, and are 18 years of age or older.

### **WHO WILL BE CONDUCTING THE RESEARCH**

Tammy Barbour, the MA candidate, will be conducting the research while supervised by Dr Jacqueline Gahagan. This study is being delivered in collaboration with Healing Our Nations.

### **WHAT YOU WILL BE ASKED TO DO**

As interviews will be audio-recorded and transcribed, consenting to be audio-recorded during your interview is a pre-requisite for participation. However, at any time you may request that the audio tape is turned off. The interview questions will explore the current state of access and acceptability of HIV testing within the Aboriginal community. All personally identifying information will be removed from the quotes, and you will not be identified.

### **POSSIBLE RISKS AND DISCOMFORTS**

There are minimal risks or discomforts anticipated during this study. However, if at any time you feel distressed and wish to take a break from or stop your participation in the interview, please inform the facilitator. You may also request that the audio-taping be temporarily stopped at any time. Your participation in this study is completely voluntary and should you decide not to answer any question(s), or end your participation in the interview; you may do so without question or consequence.

## **COMPENSATION**

You will receive a \$20 compensation/honorarium for your time. You will receive this compensation directly following the completion of this form, and it is not dependent on your participation in this study. If you choose not to complete your participation in this study, you will still be compensated for your time.

## **CONFIDENTIALITY & ANONYMITY**

While full anonymity in this study is not possible, particularly in an interview setting, all measures will be taken to ensure that you will not be identifiable to others as a participant in this study. All interview participants will be asked to maintain the confidentiality of the interview discussion. Moreover, the responses you provide will be kept confidential and will not be linked to you.

Your name will not be used in any transcripts or reports, including the use of direct quotations from the interview in reports related to the findings of this study. All personally identifying information will be removed (“cleaned”) from the transcripts, or a code name may be used. For example, if you mention the name of a fellow service-user or co-worker it will be removed from the transcript and may be replaced with “service” user or “staff”. The digital recording of this interview will be transferred electronically to a USB Memory Flash Drive and used by the Researcher to transcribe the interview into an electronic document. At this time, all personal identifying information will be removed. If you wish to review the transcript, you may do so by calling the Researcher at (902) 448-7055 or the Supervisor at (902) 494-1155 within one month of your interview. You will then be able to review the “clean” transcript, which will be identified only by the date your interview was conducted and may remove any information you deem too sensitive for use in the study.

Once the document is complete, the original recording will be deleted, and a unique number will be assigned to the transcript. This number is only used to tell the Researcher the difference between the interviews during data analysis and in no way, will it provide a means to link the transcript to your identity. All transcripts will be kept in a secure location in a locked office within the School of Health and Human Performance at Dalhousie University. All materials will be kept securely stored for a period of 7 years after publication, at which time they will be destroyed. This consent form and any other forms that contain personal information such as your name will be stored in a locked filing cabinet, in a secure office within the School of Health and Human Performance. The data will be stored separately from the transcripts.

## QUESTIONS

During the interview, if you have any questions about the interview, the study, or your participation, please do not hesitate to ask the facilitator. Should you have any questions following the interview, you may contact Tammy Barbour at (902) 448-7055, email [tammy.barbourloade@dal.ca](mailto:tammy.barbourloade@dal.ca) or the Supervisor Dr Jacqueline Gahagan at (902) 494-1155, email [Jacqueline.gahagan@dal.ca](mailto:Jacqueline.gahagan@dal.ca)

## PROBLEMS OF CONCERNS

If you have any difficulties with or wish to voice concern about, any aspect of your participation in this study, you may contact Catherine Connors, Director of Dalhousie University's Office of Human Research Ethics Administration for assistance at (902) 494-1462, [Catherine.connors@dal.ca](mailto:Catherine.connors@dal.ca). Collect calls are always accepted.

**SIGNATURE PAGE**

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***HIV TESTING IN NOVA SCOTIA: AN INDIGENOUS PERSPECTIVE ON ACCESS AND ACCEPTABILITY***

I have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I hereby consent to take part in this study. I understand that my participation is voluntary and that I am free to withdraw from the study at any time.

Please check the following **only** if you agree with the statement.

- I have read and understood this consent form.
- I understand that my participation is voluntary and that I may withdraw at any time without consequence.
- I consent to be audio-recorded as this is required for transcription.
- I consent for my interview transcripts, which will not contain any personally identifying information, to be sent outside Dalhousie University to the Community Research Review Team (CRRT).
- I understand that should I wish to review the transcript of my interview I may do so by contacting the Researcher within one month of my interview, as dated below.
- I consent to allow direct but unidentified quotations from my transcription to be used in presentations and papers.
- I would like to receive a copy of the results of this study.

Participant Name: \_\_\_\_\_

Participant Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Facilitator Name: \_\_\_\_\_

Facilitator Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Please provide a complete mailing address in the space below if you would like to receive a copy of the study results. This information will not be linked to your transcript and will be kept confidential.