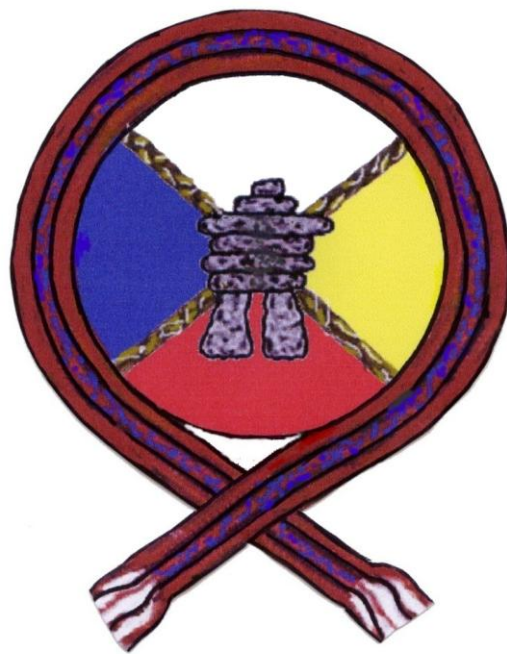
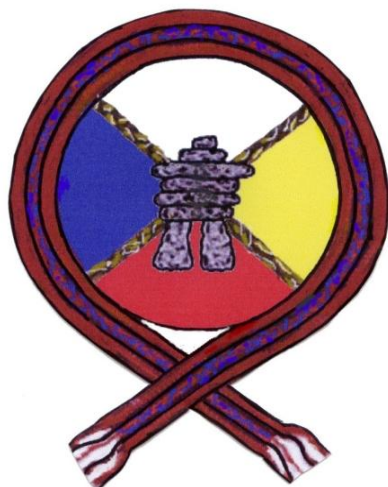


**The Diagnosis and Care of HIV Infection in
Canadian Aboriginal Youth**



**A National Community-Based
Collaborative Research Project**

January, 2008



The Diagnosis and Care of HIV Infection in Canadian Aboriginal Youth

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Final Report

January 2008

*The final report of this study is dedicated to
an enthusiastic youth member of the Advisory Committee*

Thomas K. Harper, Flying Eagle Man

November 28, 1975 - March 13, 2007



*The logo design was inspired by the Métis sash, the
Medicine Wheel and the Inukshuk, which are Aboriginal
symbols of heritage, life, health sacredness and
leadership. This study logo was created by Sonia Isaac
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- Wabano Centre for Aboriginal Health, Ottawa, Ontario
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Facilitating agencies and institutions

This community based project was a collaborative effort between the Canadian Aboriginal AIDS Network (CAAN), the Public Health Agency of Canada (PHAC) and researchers at the Universities of Alberta, Calgary and Toronto. In addition, 11 community organizations from across Canada, who provide services to Aboriginal youth, participated in the project. Individual participants in the advisory committee included Elders, family members of persons diagnosed with HIV, and Aboriginal youth. We thank them for their guidance, perspectives and wisdom.

Participants

The research team acknowledges the participants in our study for their willingness to share very personal aspects of their lives. For this, we are humbled and most grateful.

Executive Summary

This report presents findings from a Canadian Institutes for Health Research (CIHR) funded project titled “*The Diagnosis and Care of HIV Infection in Canadian Aboriginal Youth*”. The purpose of this national community-based study was to explore HIV testing and care decisions in Canadian Aboriginal youth. Three main areas of inquiry were: *the decision to test; the testing experience and the relationship between testing and care*. This report is organized into these three areas of inquiry in discussing the findings of the project.

Design and Methods

The project used a community-based research (CBR) approach and incorporated Ownership, Control, Access and Possession (OCAP) principles for research involving Aboriginal communities. Ethical and cultural considerations were addressed through appropriate institutional and governmental approvals at project locations across Canada.

This project represented a collaborative effort between the Canadian Aboriginal AIDS Network (CAAN), the Public Health Agency of Canada (PHAC), and researchers at the Universities of Alberta, Calgary and Toronto. The research team received direction and guidance on the research questions and the design of the study from a community advisory committee (CAC) that included Aboriginal youth, Aboriginal Elders and representatives from community based organizations.

An exploratory descriptive design was selected for the study due to the limited knowledge about HIV testing in Aboriginal youth in Canada. Mixed methods, including a cross-sectional survey and in-depth interviews, were used to collect data.

The study was conducted in partnership with eleven community based organizations from across the country that included Aboriginal AIDS service organizations, Aboriginal health centers and friendship centers. These organizations assisted with recruiting participants between January 2004 and February 2005. Aboriginal men and women between 15 and 30 years of age, living off reserve in rural and urban communities, English or French speaking, were eligible to participate.

Analysis

Survey responses were coded and entered into SPSS 11.5 statistical software program for quantitative data analysis. Descriptive statistics were produced for all survey items, and cross-tabulations and associational statistics were produced for some key outcomes including HIV testing. The interviews were audio taped and transcribed verbatim. The qualitative software program QSR**N6* was used to assist with the labeling, revising and retrieval of codes during analysis of the interviews. Analysis of the qualitative data was completed by members of the research team using an inductive approach.

Findings

Youth from all ten provinces and one territory contributed to the data set. The organizations were purposively selected to assist in recruiting participants who had received an HIV test, and knew they were HIV sero-positive or sero-negative, and those who had not received a test and did not know their HIV status. Four hundred and thirteen (413) Aboriginal youth from Vancouver, Edmonton, Winnipeg, Ottawa, Toronto, Montreal, Halifax, Labrador and Inuvik completed the survey. Forty seven percent of survey participants were male and 52.8% were female. More than half of the participants identified themselves as being First Nations (56.2%). Most survey participants spoke English (92.3%). The majority of youth identified themselves as heterosexual (84.7%). Only (16.2%) of respondents had completed high school and most of the youth had incomes of less than \$20,000/year (85%). For living arrangements, the youth reported varied housing situations with the majority living on their own (35.8%) or with their parents (31.0%). Slightly more than half of the youth (50.8%) have been tested for HIV. Of these, 26 participants out of 413 youths completing the survey had a positive HIV test result.

Twenty-eight interviews with Aboriginal youth were conducted. Interview participants were between the ages of 16 and 30 years with an average age of 24.4 years. Sixteen of the youth were female and 12 were male. Education levels of the interview participants varied – 12 had less than high school, 5 had completed high school, and 11 had studied at a post-secondary institution. Of the 28 interview participants, 25 reported ever having an HIV test and 9 of the 28 participants (31.1%) reported being HIV positive. Five of the youth became infected through intravenous drug use and four became infected through sexual contact.

The decision to test

For Aboriginal youth who were surveyed, the most common reasons given for HIV testing included having sex without a condom (43.6%), and for female respondents, pregnancy or suspicion of pregnancy (35.4%). The most common reasons for not getting tested were the beliefs that youth were at low risk for HIV (45.3%) and that they had not had sex with an infected person (34.5%). Survey findings suggest that youth who had never tested for HIV were more likely to be younger, male, heterosexual, students and not following traditional Aboriginal practices. Many of the Aboriginal youth who participated in interviews believed that youth have a feeling of invulnerability in relation to their HIV risk. Many commented that topics such as HIV/AIDS and sexuality were taboo to openly discuss in small communities and that many youth still believed that HIV/AIDS was a “scary” disease associated with death.

The testing experience

Fifty-one percent of the survey respondents (210 of 413 youth) had ever been tested for HIV. The majority of youth (86.5%) had their most recent HIV test in the community where they lived or had lived at the time of the test. Thirty-four percent of the youth went to a physician for their most recent test, and 17.1% had gone to the hospital. While getting tested, 23.3% of respondents noted that they were not given any information and 28.1% could not remember what information they were given. Over three quarters of youth felt that they had been treated with care (79.9%), respect (77.4%) or kindness (75.9%) when receiving their HIV test, but a significant minority indicated they were treated with fear (12.3%), discrimination (11.2%) or avoidance (9.7%). In an open-ended question on emotional reactions to the test, survey respondents expressed feelings of anxiety and apprehension about the possibility of testing HIV positive.

Regular HIV testing was viewed by those interviewed as routine, especially when coupled with checks for other sexually transmitted infections or as part of the standard of medical care when individuals become pregnant. Several youth also expressed support for “*drop in*” testing sites due to the flexibility of a service where youth could show up and have a test at any time. For some, motivation to get tested was predicated on a *realistic self assessment* that past risky behavior may have placed them at greater risk of HIV. For others, *fear of HIV infection* eclipsed this assessment of past high risk behavior. As well, the involvement of parents/partners in the decision to get tested could be both supportive or a barrier. Youth who were interviewed expressed the need for service providers to be professional but have a caring, understanding and patient approach. Establishing relationships with the youth without compromising confidentiality was important to them. Youth supported an approach of camouflaging HIV testing services in the context of general health services.

The relationship between testing and care

Of the 26 surveyed youth who reported they were HIV positive, 8 (30.8%) indicated they had symptoms related to HIV/AIDS at the time of diagnosis, including 6 (23.1%) who were told they had AIDS at the time of diagnosis. Thus, findings suggest that a substantial proportion of HIV diagnoses among Aboriginal youth are not made until late in the course of the disease, thereby limiting prevention and care opportunities. In addition, only 12 of 25 (48.0%) indicated they had seen a physician after receiving the positive HIV test result, and overall, only 38% of Aboriginal youth who had a positive HIV test had seen the physician within one year of their diagnosis. Youth who were interviewed showed similar patterns. For these youth, delays in seeking care after diagnosis varied from a few months to seven years. Reasons for delaying care or not seeking care were: being scared, being preoccupied with substance abuse, not caring, not wanting to live, and not knowing anything about HIV care options. Interview participants stressed the importance of stable housing, family support and support services such as AIDS service organizations in helping them manage their HIV.

Conclusion

The results of this community-based research study underscore the need for supportive health policy and models of service provision which encourage testing in youth who engage in high-risk behaviors. Enhanced pre- and post-test counselling could be important points of intervention for Aboriginal youth. Better counselling after diagnosis and community and street outreach may be effective means of connecting more Aboriginal youth to care.

Introduction

Research Purpose and Questions

HIV infection is a serious concern in the Canadian Aboriginal population, particularly among youth; however, there is limited attention to this issue in research literature (Clarke, Friedman, & Hoffman-Goetz, 2005). Approximately two-thirds of the Canadian Aboriginal population is under the age of 30 (Majumdar, Chambers, & Roberts, 2004) with a median age of 24.7 years (Shah, 2004). Additionally, younger people perceive that they are less vulnerable to HIV infection (Tseng, 1996). Also of concern is the under-use of HIV testing in at-risk adolescents (Grant et al., 2006). High rates of teenage pregnancy, (Ontario Federation of Indian Friendship Centres [OFIFC], 2002), inconsistent use of condoms (OFIFC, 2002; Calzavara, Burchell, Myers et al., 1998) and high rates of sexually transmitted diseases (Shields et al., 2004) as well as substance abuse and injected drug use (Majumdar et al., 2004), provide evidence of the vulnerability of Aboriginal youth to HIV infection.

The Public Health Agency of Canada (PHAC) reports that Canadian Aboriginal persons are infected at a younger age than non-Aboriginal persons (PHAC 2005). HIV prevention approaches have traditionally focused on the interruption of the disease prior to infection. Investigation of factors that increase or limit the spread of the virus in infected individuals has been identified as an urgent research initiative (Schiltz & Sandfort, 2000). With an estimated 30% of persons with HIV currently unaware of their status, more information is needed about individuals who are at risk of HIV but have not been tested (PHAC, 2005). A key strategy in preventing the spread of HIV in Aboriginal communities is the provision of accessible, confidential and culturally sensitive testing services. In addition, for those who test positive, counselling programs to promote healthy behaviours in the period following infection is recommended. In order to focus prevention activities in the post-infection period, the factors that motivate individuals to have an HIV test, and subsequently make decisions about their care and treatment must be investigated. Research is required on issues related to HIV testing in the Canadian population generally (Myers, Haubrich, Cockerill, et al., 1998), and the Aboriginal population specifically (Health Canada, 1998).

The purpose of this study therefore was to explore HIV testing and care decisions in Canadian Aboriginal youth. Five research questions were addressed in the study which, when grouped, fall into three areas:

The decision to test:

1. Why do some Aboriginal youth decide to have an HIV test, while others do not?
2. How do Aboriginal youth view HIV testing?

The testing experience:

3. What is the experience of Aboriginal youth when they present for testing?

The relationship between testing and care:

4. What is the relationship between HIV testing and the decision to initiate treatment among Aboriginal youth?
5. How do Aboriginal youth make decisions about the care and treatment of their HIV illness?

This report is organized into these three areas of inquiry in discussing the findings of the project.

Definitions

1. HIV care and treatment

HIV care includes strategies to enhance the well-being of an HIV sero-positive individual, including maintaining personal health. The range of strategies that can be used to promote health include biomedical approaches (e.g. anti-retrovirals, visits to a physician), traditional practices (e.g. sweat lodges, traditional medicine), staying healthy (e.g. sleep, nutrition, exercise) alternative therapies (e.g. herbal) and use of community services (e.g. connecting with an AIDS organization).

2. Aboriginal youth

For the purposes of this study Aboriginal youth were defined as men and women between the ages of 15 and 30 years of age who self identified as Aboriginal (including First Nation, Métis, or Inuit).

3. HIV Test

An HIV test is an antibody blood test to tell whether one has been infected with human immunodeficiency virus (HIV). HIV antibodies are produced by the body after an individual becomes infected with the virus. The HIV antibody test measures antibodies, not the HIV virus. This study captures self-reported HIV antibody testing which an individual may have had at any time prior to the study. See *HIV-positive status* below.

4. HIV-positive status

Defined in this report as self-reported from a participant stating that he/she had been found to be HIV sero-positive according to a lab test done on a blood sample drawn at a health clinic or a voluntary counselling and testing centre (lab test detects the presence of antibodies to HIV). Participants in this study were not required to have additional blood testing to confirm their self-reported HIV status.

Background and Literature Review

HIV illness¹ has been identified by individuals (Alberta Health, 1995; Houston, 1995; Lambert, 1993), community agencies (Mill & DesJardins 1996), professional organizations (Aboriginal Nurses Association of Canada, 1996), and governments (Health Canada, 2001; 2002a) as a serious concern in the Canadian Aboriginal population. In Canada, Aboriginal people are over-represented in estimates of HIV infections and the number of Aboriginal people living with HIV increased by 91% between 1996 and 1999 (Health Canada, 2001). Of testing results among Aboriginal persons, youth comprised 31.4% of the total positive HIV test reports from 1998 to 2003 (PHAC, 2004). Similarly, sexually transmitted infections, which potentially increase the transmission and acquisition of HIV, disproportionately affect the Aboriginal population (Shields et al., 2004). Youth are one sub-group of the Aboriginal population that is particularly vulnerable to HIV infection (Royal Commission on Aboriginal Peoples, 1996). Of grave concern is that Aboriginal people living with HIV are diagnosed and receive treatment later in their illness than do non-Aboriginal people living with HIV (PHAC, 2004; Geduld & Archibald, 2002; Miller, et al., 2004). Patterns of health care utilization in individuals with AIDS are significantly associated with survival time (Montgomery et al. 2002).

Despite educational HIV/AIDS prevention programs within Aboriginal communities, strategies specific to the youth are lacking (Majumdar et al., 2004). In order to focus prevention activities on the post-infection period, the factors that motivate individuals to have an HIV test, and subsequently make decisions about their care and treatment, must be investigated. A study with non-Aboriginal youth demonstrated that rates of HIV testing in youth is low and that as a group, youth are a “disadvantaged and disenfranchised population that eludes traditional case-finding strategies” (Grant et al., 2006, p.469). In Canada there are disproportionately few resources directed at the needs of HIV-positive youth (Flicker et al., 2005). Research is required on issues related to HIV testing in the Canadian population generally (Myers et al. 1998), and the Aboriginal population specifically (Health Canada, 1998). Although it is acknowledged that research to improve prevention of HIV infection in this group is essential (Majumdar et al, 2004), to our knowledge, at the time of the study, there had been no research that expressly examined the testing and care of HIV infection in Canadian Aboriginal youth.

A variety of social, economic, and political factors contribute to the vulnerability of the Canadian Aboriginal population to HIV infection and limit the ability of communities to give high priority to HIV prevention initiatives. Many Aboriginal peoples face poverty, drug abuse, violence and suicide. Marginalization that resulted from a colonial legacy in Aboriginal communities in Canada continues to contribute to social suffering and health disparities in the Aboriginal population (Adelson, 2005). Furthermore, the stigmatization of Aboriginal people living with HIV/AIDS has been characterized by the continued association with homosexuality (Deschamps, 1998). Deschamps (1998) noted that “AIDS related stigma has had dire consequences for two-spirited people. The effects of being both homosexual and Aboriginal are devastating... self

¹ The term HIV **illness** is used to encompass the individual, cultural and social responses to HIV infection and is distinct from the concept of **disease** that refers primarily to the breakdown of a biological process (Kleinman, 1980).

destructive behavior among two-spirited youth in the forms of substance abuse, suicide, unsafe sexual practices, are very extensive” (p.34).

In a Canadian study, Heath found that among men who had sex with men, Aboriginal men were more likely than non-Aboriginal men to have experienced factors considered to be antecedents of HIV infection, including sexual abuse, poverty, poor mental health and involvement in the sex trade (Heath et al, 1999). Similarly, most of the HIV positive Aboriginal women in an Alberta study had experienced abusive relationships during their formative years (Mill, 1997). The ‘risk behaviours’ of these women were reframed as ‘survival techniques’ to acknowledge the impact of this abuse. In some Aboriginal communities, the urgent need to address social problems including poverty, unemployment, poor housing and sanitation may result in HIV and AIDS initiatives having lower priority (Tseng, 1996). Additionally, Aboriginal youth constitute over one-third of street involved youth in Canada (PHAC, 2005). The broad determinants of HIV infection in the Aboriginal population necessitate the design of prevention interventions at multiple levels, using multiple strategies.

The design of HIV prevention programs has been primarily based on theories that emphasize individual factors that influence behaviours. Several authors have highlighted the limitations of this approach and emphasized the need for prevention programs that acknowledge and target the broad economic, cultural and social factors that influence behaviour (Adrien et al., 1996; Mill & Anarfi, 2002; Myers et al., 1993; Zwi, 1993). CAAN acknowledges that youth need to be fully involved in determining interventions to address needs (CAAN, 2003). Similarly, the diagnosis and care of HIV infection in Aboriginal youth is influenced by cultural beliefs and social factors, as well as emotional and behavioural influences, which must be considered in the design of services (Majumdar et al., 2004). Therefore, a conceptual framework based on an ecological approach to health was used to guide this study. An ecological approach acknowledges the complex relationship between the individual factors influencing health and the broader cultural, social, political and economic environment that provides the context for health (Green, Richard & Potvin, 1996; Stokols, 1996). When considering HIV testing and confidentiality within Aboriginal communities, a cultural perspective must be incorporated in consideration of the social history of oppression, racism and colonialism (Shah, 2004; Matiation, 1999a).

HIV Infection in Aboriginal Youth

HIV infection has the potential to have a profound effect on Aboriginal youth. As two-thirds of the Canadian Aboriginal population is under the age of 30 and because youth generally have the perception that they are less vulnerable to HIV infection (Tseng, 1996), research-based interventions to improve prevention in this group are needed (Majumdar, Chambers, & Roberts, 2004). In Canada, Aboriginal persons are infected with HIV at a younger age than non-Aboriginal persons (PHAC, 2005). An extensive survey in Ontario on-reserve, Aboriginal communities determined that sexual behaviour, including having multiple partners without the consistent use of condoms, placed individuals at risk for HIV infection (Calzavara, Bullock, Myers, Marshall & Cockerill., 1999). Among Aboriginal youth in the survey, consistent condom use was rare (Calzavara, Burchell, Myers, et al., 1998). A survey of the sexual health of Aboriginal youth in Ontario (OFIFC, 2002) found that sexual practices, including early initiation of sexual activity and inconsistent use of contraception, were associated with high rates of

teenage pregnancy. These findings provide evidence of the vulnerability of Aboriginal youth to sexually transmitted diseases including HIV infection (Royal Commission on Aboriginal Peoples, 1996; OFIFC, 2002).

Aboriginal views toward health and illness

Views toward health and illness in the Aboriginal population are relevant to the understanding of attitudes toward HIV testing. Traditionally, illness was viewed as a blessing from the Creator that would encourage reflection on one's life, promote personal responsibility for one's life, and restore balance in one's life (Brown, 1990). The belief that a "disease must be felt" before treatment is sought was documented during a research project in northern Alberta (Morse, Young & Swartz, 1991), and more recently in a study of the experience of Aboriginal HIV positive women (Mill, 2000). This belief may result in some Aboriginal people being less likely to request an HIV test, or, if positive, initiate treatment, when they feel healthy. An individual's perception of risk to HIV will also impact their perceived need for an HIV test. A large survey to document the knowledge and attitudes of First Nations individuals toward AIDS found that many participants perceived that AIDS was a 'white man's disease' and a large proportion did not feel that they were at risk for HIV infection (Myers et al., 1993). Several authors have emphasized the need for HIV prevention programs in Aboriginal communities to be grounded in the beliefs, attitudes and behavioural norms of the culture (Aboriginal Nurses Association of Canada, 1996; Miller et al., 2006, Weaver, 1999).

Voluntary counselling and testing

The availability of voluntary counselling and testing (VCT) is a key component of comprehensive HIV prevention programs (Mill & Anarfi, 2002; UNAIDS 2004). In addition, HIV surveillance provides important epidemiological data needed to monitor the epidemic, measure the impact of intervention programs, and plan appropriate health services. HIV testing and counselling are viewed as methods to promote behaviour change and control the spread of HIV (Norton, Miller & Johnson, 1997). Specifically it has been argued that individuals who know that they are HIV positive are more likely to practice safer sex (Tseng, 1996). In some groups, this appears to be the case. Several meta-analyses and systematic reviews (Weinhardt, Carey, Johnson & Bickman, 1999; Wolitski MacGowan, Higgins & Jorgenson, 1997) have shown that in specific contexts (e.g., for those who are HIV positive or in sero-discordant relationships), sexual risk behavior decreases after HIV testing; however, for other groups (e.g., women, injection drug users), the relationship between testing and reduced sexual risk is not clear. Researchers and health professionals have also raised several negative outcomes related to the provision of VCT. A study in Tanzania (Maman, Mbwambo, Sweat, Hogan & Kilonzo 1999) found that only 22% of HIV-infected women disclosed their HIV status to their partner, whereas 69% of non-infected women disclosed their status. In addition, negative social outcomes following disclosure of HIV status, including marital conflict (Maman et al., 1999), blame and fear (Keogh, Allen, Almedal & Temahagili, 1994; Mill, 2003) and violence (Gielen, McDonnell, Wu, O'Campo, & Faden, 2001; Gielen, O'Campo, Faden & Eke, 1997), have been reported. The provision of pre and post-test counselling with an HIV test is the recommended practice for the provision of HIV care; however there is evidence that counselling is not always provided.

(Silvestre, Gehl, Encandela & Schelzel, 2000), Research with Aboriginal two-spirited² men across Canada determined that almost half (42%) of the participants who had received an HIV test had not received HIV counselling (Monette & Albert, 2001). A Canadian study examining the HIV test experience reported that test recipients desire services that provide respectful, sensitive interactions, with personalized information and decision-making support about the test, in a setting that is convenient and private (Worthington & Myers, 2002). From the test provider perspective, best practices in test counselling include ensuring information and education to support HIV risk reduction; individualization of risk assessment and psychological need; ensuring test results are given in person; providing information and referrals; and facilitating partner notification (Myers, Worthington, Haubrich, Ryder & Calzavara, 2003).

Testing strategies

Current approaches to HIV testing in Canada have developed based on different goals in order to address the preferences of different populations. Nominal, non-nominal and anonymous HIV testing can be offered and provide varying degrees of privacy, autonomy and protection of individual rights (PHAC, 2005). Nominal testing refers to HIV testing that can be linked to the person through a personal identifier. In this instance, the patient's physician must report the test result to the local medical officer of health, who in turn must ensure that the person's sexual and drug use contacts are notified. Following non-nominal testing a physician can link the HIV test result to the person through an identification code; however, the result is not reported to the medical officer of health. The physician and patient are responsible for notifying contacts about potential exposure. Anonymous testing, on the other hand, provides complete anonymity to the individual wishing an HIV test. Neither the physician ordering the test, nor anyone else knows the identity of the patient. This approach is based on the belief that individuals at very high risk of acquiring HIV may be reluctant to obtain testing if anonymity is not assured. An analysis of the success of anonymous testing in Ontario (McGee, Lirette, Tripp & Major, 2002) found that clients accessing anonymous HIV testing had consistently higher positivity rates than those accessing nominal or coded testing facilities, indicating that people at high risk for HIV infection are more likely to chose anonymous testing.

The reporting of HIV infection in Canada is governed by provincial or territorial legislation and requires that nominal or non-nominal information about an individual who tests positive for HIV be reported to the provincial or territorial public health officials. As of April 2002, HIV infection was legally reportable in all provinces and territories with the exception of British Columbia (Health Canada, 2002b). Although nominal and non-nominal testing are available in the majority of provinces and territories, anonymous testing is not available in the Yukon, North West Territories, Nunavut, Manitoba and Prince Edward Island (Health Canada, 2002b). In relation to ethnicity, approximately 90% of AIDS case reports include information about ethnicity, whereas only 30% of HIV test reports include ethnicity data (Health Canada, 2002c).

Barriers to HIV testing in Aboriginal communities

² Two-spirited is often used to refer to Aboriginal people who identify themselves as gay, lesbian, bisexual or transgender (Matiation, 1999b, p.7), because it is "...more culturally relevant to Aboriginal lesbians and gay men [and recognizes] the traditions and sacredness of [a] people who maintain a balance by housing both the male and female spirit..." (Deschamps, 1998 n.d., p. 10).

Access, particularly for individuals who are at high risk for infection, has been identified as a barrier to HIV testing (Siegel, Raveis, & Gorey, 1998). Many Aboriginal people face significant barriers to HIV testing due to the remoteness of communities and confidentiality concerns, particularly in small communities. Furthermore, Aboriginal individuals who wish to receive an HIV test may not feel comfortable accessing mainstream health services (Browne & Fiske, 2001; Crown et al., 1993; Matiation, 1999a). Small communities are often unable to offer the specialized support services required for individuals' who test positive for HIV (Crown et al., 1993). Lack of awareness of the disease, AIDS stigma, and initial lack of symptoms were identified as challenges to HIV testing in the Alberta Aboriginal HIV Strategy (Health Canada & Alberta Health and Wellness, 2001). A report completed for the CAAN and the Canadian HIV/AIDS Legal Network (Matiation, 1999a) highlights the issues of confidentiality and inadequate pre and post-test counselling in relation to HIV testing in Aboriginal communities. Recommendations from the report include the need for: specific informed consent for HIV testing; the availability of anonymous testing for all Aboriginal people; education programs to decrease stigmatization related to HIV testing; the provision of pre and post-test counselling by persons who have received training in cultural sensitivity or are of Aboriginal descent; the availability of pre and post-test counselling within Aboriginal communities and in mainstream facilities; non-nominal reporting of HIV infection and AIDS; the development of confidentiality policies for organizations involved in HIV testing and counselling; and the implementation of partner notification programs (Matiation, 1999a).

In an Alberta study (Bucharski, Reutter & Olgivie, 2006), Aboriginal women living with HIV identified the following barriers to HIV testing: fear of testing positive and subsequent judging by Aboriginal people; perceived lack of anonymity; feelings of shame; questioning about risk behaviour; and judgment from testers. This group of Aboriginal women identified several principles related to an ideal testing situation: Aboriginal determination of HIV policy and program development, the use of a harm reduction approach, orientation to the present and providing opportunities for choice. Interestingly, the majority of this group of women stated that they would have preferred to have an Aboriginal tester and not to be asked about their 'risk behaviours'. Aboriginal people in coastal Labrador reported that stigma, concerns regarding confidentiality, fear of the result, and lack of social support were the primary barriers to testing (Ratnam & Myers, 2000). In the Labrador study, participants suggested using a range of formats to provide information on HIV testing services, offering HIV tests in combination with routine blood tests, and using testers from outside the community. Individuals may be less likely to request an HIV test if they do not perceive themselves to be at risk for HIV infection. Aboriginal individuals living in Montreal believed that the only people at risk for acquiring HIV were those individuals who traveled between reserves and cities, new urban arrivals, particularly teenagers and women working in prostitution, and gay men (Brassard, Smeja, & Valverde, 1996).

Once an individual has received an HIV positive test, AIDS stigma and a fear of labelling may delay them from seeking out, and engaging with, appropriate health services (Chesney & Smith, 1999; Herek, 1999; Mill, 2003; Rudy, Newman, Duan, Kelly, Roberts et al., 2005). Health practitioners have been identified as a source of stigma and discrimination for individuals living with HIV (Carr & Gramling, 2004; Chesney & Smith, 1999; Matiation, 1999b; Mill, 2003; Mwinituo & Mill, 2006). Aboriginal persons having HIV/AIDS (APHAs) may also be reticent to

access care that is not culturally competent. A study with two-spirited Aboriginal men across Canada, found that of the 49% of men in the sample who were HIV positive, only 42% were using any type of Western treatment or therapy (Monette & Albert, 2001). The participants identified the following barriers in accessing health and social services: feeling unwelcome, fear of health and social services workers and organizations, fear of discrimination, and lack of transportation.

HIV testing in Aboriginal communities

A lack of concrete epidemiologic data and a reliance on anecdotal evidence, has limited the development of sound knowledge of the HIV epidemic in Aboriginal communities in Canada (Matiation, 1999a). This gap in knowledge also applies to HIV testing behaviour. Houston (1995) suggested that Aboriginal people are less likely to be tested for HIV because they do not perceive themselves to be at risk, and are skeptical about the value of testing and the motivation of the tester. In a study to compare the HIV testing behaviours of Aboriginal and non-Aboriginal Ontario inmates (Calzavara, Burchell, Schlossberg et al., 1998), researchers found that Aboriginal inmates were less likely to have ever had an HIV test and more likely to report that they didn't know where to get a test. An analysis of cases of AIDS reported to the Public Health Agency of Canada between 1996 and 2005 (Stokes, Pennock & Archibald, 2006) revealed that Aboriginal persons were significantly more likely to have had a late diagnosis of their HIV infection. A late diagnosis was defined as less than 12 months between their first positive HIV test and a diagnosis with AIDS. This trend was also suggested in an analysis of deaths due to AIDS among First Nations individuals in Vancouver (Goldstone et al., 1998). First Nations individuals were sicker earlier, had shorter survival rates, and had more admissions and hospital days than non First Nations individuals. Although some evidence suggests that Aboriginal youth are accessing HIV testing as much or more than the general population (Nguyen, Deleary, & Swaminathan, 2000), evidence suggests the reverse in adolescents generally (Grant et al., 2006), highlighting the need for further research to explore the testing behaviour of Aboriginal youth.

Research Design and Methods

An exploratory descriptive design was selected for the study due to the limited knowledge about HIV testing in Aboriginal youth in Canada. Mixed methods, including a cross-sectional survey and in-depth interviews, were used to collect data. To achieve our goal of exploring and describing Aboriginal youth experiences and perceptions of HIV testing and care we used a community-based, collaborative research approach throughout the study. The project was guided by the principles of OCAP³ (Patterson, Jackson & Edwards, 2006; Schnarch, 2004) and had significant community involvement and support: Aboriginal co-investigators ensured that the research was relevant to Aboriginal communities and a Community Advisory Committee comprised of Aboriginal youth, Elders and community members helped guide the research and ensure that it was culturally appropriate. Consistent with OCAP principles, the advisory committee and researchers collaborated within a dynamic and culturally responsive framework in exploring HIV testing in Aboriginal youth.

Data collection was carried out with the assistance of eleven (11) community based organizations from across the country including Aboriginal AIDS service organizations, Aboriginal health centres and friendship centres. The organizations were purposively selected to assist in recruiting participants who had received an HIV test, and knew they were HIV sero-positive or sero-negative, and those who had not received a test and did not know their HIV status. Care was taken to invite collaboration from off-reserve agencies who served a cross section of First Nations (including Innu), Inuit (including Inuvialuit) and Métis youth between the ages of 15-30. These agencies provided recruitment assistance in nine (9) locations across the country, including Vancouver, Edmonton, Winnipeg, Ottawa, Toronto, Montreal, Halifax, Happy Valley-Goose Bay, and Inuvik. Project coordinators were located in both Edmonton and Ottawa.

Ethical Considerations

Ethics committees at the Universities of Alberta, Calgary, and Toronto, and Health Canada (prior to the creation of the Public Health Agency of Canada) approved the research project. Ethical approval was also received from the Aurora Research Institute, an organization that oversees scientific research in the Northwest Territories.

Prior to each survey and interview, informed consent was obtained from each study participant. The written consent form described the project in brief, the purpose and nature of the survey or interview, and outlined the potential benefits and risks of participating in the study (Appendix A). The consent form also gave assurance of confidentiality, outlined the procedures for maintaining anonymity, explained the participant's right to withdraw from the study or refuse to answer particular questions and the rationale for keeping transcripts on file. Each consent form was read and explained to the participant before being signed by both the participant and project coordinator. Participants were asked to sign their real name, their initials or a pseudonym of their choosing. All consent forms were kept in a locked filing cabinet separate from the transcripts to ensure confidentiality.

³ OCAP = Ownership, Control, Access and Possession. In brief, OCAP is a set of guidelines for ensuring Aboriginal self-determination in research.

In keeping with common practice for community-based research with Aboriginal participants, survey and interview respondents were provided with a small honorarium for their participation. In addition, each organization was compensated for staff time required for recruitment, based on an average time allotment of one hour per participant recruited.

Population and Sample

The target population from which the sample was drawn was Canadian Aboriginal youth living off reserve in rural and urban communities. The term Aboriginal as used in this study included individuals who identified themselves as Métis, First Nations⁴ or Inuit regardless of treaty status (McLeod, 1997). In Canada, the term ‘status’ refers to those individuals legally recognized by the federal government under the Indian Act to be Indian (Waldrum, Herring & Young, 1995). The inclusion criteria for the participants included: Aboriginal men and women between 15 and 30 years of age, and English or French speaking. Both Aboriginal youth who had received an HIV test and those who had not were eligible to participate. Completing the survey was not a prerequisite for participating in the interviews although several youth completed both.

Four hundred and thirteen (413) Aboriginal youth from Vancouver, Edmonton, Winnipeg, Ottawa, Toronto, Montreal, Halifax, Labrador and Inuvik completed the survey between January and October 2004. Twenty-eight (28) Aboriginal youth participated in in-depth, semi-structured interviews between August 2004 and February 2005. Refer to page 24-26 of this report for a detailed description of the study sample.

Data Collection Methods

The purpose of the survey was to examine the reasons Aboriginal youth do not test for HIV or decide to have an HIV test, their preferences in HIV testing services, and the factors that influence their decision-making about HIV care. A draft survey tool was developed based on an extensive review of the published literature, unpublished reports on the issue of HIV testing, and the experience of the research team members. The self-administered survey instrument was developed in collaboration with the Community Advisory Committee and pilot tested in the fall of 2003 with two groups of Aboriginal youth (one English speaking group and one French speaking group). Once the survey instrument was finalized and translated into French, we invited a representative from each participating organization to a training session on the survey implementation (see Appendices B, C). Project coordinators worked with representatives from each of the participating agencies to begin the recruitment of youth to the study. The project coordinator made a follow-up visit to each study site to monitor the distribution of the surveys and assist with data collection.

Convenience and network sampling (Brink & Wood, 1994) was used to recruit participants for this study with the assistance of collaborating agencies. Key persons in each of the collaborating agencies were identified as contact persons and these individuals took responsibility for the recruitment of participants for both the survey and interviews. Participants were provided with a

⁴ Today ‘First Nations’ has replaced the term ‘Native’ in general usage (PHAC, 2001).

private space within the participating agency to complete their self-administered survey while the project coordinator was available to answer questions that might arise during completion of the survey instrument. To preserve the participant's confidentiality, participants were asked to place their completed survey in an unmarked envelope and seal it before returning it to the project coordinator. The number of surveys completed at each organization varied, and was somewhat reflective of the number of youth accessing the organization.

The purpose of the interviews was to allow participants to provide a more in-depth account of their experiences or perceptions of HIV testing. Therefore, guiding questions (Appendix D) were developed to reflect the same thematic areas that were covered by the survey instrument. To maintain a balance between consistency and flexibility (May, 1991), the same guiding questions were used for all participants; however, emphasis on particular questions varied according to the experiences of the interview participant. For example, for those who had not tested, the interviewer focused on questions regarding youth perceptions of HIV testing, potential reasons for not receiving a test, and general knowledge of HIV treatment. For those who had received an HIV test, the interviewer focused on questions regarding the experiences with the tester, their reasons for testing, reactions to receiving the results and follow-up care for those who tested positive. This approach allowed each topic to be explored similarly with each participant but also for the unique experiences of each individual to be drawn out. All interviews lasted between 45 and 90 minutes and at the end of each session demographic information was collected from the participants (Appendix E). They were conducted in a mutually agreed upon place (most often in the participating agency) and tape recorded with the permission of the interview participant.

Following the preliminary analysis of the surveys, the project coordinators contacted the collaborating agencies to arrange to conduct the interviews. Project coordinators traveled to Vancouver, Toronto, Montreal, Halifax and Inuvik at mutually agreed upon times to meet interview participants, to sign the required consent forms, and to conduct one-on-one interviews in a private space. Care was taken to interview youth who had not received an HIV test, youth who had received an HIV test and those who had tested HIV positive and HIV negative. However, because of our interest in understanding the HIV testing experience and the ability of those who had received a test to speak to this issue, an extra effort was made to recruit those who had received an HIV test.

Data Management and Analysis

Surveys

Survey responses were coded and entered into SPSS 11.5 statistical software program for quantitative data analysis. Data were cleaned through a process of verification of cross-tabulations, and any entry errors noted were corrected. Some variables were recoded to extend or collapse response categories to more accurately reflect survey responses. A codebook was produced to present descriptive statistics (frequencies and percentages or means and standard deviations) for all survey items. Bivariate relationships were examined using appropriate statistics (e.g., Chi-square, t-test), with statistical significance set at the 95% confidence level ($p < .05$). Chi-square test and Fisher's Exact test were used for comparisons of proportions. A

two-sided p value of less than 0.05 was considered to indicate statistical significance. Open-ended survey item responses were coded using thematic analysis.

Interviews

All interviews were tape recorded with the permission of the interview participant. Each taped interview was duplicated and the original audio tape was kept in a locked filing cabinet while the copy was transcribed by a professional transcriptionist. Transcribed interviews were then returned to the project coordinators for ‘cleaning’.⁵ The coding framework for the interviews was inductively developed by three members of the research team, including the principal investigator, one of the co-investigators and the project coordinator, all with extensive experience in qualitative data analysis. The development of the framework was based on the reading and discussion of three interviews to develop consensus on the emerging themes. The research team members agreed on descriptive labels or codes for particular segments of data and all subsequent interviews were then analyzed and coded according to these themes. The qualitative software program QSR*N6 (NUD*IST) was used to assist with the labeling, revising and retrieval of codes during analysis. As the project coordinator’s understanding of the interview findings developed, codes were added or renamed as necessary in consultation with members of the research team. Where applicable to quotes presented in this document, “I” denotes the Interviewer, and “P” denotes interview participant.

Reliability and Rigor

To ensure methodological consistency across the project, one staff person from each of the organizations were invited to Ottawa in June 2003 for a training workshop focusing on recruitment. This helped to ensure that the surveys were distributed and collected in a uniform manner and that the staff person had a sound knowledge of the research protocol. Following this workshop, information packages containing plain language posters, business cards and brochures (see Appendices F,G,H) describing the study objectives, eligibility criteria and how to get involved were sent to each of the agencies to assist in the recruitment process. The Community Advisory Committee and the youth participating in pilot testing of the survey provided comments on the survey design to enhance face validity. Project coordinators were available by telephone or email to provide methodological support to participating organizations. At a mutually agreed upon time, project coordinators then traveled to each of the data collection sites to meet with study participants, administer surveys and conduct interviews.

⁵ ‘Cleaning’ was a two-step process consisting of 1) checking the transcribed interview against the recorded interview for accuracy and 2) removing all identifying information and references to ensure participant’s anonymity and confidentiality.

Capacity Building

In early 2002, the executive director and a staff member from CAAN and two senior public health scientists in the Centre for Infectious Disease Prevention and Control at Health Canada (now the Public Health Agency of Canada) met with a researcher from the U of A to design the project. This research project represented a collaborative effort to address the urgent issue of HIV testing in Aboriginal youth as identified by CAAN, Health Canada, and academia. The research team was assembled to reflect this partnership; staff from CAAN, epidemiologists from PHAC and academic faculty from the Universities of Alberta, Calgary, and Toronto, representing faculties of nursing, social work, and medicine. The project involved extensive Aboriginal community involvement with a range of AIDS service organizations, health centres, community organizations, and friendship centres across Canada.

Capacity building was a goal throughout the research project. The research team initially hired an Aboriginal research coordinator at one site to facilitate data collection using the survey and interviews. A Community Advisory Committee (CAC) meeting was held early in the project with youth, Elders, and community agency personnel in attendance. Appendix I shows the Advisory Committee Terms of Reference document developed from this meeting. Several subsequent meetings were held over the course of the project for guidance and research training. A 2-day dissemination workshop was held in Regina, Saskatchewan in October 2005 during the preliminary data analysis period (Appendix J). The overall goal of the workshop was to discuss and verify findings, and get community feedback on the next steps in the research process. This was also an opportunity to assist with the development of the research skills of the CAC and promote culturally relevant research with non-Aboriginal researchers.

History of Project

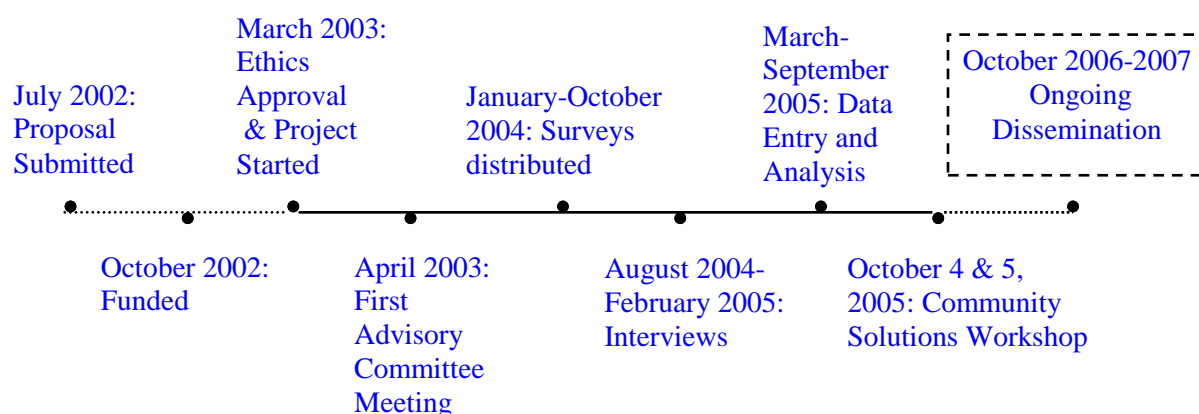


Figure 1. *History of Project*

Findings

Detailed Sample Characteristics

Survey Respondents

Age, Gender and Aboriginal background

Questionnaires (see Appendix D) were completed by 413 Aboriginal youths ranging from 15 to 30 years of age with an average age of 21.5 years (SD 4.4). In this sample, 194 (47.0%) were male, 218 (52.8%) female and one person (0.2%) self identified as transgender. More than half of the youth reported having First Nations Status, while the remaining youth identified as Métis, Inuit First Nations Non-status, Inuvialuit or other (see Figure 2).

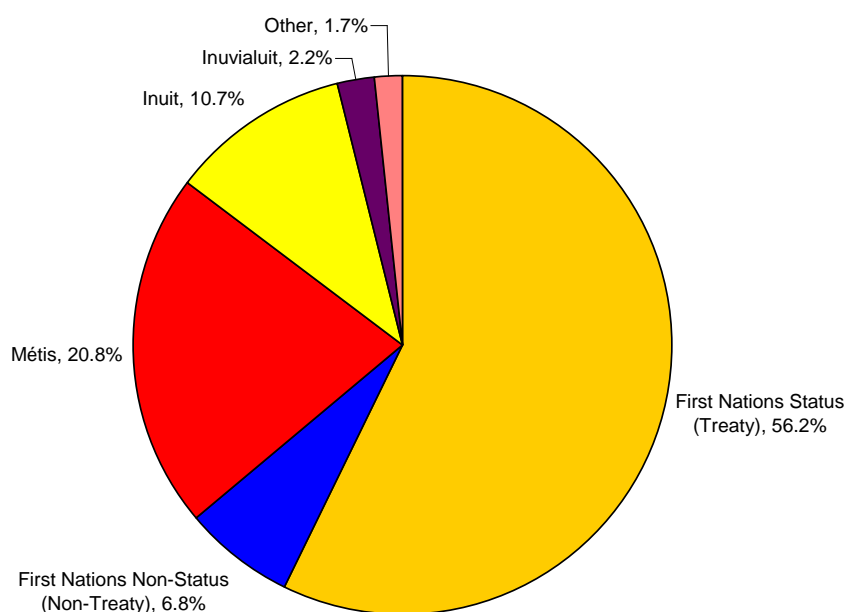


Figure 2. *Aboriginal Background of Participants (n=413)*

Languages

English (92.3%) was the most common language that was first spoken in childhood, followed by an Aboriginal language (20.6%) and/or French (7.7%). The Aboriginal language most frequently identified was Cree, followed by northern Aboriginal languages (Innu, Dogrib, etc.). The youth reported speaking abilities in English (97.8%), French (13.1%), and an Aboriginal language (22.0%). The most common Aboriginal language spoken at the time of the survey was Cree, followed by Ojibwa and northern Aboriginal languages.

Sexual identification and marital status

Most of the youth self-identified as heterosexual or straight (84.7%). Thirteen percent (13.1%) of participants self-identified as gay/lesbian/two spirit or bisexual while 1.5% self-identified as *other*. Sixty-nine percent (69.2%) of participants stated that they were single, while 20.3% were in a common-law relationship. Some were married (3.6%) and about the same number (3.4%) had been in a relationship but were now separated, divorced or widowed.

Education

Half of the young people had some high school (49.9%) and 16.2% had completed high school. While 7.8% had completed college or university, and 14.6% had some post secondary education, 10.7% completed grade 8 or less. At the time of the survey, 32.7% were full time students and 9.0% were studying part-time.

Religion and spirituality

In response to the question, “Do you currently follow a religion?”, 41.4% of youth indicated they followed a religion, while 56.9% reported that they did not follow a religion. The religions identified ranged from organized religions to stated individualized religion. The main religion identified was Catholic (17.7%), followed by various Protestant denominations. Forty-one percent of the youth indicated they followed traditional Aboriginal practices. Some youth reported multiple Aboriginal practices. The most common practices included ceremonies, dancing, sweats, smudging, and drumming. A few reported that activities in nature such as hunting or fishing, and powwows were Aboriginal practices that they followed. The majority of youth who identified powwows and sweats/smudging as a component of their Aboriginal practices lived in larger urban communities.

Places of residence

The majority of youth (64.4%) were living in an urban centre with a population over 10,000 people. Of the youth living in small communities, three-quarters lived in an Aboriginal community. Two-thirds of the 32 youth reported that the remote community they lived in was an Aboriginal community, remote enough to require flights in or out of the community sometime during the year. Most of the youth had their own home or apartment (35.8%) or lived in their parent’s home (31.0%). In addition, a number of youth reported a variety of other living arrangements such as living in a friend’s home (9.7%), in a rooming house (3.1%), shelter or safe house (4.4%), hotel (3.4%), being homeless (4.6%), and other living arrangement (8.2%).

Income sources

Almost 85% of the youth reported income of less than \$20,000. Most (63.7%) reported having a single source of income: a job was the most frequently reported source of income (37.3%) with social support [welfare] following second (29.3%). Multiple other sources of income were reported in small numbers such as student loans, support of parents or community agencies, government sources such as GST credits and family allowance, and street sources. 6.5% of

youth had no source of income. Some youth had several sources of income with 16.4% having 3 to 5 sources of income and 5.2% having more than 5 sources, the greatest number being 15 distinct sources for obtaining funds.

HIV testing

Slightly more than half (50.8%) of the youth who completed a survey had been tested for HIV. Of these, 26 individuals had a positive test result.

Interview Participants

In-depth interviews were completed with 28 Aboriginal youth to develop a more in-depth understanding of HIV testing. Most of these youth were First Nations (25), while two were Inuit and one Métis. Interview participants were between ages 16 and 30 with an average age of 24.4 years (5 were 16-19, 10 were 20-24, and 13 were 25-30 years of age). Twenty-five had tested for HIV while 3 had not. Sixteen of the participants were female and 12 were male. In this sample of interviewed youth, 9 shared in the interview that they were HIV-positive (modes of transmission included 5 related to injection drug use, 3 related to heterosexual activity, and 1 male self identified as having had sex with men). It is important to emphasize that the interview sample was weighted towards individuals who had tested for HIV to reflect the research interest.

While youth participating in the interviews shared many stories of very challenging circumstances (e.g., street involvement including prostitution, sexual abuse as children, parental neglect, homelessness, trouble with the law, and difficulties adjusting to the differences of urban life, etc.), many also shared stories that reflected their sense of personal responsibility (i.e., advancing their education, etc.), their involvement in community/family/cultural activities (i.e., a strong sense of community involvement, including participation in ceremonies, high levels of parental involvement, etc.), and their focus on personal health (i.e., regular testing patterns and when diagnosed with HIV many were under the care of a physician and/or did not have symptoms at the time of testing, etc.). Although a number of youth (but not all) commented that their own parents were less than ideal role models, many youth participants were taking steps to ensure that they became positive role models for their own children and in some cases, the children of others (i.e., talking with their own children about the importance of safer sex and healthy sexuality, providing a safe place for children of the community to gather, etc.).

It is important to note, that challenging life circumstances influenced the ability of many of the interviewed youth to make positive health decisions. For example, two of the active injection drug users took more than a year to consult a physician following diagnosis with HIV. However, many youth were actively engaged in and/or planning positive changes for the future. While some interview participants has not completed their education or were not currently attending school, 11 youth had studied at a post-secondary institution, and of these, 4 had completed a college or university degree. Thus while some faced challenging circumstances, youth were positive about their futures.

SECTION ONE: The Decision to Test

Research questions

The decision to test:

1. Why do some Aboriginal youth decide to have an HIV test, while others do not?
2. How do Aboriginal youth view HIV testing?

Reasons for receiving an HIV test

Many of the Aboriginal youth survey participants were recruited from AIDS service organizations, Aboriginal health centres and friendship centres. As such, they were more likely to have had access to HIV counselling and testing than the general Aboriginal youth population. In this context, approximately half (50.8%) of the 413 Aboriginal youth in this cross-sectional study had been previously tested for HIV. The most common reasons for HIV testing given by those surveyed included (see Figure 3):

- “I had sex without a condom”(43.6%)
- “I was pregnant or thought I was” (35.4%)
- “I get tested regularly” (28.9%)
- “I am at high risk for HIV infection” (27.5%)
- “I was in a new relationship” (23.7%)
- “It was part of the screening for STDs (20.9%)

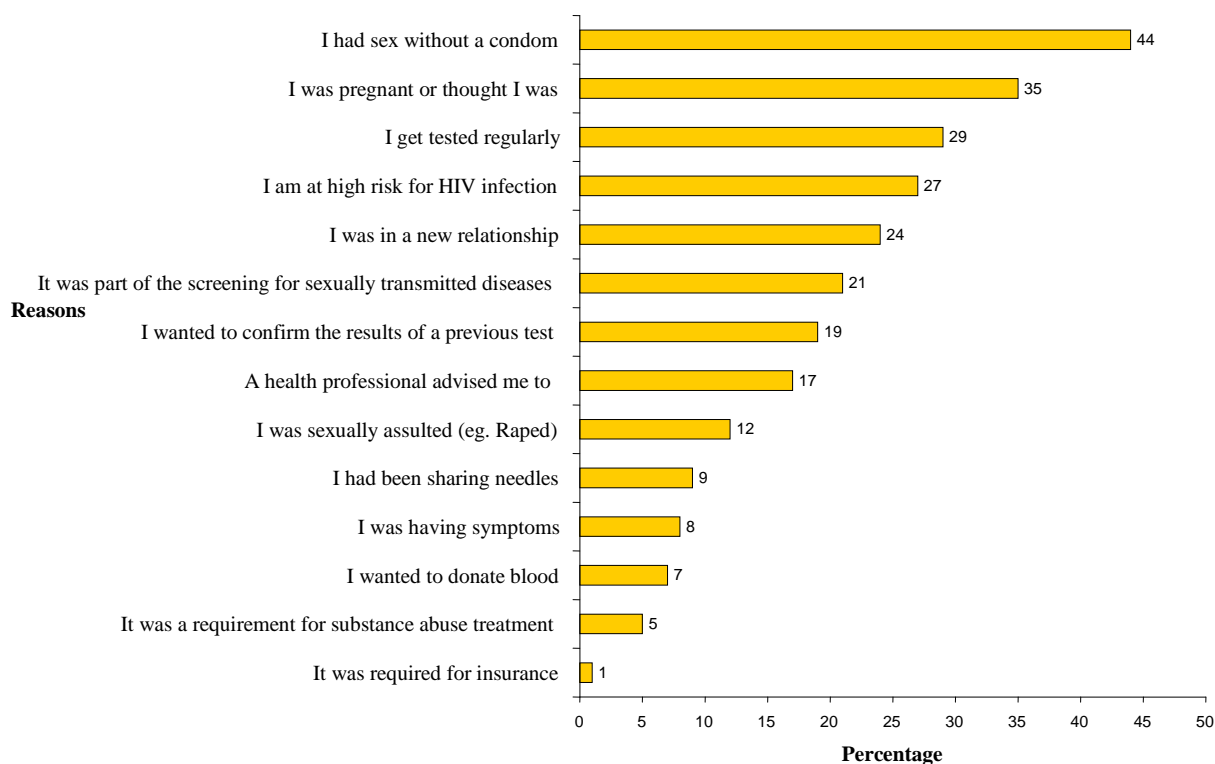


Figure 3. Reasons for HIV Testing (n=413)

Note: Survey participants could choose multiple reasons

HIV Testing: Why youth had never tested for HIV

Approximately half (49.2%) of the 413 Aboriginal youth surveyed had never been tested for HIV. The most common reasons for not having gone for HIV testing include (see Figure 4):

- “I am at low risk for HIV/AIDS” (45.3%)
- “I have never had sex with an infected person” (34.5%)
- “I always have safe sex”(33.3%)
- “I never share needles” (26.1%)
- “My doctor/nurse said I was not at risk or didn’t recommend testing” (26.1%)
- “I am healthy” (25.6%)

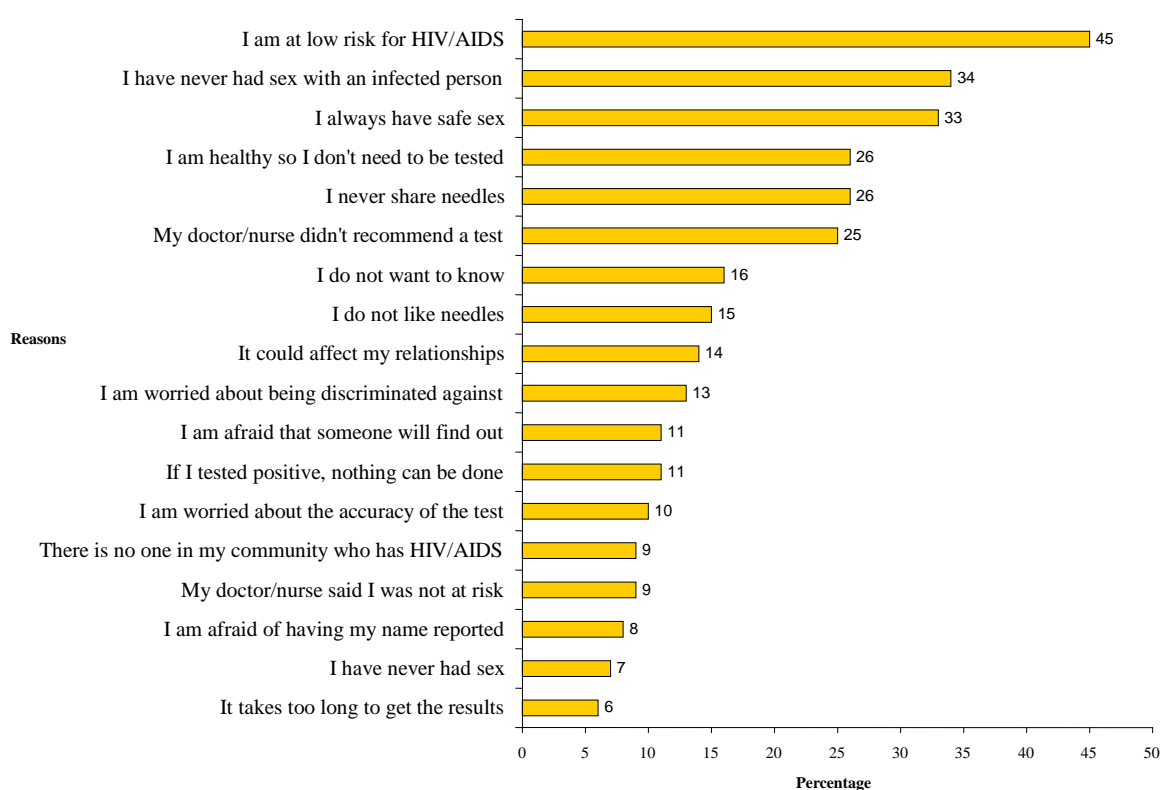


Figure 4. *Reasons for Not Having HIV Testing (n=413)*

Note: Survey participants could choose multiple reasons

HIV Testing: How different were the youth who never had an HIV test when compared to those who had been tested at least once in their lifetime?

Table 1 *Characteristics of Testers and Non-Testers*

Characteristics	Never had HIV Test (n=203)	Had HIV test (n=210)	P-value
	Frequency (%)		
Age 15-19 years	117/201 (58.2)	40/208 (19.2)	<0.001
French as 1 st spoken language	7/203 (3.4)	25/210 (11.9)	0.001
Male	115/203 (56.7)	79/210 (37.6)	<0.001
Heterosexual	188/201 (93.5)	162/209 (77.5)	<0.001
Single	160/201 (79.0)	126/207 (60.9)	<0.001
Student	108/202 (53%)	64/209 (30.0)	<0.001
Follow traditional Aboriginal practices	73/200 (36.5)	98/204 (48.0)	0.02
First Nations	110/202 (54.5)	153/205 (74.6)	<0.001
Living in First Nations, Métis or Inuit community	75/201 (37.3%)	47/208 (22.6%)	0.001
Living in a city with more than 10,000 people	109/200 (54.5)	157/207 (75.8)	<0.001
Living at home of parent(s)	94/200 (47.0)	34/209 (16.3)	<0.001
Income from job	89/203 (43.8)	65/209 (31.1)	0.008
Income from welfare	34/203 (16.7)	88/209 (42.1)	<0.001
Financial support by parents	26/203 (12.8)	9/209 (4.3)	0.002
Income from street	18/203 (8.9)	36/209 (17.2)	0.01
Ever had an STD other than HIV	25/201 (12.4)	99/208 (47.6)	<0.001
Oral sex in past 6 months	117/198 (59.1)	145/207 (70.0)	0.02
Anal sex in past 6 months	29/198 (14.6)	52/206 (25.2)	0.008
Always using condoms with anal sex in past 6 months	13/29 (44.8)	10/50 (20)	0.02
Injection drug use (IDU) in past 6 months	10/199 (5.0)	44/208 (21.2)	<0.001
Ever been pregnant (female)	31/86 (36.0)	103/130 (79.2)	<0.001

As detailed in Table 1, surveyed youth who had never been tested for HIV were more likely to have the following characteristics:

- Younger than 20 years
- Male
- Heterosexual
- Student
- Non-French mother tongue
- Not following traditional Aboriginal practices
- Métis, Inuit
- Living in First Nations, Métis, Inuit community
- Living in more remote area

- Living with parents
- Income from parental support, job and not welfare nor street
- Never had STD other than HIV
- In the past 6 months no oral sex or anal sex
- In the past 6 months, always using condoms with anal sex
- In the past 6 months, no injection drug use
- In females, never been pregnant

The decision to test for HIV was not associated with the following among surveyed youth (see Table 1):

- Education level
- Religion
- Income level
- Vaginal sex in the past 6 months
- Condom use with vaginal or oral sex in the past 6 months
- Sharing IDU needles in the past 6 months

HIV Testing: How do Aboriginal youth view HIV testing?

Surveyed youth were asked about factors that would influence their taking an HIV test (see Table 2). Among the noteworthy responses, youth indicated that if a health worker arranging for the HIV test is from the same home community, this would have deterred roughly one quarter (25.3%) of participants from HIV testing. On the other hand, the largest number of participants agreed that a doctor (53.0%) or a nurse (46.8%) would favourably influence their acceptance of an HIV test.

Table 2 *Health Worker Influence on Testing*

Characteristic: “I would have an HIV test if...”	Strongly Agree/	Neutral	Strongly
	Agree		Disagree/ Disagree
	Frequency (%)*		
I knew the health worker (n=400)	152 (38.1)	199 (48.2)	49 (12.3)
The health worker were from the same cultural background (n=399)	130 (32.6)	230 (57.6)	39 (11.8)
The health worker were a doctor (n=400)	212 (53.0)	173 (43.3)	15 (3.8)
The health worker were a nurse (n=400)	187 (46.8)	187 (46.8)	26 (6.5)
The health worker were of the same sex (n=399)	140 (36.3)	214 (53.6)	40 (10.1)
The health worker were from my home community (n=400)	76 (19.0)	223 (55.8)	101 (25.3)
The health worker were close to my age (n=397)	81 (20.4)	262 (66.0)	54 (13.6)

*Excludes missing values

Over two-thirds (68.1%) felt that HIV testing during pregnancy was a good idea, with another quarter (24.9%) undecided. Fewer females were undecided (16.2%) than males (34.6%). Among female youth participants, 61.5% had been pregnant at least once. Of those, 83.5% (compared to 59.8% of females who had never been pregnant) thought that it is a good idea to have an HIV test during pregnancy and 83.6% would want an HIV test if they were pregnant in the future.

However, among youth with a history of pregnancy, only 60.4% had had HIV testing during pregnancy and 6.0% did not know if they were tested during pregnancy.

Attitudes to Sexuality

Youth who participated in interviews were also asked about the circumstances surrounding HIV testing and reasons for testing or not testing. Analysis of the interview transcripts revealed that themes related to the youth's attitudes to sexuality and HIV and AIDS were important.

Invulnerability – “It can't happen to me”

Many of the participants mentioned that youth often had a feeling of invulnerability in relation to HIV risk. Oliver thought that youth were concerned about pregnancies, but did not worry about STIs or HIV.

But they don't think about HIV or any other sexually transmitted infections or anything. But they think about pregnancies. Just totally blank to their mind about [pause] STIs and AIDS. It's totally blank to it. That's the last thing they're thinkin' of when they're doin' it. They're thinkin' of “Am I going to get this girl pregnant?” [laughs] That's the only thing they're thinkin' of.

(Oliver, FN, Male)

Aboriginals have a feeling that they can walk on water without getting hurt, you know, play with fire without getting hurt. So to change the AIDS thing, would have to change the mentality, that's what I think.

(Carl, FN, Male)

All kids engage in risky behaviour. It's part of being young, is just taking risks and taking chances and being dumb, in some cases. They know that their friends are doing it and have been doing it, and they're fine, and they've not had any problems, no one's gotten pregnant yet or whatever, then they'll probably be wanting to do the same thing.

(Irene, FN, Female)

A few of the youth interviewed mentioned the feeling of invulnerability in relation to their own risk of HIV:

Yeah, because, I don't know, it just didn't seem like it could happen to me, you know. But I guess it can happen to anybody.

(Zinn, FN, Female)

Well, I mean, you learn it in school, right, so — well, the schools that I went to, anyway. You learn it there, plus the drop-ins that I would go to, you learn it from there, too; like, the counselors there, too. So I knew it was risky, but at the time, I didn't care; I was just young and stupid.

(Beth, FN, Female)

...But at the same time, you're, like, "Oh, you know, it doesn't — he seems like an okay guy or an okay girl — good girl, good guy." [laughs] I don't know; doesn't seem to take drugs. Basically, you're [long pause] I think it's like mental blocks, where people say, "no, no, it can't happen to me."

(Gwen, FN, Female)

Melanie had tried to encourage her friends to have an HIV test but her suggestion was often not taken seriously because of their belief that "...it won't happen to me."

Sex as a taboo topic

Another important theme that emerged from the findings was that topics such as HIV, AIDS and sexuality were taboo in small reserve communities and were not talked about openly. Although Irene was living in a small northern community at the time of the interview, she had been raised in a large urban area in the south.

It's just a different way of life. I mean we can look at it as a southerner, as someone who's been used to a different culture, one where in school, I was taught about AIDS and HIV and not having sex before a certain age, and not getting pregnant, and stuff like that. Then I came up here and pretty much everyone I met — like young, old, whatever — they've had kids when they're very young, before they've even finished high school...I mean everything seems to be different here. Just the way children are raised and what they're taught, it's kind of like they're left to fend for themselves.

(Irene, FN, Female)

Similarly, Melanie recalled that her mother had been afraid to talk to her about the need for pap smears once she became sexually active:

I didn't know I was supposed to be going since then. I didn't know...Nobody told me. My mom was too scared to tell me. My mom was, my mom didn't want to talk to me about that....Because most Native youth ain't open with their parents...I wasn't open with my mother.

(Melanie, FN, Female)

Rural/Urban differences

A few of the participants had found that different types of sexuality (eg gay, lesbian) were not well tolerated on reserves. One female participant had found it easier to live in a larger city as a two-spirited woman:

I suppose the other reason why, too, I like the city is because it's more accepted out here, as opposed to a small city or a small rez. That's some of the reason why I, too, am scared to go back home and visit with my family...

(Rachel, FN, Female)

Similarly, Sam had left his reserve at the age of 19 because he was tired of “living a lie” in relation to his sexual orientation:

I came when I was 19. I left (eastern Canadian city) and the reservation up north. Tried (eastern Canadian city #2) for a year and that didn't work out too well. Got tired of living a lie and two different lives all the time to my family on the phone and to what actually who I was and what I was going through...

(Sam, FN, Male)

Attitudes toward condoms

A few of the participants commented on their view and use of condoms. Oliver recalled receiving advice from his father to use condoms; however, had only used them on a few occasions:

He told me to wrap up. [laughs] That's all he told me about it... I've done it twice. I've only wore condoms twice. I don't know why. I just [pause] I don't know why. [laughs] Can't explain to you why. I'm not sure.

(Oliver, FN, Male)

Melanie had found that some men did not like using condoms; however, she insisted that they use one with her:

...Plus you might have some people, like some guys really, they're, like, “Oh, I don't like wearing condoms.” They don't like the feel...

(Melanie, FN, Female)

Impact of sexual abuse

Two of the young women related their current sexual behaviour to the sexual abuse that they had endured as a young girl. Zelda believed that youth were becoming sexually active at an earlier age and related her early sexual initiation to the sexual abuse she had experienced:

...I started sex at an early age; I started at 11 years old living with my common-law... Then by 13, I was a prostitute in the street. So kids aren't usually 15 when they

have sex; they're starting to have sex at a younger age. It's for the bars and that. For me, I went through sex and stuff, like, through sexual abuse, you know, and it just made me more curious and wanting to fit in with other people, so that's why I chose to do that.

(Zelda, FN, Female)

...I had depression, and I was trying to recall [memories of] being sexually abused, 'cause my sexual history now and hers is pretty similar to mine, but she is very high risk behaviour...If you don't care about yourself, you're going to sleep around without condoms. You will. I try really hard when I have a new partner to use condoms, but when I'm drunk, [sighs] I'll sleep with him, and then I'll black out, and then I won't remember.

(Kayla, Inuit, Female)

Kayla related the sexual abuse and other social problems that Aboriginal individuals and communities were experiencing to residential schools. She also felt that the social problems resulting from residential schools were impacting the choices that youth made:

How residential school has f'd up in the head my dad is. About [losing my] grandma [and her ways]. 15 kids in poverty from how many different men she had. My mom, for being abused by her mom. It's hard. We've got more problems than white people, and we're not coping and dealing with things. We've only maybe the last hundred years to get used to everything that's happened, and we're still — we're losing our language and our culture, our self-respect, our —. So we're [all] lost...They [youth] don't feel like anyone cares or loves them, because they're seeing abuse — drug, alcohol abuse at home, verbal abuse.

(Kayla, Inuit, Female)

Reflecting back (Changing attitudes and knowledge over time)

Some of the youth spoke about sexual attitudes and/or behaviours that had changed over time. For example, in response to a question about high risk sexual behaviour, one young woman recalled:

Yeah. I was sort of like that, too, when I was younger, but I would still go get tested anyway.

(Beth, FN, Female)

Similarly, a few of the participants commented that they had noticed a change in knowledge about HIV and AIDS over time. They believed that the youth of 'today' had more knowledge than they had when they were younger. Furthermore, several participants commented that HIV and AIDS was not a common topic of conversation among Aboriginal youth:

It's a topic that's not really brought up any more. It's coming to a point where it's almost common sense. You know what I mean? The kids now — the kids back when I was younger aren't as well educated — they're more educated now than they were before, and they have common sense that's more greater when I was younger.

(Adam, FN, Male)

I think a lot of people have a lot of knowledge about it. I actually think that more the people who are older, older drug addicts, are more knowledgeable than the younger ones. They know stuff about not sharing, and not using water, dirty water, and sanitizing your spoons and stuff. Stuff that I didn't know when I started poking those in my arms.

(Trent, FN, Male)

Attitudes to HIV and AIDS

Youth who participated in interviews were also asked about their attitudes towards HIV and AIDS. AIDS as a “death sentence” and fear of AIDS were common themes in interviews.

AIDS as a death sentence

About 25 % of the interview participants mentioned that they still associated HIV and AIDS with a death sentence. For example, when asked about the differences between HIV and hepatitis C, Sara shared her thoughts:

There's a very big difference there. Hep C, I make the decision as to whether I let the disease kill me or not....once it (HIV) changes into the actual virus, you catch a cold, and you die. I mean, that sucks. I don't even have that great of an immune system, as it is...Doesn't matter what anybody tells me, that's still a horrible disease. Seventy-five percent of the people who get it die from it. Doesn't matter what anybody says, that's a scary thought.

(Sara, Métis, Female)

Zinn had been for an HIV test and was negative. She believed that receiving the results of a positive HIV test was the worst thing that could happen to someone. How a person reacted would depend on how they felt about themselves.

Oh, God, it's probably the worst thing you could ever hear — depending on if you care or not...If it was someone who is really careful and stuff and made a mistake and they got it, I'm sure it would be like the end of the world, like a wall would come crashing down.

(Zinn, FN, Female)

Fear of AIDS

Many of the participants stated that they still found AIDS to be a “scary” disease:

I think people should just go regularly, just go and get it as part of the check-up, because it is a dangerous disease, and it is scary...

(Beth, FN, Female)

Me, I'm scared, and I'm going to — soon, I'm planning on going and testing myself, making another test, because AIDS is something scary, and that ruins a lot of lives.

(Hazel, FN, Female)

I'm afraid of all the STDs altogether. STDs top to bottom. That's all something very frightening. Some of them can be treated, but some of them can't be. And with me already having Hepatitis C, I mean, I just [pause] I'm nervous about all of them. I think AIDS is something that there's a lower risk of me having that, but it is something I'm very, very scared of. With all rights, I should be.

(Sara, Métis, Female)

Rachel believed that a fear of the unknown contributed to the fear that was associated with HIV:

Well, yeah, because if you're not familiar with something, you're going to be afraid of it, right? ...You're going to be scared of doing something like that. That's why I procrastinated on getting HIV testing done. I had to get me pregnant in order to get my HIV test done.

(Rachel, FN, Female)

Jason was a 23 year old male who was HIV negative. He described the relationship between being HIV positive and deciding to take treatment as “they both take a lot of guts”.

HIV and children

Several of the participants felt that it was very important to have an HIV test before becoming pregnant and felt quite strongly that if a woman was HIV positive she should not have children. A few of the participants believed that an HIV positive mother would always pass the virus to her child and believed that women who were HIV positive should not have children:

Plus, let's say the person wants to have a kid, that would be a really good reason to go out yourself and do the exam, not wait to be pregnant and they do the test for you because they have to. It's better if you go and do it, because I think having a kid with AIDS, it's almost killing a kid. That should be illegal.

(Hazel, FN, Female)

No. I wouldn't have children if I have AIDS. I wouldn't. I'd probably kill myself, to be honest with you. That's not something that I'm willing to live with...

(Sara, Métis, Female)

Two young women, on the other hand, had given birth to children who were negative since becoming HIV positive themselves. Yvonne had been HIV positive for 6 years and was very proud to have given birth to 4 beautiful children after she had received her diagnosis:

But now, I totally regret the choices that I made, because I'm — I can't really say that I totally regret, because since I became HIV positive, there's been a lot of good things in my life, one being — well, mostly being my children. Because I've got four beautiful children that are HIV negative, and they're happy.

(Yvonne, FN, Female)

Edward was very pleased that he had fathered a healthy baby 6 months before receiving his HIV positive diagnosis. He believed that if he died, he would leave part of himself in his son:

So I like every time I say, "Thank you, God," because you give a beautiful gift. I got a son. Six months before I [became] HIV [positive], I make a son...And me, if I'm going to die, I've got a part of my body there. That's why I'm every time happy.

(Edward, FN, Male)

SECTION TWO: The Experience of Testing

Research question

The Experience of Testing:

3. What is the experience of Aboriginal youth when they present for testing?

Approximately half (50.8%) of the survey respondents (210 of 413 Aboriginal youth) reported that they had ever been tested for HIV. This section of the report summarizes their experiences of testing, reactions to it, and comments about the testing experience.

HIV Testing: When and how often have Aboriginal youth tested?

The majority of youth (61.4%) who had tested had experienced their first HIV test in the five years prior to the survey (from 1999 to 2004). Another 24.6% had taken their first HIV test between 1995-1998. The remaining 14.0% had experienced their first test in the early 1990s, with one youth reporting a first test in 1984. As might be expected, age was negatively correlated with year of first test (Spearman's $\rho = -.47$, $p < .001$), i.e., those who were older were more likely to have tested in an earlier year.

Almost three-quarters (74.1%) of youth who had been tested (129/174 question respondents) reported they had taken their last test between 2002 and 2004, and only 13.3% (28) of those who had ever tested for HIV reported that they had not tested within the last two years. The majority of youth (60.0%) had tested once (36.8%) or twice (23.2%) in the last two years, and approximately one-quarter (25.2%) had tested more than twice, with 10 youth indicating they had tested more than five times in the past two years (see Figure 5). While some of these youth may have been reporting all HIV tests ever taken, results still suggest multiple and/or recent test experiences on the part of a substantial number of youth who have ever tested.

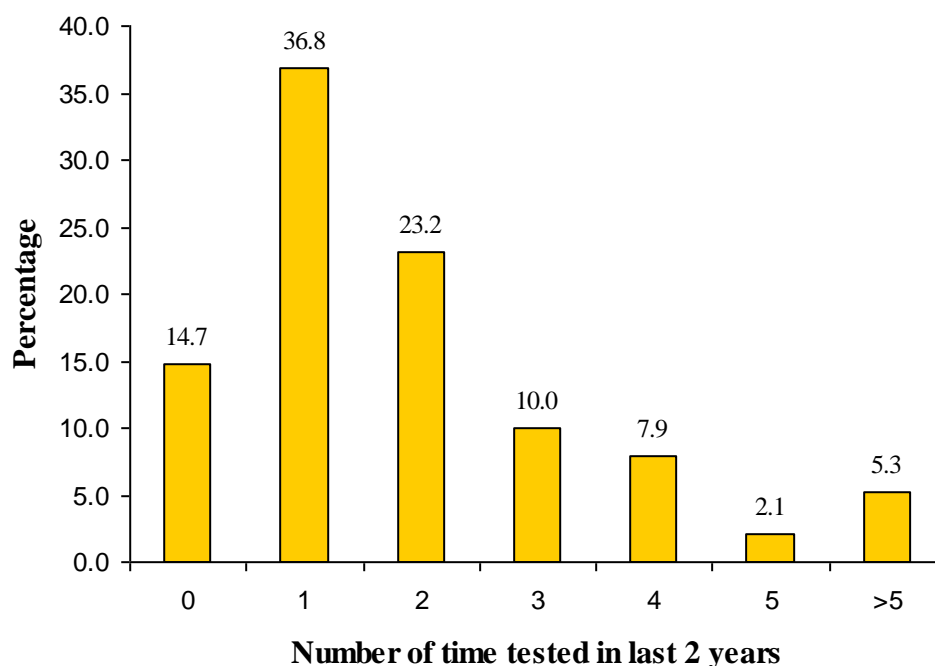


Figure 5. *Number of Times Youth Were Tested Within Last 2 Years (n=210)*

HIV Testing: Who gets tested for HIV?

The youth who had been tested for HIV were more likely to report risk factors for HIV infection. For example, compared to those not tested for HIV, testers were more likely to report a previous diagnosis of a sexually transmitted infection (47% vs 12%), a history of injecting drug use (21% vs 5%), or having had anal sex with any partner (25% vs 15%).

HIV Testing: Where do Aboriginal youth go for testing?

For their most recent HIV test, most (70.6%) youth tested in the community where they were currently living, while the other 57 (29.4%) indicated they tested outside of the community where they were currently living, although 17 of these youth indicated they tested in the community where they were living at the time of the test. Thus, 154 youth (86.5%) tested in the community where they were currently living or had lived at the time of the test. For the 40 youth who tested outside their current community or the community where they lived at the time of the HIV test, 10 (25.0%) indicated that they did so because ‘no one knew me,’ 9 (22.5%) because ‘I knew the health worker, 6 (15.0%) because there was no HIV testing in their community, and 3 (7.5%) because ‘my family was there to support me.’

The largest percentage of youth (34.1%) had gone to a physician for their most recent HIV test, while another 17.1% had gone to a hospital, 14.1% had gone to a community or public health centre, and 13.7% had attended a walk-in clinic. Very few had used other forms of testing services for their most recent test, including an anonymous testing clinic (4.4%), STD/STI clinic

(3.9%), nursing station (1.0%), friendship centre (0.5%), AIDS organization (0.5%) or mobile service (0.5%). Seven individuals had been tested as part of a research study or while in prison or a drug/alcohol treatment centre, and so their testing may not have been fully voluntary (see Figure 6).

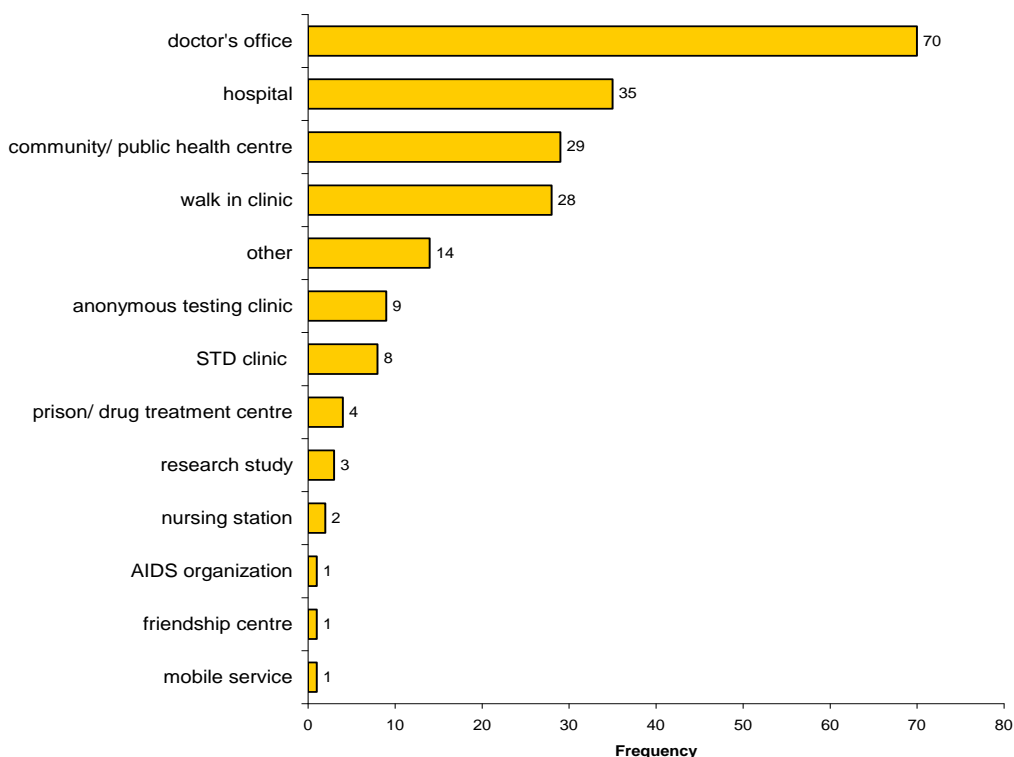


Figure 6. *Place where youth were tested (n=210)*

HIV Testing: Who ordered the test?

The majority of youth reported that the person who ordered their most recent HIV test was a female (57.9%), with female youth being more likely to see a female test provider than male youth (64% vs. 43%, Chi-square=10.85, $p < .01$). More than half (53.5%) indicated that they knew the test provider. 62.5% of youth reported that the person who ordered the test was a physician, while 41.2% reported that the person ordering the test was a nurse. Only 21 (11.5%) indicated that the person who ordered the test was about the same age, and 27 (15%) said the test provider had a similar cultural background (e.g., First Nations, Métis or Inuit). Four youth indicated that the person who ordered the test was similar to them in another way (e.g., a parent, from the same geographic region).

HIV Testing: What information were youth given when presenting for an HIV test?

Youth were asked about types of information they received when they went for their most recent HIV test. Almost one quarter (23.3%) indicated they were not given any information, and 28.1% could not remember what information they were given (see Table 3). Only one-fifth remembered

being given information about preventing the spread of HIV when using IV drugs (21.8%), protecting sexual partners from HIV (19.9%), or the effects of HIV disease on the body (19.9%). Fewer than one-fifth remembered receiving support and counselling (16.6%), information on the treatment for HIV infection (13.7%), or HIV reporting obligations (10.4%). There were no significant difference between youth who tested HIV positive and those who tested negative in the types of information they reported receiving.

Table 3 Information Received at Testing

Information provided at most recent HIV test (n=210)	
	Freq. (%)
I don't remember	59 (28.1)
Not given any information	49 (23.3)
Prevention for IDU	46 (21.9)
Protecting sexual partners	42 (20.0)
Effects of HIV disease	42 (20.0)
Support/Counselling	35 (16.7)
Treatment for HIV infection	29 (13.8)
HIV reporting obligations	22 (10.5)

Note: Column does not total due to multiple responses. Frequency and valid percent excludes missing cases.

Youth were also asked whether their questions were answered when they went for their most recent HIV test. Fifty percent said 'yes, all of them', 26% said 'yes, some of them', and 23.5% said 'no' (see Figure 7). Youth who were HIV negative were more likely to have their questions answered (55%) than those who were HIV positive (42%) or those who didn't know/results not clear (25%).

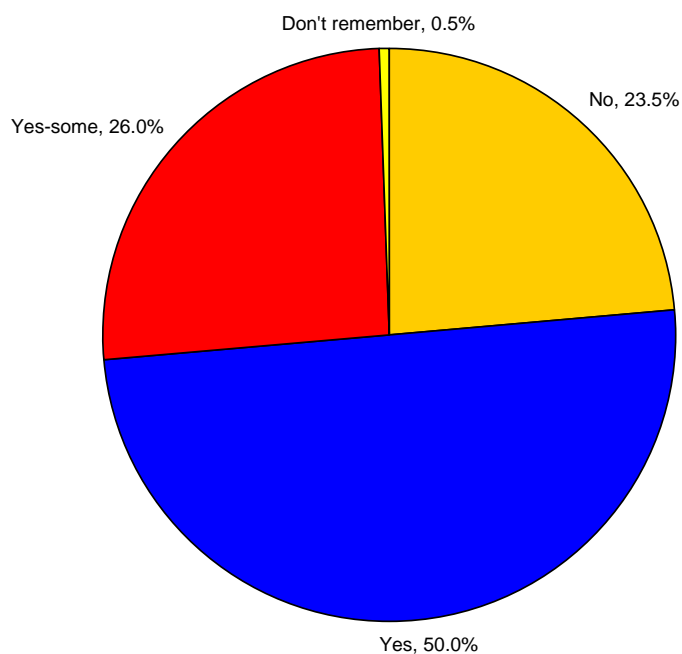


Figure 7. *Were Questions Answered When Youth Got Tested?*(n=210)

HIV Testing: How did Aboriginal youth feel about how they were treated?

Youth who had been tested were asked a series of questions about how they were treated during their most recent HIV test (see Table 4). Although over three-quarters of participants felt they had been treated with care (79.9%), respect (77.4%), or kindness (75.9%) when they received an HIV test, there was still a significant minority who had negative experiences. Twelve percent (12.3%) of participants indicated they were treated by service providers with fear, 11.2% with discrimination, and 9.7% with avoidance. Another 14.8% indicated they had been treated in a bored, disinterested way (see Table 4).

Table 4 *Perceptions of How Youth Were Treated at Their Most Recent Test*

Youth perceptions of how they were treated at their most recent HIV test (n=210)			
Characteristic: “I was treated [with]...”	Strongly Agree/Agree	Neutral	Strongly Disagree /Disagree
	Frequency. (%)		
Care	159 (79.9)	31 (15.6)	9 (4.5)
Respect	153 (77.4)	37 (18.6)	8 (4.0)
Kindness	151 (75.9)	40 (20.1)	8 (4.0)
Hostility	37 (19.0)	39 (20.0)	119 (61.0)
In a bored, disinterested way	29 (14.8)	47 (24.0)	120 (61.2)
Fear	24 (12.3)	27 (13.8)	144 (73.9)
Discrimination	22 (11.2)	32 (16.4)	141 (72.3)
Avoidance	19 (9.7)	32 (16.3)	145 (73.9)

Note: Frequency and valid percent excludes missing cases (i.e., “No Response” and “Do Not Know,” etc.).

HIV Testing: How did Aboriginal youth feel about being asked about sexual behaviour and alcohol and drug use?

Approximately three-quarters (72.4%) of youth who had been tested indicated that at their most recent HIV test they were asked about their past sexual behaviour, while 22.4% indicated they were not (5.2% of those who had tested did not respond to the question). Of those who responded to the question, the majority (63.1%) indicated they felt comfortable when being asked about sexual behaviours. However, over one-third indicated they felt scared (38.8%) or embarrassed (34.9%), and about one-quarter said they felt ashamed (23.5%). As well, approximately one-fifth indicated they felt upset (19.6%), and 13.5% indicated they felt angry when being asked about their sexual behaviour (see Table 5).

Table 5 *Comfort with Questions Regarding Sexual Behaviour*

How youth felt at their most recent HIV test when asked about sexual behaviour (n=199)			
Characteristic: “I felt...”	Strongly Agree/Agree	Neutral	Strongly Disagree /Disagree
	Frequency (%)		
Comfortable	94 (63.1)	37 (24.8)	18 (4.0)
Scared	57 (38.8)	36 (24.5)	54 (36.7)
Embarrassed	52 (34.9)	42 (28.2)	55 (36.9)
Ashamed	35 (23.5)	31 (20.8)	83 (55.7)
Upset	29 (19.6)	32 (21.6)	87 (58.8)
Angry	20 (13.5)	32 (21.6)	96 (64.9)

Note: Frequency and valid percent excludes missing cases (i.e., “No Response” and “Do Not Know,” etc.).

A slightly smaller percentage of youth (63.1%) indicated that at their most recent HIV test they were asked about past alcohol and drug use. Non-response to this item was similar to the question on being asked about sexual behaviour, with 15 (7.1%) of eligible youth not responding to the question. As with the question on being asked about sexual behaviour, most (62.9%) youth

indicated they were comfortable when being asked questions about alcohol and drug use, but significant minorities reported more negative responses (see Table 6).

Table 6 *Comfort with Questions Regarding Alcohol and Drug Use*

How youth felt at their most recent HIV test when asked about alcohol and drug use (n=195)			
Characteristic: “I felt...”	Strongly Agree/Agree	Neutral	Strongly Disagree /Disagree
	Frequency. (%)		
Comfortable	78 (62.9)	36 (29.0)	10 (8.0)
Scared	29 (23.6)	30 (24.4)	64 (52.0)
Embarrassed	26 (21.1)	36 (29.3)	61 (49.6)
Ashamed	25 (20.5)	33 (27.0)	64 (51.5)
Upset	18 (14.6)	32 (26.0)	73 (59.4)
Angry	15 (12.3)	28 (23.0)	79 (64.8)

Note: Frequency and valid percent excludes missing cases (i.e., “No Response” and “Do Not Know,” etc.).

HIV Testing: How did Aboriginal youth react emotionally to HIV testing?

Almost four-fifths (79.0%) of the Aboriginal youth who had an HIV test responded to an open-ended question asking them to describe their emotions when taking an HIV test. The majority of comments (106/166, or 63.9%) summarized feelings of anxiety or apprehension about the possibility of testing HIV positive. Many summarized their feelings in a few words (“anxious,” “scared,” “fear,” “worried,” “holy shit scared,” “terrified”) while some gave more elaborate descriptions. One youth wrote, “Pretty baked – smoked a lot of weed that day”, while another wrote, “I felt scared, blaming myself that my past caught up to me,” and another wrote “I felt anxious even though I’ve been with the same partner for almost four years. Who knows when it could surface? Maybe my partner has been unfaithful?” Another normalized the experience of anxiety: “I felt nervous because I had the actual HIV test done – feeling scared is a normal emotion,” and another said, “I felt nervous but hopeful.” Beyond anxiety, a few youth indicated that they felt “lost,” “confused,” “alone,” “sad,” or that they felt “negative about life.”

A small number of youth reported negative feelings about the HIV test experience itself. A few indicated they were embarrassed, ashamed, or uncomfortable during testing, and one wrote “you wonder what the person who is testing you is thinking.” Two youth reported being upset because they had been tested for HIV without their knowledge, and one youth indicated, “I don’t like being questioned by a white doctor.”

A smaller percentage, but still a substantial one (31/166, 18.7%) reported little if any negative feelings about HIV testing. These youth reported feeling “ok,” “normal,” “calm,” “comfortable,” “pas inquiète,” or “relaxed” when they had an HIV test. One youth wrote, “I wasn’t upset or anything, I just thought it to be a good idea,” and another indicated, “I didn’t feel anything because I was comfortable with it.” A few were more specific about why they felt this way, “I felt comfortable because I was confident that I didn’t have any HIV disease,” and another wrote “I wanted to get tested for happiness.” One youth reported feeling “brave.”

HIV Testing: What advice did Aboriginal youth have?

Fifty-seven percent (121) of those who had experienced an HIV test provided comments in response to an open-ended question on how to improve the testing experience for others. The largest group of respondents to this question (33/121, or 27.3%) used this space to encourage others to get tested for HIV despite the anxiety it may provoke, with comments like “Just do it”, “Reste calme, man,” “Don’t be scared, it’s part of life and you’ll feel ok after it’s done with,” or “Go for it, it might save your life and others’ too.” Several (5) respondents suggested that other youth should bring a relative or friend with them for support: “Bring a close friend to ensure you that everything will be okay and have a lot of support if needed.”

Youth had a range of suggestions for the improvement of testing services, largely pertaining to the three professional relationship components: interpersonal style (respect), emotional support, and information. Many used the word “respect” explicitly when referring to interpersonal style, and others made comments like, “Ask them in a way they don’t feel ashamed,” or “Have doctors that don’t judge; it’s not a bad thing to get tested.” One youth wrote, “Be understanding, patient, and treat people with respect. If they act ignorant ask them to come back when they are calm.” Comfort and emotional support were also commented on repeatedly: “Just to make the person feel at home – comfortable,” “Let them know they don’t have to be scared,” and one youth advised test providers, “Not to discriminate against them [i.e., youth] or treat them as if you are afraid of them.” Many youth also indicated that “more information,” or “more pre and post test counselling” would be helpful, and several others also commented on the information needs of health professionals (e.g., “Doctors and nurses strongly need to be aware of the disease.”). One youth provided a fairly detailed description of the type of information exchange that should go on: “Have the office full of queer positive posters and information. Prompt the visitor, ‘Do you have any questions?’ and ‘Do you know about...?’, etc.”

In addition to the three major professional relationship components, youth expressed concerns about confidentiality of the test results, informing individuals that they were being tested for HIV, and availability of HIV testing services. A few also suggested that HIV test results should be available more quickly. Finally, several (8) used the space to comment on their satisfaction with HIV testing experiences, with comments like “Mine were all positive experiences,” “None – it seems well thought out to me,” or, “Nothing – maybe it’s okay for me because I go to street nurses, and they are unjudgemental.”

HIV Testing: Test results

Of the 210 youth who indicated they had had an HIV test, 205 responded directly to the question, “What were the results of your most recent HIV/AIDS test?” Twenty-six youth (12.7 %) indicated they tested HIV positive, 158 (77.0%) said they tested HIV negative, 5 (2.4%) said that their results were not clear and they would have to go back for another test, and 16 (7.8%) said they did not know their HIV status because they had not received their test result (see Figure 8).

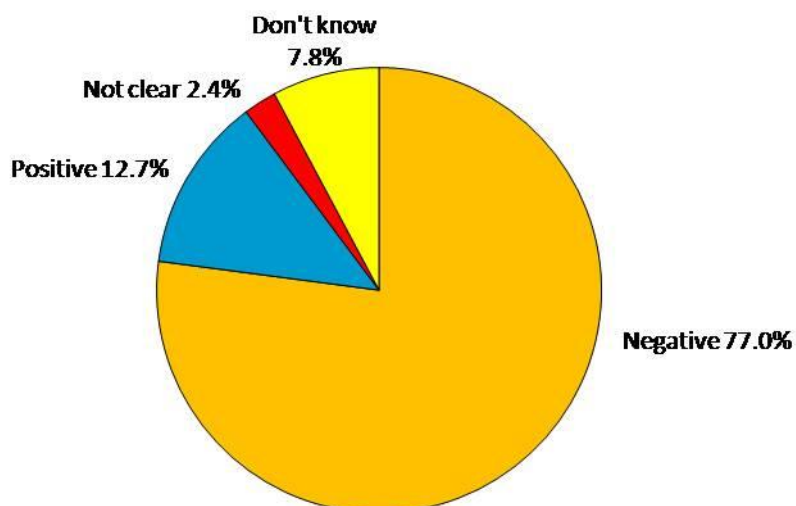


Figure 8. *Result of HIV Test (n=205)*

The Experience of Testing – Qualitative analysis

In reviewing qualitative data for the 28 in-depth interviews under the node “experience of HIV testing” the focus was to understand decisions to test (e.g., reasons to test and location, etc.), perceptions or views of HIV testing (e.g., reactions to results, etc.), and the characteristics of experience when presenting for HIV testing. The qualitative findings on the experience of testing overlap and/or supplement survey findings.

HIV Testing: Where and how often have Aboriginal Youth Tested?

Frequency of testing

For Aboriginal youth interview participants, many report regular HIV testing patterns. In many cases, regular HIV testing was viewed as a matter of course and was often coupled with regular checks for other sexually transmitted infections or was something that was considered as routine when individuals become pregnant. Participants shared their HIV testing experiences:

Oh, I get tested every 3 months for everything...Chlamydia, gonorrhea, everything. From bottom to the top, everything...so I get my HIV testing as well...I like to get tested regularly. I'm a hypochondriac, so it's, like, you know [laughs], like, to know there's nothing wrong with me.

(Sara, Métis, Female)

I: So you've had a couple done, you said. P: Yeah. I: How many, do you remember? P: Had, like [long pause], well, could they do a test and they do it again, what, three months after, or something, or a couple of months after, or something, to make sure? I: To

confirm, yeah. P: I think I had, like, two. I: Two other ones, or two, including the pregnancy one? P: Well, one, I had two pregnancies, so I had two done, and I then I had two others, one time. I: So four in total.

(Paulette, FN, Female)

I: Is this your first HIV test? P: I think I had one before that, that time before, too, and I believe it came back negative. Everything came back negative the last time.

(Zinn, FN, Female)

Yeah. I think I had a total of [pause] usually I get tested about at least once a year; I know that. But so far this year, it's been twice a year. Last year was twice a year too. I think the first year I did it, it was only just a once-a-year thing, and then ever since after that, it's been twice a year. So far, I know I've done it twice this year.

(Rachel, FN, Female)

Several of the interview participants considered themselves to be 'regular testers'. They tested more frequently than others and each for their own reasons. In the following passage, Adam expressed a common reason for testing regularly:

Now I have a girlfriend that I've been going out with for over a year, and every – once a year, I go and I get tested. I get a physical and I get blood work done and everything, just – because you never know...you know what I mean? There's so many ways to - I just get everything done and out of the way just to keep on top of what's going on with myself.

(Adam, FN, Male)

Of those interview participants who spoke of their last HIV test and were not known to be HIV positive, the time since their last HIV test ranged from two weeks to 6 years. The majority had tested within the past year.

Pregnancy

Several individuals reported HIV testing as a standard of care for pregnancy. Health care providers recommended testing to participants.

They just did it, because it's part of the processes when you get pregnant; you have to do all the tests.

(Hazel, Métis, Female)

Yeah, I was pregnant. [Laughs] They said you had to get one done, and I'm, like, "okay." ... I think they gave me the choice of getting one done, cause I think it was optional, but I guess for me, if I was going to have a child, I think I'd want to know. So if I passed it, I know what I was in, at least, you know, give the proper care to my child. So I think what's why I did it. But I didn't want to do it (laughs).

(Paulette, FN, Female)

... The first time I got an HIV test was when I was pregnant, because I guess that's part, when you get pregnant, you have the option of getting tested for HIV or not. Then if you are positive, there some sort of proper procedure where they give you some sort of medication where it prevent the baby from contracting the disease. I don't know, something like that. So I figured might as well, because at the time, my baby's father was, I guess you'd say, a promiscuous man, and I had to find out the hard way

(Rachel, FN, Female)

Where to go for testing

The type of service offering HIV testing was an important consideration for youth when deciding where to go for HIV testing. Aboriginal youth participants often tested in hospital or clinic settings and where physician/nursing services were offered.

I would probably go directly to the hospital. Last summer, I had it done by a clinic. I got pregnant, and the clinic did it for me.

(Hazel, Métis, Female)

At [name clinic]. 'Cause I used to go out, every so often, just go around visit them, see them, and my girlfriend [laughs] was another reason [both laugh] I had that done there.

(Oliver, FN, Male)

I got that one done at my doctor's. They didn't really say anything. They just asked if I wanted it done, and I'm, like, "Okay." I: Do you remember anything about your first experience? Was it at the same STD clinic? P: Yeah, it was at the same place. I: The same nurse? P: No, different nurse.

(Zinn, FN, Female)

At the family clinic here in [Northern Canadian City 2].

(Kayla, FN/Inuit, Female)

I: Did you go here in the community, or did you go into town? P: In town at the hospital.

(Melanie, FN, Female)

I: If you wanted to go for an HIV test, where would you go? P: Probably to the clinic. I: Which clinic is that? P: STD, [name of hospital clinic]. (Pause) It's right downtown. Everybody knows where it is.

(Zinn, FN, Female)

While most participants tested at medical clinics, hospitals, etc., several youth also reported testing at a drop- in location suggesting flexibility in service design was a key motivator to the decision to test – a place where one could simply show up and have a test anytime.

I: So there was a section that was solely for HIV testing? It was a drop-in; you could just show up and have a test anytime? P: Yeah.

(Adam, FN, Male)

I: Okay. Can you tell me about the last HIV test you had, where you went for it? P: Here, the centre. There was some nurse from the [community health clinic]. I: Do you know if that was an anonymous test, or was it a confidential? P: It was anonymous, supposed to be anyway. There were a lot of clients here at that time. They come here usually once a year.

(Darren, Inuit, Male)

HIV Testing: When have Aboriginal youth tested?

Taking care

For several participants, taking care of themselves and others were important considerations and motivation to test for HIV. One participant, for example, shared how knowing the results of an HIV test could “*set it straight*” while for another it was simply to make sure everything was “*okay*.”

[I've] been thinking about it for awhile, and I was kind of, like, “Maybe I should go, because, like, [pause] it's a duty to myself.” Like, [pause] if I do have it, I have to take certain measures to take care of myself. I don't know; it was, like, I was really uncertain about it, and I guess I just wanted to set it straight, and also know that I want to take care of myself, or if I should take care of myself, actually.

(Gwen, FN, Female)

It was just more I don't want to be sick. Like, I just wanted to make sure I was okay, for myself and for him as well.

(Zinn, FN, Female)

Self assessment

For some participants, the decision to test was predicated on a realistic self-assessment that past behavior may have placed them at risk for HIV. Several youth participating in an interview reported unprotected sexual relationships, street involvement, or injection drug use as a factor in their decision to test for HIV.

Well, I was wild when I was younger, so I had – I had slept with some people I probably shouldn't have, and it was unprotected, so I'd get really scared, and I'd go get it tested ... because the lifestyle I had was not very safe.

(Beth, FN, Female)

Yeah, I had unprotected sex with my boyfriend. I'd been with him two years, with him. He never had an HIV test, that's the thing, like [pause] I don't know [pause]. I: You just thought it was a good idea? P: Yeah [both laugh].

(Gwen, FN, Female)

I go every time when I don't use the condom, but it's rare...Every time [I] use a condom. Sometime if the girl is okay, and she show me the result, the positive or negative, only that.

(Franco, FN, Male)

Why I had one, not really sure. Slept with a lot of women, never used a condom ... so I decided to get one.

(Oliver, FN, Male)

... So that was the main reason why I also went and got a test done, because of the fact that okay, she's kind of hustling on the street from time to time, and it's like, you know, you can never be too safe or too sure, 'cause obviously, condoms aren't always 100 percent. They're like, what, 98, 99.9 percent safe? Like, you can never know. So just to be on the safe side, I like to get checked out.

(Rachel, FN, Female)

I had unprotected sex, and it scared me, so I just went down and got tested. I waited, like 5 months, though. Like, I didn't have see any signs of an STD or anything, no pregnancy, but then I thought, "I should go get tested anyways." Cause, I started seeing somebody else and I didn't want to – like, if I was in contact with something, I didn't want to give it to him.

(Zinn, FN, Female)

I thought if I was HIV positive, I thought it was better if I found out [chuckles] sooner or later. I guess I was pretty sure that I had it...It was because I used needles, and a lot times, I just didn't care; I would use a used needle, and I didn't care. And that's the way it gets when you're a drug addict; you just don't care about things like that, right? I just used dirty needles and not give a shit. I done it so many times; you know the majority of people down here that use needles, they have HIV.

(Trent, FN, Male)

Fear of HIV infection

For other participants, the decision to test was not as pragmatically focused on risk assessment. Rather, and even when the two reasons seem to overlap (risk assessment and fear of infection), findings suggest that the decision to test for HIV was largely motivated by a fear of HIV infection rather than any realistic assessment of past high risk behaviour. As several participants shared:

I: Can you think of a reason why somebody would want to have a test? P: 'Cause he's scared. I: He's scared? P: Um-huh. He's scared and whatever. [pause] Yeah, scared. I: He's scared of getting HIV. P: Yeah, probably.

(Franco, FN, Male)

Yeah. I'm always scared – well, I've had the same partner for 3 years, but I was scared, because I had an HIV test done before last summer – I think it was, like, 4 years ago, and

I was negative, but 3 years, I have the same partner, but sometime – well, I have to say I cheated on him a few times. He’s told me he’s faithful, but I’m not sure if he was faithful the whole time. So I was scared, myself, because AIDS for me is a big thing. [laughs] Yeah. – Note: Hazel reports her partner at the time was an injection drug user and although she trusts him, she remains afraid of possible consequences related to HIV infection.

(Hazel, Métis, Female)

Yeah. I like to get tested regularly. I’m a hypochondriac, so it’s, like, you know (laughs), like, to know there’s nothing wrong with me. Plus I’ve got liver problems, so I have to get blood work done all the time.

(Sara, Métis, Female)

I: So they started pretty early with you. So can you remember the first time when you considered having an HIV test? P: [pause] I think the first time I had a partner. Because after I did, it was, like, all my parents, what they would tell me, would just run through my head a lot, and it would scare me. So I’d be, like, “What if I just happened to be that little one, like that little percent that just happened to contract it without knowing?” I don’t know him for his whole life, so I don’t know, so I would, yeah; I got tested as soon as I could.

(Zoe, FN, Female)

For Hazel, sexual assault was the reason she decided to test for HIV.

I: You mentioned earlier that when you were in the hospital, that wasn’t the first time you’d had an AIDS test; there was another time. When was the first time you had an HIV test? P: That was in the States when I got raped, and the people were saying around town that the guy who raped me had AIDS. That was really scary, ‘cause that guy, he was going to jail and all that stuff. So I got checked, I phone[d] the cops, I made a report. They passed me that AIDS test, and I didn’t have it.

(Hazel, Métis, Female)

For other participants, difficulties trusting intimate partners or having casual sexual partners provided motivation to access HIV testing services.

What happened was I had a sexual encounter with a lady, and what happened was that the condom I had broke, and it just got me — I got to thinking that this was my first — like, it was a one-night stand kind of thing, and it was my first time being with this person, and I wasn’t too sure where this person’s been. So just to be extra cautious, I went and I got a test done.

(Adam, FN, Male)

Well, that’s my concern. Because me, I have a woman with a child; I prefer to check up, because I never know, never know about my woman. Like I’m here at the centre, and she’s in [another city], so [I] never know if she’s behind my back doing that. That’s my first concern.

(Darren, Inuit, Male)

Why I had it done is because I was with a guy for a very short period of time, but after we broke up, I really stopped trusting him and stopped trusting everything that he had said to me when we were together. It kind of made me nervous that we had had unprotected sex, so I had an HIV test done.

(Irene, FN, Female)

So it's, like, I knew she wasn't hustling all the time. It was just those times when we weren't together, she could be hustling. But who, who — well, I do kind of care, but still, you know what I mean? I was just pretty much doing it just to be safe, 'cause if she's doing all this hustling and stuff, you can never be too careful, right? Or what have you.

(Rachel, FN, Female)

Well, there [were] rumours goin' around that I supposedly slept with that guy that had HIV, and I know I didn't. The thing is, is that my boyfriend was kind of [pause] kind of freakin' about it; like, "You go get tested, because I know if you don't have anything, I don't have anything."

(Melanie, FN, Female)

Several participants noted they would balance the decision to test with the discomfort of condom use. A new relationship was also a factor in deciding to test. Several individuals shared this:

... I was entering a new relationship, and at point in time, condoms were irritating me. I don't know if it was the latex or what, but we couldn't use them, so I wanted to be able to have sex with my new boyfriend, so I had a test done to make sure that things were fine, so that we would be fine.

(Irene, FN, Female)

"I should go get tested anyways." 'Cause I started seeing somebody else, and I didn't want to — like, if I was in contact with something, I didn't want to give it to him.

(Zinn, FN, Female)

Well, when I would change — if I would have a different partner then yes, I would [get tested] on a regular basis because I don't know anyone. Nowadays things are getting scarier. I hear that HIV, it's getting higher because people aren't informed about it. It's just like it could be floating around there in the group I'm with and I wouldn't even know... The last time I was tested was 2 months ago.

(Zoe, FN, Female)

Health service providers

Several individuals decided on testing following a service provider recommendation.

Someone really just said, [pause] well, I think my doctor did; I was going to my annual check-up thing. Like, "You haven't had an HIV test for a while." I'm like, "No." [Laughs] "I think it's about time again." Because of my stupid behaviour. [Both laughs].
(Paulette, FN, Female)

Building on the theme of service provider recommendation, for other participants HIV testing was viewed as part of routine medical care.

I: It was a check-up? P: Um-huh. I: It was just a general check-up. P: Check-up for [Diseases], MTS or IHV. I: HIV? P: Yeah. AIDS. That's all.
(Franco, FN, Male)

I like to get tested regularly.
(Sara, Métis, Female)

I don't think, in general, it was a HIV test, but it's just more of the boxes he checked off. You know? Like, when he's checkin' off the, when he takes your blood and he gives it to the guy that took my blood test, and he checks off the boxes, that's one of the ones that was checked off.
(Oliver, FN, Male)

It was a blood test, and yeah, she poked me. She took a whole bunch of my blood in a couple different tubes, and that was it. She told me this was an HIV test. I said, "Alright." Just pretty much a total general examination; I got everything done, like the whole works.
(Zinn, FN, Female)

However, one participant decided to stop testing at a service provider's recommendation. Beth shared the following:

I always thought something was wrong with me, so I'd always go and get tested, not mainly for HIV, but for other things as well. After a while, the doctors sat me down and said, "You're going to have to stop coming, 'cause there's nothing wrong with you." So I stopped going, and it's been about a year and a half that I stopped coming. [laughs] I was thinking about going back just to get a regular check-up, 'cause I haven't gotten a check-up for a year and a half. [both laugh].
(Beth, FN, Female)

Involvement of parents

For others, the involvement of parents was important, not only as sources of factual information but for support when testing for HIV. Open and honest communication and the feeling that Aboriginal youth could approach parents without judgment on condom use or other information were important for youth participants not only practicing safe sex but testing for HIV as well.

I mean, family is going to be a big part of it. If they've never been lectured about it, never been given information about it, and should have been, because you need to get it before. I don't even think it's offered in school till, like, high school, and we all know

that kids are having sex before they go to high school – well, some kids these days – a lot of kids these days. So family values, for sure; what family talk about, how open families are to talk about stuff like that, for sure.

(Irene, FN, Female)

If I was HIV positive, I'd tell my dad. Like, I don't tell my parents I'm in a relationship. When they find out, my dad calls me and tells me to use condoms and be careful.

(Kayla, FN/Inuit, Female)

Oh, no. It was just my dad that kind of gave it to me, 'cause he knew how many women I slept with, and he knows me pretty, he knows, you know, I'm not [pause] we're not very private, we tell each other a bit of stuff.

(Oliver, FN, Male)

Rachel planned to talk with her son about safer sex; however, had not been educated about sexuality by her parents:

I don't know, but there's got to be a way to educate the kids about this more. I know I've, being a parent, I know that's going to come up for me one day, having to educate my son about AIDS and HIV and the proper way of having safer sex. And whether it be, like, if he's in a hetero relationship or if he's in, like, [a] same sex relationship, these are the things that I'm going to have to be a mother to him about. Obviously, I never had no one. My parents never told me about all this stuff. They just pretty much kept me in the darkness about sex. I'm like, 15, "Sex? What's that?" You know?

(Rachel, FN, Female)

However, involving parents was not something that was equally important to all participants in our sample. Several youth feared negative parental attitudes towards sexuality, decision-making in sexual relationships, injection drug use, or in testing for HIV:

Do I tell my parents, or do I not? [laughs] 'Cause then they're going to wonder how you got it. [laughs]. It's not like you want your mom to know that you inject needles every day or something [both laugh]. It's bad enough if you tell your mom that you're gay or something [both laugh]. That's all she needs.

(Paulette, FN, Female)

I: Did you ever have any discussions with your parents or more than, say, one friend, about that kind of stuff? P: My mom had the attitude "If you ever got HIV, you wouldn't be under my roof any more." She had that sort of attitude. My dad, I don't know; I don't know.

(Beth, FN, Female)

Regardless why youth decided to test, the decision to test was not only about overcoming fears associated with possible risk of infection, but also about confronting negative stereotypes. Gwen shared her perceptions of HIV testing:

I felt very uneasy with the situation, you know, going to get an HIV testing, [pause] 'cause there's so many stereotypes around HIV. There's like druggie, prostitute, hanging around in bad circles, you know — well, bad, you know what I mean. Like, it's not something I'm very proud of doing, even though I am taking ... I'm doing something that's positive.

(Gwen, FN, Female)

Lack of Partner Involvement

Several participants commented that partners were not involved in the decision to test or attending clinic with them. For a few women, the decision to not involve a partner was based on the belief that partners would not be supportive of their decision.

I didn't bother telling him until after I went and did all my blood work, that they checked to make sure that things were going all fine with the pregnancy. Oh, my God, he freaked right out on me. Like, he was, "What the fuck? Why you got to go do that?" I'm, like, "Well, just because I want to." Then I told him, for one, it'd just be safe for the baby, and two, if you're going around doing anything you see, I've got to take care of me, too, you know. I don't know. I think he was just kind of scared or pissed off because I went ahead and did this test, because if I did have it, he knew that he was the one who probably gave it to me, 'cause obviously, I'm not really promiscuous or anything. If I am in a relationship, I do like to keep that sort of monogamy thing in sight. But what can you do? It's a good thing it came out negative.

(Rachel, FN, Female)

I: Too late now. [both laugh] Can't kick you out. So when you went for your HIV test, did I ask you if you went by yourself? I think you said you did, because you wanted your boyfriend to go with you, and he wouldn't? P: Yeah, I went by myself. I went to the doctor, and I said, "Okay, I want a pap test done, and I want an STD test done."

(Melanie, FN, Female)

Characteristics of the Testing Service/Service Providers

Characteristics of the service providers providing a HIV test appeared important to Aboriginal youth participants. Although it was not important for a service provider to be of a similar cultural background, a caring, understanding and patient approach was something that was highly valued by participants. A service provider that was "calm" and attempted to make individuals feel comfortable and at ease was a quality that was highly valued.

I: Do you think that it has to be someone of Aboriginal culture, or ... P: No, no, just someone that you know that's got a good way with people. Like, she's very caring and very understanding and very patient. For me, when I go to the city — I spent 6 months in (Western Canadian City 2) this spring, and I went to eight different doctors before I found a doctor that I was comfortable with, and I talked to him because I had unprotected sex with someone, and I wanted to get an HIV/AIDS test done, but I had

bigger health issues going on, so he couldn't address them at that time because I just met him in my fourth month in [Western Canadian city 2]. But sometimes, I don't know; it doesn't matter. I mean, like, the ones down south are just — I go there, tell them whatever, and they deal with it as they see me. They don't really get to know me because I'm not going to be there long. But still, for me to find a doctor that I feel comfortable with, who can respect me. Like, shake my hand, look me in the eye, and don't just treat me like money, you know.

(Kayla, FN/Inuit, Female)

They were very nice, very [pause] very calm, very [long pause]. They just tried to — well, not tried to make me feel comfortable; you know, just the atmosphere, I guess, they just — the way they were, it put me at ease, I guess. [pause] But I was very uneasy to begin with, going to get an HIV test.

(Gwen, FN, Female)

Similarly having an established relationship with the service provider, may reduce the anxiety felt by youth who go through the testing experience.

[... There] wasn't much to it, because the guy that did it, I knew, personally. I: He's a friend of yours? P: Well, not a friend, but a friend of my father's, and he's, I've known him for a long time, so it was just take the blood out, and he tested for other things, too. He just was lookin' around my blood, [both laugh] see what's in it.

(Oliver, FN, Male)

Oh, yeah. Well, I made the appointment here, and then she told me the time to go over there, so I went over there and I waited about an hour. She came and got me, and I know her, like, from here, so she's, like, "[name], let's go." She took me into the room, and she started doing her tests. She asked me what I wanted done, and I said, "Everything," and she said okay. So she did the pap, she did the HIV, and she did the oral and anal swabs, and that was it. She told me, "Dress up. You're ready to go." I said, "Wahoo, I'm out of here." My mom and my boyfriend were waiting in the car, so, and they were both sleeping when I got there.

(Zinn, FN, Female)

Having an established relationship does not; however, mean that confidentiality in the testing experience was comprised. Several participants articulated their need for confidentiality in HIV testing. As one participant shared:

I: Do you think that a lot of youth do that, go down south to get a doctor, rather than here? P: Well, if they can have the chance, but not a lot of people — they usually come from the north, they go down, and they go shopping, and they go gambling. Unless it's health-related. 'Cause I know some doctors send people out for allergy tests, whatever, and if they have medical problems or [if they have] to go down, they might tell a doctor. But I don't know. When I was worried about having HIV or getting HIV because I was having high-risk sex with different partners, at times, I got scared. Like, what if I did my HIV test, and it came back positive? Who would know? [laughs] Would this doctor —

like, who else was at the doctor's office who might come in contact with that information, and that kind of freaked me out. But right now, I'm [at a point in my life where] I don't care. [laughs].

(Kayla, FN/Inuit, Female)

Service providers that brought a sense of professionalism to their roles providing HIV testing were valued. Professionalism was very much related to not only being able to provide accurate information, but was equally related to having an open, accepting, and nonjudgmental attitude. One participant shared the following:

I was — at the moment, it was kind of a scary situation, but then after the fact, it seems alright. The doctors are professional about what they do and stuff like that, so —. Although I guess I was kind of afraid of being judged or whatever, but when I went in there, it was like, they're supposed to be professionals. I just got some blood drawn and that was it; I got my test taken.

(Adam, FN, Male)

However, being overly professional, at the expense of care, respect and understanding could be viewed as a bit too distant and cool. As Adam continues:

I guess another thing would be that it was almost like they were a little too cold. Like, if somebody did have it, "Okay, you have it. You're positive. Sorry." You know what I mean? "Here's some pamphlets." You know what I mean? Which would be kind of if I did have it, I would have felt like, "Where do I turn now?" You know what I mean? I think that they could have been a little more compassionate, or just even talk about it. Because my original doctor that I've had since I moved here wasn't the same person that did the test. They have another section where you could just walk in for that kind of thing, STD and HIV testing. So that's the one where I didn't have to make an appointment, so I just walked in and I had a doctor who I'd never dealt with before.

(Adam, FN, Male)

Characteristics of the Service

Organizations that offered anonymous HIV testing services facilitated access for some participants:

At that time, I was really confused, and I didn't know — I was thinking, "What happens if I do have AIDS or something like that?" So I went for the anonymous one; I got the anonymous test done, and I was getting worried about what would I do, what would I do. I was really confused, and I didn't know what to think.

(Adam, FN, Male)

I know once a week, they have this organization come in called [name]. I'm not too sure what they do, but they do, like, anonymous HIV testing. I think they also provide other health services, but in order to access them, I think you have to contact them. I don't

know what it is that you have to do, but I know I've accessed getting HIV tests done through [name of program].

(Rachel, FN, Female)

Another characteristic of HIV testing services that was valued by participants was the ability to access other medical services at the same time as HIV testing. Zinn appreciated having everything done at the same time:

I usually book an appointment at the clinic, and go right down there, 'cause they do everything there; like, everything all in one shot. Whereas having to go back, and back again, I'd rather have it all done in the same day.

(Zinn, FN, Female)

However, positive characteristics of a HIV testing service could be negated by things such as length of time waiting for results. Waiting too long could be a “nerve-wracking” and “stomach-turning” experience for some youth.

I did it all on my own, and then I went back in, got my confirmation. Oh, it's nerve-wracking', because you have to wait two weeks!

(Melanie, FN, Female)

So I had all that testing done. When I think back on that, that was, like, the worst two weeks of my life.

(Sara, Métis, Female)

Like I [pause] it took me a while. I had to go to my gynaecologist; she referred me to a clinic [pause], and [pause] then it took a few weeks, like, three. Yeah, I had to do it twice, actually, because the first time, there wasn't enough blood in the vials. So it took 6 weeks or something, or 3 weeks, I think, and then I had to go back and they had to take another one, and it took another while. [laughs] So it was sketchy for me, [pause] sort of nerve-wracking.

(Gwen, FN, Female)

'Cause I was young, and things were running through my mind, like, “Oh, my God, oh, my God!” Then after I got the test done, I was just — a week, I think it was a week or two weeks, it was just my stomach turning, waiting for the call. [laughs].

(Adam, FN, Male)

I: Were you any less nervous [the second time you had a test]? P: I was a little bit less nervous, 'cause I knew what it was about, so I kind of knew what to expect. But it's just that whole waiting to know the result is what kills you.

(Paulette, FN, Female)

Camouflaging HIV testing services in the context of other general health services was recommended by some participants. As one participant shared:

You're walking up to the [name of clinic], and there's people all around, and it says in real big letters, "STD Centre." People look at you like, "What the heck?" When I was going in the last time, there was a bunch of native guys across the street, and I was, like, "Oh, I have to walk by all these people. I wonder what they're thinking." It really just matters if you care what other people think of what you do. It doesn't really bother you if you've been hanging out, doing your thing, but ...

(Zinn, FN, Female)

Perceptions of the Test

Information Provided

Some of participants were provided with relevant information related to precautions that would prevent future infection while others were provided condoms. One participant commented that service providers, in addition to providing information, lectured participants related to risky behaviour.

No, they called me and told me to come in. So I was, like, "Oh, my God, oh, my God!" Then after, I was alright. They told me right there, they told me what kind of precautions to take to keep from having this kind of thing happen again, and then basically a kind of like a little tap on the wrist story, like, "You got to be careful out there, you're lucky this time." You know. But after getting the cotton swab test, I kind of went on the straight and narrow. [laughs].

(Adam, FN, Male)

I: Did you have any questions for them when you went, and did they answer those? What kind of questions did you ask them? P: When should I get my next HIV test done, 'cause what if I had it and it wasn't showing up in the tests; like, when's the next — how many months later after the first one should I have another one. Those were the kind of questions. And about using latex condoms. Like, there's no backup plan when you have a condom. I mean, I've used emergency contraception, but it doesn't protect against HIV. It's in bodily fluids, so it doesn't. So just more questions about those; like they supply us with condoms.

(Kayla, FN\Inuit, Female)

Lack of Information

A significant portion of participants; however, noted that little or no information was provided related to HIV risk behaviours. One individual mentioned, for example, not having received information about HIV, following her test:

Once again [I got the test done ...] but they didn't explain anything or anything.

(Paulette, FN, Female)

I: Sometimes nurses and doctors talk about HIV before someone gets a test, about what HIV is, and if you were positive, about treatment options. Did she talk about that? [...]

P: She said if there's any problem, she'd call me. She has the number to my home and the number here, and she said if I don't hear from her, then everything's okay, and I have not heard from her.

(Zinn, FN, Female)

I: Let me see (pause). When you had that test, did they talk to you at all about HIV or about the test? P: No. [...] *I: Did you have an opportunity to ask any questions? P: No, its okay.*

(Franco, FN, Male)

I: When you tested at the hospital, what was that experience like? Did you have the opportunity to ask questions? Did they talk to you at all about what the test was, or anything else? P: No, they didn't really tell me much. It wasn't a really good experience, because they didn't even — they didn't only do the AIDS test, there was a few other tests. So they took two or three needles, and I was scared. I was alone, scared. That's about it.

(Hazel, Métis, Female)

I don't think he, I don't know what he checked for. I knew it was, like, HIV. There was a couple of other boxes he checked off. He checked off a lot, but I knew HIV for sure. I: Was there any — you said you guys didn't really talk about it that much. Did you talk about it at all? Did he tell you that he was testing you for HIV, or you just saw him check off the box? P: I just saw him check off the box. That's all he had to do. [laughs].

(Oliver, FN, Male)

SECTION THREE: The Relationship between HIV Testing and Decisions about Care

Research question

The relationship between testing and care:

4. What is the relationship between HIV testing and the decision to initiate treatment among Aboriginal youth?
5. How do Aboriginal youth make decisions about the care and treatment of their HIV illness?

Survey Respondents

Of the 26 youth who participated in the survey who reported being HIV-positive, eight (30.8%) had symptoms related to HIV/AIDS at the time of HIV diagnosis, including six (23.1%) who were told they had AIDS. These findings imply that a substantial proportion of HIV diagnoses among Aboriginal youth are not made until relatively late in the course of disease, thereby limiting opportunities for early prevention and care.

Of the 26 youth who reported being HIV-positive, further information on access to care was available for 25 youth. Of these, 12 (48.0%) said that they had visited a doctor after HIV diagnosis and of this group, 10 provided information on the time interval between their HIV diagnosis and when they first saw a doctor regarding their HIV infection. As noted in Table 7, five individuals first saw a doctor within 3 months after their HIV diagnosis, two individuals saw a doctor between 4 and 6 months after diagnosis, one individual between 7 and 12 months, one between 13 months and 2 years, and one more than 2 years after diagnosis. Overall, 8 individuals (80.0% of sample) had seen a doctor for HIV care assessment within one year of diagnosis. Therefore, in this limited sample, only 38% (80% of 48%) of Aboriginal youth who had a positive HIV test were assessed for care by a doctor within one year of their diagnosis.

Table 7 *Frequency Distribution of Time Interval between HIV Diagnosis and First Visit to Doctor for HIV Care Assessment.*

Time interval	Frequency	Percent
0-3 months	5	50.0
4-6 months	2	20.0
7-12 months	1	10.0
13 months - 2 years	1	10.0
more than 2 years	1	10.0
Total	10	100.0

Interview Respondents

Of the 28 participants we interviewed, 25 reported ever having an HIV test and nine (9) of the twenty-eight (28) participants (31.1%) reported being HIV positive. All positive participants were First Nations between the ages of 24 and 30. Of these 9 participants, 5 were female and 4 were male. Five (5) participants reported the mode of transmission as injection drug use, 3 reported hetero-sex with a male, and 1 reported same-sex with a male as the mode of transmission. This section of the report summarizes the qualitative findings related to the relationship between HIV testing and the decision to initiate treatment. It also summarizes the qualitative findings related to how Aboriginal youth made decisions about the care and treatment of their HIV illness.

Stage of HIV Disease at time of HIV Testing

Most interview participants did not speak of having symptoms of HIV at the time of HIV testing. However, a few participants who were active injection drug users at the time of diagnosis reported having symptoms as one of their reasons for seeking an HIV test.

I knew I was positive...because of the symptoms I got and because I didn't care. I would share spoons with a person I knew was HIV positive.

(Zak, FN, Male)

I guess I was pretty sure that I had it...because I used needles and a lot of times I just didn't care. I would use a used needle and I just didn't care...Another thing too was I was having those night sweats. You know those kind of sweats? And I knew that that was a symptom of having HIV. I remember that was bad, yeah.

(Trent, FN, Male)

That both of these participants were injection drug users and had symptoms of HIV illness at the time of diagnosis suggests that they were not getting tested for HIV despite their high risk behaviours. This was confirmed by the fact that both participants indicated they knew they were at high risk but 'didn't care'. It also implies that once they did test for HIV their illness was more advanced.

None of the interview participants reported that they had AIDS at the time of the interview or at the time of diagnosis.

Accessing Care Following Diagnosis

At the time of the interview, all 9 participants who tested positive for HIV had visited a doctor to discuss HIV treatment options. Most saw their physicians regularly to monitor their health; however, their experiences with health professionals and the length of time between diagnosis and care varied considerably for each participant. Some participants consulted a health professional within a few months of receiving a positive diagnosis while others waited years.

At the time of our interview Zak, a 26 year old, First Nations male, had been positive for approximately 1.5 years. He had tested positive while in prison and reported that “*after [they told me I was positive] there was a bunch of counselors that came to see me to help me deal with it*”. Zak was satisfied with the level of information and care he received at the time of diagnosis and within a short period of time was under regular doctor’s care.

Zelda also accessed care very quickly after her diagnosis; however, felt that the level of information she received was unacceptable. With perseverance and persistence on her own behalf, she was able to get the help she needed:

For me, when I was diagnosed, the doctor where I’m from had just said, “Okay, you’re HIV positive” ...And that was all there is...I had to tell him that I’m pregnant. I should be on some meds. I was the one that told him that my baby needs the meds to reduce the risks. It’s, like... “You should phone [provincial AIDS service provider] or somebody, and talk to them.” He did, and they got a hold of the infectious disease clinic, and that’s where they sent me to go get my meds. But it took about 3 weeks before I could get down there after I found out I was diagnosed; 3 weeks to a month.

(Zelda, FN, Female)

Edward, a 30 year old, First Nations male was also offered very little help upon receiving his diagnosis. However, on his own initiative he was able to contact a health professional within a short period of receiving his test report. Edward tested positive nearly 10 years prior to the time of the interview. Like Zak (above), Edward was given a positive diagnosis while in prison but unlike Zak, Edward was left to deal with this news on his own. When asked to describe his experience receiving a positive diagnosis, Edward reported that two weeks after taking the test, the results “*...come [back positive]. It’s got a line there. He say, ‘okay, you’ve got {HIV}. ...Go to your [cell] ...No medication, no discussion, no see doctor. Just ‘If you get out go to see a doctor for HIV’*”. When Edward was released from prison he was finally able to seek a doctor’s attention.

For a few interview participants it was 6 months after diagnosis before they finally visited a doctor to discuss their treatment options. Approximately 6 months after receiving her positive diagnosis, Yvonne was raped and became pregnant. Yvonne’s sister convinced her to keep the baby, and to see an HIV specialist to discuss her treatment options. Likewise, it took Sam 6 months before he was ready to see a physician.

[Aboriginal organization] gave me a referral... But that bounced back and forth between answering machines, trying to make the initial appointment for about 6 months... I didn’t really want to go see him, because I didn’t want to know my results or my counts or none of those things. Because when you get your counts and your viral load, it lets you know where you stand. So I was sort of hesitant and scared at the beginning that I didn’t want to go get them.

(Sam, FN, Male)

Two of the active injection drug users took more than a year to consult a physician about their treatment options.

How I got my meds was when I was in the hospital with pneumonia, I was also - I was a junkie right? I was a heroin addict. One of the doctors from this neighbourhood comes in, and he's a methadone doctor, and he got me on methadone. For me, going to the clinic to get my methadone script, I had to — they helped me out with my HIV...It was about a year [after my diagnosis].

(Trent, FN, Male)

Vanessa reported that it took her 7 years to contact a health professional to discuss her treatment options.

I: So when you hooked up with this doctor about a year ago, is that the first time that you had any sort of medical attention? R: Yeah. That's going good, the doctor, yeah....[S]he gives me tons of information. I didn't know nothing about care or anything like that, but since I came to [western Canadian city 1], I need care.

(Vanessa, FN, Female)

Vanessa migrated to [western Canadian city 1] almost 2 1/2 years prior to the time of the interview and had started to access the community clinic 6 months after that. At the time of the interview she was seeing her physician on a weekly basis.

Reasons for not seeking care

As noted above, the length of time to seek care for their HIV illness varied for our interview participants from a few months to 7 years. When asked why they did not seek care immediately, participants reported being scared or not wanting to know their counts; being pre-occupied with drugs or alcohol; not wanting to live; and not knowing anything about care.

When I finally did test positive, it was really hard for me — it was really hard for me not to jump off a bridge. 'Cause I was staying in a woman's shelter at the time, and I had to walk over this really great big huge bridge, and I remember stopping in the middle and looking, and I was thinking, "What the hell's the point of living? I'm positive now, and I'm going to die. The world has ended," and stuff like that... I was in a daze for quite a while after that. I started drinking more — I didn't want to be sober, 'cause I didn't want to think about my disease, and I didn't want to think about dying and the whole AIDS thing, whether or not I was going to be able to have kids or not.

(Yvonne, FN, Female)

I didn't really want to go see [a doctor], because I didn't want to know my results or my counts or none of those things. Because when you get your counts and your viral load, it lets you know where you stand. So I was sort of hesitant and scared at the beginning that I didn't want to go get them.

(Sam, FN, Male)

[After my diagnosis] I was on a down low...I wasn't seeing doctors and stuff like that. I was really in a bad situation. I was doing lots of drugs and stuff like that. I didn't know anything about care.

(Vanessa, FN, Female)

Another participant continued to use injection drugs and to avoid his HIV positive diagnosis until he was admitted to hospital with pneumonia.

[Drug addicts are] more interested in using drugs than maintaining their health. I've really seen people who are really, really ill, and they don't notice that they're ill, 'cause they're using drugs...That's the way I was too. Before, I got really, really sick, and I ended up in the hospital where I just...My pneumonia was so bad that I called the ambulance, I waited for so long...I was just too preoccupied with using drugs to [seek care].

(Trent, FN, Male)

Strategies Used for Managing HIV

By the time of the interview all interview participants who reported living positive had taken steps to manage their HIV in some way. Almost all participants chose bio-medicine in conjunction with lifestyle modifications such as cutting back on drinking or drugs, or changing their diet, nutrition or rest patterns. Some participants chose to use traditional Aboriginal medicine to help manage their HIV while others spoke of complimentary or alternative medicines.

Bio-medicine

Eight of the 9 participants who reported being HIV positive were under a doctor's care at the time of the interview. However, only 2 were currently taking HIV medication and 5 had taken HIV medications at some point since their diagnosis.

Previous use of HIV medication

Five of the 9 HIV positive interview participants had been on HIV medication at some point since their diagnosis. Of the 5 females in our HIV positive sample, 3 had been pregnant at least once since testing positive for HIV. All 3 of these participants had taken HIV medications in the last trimester of their pregnancy to reduce the likelihood of mother-to-child transmission.

When I was pregnant, yeah, I was, like, 7 months pregnant; that was last year, year and a half ago, they put me on medication so the baby couldn't get it.

(Winona, FN, Female)

Well, the specialist told me that...I would have to go on medication to lower the risk of the baby [contracting] HIV, and that I would also have to have a C-section to lower the risk of the baby [contracting] HIV from me...They started me on meds in the last trimester of my pregnancy, and the reason for that was [pause] because in the first two

trimesters, the baby's developing all its organs and its brains, internal and external organs and stuff, and the medications that they have for women that are positive could possibly damage — or [pause] not really damage, but harm the baby within the first two trimesters. So by the third trimester, they're pretty much done, and they're just growing, so yeah, I guess that's why they told me that it sounds best to start in the last trimester...
(Yvonne, FN, Female)

In all cases, HIV medication was successful in preventing the vertical transmission of HIV. All three women stopped taking HIV medications once their babies were born and two of the three had not resumed HIV medication at the time of the interview.

Of the male interview participants who were living positive, only one had been prescribed medications but was no longer taking them. Edward's doctor recommended HIV medications when he was diagnosed in 1995; however, he did not like the way the medications made him feel so he stopped taking them altogether.

[My doctor], he gave me some pills. So sometime take, I don't take, sometimes I take it, I don't take it. Now I don't take it....If I take my medication, I feel some more sick. That's why I don't need.

(Edward, FN, Male)

Edward was the only interview participant who did not see a doctor regularly.

Current use of HIV medication

At the time of the interviews, only two of the nine HIV positive interview participants reported using HIV medications to manage their illness. One other participant was about to initiate treatment. Of these three interview participants all reported initiating treatment on the advice of their doctor once they experienced declining health, low CD4 counts or high viral load counts.

How I got my meds was when I was in the hospital with pneumonia, I was also - I was a junkie right? I was a heroin addict. One of the doctors from this neighbourhood comes in, and he's a methadone doctor, and he got me on methadone. For me, going to the clinic to get my methadone script, I had to — they helped me out with my HIV...It was about a year [after my diagnosis].

(Trent, FN, Male)

[I went on HIV meds when] my viral load went up, and my CD4 count was starting to go down. I can't remember the numbers. I think I was over 200 or something for my viral load. [pause] Yeah. And my CD4 count was going under 500.

(Yvonne, FN, Female)

At the time of the interview Vanessa, who had been living positive for 8 years, was about to initiate treatment on the advice of her doctor.

Reasons for staying on HIV medication (Adherence)

Again, participants reported various reasons for staying on HIV medication once prescribed, including feeling healthier, and wanting to be around to watch their children grow.

Since I've started, I've been taking the same pills. It's probably a lot of it has to do with the way my health is. I feel a lot healthier than I was before, and I don't have night sweats any more. That's probably the reason that I keep taking them. The doctors say that I can probably live for a long time if I just, you know, if I keep taking my medicine. So that's kind of an incentive to keep taking them.

(Trent, FN, Male)

Just knowing that now that I'm on medication, and my disease won't progress into AIDS as fast as I thought it would in the beginning, I'm going to be around for a long time for my kids. I'm going to see them go to college and get married and stuff like that. That's – I have something to look forward to, and that's what I've been holding onto, is my kids' future. Not necessarily my future, it's just all for my kids...[T]hat's why I try so hard to live, is because of them. I don't want to, all of a sudden, die on them...I like being able to watch them learn and grow...If it wasn't for them, I wouldn't be here today.

(Yvonne, FN, Female)

Future use of HIV medication

As mentioned above, of the nine interview participants who were HIV positive, only two were taking HIV medications at the time of the interview and another was scheduled to start in the weeks following. Of the six interview participants who were not taking HIV medications, opinions varied on whether and when they might start.

Edward was the most steadfast about not taking HIV medications. At the time of the interview Edward was thoroughly entrenched in street-life and did not foresee a time when this might change.

If I'm come back ten years ago I'm doing the same thing...I never regret for my life. I like my life. Because me, I'm living very fast. I've got just the gas pedal, clutch, I don't have a brake. If I brake, I'm dead.

(Edward, FN, Male)

Other positive youth were more open to the idea of taking medication for their HIV.

Probably twice a month [I see my doctor] ...Usually right now, I don't think they're going to bother me any more [about HIV medication], because they said my count's pretty good. There's no — like, my HIV is staying really good right now, and I won't have to go on any medication.

(Winona, FN, Female)

I'll probably end up on the medication just like everybody else, but before I get that far, I probably will be doing some kind of herbal things. But I mean, eventually, you have to take the medications, I mean, if you want to live, at some point.

(Ursula, FN, Female)

Several participants said they were not taking HIV medications because they felt healthy, their doctor had not recommended them, or a combination of both.

I don't feel really painful. Like, I don't get [pause] I don't get ill or anything like that. I don't catch colds, things like that... my counts are good...I've tried bringing it up [with my doctor] all the time, about medication, and he keeps putting it away. Like, back in my file...I thought that I would [need medication] but as long as he says that I'm pretty healthy, I guess I just trust him.

(Winona, FN, Female)

[My doctor] doesn't advise me at this time that I should be on [medication], because I was diagnosed in 2003, and his policy is a lot of people, a lot of doctors, what they do is they see the problem, and they figure medication is the answer for immediate treatment...So Dr. [X]'s view is that look after yourself, treat yourself well...As long as you keep that up, and there's no major incidences or health reasons, he feels that it's best that you just stay on the way you are until something does happen that you require the medications, and then he will research into it to find the best ones for your lifestyle or for you.

(Sam, FN, Male)

I feel healthy most of the time. I've gotten sick twice since I've had it — a year. Nothing too serious ends me up in the hospital, nothing too serious where I have to be on meds. It's like I'm not on meds right now, 'cause my immune system's healthy...

(Zelda, FN, Female)

Of the 7 HIV positive participants who were not using HIV medications, Edward was the only one who reported side effects as a reason for not taking HIV medication.

If I take my medication, I feel some more sick. That's why I don't need.

(Edward, FN, Male)

Interview participants who were not HIV positive also expressed opinions on why HIV positive Aboriginal youth might not take HIV medication. Among these reasons were side effects, life style, and a dislike of pills or chemicals.

One of my neighbours is positive where I'm staying now...At first, when he found out he had AIDS, he was taking the treatments, taking all the pills — many, many pills. But now, he quit....Because he was sick and tired of too many pills, first of all; too many pills. And he was drinking a lot, that guy, and he had a really bad seizure from drinking, and after that happened, that's when he quit the pills. [Now] he doesn't feel that he needs the pills.

If he's eating and sleeping good and only drinking a few beers a day, or a glass of wine, he feels that he doesn't need the pills any more.

(Hazel, FN, Female)

I: So do you think that there is a reason that somebody would be on medication, but not take it? R: Well, twofold, which is they have trouble doing things day-to-day: they forget, or they just — maybe they don't eat enough, or the medication makes them sick. Like, for example, my boyfriend, it makes him sick sometimes. I mean, there's a lot of side-effects, I know, but people have trouble taking their medication because of side-effects, or just because of [pause] you know, instability in their lives, right, because they don't have a good home, or they just don't have food, or they don't have [pause] do you know what I mean? Stuff like that.

(Ursula, FN, Female)

For me, I don't like to take a lot of pills and chemicals; I don't like to have it in my body, as much as I can at all help it. So I would probably, knowing me, try as much alternative medicine as I possibly could. If it just continued to progressively and quickly get worse, then I would go with more [biomedical] means of getting myself feeling okay enough to get through.

(Irene, FN, Female)

I: Is there a reason, do you think, that people would not take medication? R: They think they're strong enough. They've been strong all their lives, so it's hard for a strong person to start taking pills, especially when they're not used to it. [pause] Why they would not take the pills is a pretty good question. I don't know why. Because they just don't care any more. Maybe they're thinking — some people when they have AIDS, they just want to die; they don't care.

(Hazel, FN, Female)

Aboriginal medicine

Several HIV positive interview participants spoke of using Aboriginal medicine or traditions to help manage their HIV. Some spoke of using Aboriginal medicines in place of HIV medication and others spoke of using Aboriginal medicines as one strategy among many that they were using to manage their HIV.

Edward had stopped taking his HIV medications because he did not like the way they made him feel. However, he felt confident that Aboriginal medicine would make him feel better.

If I take my medication, I feel some more sick. That's why I don't need. Fuck. Maybe if I can go to my country, I get some medication, Amerindian, tisane, it would be some better.

(Edward, FN, Male)

Unfortunately, at the time of the interview Edward had not been back to 'his country' for a very long time and therefore had not had access to the medicine he desired.

Sam had recently reconnected with his culture and felt that picking medicines and learning about their properties was an important part of managing his HIV.

I didn't really know my culture until I was 16, so I came back to it. Then after this summer, spending a summer...picking these medicines and finding where they grow, and understand what they do, gave me a bit more knowledge about why not try them, why not pick them and try them? A lot of people had tried just herbal medicines and stuff, and herbal cure for their HIV, and they're doing quite well, surprisingly. So I figured I'd try this route. [It] has a lot of power if there's belief in your culture.

(Sam, FN, Male)

A few participants, although not using Aboriginal traditions or medicines at the time of the interview, expressed a deep respect for their healing power and a desire to use Aboriginal medicines and ceremonies in the future.

I don't participate in [sweats] yet. I don't feel I'm ready for 'em exactly. There's a lot of emotional issues that could be brought up in it and whatnot that I have not dealt with yet, so I'm going to deal with those first before I go take the next step and go through that level of things. In time, hopefully, I will.

(Sam, FN, Male)

I'm still pretty scared about going to sweats; I don't want to freak the elders out with my feelings or my disease...I'm scared that I might hurt the elder with everything that's been inside me for so long...I'm never going to close the door on my traditional ways, but I'm just not ready for that right now.

(Yvonne, FN, Female)

Among those interview participants who tested negative for HIV, there was also some interest in the use of Aboriginal traditions to treat HIV should they ever become positive.

I: Do you think that you would ever use an Aboriginal tradition? R: Definitely would. Definitely would. I don't know what's out there for that type of illness, to treat for HIV in Aboriginal means, but I would research, and I would talk to as many elders as I could, as many people as I could, to find out what it is that they thought I could do to help me get through.

(Irene, FN, Female)

Complementary and Alternative Medicine (CAM)

A few interview participants, one HIV positive and one HIV negative, expressed interest in complementary or alternative medicine although their prohibitive expense was cited by one participant as a reason for not using CAM.

I don't like to take a lot of pills and chemicals; I don't like to have it in my body, as much as I can at all help it. So [if I were HIV positive] I would probably, knowing me, try as much alternative medicine as I possibly could. If it just continued to progressively

and quickly get worse, then I would go with more traditional means of getting myself feeling okay enough to get through.

(Irene, FN, Female)

I used to take milk thistle for my liver, I used to take hops, I used to take [pause] spirullena, just different stuff, supplements, stuff like that. [But I don't do that any more because] I haven't got the money for it, really. I applied for the nutritional supplement, which is an extra 200 bucks a month, but I have to — actually, I have to get the application. I lost it, and I have to apply again. But I'm damned if I'll pay for stuff, 'cause stuff costs money.

(Ursula, FN, Female)

Marijuana Use

Only one interview participant reported that marijuana was an important part of managing his HIV.

[If] I'm feeling so bad...I'm just use this [holds up yogurt pack]. I'm just ate some yogurt, I'm take some natural _____ weed. Because if I take a weed, I can go to eat, good sleep, and I'm take a force.

(Edward, FN, Male)

Lifestyle Modification

Almost all HIV positive interview participants reported that they had modified their lifestyle in some way since their positive diagnosis. Drinking less, taking fewer street drugs, eating better and sleeping more were among the strategies acknowledged by all participants to be helpful in managing their HIV.

Modifying drinking and drug use

Several interview participants reported that cutting back on their drinking or drug use was essential to managing their HIV.

I don't stay up until 2:00 in the morning anymore, clubbing or any of that crazy stuff. It's just too hard on me the next day. So I watch my drinking and stuff; I don't do that as much anymore.

(Sam, FN, Male)

[My]HIV is staying really good right now, and I won't have to go on any medication. So mostly I just try to eat healthy and that gives me — like, if I have good nutrition, I can handle myself more.

(Winona, FN, Female)

One of the reasons my immune system is healthy is 'cause...I quit IV drug use... Sure we have the odd relapse here and there, but it's nothing compared to what we were like living in [western province 1]...A little toke here or wherever, or take one morphine, that, you know, just as long as I'm not doing it every day, putting my health at risk.

(Zelda, FN, Female)

As noted in the above quotes, interview participants were having varying degrees of success in modifying their drinking or drug using habits although most expressed a desire to stop taking drugs entirely. Several interview participants had signed on to a methadone program in an effort to break themselves of their addiction. Trent, a 30 year old First Nations male, reported that *"if I could have my way I would stop using [drugs] totally, altogether"*.

Some participants reported that stable housing in the city or on reserve was an essential element of their plan to cut back on drinking and drug use and at least some felt thwarted in their efforts to modify their drinking and drug use behaviour because of their living situation. Trent felt that part of his problem was that *"I live in [a neighborhood known for drug use] which is kind of self-defeating."* At the time of the interview Trent was having trouble staying clean because he was constantly reminded of his addiction by seeing others use drugs around him. He was looking for housing outside of the neighbourhood he referred to.

Other participants reported that stable housing on reserve, away from urban centres that are associated with drug use, was essential to the way they managed their HIV.

[G]etting off the street, quit[ing] prostituting, quit[ing] IV drug use...and mov[ing] out of [western province 1] because...I can't stay away from drug use there...[was important because] there's no way I was going to be able to live a long healthy life with HIV [if I stayed]...That's when [my husband] mentioned his reserve and I just wanted to get the hell out of [western province 1] because I was scared; I didn't want to die. That's when we went to [western province 2]...[Now we] have a roof over our head, we have a home that we've never had before. I have furniture [and] I have food in my fridge. Before, when I was in [western province 1] on the street, I lived in shelters, I slept on the street in front of churches, I stayed in crack shops. If not, I've sat on the corner all night soliciting my body to old gross men.

(Zelda, FN, Female)

Since we've [moved back to the reserve] everything's just been really good for me. Like, my whole life has changed, from being a drunken junkie sleeping in parks and youth centres, to having beautiful furniture and cable and a phone, and being able to pay for my bills, and make sure that my house is clean for my kids, and having my kids clean every day, and cooking every day, and everything. I'm a totally different person. Whereas before I'd be living in a hotel room and my hotel room would be messy all the time. But my house is always clean and there's always food in my cupboards.

(Yvonne, FN, Female)

However, this is not to say that living on reserve was without its challenges. Several participants, some of whom reported that living on reserve had saved or changed their life, also reported that

the AIDS-related discrimination that they encountered on reserve sometimes made their life difficult.

[We] can sense some discrimination from people. Actually, I sense a lot of it. I kind of get – it's been really getting me down, depressed...It's come to where we are discriminated and [people] wanting us to leave the community. People coming to us, telling us, "this person said that", saying that, "You guys should go back to where you guys got your disease from" or to where [my husband was attacked]...It's not as bad now, but some days, it does come up.

(Zelda, FN, Female)

I haven't disclosed back home yet...My sister, she's more worried about my kids' safety than about me disclosing to my community...She's afraid for my children and she's also afraid for me. She doesn't want people to turn around and start trying to kick me off the reserve, because since we've been there, everything's just been really good for me.

(Yvonne, FN, Female)

Diet, nutrition and rest

All interview participants reported staying healthy through diet, nutrition and rest as a means of caring for their HIV.

One of the reasons my immune system is so healthy is because I'm eating and I'm taking care of myself. I make sure I do.

(Zelda, FN, Female)

It changed my entire lifestyle...[I] couldn't stay up till 4:00 in the morning and then wake up at 8 o'clock the next day like nothing happened. You need more time to recover from things now. You have to take that time for yourself to make sure that you feel better, and you don't try to push yourself too hard...Before, I didn't have a care in the world. I was, like, "I can do it. I'm young, I can do anything." ...But after I got this, it makes you really look at yourself in a different view; like, you're NOT indestructible any more. You can get sicker than most people can.... And just eating better, nutrition-wise and stuff. I think after I got diagnosed, I was about 50 pounds overweight. The weight loss I experienced wasn't because of HIV, it was because I wanted to, because I started taking more care of myself, like, eating salads and regular meals. Things like that; my diet changed completely.

(Sam, FN, Male)

Several of our participants were active injection drug users at the time of the interview and some were still thoroughly entrenched in street life. However, they too were conscious of the role that nutrition and rest played in keeping them healthy. When asked what she did to manage her HIV, Winona, a FN female, replied that "*mostly I just try to eat healthy and that gives me — like, if I have good nutrition, I can handle myself more.*"

Likewise, Edward, a FN male, reported modifications in diet and lifestyle as a means of managing his HIV. At the time of the interview Edward was living on the street; however, at various points in the interview Edward mentioned eating, getting lots of rest, showering and relaxing as being good for his mental and physical health. He managed many of these with the help of Aboriginal AIDS Service Organizations and other support services.

Social/Emotional support

Several interview participants reported that the support they received from friends, family and community was essential to the speed with which they sought care and to their on-going well-being.

After talking to a lot of my friends who are HIV positive and had been through this, they said, "It's not only for your good, it's just for — it's a peace of mind that you know where you stand on the scale of HIV." ...So after enough friends coaxed me into it...one friend said, "I'll come with you to the doctor's for the first visit, if that's what you'd like." [So] he came with me [and we] handled it.

(Sam, FN, Male)

I: It sounds like your family is fairly supportive then? R: Yeah, they are. Even if I go see them, just about the first question they ask is where did I come from. I tell them I came from [aboriginal health centre] and usually, they cook me extra for my dinner or anything like that. They give me some money for groceries when I leave. I can sit on the couch, lie down, watch TV, visit my daughter.

(Winona, FN, Female)

I'm not really worrying about what other people think. Well some days I do and [my husband] has been a big support around that area, telling me "Don't worry what people think. It's not what they think, it's what you think." He's just always there to support me.

(Zelda, FN, Female)

I can't really say I did it [sought care for HIV] on my own...I told my sister I was pregnant and she was just excited. She was, you know, jumping up and down, running into the bar telling everyone, "My sister's pregnant!" ...Then she told me that I had to quit my drinking and drugging and that if she ever caught me drinking or anything...then she would take the baby away on me...So that's what I did; I quit drinking and drugging and they sent me to a specialist.

(Yvonne, FN, Female)

Yvonne went on to say that she now enjoys the support of her siblings who live on the same reserve.

Health services

Interview participants reported a variety of experiences when accessing health-related services, obtaining an HIV test, or seeking HIV treatment. Some participants preferred Aboriginal-specific

health services, others preferred non-Aboriginal health services, and still others preferred both but under different circumstances. Some of the more frequent issues that arose in interviews were racial or HIV-related discrimination, impersonal service, discomfort with health care provider and barriers to access.

Access and availability

Some participants stated that access or availability was the most important element in their choice of where to seek health-related services.

Because the [Aboriginal health centre] is so far from my house that I don't end up going there. So if I take the time, I'll come all the way down to the [XYZ Community Health Centre], but that's still quite far, because I'm in the west end. So I'll either go to a medical — the [ABC Medical Clinic], or to another clinic that's close by.

(Beth, FN, Female)

I go to [name] Clinic. I go there just because it's free services. I'm on welfare right now, but I went there because I didn't have any benefits at the time, and then I just — I've dealt with a few things with those guys, and now I'm just comfortable with them, so I continue to go there.

(Sara, Métis, Female)

Aboriginal health services

For other participants, the degree of comfort or rapport they felt with their health care provider outweighed issues of access. In many cases, participants felt more comfortable with Aboriginal health care providers or health care providers in an Aboriginal environment. Participants who were more comfortable with Aboriginal health services were drawn to a common culture, a non-judgmental attitude from Aboriginal health care providers, a more caring and personalized service - particularly among public-health nurses and a familiarity that comes from long-time association.

The [Aboriginal health centre] is one of the biggest health centres for Aboriginal people in the community...It's a community health centre. They have nurses and doctors on site, so people go there. People that come from different communities, Aboriginal communities, they don't feel comfortable going somewhere outside of their community because they've been isolated on a reserve or whatever with their community, that they just feel more comfortable having an Aboriginal doctor. So when they go there, they feel more relaxed, and stuff.

(Adam, FN, Male)

I usually try to go see my doctor back home in [reserve outside of city] for any kind of health services... So that's pretty much where I try to keep all of my appointments and keep up with my regular doctor, and ask him. If I have concerns, then it's usually my doctor in [reserve outside of city]... [I]t's not too far for me to go back to see my own

doctor where I feel more comfortable asking him questions, as opposed to asking a stranger.

(Carl, FN, Male)

We don't go to the family physician; usually, we go to the public health nurse because it's just easier, I guess... 'Cause she's a female, and she's a mother, and she's Aboriginal and she's a member of our community for a long time, whereas doctors are usually white. [laughs] They're just here for a little while and they leave, and they don't really get to know you and they don't stick with you, whereas [name]'s been here forever.

(Kayla, Inuit, Female)

I normally access, like, the native organizations here in the city. I know it's just my own personal reasons, I guess. I access this place called [Aboriginal health centre]... So I'll just pretty much access their services for whatever it is that I need for my health through them.

(Rachel, FN, Female)

Another element of Aboriginal health care that interview participants enjoyed was the integration of services that was often an element of Aboriginal organizations. In many cases, this offered a kind of 'one-stop shopping' and in others, it offered an easy way to get connected to other services that one might need.

There is the [Aboriginal health centre], which is in [part of city], and a lot of the youth that come here [to Aboriginal youth drop-in] also go there when something is going on over there. But there's nothing very major youth-related that happens at the [Aboriginal health centre], but when it does, most of the youth from here just go over there. So no, they just bounce around from place to place. But the [Aboriginal health centre] has, like, everything you can imagine for health-related issues...It's also a clinic, just for Aboriginal people, so they go there. Plus there's counselling and traditional healing and circles; things like that. I think they have a little office that does, like, HIV testing and stuff like that.

(Beth, FN, Female)

Just like any other organization here in [eastern Canadian city], they have their ties with each other. The youth program at [Aboriginal shelter] has contacts with them here. They frequently do programs together, and I know the president here, [Mr. X], has close ties with [Aboriginal health centre], and tries to incorporate what we're doing there with them. Yeah, it's more like branches. Like, this would be social, and [Aboriginal health centre] would be more physical health, [Aboriginal shelter] would be more mental health. You know, they aim — instead of spreading themselves too thin, they focus on one area, and then they have ties with the other organizations.

(Carl, FN, Male)

We get health professionals and people that come in once a week [to Aboriginal organization], usually on movie nights, and actually use this room for their —

they'll do blood work or give you flu shots, or they'll actually do anonymous testing for you and everything. But that only started about a year ago; that wasn't in place for the longest time. Or a needle exchange program. But it's been in the works for about 2 years, and finally became reality last year.

(Sam, FN, Male)

However, not all participants were happy with the way they were treated at Aboriginal health centres. Some had concerns around privacy and confidentiality while others had concerns about mishandling of their files.

Probably I think [Aboriginal health centre] does offer [HIV tests], but for personal, I know everybody who works there, so I wouldn't go there! I don't think I'd be going there.

(Carl, FN, Male)

The thing is with the Aboriginal community is what is known is a lot of gossip, a lot of people talk, so I think that a lot of people are afraid that if they do go and get a testing, that this person knowing someone — 'cause it's always everywhere you go, it's like, "Oh, hey, you're so-and-so's son" or daughter, you know. Then there's always talk of like, "Oh, yeah, stay away from so-and-so's daughter or son. I hear he's trouble."

(Adam, FN, Male)

Ursula recounted her experience receiving the results of an HIV test at an Aboriginal health centre. She felt her case was handled poorly:

I remember when I had my positive test, it was at [aboriginal health centre] and I think that the way that I found out was really bad, because they had the results in a book, and there was nobody in the room, and I found out about myself before the doctor even came in the room. I found out that I was positive by myself, and nobody... [T]he book was just right there; it was open. ... So that definitely messed me up, yeah. That was pretty irresponsible of them. But yeah, they came in and they realized that the book was there. Like, "Oh, you're not supposed to see that." It's, like, "Well, it's a little too late now!" ... But I don't go to that clinic anymore, because they really messed up.

(Ursula, FN, Female)

Non-Aboriginal health services

For other participants, the important element in choice of health care provider seemed to be personal rather than cultural. These participants reported that they were drawn to personal service, regardless of cultural background.

[T]he clinic that I do like is a community health centre that is right in [part of city] ... I can't remember what that community health centre is called, but that's the place I like going to because the nurses are so nice.

(Beth, FN, Female)

'Cause I'd rather go to a public health nurse and do my pap smear and my HIV testing than go to a physician. Because the physicians are so cold for me, and they don't really care; they don't act like they care. Whereas public health nurses, they're more — they know more about you, and they're more easy to talk to. The last two HIV tests, I got done with public health nurses, and they're both female, and they're in small communities, like here in [Northern Canadian city 2] and in [Northern Canadian city 3]. I just prefer public health nurses because they're easier to talk to, and they can sit and listen, whereas a doctor doesn't have that much time 'cause he's got scheduled patients that he has to see.

(Kayla, Inuit, Female)

I: Do you think that [the health care provider] has to be someone of Aboriginal culture, or – R: No, no, just someone that you know that's got a good way with people. Like, she's very caring and very understanding and very patient.

(Kayla, Inuit, Female)

However, not all participants had satisfactory experiences with non-Aboriginal health care. Some participants reported experiences of racism and discrimination while others noted the impersonal nature of non-Aboriginal health services in their region.

If I was HIV positive, I would probably [pause] not choose to have the treatment for a couple of months, just to get used to being HIV positive. I don't know; for me, I had an overactive thyroid, and it wasn't discovered until I ended up in a hospital in [Northern Canadian city 6], and I had it probably for 8 years. For me, it just confirmed my belief that doctors don't really care in the north what happens to you, not to Aboriginal people anyway, I don't think. I've seen a lot of racism in [northern Canadian city 3] from the doctor who's there.

(Kayla, Inuit, Female)

[My doctor's] colleagues know that his practice is HIV, so they know what to expect when you get [referred to them]. So there's no [pause] you don't feel all [pause] they sort of treat you differently if they know that you're HIV at hospital or something. They wear masks and gloves, and they won't come near me. They put your cup or anything that you used into the biohazard dispenser, and all this stuff. I still see it happening, and I just shake my head. I'm, like, "You need to be more educated on this than you are, because you're a health care professional, I'm not, and I seem to know more than you do." So to me, it's, "Why are you even working here if you treat people that way?"

(Sam, FN, Male)

It's very cut and paste, in and out, and they don't take the extra time to look for the care that you need, it's basically, "That's on your own; I've got the next patient to deal with. See you next time you get hurt" or whatever.

(Sam, FN, Male)

Support Services

The experiences of interview participants varied greatly in terms of the support services they sought following their positive HIV test result. Of those who used support services, Aboriginal organizations and health centres, Aboriginal AIDS service organizations, AIDS service organizations and community or public health clinics were thought to be very helpful.

One of the most frequently mentioned services accessed by HIV positive interview participants was a food bank or meal programs.

[The food bank] has taken off fairly well. We've got a lot of people coming in, it's used quite heavily, so we have no problem keeping it going... They grab what they need, and for their family members, and they take it home. Or you can come in if it's for a friend or a partner or somebody who's too ill to make it in. And we'll actually do home deliveries for certain people. If we know that they're [pause] not able to physically make it to the agency, we'll actually make up baskets for them and take it to their house and drop it off, and put it away for them. Whatever needs to be done; it could be home visits, also. It all works out.

(Sam, FN, Male)

I used to go [to aboriginal health centre] to eat, but now I go to the [non- Aboriginal AIDS resource centre] ...that's a daycare program for HIV positive people. They have breakfast and lunch, they have an art room, they have laundry, they have answers... Mostly I just go there for food and I use the nap room... I used to come here, mostly to eat, for the meal program, type thing... [I found out about it] I guess from the [aboriginal health centre], the actual clinic, I guess I was talking to them about something, and maybe they thought I needed resources, and they told me about the — I guess I was hungry that day, and I was just trying to figure out where to get food, so they told me that because I'm HIV positive, I could go to the meal program or whatever...

(Ursula, FN, Female)

I started coming here [to Aboriginal health centre] 2-1/2 years ago, for 2 years, yeah. It's an okay place; you get food, you get everything. It's okay.

(Vanessa, FN, Female)

Yeah, and I come here [to Aboriginal health centre] almost every day, from about 9 o'clock to 3 o'clock... We watch movies, have breakfast. I can see some friends. I can sit at a table alone and think why I'm there, 'cause I just want to pass some time on mostly thinking about my family, like, [pause] right now, yeah.

(Winona, FN, Female)

Then there was the [church]; you could eat there every day at lunch. And once a — I think it was on Sundays, they would have two meals there. There was also the, oh, I can't remember that one, but it was right on skid row, they used to have a soup line there every night.

(Yvonne, FN, Female)

[Aboriginal drop-in] is good place, because every time I can eat there. I've got some shower and eat, clothing. Everyday it's there. It's good for me...I [also] go for take some good lunch at the [men's shelter]. That's the best place. Five star.

(Edward, FN, Male)

What it was, was I used to be a hard drug user, but right now, a lot of times when you use drugs, you don't eat too much, and they [aboriginal health centre] give free meals down there. So that's what it was; it was just about going to eat...That's what it was.

(Trent, FN, Male)

Participants also spoke frequently of the multitude of services that were available under one roof. Some participants were well connected with various health and social services that were available in their city, but most preferred to have all their needs met in one place.

The other programs [at Aboriginal organization], like movie nights and beading and crafts and stuff, now that they're providing more substantial meals and snacks and stuff for the clients to come and have and take part in, it just seems to be that more and more membership is showing up...[We also] get health professionals and people that come in once a week, usually movie nights, they actually use this room for their – they'll do blood work or give you flu shots, or they'll do anonymous testing for you and everything.

(Sam, FN, Male)

I started coming here [to Aboriginal health centre] 2-1/2 years ago, for 2 years, yeah. It's an okay place; you get food, you get everything. It's okay. [Also] they sometimes give you coats and runners and stuff, but the health program is pretty good, because my doctor takes good care of me; I'm on methadone. She takes good care of me and stuff like that.

(Vanessa, FN, Female)

[N]ow I go to the [non-Aboriginal AIDS resource centre] ...that's a daycare program for HIV positive people. They have breakfast and lunch, they have an art room, they have laundry, they have showers, they have music, they have a living room with a fireplace, they have workshops, women's groups, men's group, they have nap rooms, they have nurses there, dietitians, The have, like, everything. A lot of stuff....It's really helpful I find. It's been really helpful for me to go there.

(Ursula, FN, Female)

I come here to [Aboriginal health centre] to do arts and crafts [but] the majority of people just come to eat...Then there's the drop-in, which has to do with just people with HIV, and then there's the pharmacy, and then there's the clinic, you know, where the doctor's are, and the dentist. And then there's a program downstairs; it's [pause] the recovery program I guess.

(Trent, FN, Male)

Another important feature of support services for people living with HIV was continuity. A number of participants remarked on the importance of having a place to go to every day where they could see familiar faces, eat, relax or simply hang-out.

Like, for me, I need it, like – I mean, I’m the kind of person that I need something consistent, something every day or something, you know...I mean, the [HIV resource centre] helps, ‘cause I can go there every day, right, so that’s something that definitely helps. I mean, that falls into that category. There’s always people around, and I see a lot of the same people every day, so that’s really helpful.

(Ursula, FN, Female)

I come here [to Aboriginal health centre] almost every day, from 9:00 to 3:00...We watch movies, have breakfast. I can see some friends. I can sit at a table alone and think why I’m there, ‘cause I just want to pass some time on mostly thinking about my family.

(Winona, FN, Female)

For some interview participants, a key role of service organizations was to connect them to other services or to information.

Here [at Aboriginal organization] it’s a little more thorough; they’ll actually call the doctor on your behalf and type up a letter, explaining that you were referred from this agency, what it’s for. Yeah, it seems to go a lot easier when you do it that way...It’s more one-on-one with people now. It’s not like a referral agency, just a number, and we just take you and then put you on a piece of paper and ship you off somewhere else, and you’re someone else’s problem now. No. They also do follow-up here too; they call you back after about a month or so, and ask you, “Did that go well? Did you get the care you needed?” and stuff.

(Sam, FN, Male)

I needed to have some kind of control because I basically had none...[So] I just got a book, and I read about every possible thing that you could have...I just read everything I could find about it. You know, about illness and if you get sicknesses, infections, and how you can take care of yourself, and viral loads, CD4, and medications, everything. I read everything I could about it....and then I got involved with [AIDS organization 1], and I got the library card, and I just...jumped right in. [It was] my way of maintaining some kind of control over the whole thing, I guess.

(Ursula, FN, Female)

I just talked to some doctors and they gave me some papers to read and that most people, they’re on pills or the medication and they got a lot of support with people. And that’s what really helped out.

(Winona, FN, Female)

[After my diagnosis], I started coming here [to the Aboriginal community based organization] and started accessing more and more of the services for APHAs... So after that, then I got my connections to [AIDS service organization] and other organizations to

assist me with everything else.

(Sam, FN, Male)

Finally, a few participants mentioned the importance of Aboriginal specific support services.

Then there was the [Aboriginal centre]. I used to go there a lot. They had the drop-in centre, and they also had a school setting. It was mostly for kids that dropped out of school that wanted to try and finish school but couldn't sit in the class and listen to the teacher because, I don't know, they were too wild I guess. Because a lot of them had kids already so they didn't have the child care and stuff until they came out with this.

(Yvonne, FN, Female)

[Aboriginal centre] is good place. For First Nation guys that come to the city, sometimes is difficult for First Nation because he's lost on the city. He can die there if you don't understand what is the fuckin' life. On the city and on the north is not the same trail.

(Edward, FN, Male)

Recommendations from participants about health or social care

Some participants made recommendations related to counselling and outreach services.

The counselling of one-on-one should be on hand and available to anyone that should need it, 'cause it's those first 5 minutes or half an hour that you get that information, that result, is usually when you can either do the most good or the most damage to a person who has that slip of paper in their hand – 'cause that decides their future from that day forward. And if they don't have counselling to deal with it, then Lord knows where their path will take them or what they might do with that information if they don't understand it fully, or realize that there's more help for them, or that it's not as bad as you'd like to think it is... "The Day After Program" I guess they could call it.

(Sam, FN, Male)

Another thing about...drug addicts, they will neglect their health right? They could be really, really sick and they won't care. So it's really about the people who are either the nurses or the clinics are here, going out to the people. It's not about them waiting for people to come; they have to actually go to these people.

(Trent, FN, Male)

So I think having somebody who's Aboriginal but at the same time, professional, almost like a sense of where they can be talking to this person who's like [pause] I don't know; I'm stuck for words. I guess like a young person who's like a role model, someone who they could look at and trust, someone who's professional. You know what I mean? That comes and does testing and lets them know that, "Yeah, this is strictly confidential," and stuff like that. Maybe run the testing at community centres; like post it ahead of time "We have testing here, there", you know what I mean? Definitely somebody that they don't know, but yet somebody who looks like someone they could trust, somebody who looks professional, somebody who's young that they could talk to. What's needed in the

Aboriginal community is more strong, positive role models, like having an Aboriginal doctor or nurse come in that is not a part of their community, but seeing that there's other people outside of their community that are doing things like that.

(Adam, FN, Male)

Key Findings

Overview

The findings from the study can be grouped into 3 major themes:

- the **Decision to Test** for HIV
- the **Experience** of having an HIV test
- the **Relationship** between having an HIV test and subsequent decisions regarding care and treatment

Overall, 413 youths completed surveys and 28 participants were interviewed.

Study Sites

- Surveys and interviews were completed in partnership with 11 community agencies in Vancouver, Edmonton, Winnipeg, Happy Valley-Goose Bay, Dartmouth, Montreal, Toronto, Ottawa, and Inuvik.

Sample Characteristics

- Both the survey and interview samples were weighted toward those who have tested for HIV to reflect the interest and may not be representative of the true frequency of testing in the community.

Survey Respondents

Aboriginal youth (413) from various locations across Canada completed the survey.

- Youth ranged in age from 15-30 years, with an average age of 21.5 years.
- Fifty-two percent (52.8%) of participants were female, 47.0% were male and 0.2% transgender.
- The majority of youth (56.2%) identified as First Nations, followed by Métis (20.8%) and Inuit (10.7%).
- While all youth spoke English (97.8%) and/or French (13.1%), 22.0% also spoke an Aboriginal language.
- Most youth self-identified as heterosexual (84.7%), with 13.1% identifying as gay/lesbian/two-spirit/bisexual.
- Half of the youth had some high school (49.9% - some still enrolled) and 16.2% had completed school. As well, 22.4% had some post-secondary education. Many were students at the time of the study (41.7%).
- Most youth (64.4%) were living in an urban centre with a population over 10,000 people.
- Almost 85% of youth reported income of less than \$20,000.
- Just over half (50.8%) had been tested for HIV, with 6.3% of these testing positive. Youth were recruited from Aboriginal and non-Aboriginal AIDS service organizations, Aboriginal

health centres and friendship centres. As such, they were more likely to have had access to HIV counselling and testing than the general Aboriginal youth population.

Interview Participants

Of the 28 youth who participated in interviews:

- 25 had received testing for HIV with 9 testing positive.
- Five of those testing positive stated that they had become infected through intravenous drug use; four had become infected through sexual transmission.
- Of those who reported on their education, 11 had some post-secondary education, 5 had completed high school, while 12 left school before completing high school.
- Interviewed youth were slightly older than the survey sample with an average age of 24.4.
- These youth were living in 5 different provinces and 1 territory.
- There were 12 men and 16 women.
- The majority of these youth identified as First Nations (23) but small numbers of Inuit (2) and Métis (1) youth also participated.

Decision to Test

(Survey: n=413 Interviews: n=28)

- 210 (50.8%) of the 413 youth who participated in the survey had been tested for HIV. These youth were more likely to be younger than 20 years, male, heterosexual, a student and not following traditional Aboriginal practices.
- The decision to have an HIV test was not associated with education level, religion, income, having vaginal sex in the previous 6 months, condom use or the sharing of IDU needles in the previous 6 months.
- The most common reasons cited by youth for having an HIV test were: they had had sex without a condom (43.6%), they thought that they were pregnant (35.4%), they had an HIV test on a regular basis (28.9%), they thought that they were at high risk for HIV infection (23.7%) or it was part of the screening for STDs (20.9%).
- Approximately half (49.2%) of the youth who participated in the survey had never been tested for HIV. The most common reasons for not have gone for an HIV test included: feeling at low risk for HIV (45.3%), never having sex with an infected person (34.5%), always having safe sex (33.3%), and never sharing needles (26.1%).
- Findings from the interviews related to sexuality are relevant to the decision to test:
 - Many participants believed that it was common for youth to have a feeling of invulnerability in relation to their HIV risk.
 - Topics such as HIV, AIDS, and sexuality were not openly talked about in small reserve communities.
 - Alternative sexualities (e.g. gay, lesbian) were not well tolerated in some reserves.
- Similarly, participants views about HIV/AIDS are relevant to the decision to have an HIV test:
 - Many of the interview participants still found HIV/AIDS to be a scary disease
 - About 25% of the youth still believed that AIDS was associated with a death sentence.

- The most common reasons for HIV testing include engaging in unprotected sex, being pregnant or suspecting pregnancy, as part of a regular testing pattern, acknowledging self-assessed high risk for becoming infected, becoming involved in a new relationship, or as part of sexually transmitted infection screening.
- The most common reasons for not having gone for HIV testing include having self-assessed low risk for HIV/AIDS, never having sex with an infected person, participating in safe sexual practices, never sharing needles, being told by a health care provider that their risk was low, or because they believed themselves to be healthy.

Experience of Testing (Survey: n=210 Interviews: n=25)

Findings related to the experience of testing are based on 210 surveyed youth and 25 interviewed youth who had had an HIV test.

- **Testing:** The majority (60.0%) of the 210 youth who answered questions on their testing experiences had tested at least once within the last two years, and so were able to provide valuable information on HIV testing services.
- **Tester characteristics:** The majority of youth (86.5%) had their most recent test in the community where they lived or were living at the time of the HIV test; the largest percentage (34.1%) had gone to a physician for a test. Fifteen percent said the test provider had a similar cultural background.
- **Information:** 28.1% of youth could not remember what types of information they received when they went for their most recent test, and 23.3% indicated they were not given any information. Fifty percent indicated all their questions were answered at their last test, while 26.0% said some of their questions were answered, and 23.5% said their questions were not answered.
- **Perceptions of their treatment:** Although over three-quarters of youth felt they had been treated with care (79.9%), respect (77.4%), or kindness (75.9%) when they received an HIV test, there were a significant minority who had negative experiences (12.3% said they were treated with fear, 11.2% with discrimination, and 9.7% with avoidance).
- **Emotional Reaction to Testing:** 79.0% of youth wrote brief statements on the survey about their emotional reaction to HIV testing. The majority (63.9%) expressed feelings of anxiety or apprehension about the possibility of testing HIV positive, and 18.7% reported they did not have any negative emotional reaction, but rather felt comfortable with the testing experience. A few described negative feelings about the HIV test experience itself (feeling ashamed, embarrassed, or uncomfortable),
- **Advice for HIV testing services:** Over half (57.6%) of the youth wrote suggestions on the survey for the improvement of HIV testing services, largely pertaining to the three professional relationship components: interpersonal style (respect), emotional support, and information. In addition, youth expressed concerns about the confidentiality of the test result, informing others that they were being tested for HIV, and availability of HIV testing services.
- **Regular HIV testing** was viewed by Aboriginal youth as routine especially when coupled with checks for other sexually transmitted infections or as part of the standard of medical care when individuals become pregnant.

- While most participants preferred to get tested in hospital or clinic settings, several youth reported testing at a drop-in location due to the flexibility of just showing up and getting tested anytime.
- Motivation to get tested was primarily due to “*taking care*” of themselves and the decision to test was predicated on a realistic self assessment that past risky behavior may have placed them at greater risk of HIV.
- The qualitative findings suggest that the decision to test for HIV is largely driven as a result of fear of HIV infection rather than any realistic assessment of past high risk behavior.
- The involvement of parents/partners in the decision to get tested can be both supportive or a barrier.
 - Whilst some youth have open and honest communication with their non judgmental parents on testing decisions and their sexual behavior, other youth shared that they feared parental attitudes towards their sexuality, their sexual relationships, injection drug use and HIV testing.
 - Several participants commented that their partners were not involved in the decision to test or attend clinic with them based on the belief that they would not be supportive of their decision.
- The service provider offering HIV testing need not be of a similar cultural background but have a caring, understanding and patient approach as a characteristic.
- Service providers need to establish a relationship with the youth who get tested without compromising confidentiality.
 - Participants valued service providers that were professional yet who were still caring, respectful and understanding.
- Anonymous HIV testing services were seen as a means to promote some youth to access testing services.
 - Camouflaging HIV testing services in the context of general health services was something that the youth supported.
- A significant proportion of participants received little or no information on HIV prevention by service providers.

Relationship between Testing and Care (Survey: n=26 Interviews: n=9)

Twenty-six youth who participated in the survey and 9 who participated in an interview were HIV positive.

- Of the 413 youth who were surveyed, 210 (50.8%) had been tested for HIV at least once. Of these, 26 (12.4%) youth had tested positive. Of the 28 youth we interviewed, 25 had been tested for HIV and 9 had tested positive. These numbers are likely to be higher than those among Aboriginal youth in general. However, because of the number of youth in our sample who were experienced testers and HIV positive, they were able to provide valuable information on the relationship between HIV testing and HIV care.
- Testing Late
 - Of the 26 youth in the survey sample who reported being HIV-positive, eight (30.8%) had symptoms related to HIV/AIDS at the time of diagnosis, including six (23.1%) who had AIDS at the time of diagnosis. Of the 9 HIV-positive youth in our interview sample,

two participants reported having symptoms of HIV at the time of diagnosis. This suggests that some Aboriginal youth are getting tested late in the course of disease.

- Delaying Care
 - After diagnosis and at the time of the survey, 48% of the survey participants had seen a doctor to discuss HIV treatment options. Of those who provided information on time interval between diagnosis and assessing care (n=10), 8 sought care within one year. Of the 9 HIV positive interview participants, all had been assessed for care, but the time interval between diagnosis and seeking care varied widely, from a few months to seven years.
 - Among the reasons for delaying care-seeking or not seeking care at all, interview participants reported: being scared, being pre-occupied with drugs or alcohol, not caring, not wanting to live, and not knowing anything about care. This suggests that post-test counselling could be an important point of intervention for Aboriginal youth.
- Treatment Options
 - Of the 10 survey participants and 8 interview participants who were treating their HIV at the time of the survey, the following treatment methods were most frequently used: staying healthy through diet, nutrition and exercise; modifying lifestyles by stopping smoking/drinking/drugging; taking HIV meds; and traditional Aboriginal healing methods.
- Importance of Support
 - Several interview participants reported that stable housing and social/family support were essential to helping them manage their HIV. Support services such as Aboriginal AIDS service organizations, AIDS service organizations and community/public health clinics were also important.
- Initiative for Anti-retroviral pharmaceutical therapies (ARVs)
 - Of those not taking HIV meds, a number of reasons were reported including the following: their doctor did not recommend them, they felt healthy, they were afraid of the side effects, their lifestyle got in the way and they did not want to take HIV medications.
 - Of the 6 survey participants and 2 interview participants who were taking HIV medications at the time of the study, most reported that they started taking meds on the advice of a doctor once they experienced declining health, low CD4 counts or high viral loads.
 - When asked if they would start medications in the future, most participants reported that they would take HIV medication when their health declined, when their CD4 count went down or their viral load went up, and/or when a doctor recommended it.
 - A small number of participants reported that they would never take HIV medications or only when they absolutely had to.
 - Of those participants who made post-testing recommendations, greater/better counselling after diagnosis and street outreach were suggested as effective means of getting Aboriginal youth into care.

Research Translation Activities

A range of research translation activities have been completed, or are planned, to disseminate the findings from this project.

Presentations

Members of the research team have shared the findings in poster and oral presentations at regional, national and international workshops and conferences (see Appendix K for details). At the time of writing 11 presentations had been given based on the findings. Additionally, 5 abstracts and two non-peer reviewed articles have been published.

Manuscripts

Five manuscripts have been outlined and are being written for publication by the research team.

Dissemination Workshop

In the fall of 2005, a two day 'Community Solutions Workshop' was held in Regina, Saskatchewan to discuss and verify the findings from the research study and to get community feedback on the next steps in the research process. The research team was successful in their application to CIHR for a \$25,000 HIV/AIDS CBR program Aboriginal capacity building workshop grant. The final report of the workshop with power point presentations is attached (see Appendices L &M).

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Appendices

Appendix A. Informed Consent and Information Sheets to Participants.

A. Information letter for survey participants

Project: **The Diagnosis and Care of HIV Infection in Aboriginal Youth**

We would like to ask you to participate in a study that is being done in several regions across Canada. The study is to examine the views of Aboriginal youth about HIV testing. We are also interested in learning how youth who are HIV positive make decisions about their treatment. We hope that the information we learn from the study can be used to improve HIV testing services and treatment programs for Aboriginal youth.

If you agree to participate in the study, you will be asked to complete a survey. The survey will take about 30 minutes to complete. It can be filled in in a private room in this organization. You will be asked questions about your background, the reasons that you would have an HIV test and where you would go for a test. If you have already had an HIV test, you will be asked questions about what it was like to have the test. You will be given a small gift to thank you for your time.

Your name will not be used in the study. The contact person in this organization, the research assistant and Dr. Mill will be the only people who know that you took part in the study. The other members of the research team will not see the surveys. All information will be kept private, except when professional codes of ethics or the law requires reporting. For example, if an individual under the age of 18 requires protection, this will be sought through the appropriate Child Protection agency.

The information you provide will be kept in a locked filing cabinet for at least 5 years after the study is done. The information that we learn from the survey may be used for the teaching of others or for writing papers. It will be only used for future research if further ethical approval is obtained.

It is not expected that there will be any risk to you if you take part in the study. You may not receive any benefit from being in the study. By being in the study you may help other men and women in the future. If you become upset filling out the survey, we will refer you to a counselor. You may ask questions about the study and you may choose not to take part in it. Participation in the study is voluntary. If you decide to be in the study and change your mind, you may withdraw from the study at any time. You may also decide not to answer any one of the questions on the survey. Your care and/or service will not be affected by these decisions.

A: Information letter for survey participants (cont'd)
Project: The Diagnosis and Care of HIV Infection in Aboriginal Youth

If you have any questions about the study, you may contact any of the researchers listed below or Tracey Prentice at the Canadian Aboriginal AIDS Network. If you have any concerns during the study feel free to call Dr. Kathy Kovacs Burns collect. Dr. Kovacs Burns is not associated with the study.

Dr. Kathy Kovacs Burns
 Director, Research Planning and Development
 Faculty of Nursing
 Email: kathy.kovacsburns@ualberta.ca
 Phone: 780-492-3769

Tracey Prentice
 Project Coordinator
 Canadian Aboriginal AIDS Network
 Email: traceyp@caan.ca
 Phone: 1-888-285-2226

Thank you for your consideration of this request.

 Initial of researcher reviewing letter

 Initial of participant

Principal Investigator:
 Judy Mill
 Faculty of Nursing
 3rd Floor, Clinical Sciences Building
 Edmonton, Alberta, Canada, T6G 2G3
 Phone: 780-492-7556
 Fax: 780-492-2551

Co-Investigators:
 Chris Archibald
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 Phone: 613-941-3155

Tom Wong
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 and Sexually Transmitted Diseases,
 Centre for Infectious Disease
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Randy Jackson
 APHA Coordination Program
 Canadian Aboriginal AIDS Network
 Phone: 613-657-1817 (ext 106)

Kevin Barlow
 Executive Director
 Canadian Aboriginal AIDS Network
 Phone: 613-657-1817 (ext 110)

Ted Myers
 Professor
 HIV Social, Behavioural and Epidemiological
 Studies Unit, Faculty of Medicine
 University of Toronto
 Phone: 416-978-8979

Catherine Worthington
 Assistant Professor
 Faculty of Social Work
 University of Calgary
 Phone: 403-220-8507

B: Information letter for interview participants
Project: **The Diagnosis and Care of HIV Infection in Aboriginal Youth**

We would like to ask you to participate in a study that is being done in several regions across Canada. The study is to examine the views of Aboriginal youth about HIV testing. We are also interested in learning how youth who are HIV positive make decisions about their treatment. We hope that the information we learn from the study can be used to improve HIV testing services and treatment programs for Aboriginal youth.

If you agree to participate in the study, you will be asked to take part in an interview. You may be interviewed in your home, an agency, or another location of your choice. You will be asked the reasons that you would have an HIV test and where you would go for a test. If you have already had an HIV test, you will be asked questions about what it was like to have the test. The interview will last about one to one and a half hours. You will be given a small gift to thank you for your time.

Your name will not be used in the study. The contact person in this organization, the interviewer and Dr. Mill will be the only people who know that you took part in the study. The other members of the research team will only see the interviews after the names have been removed from them. All information will be kept private, except when professional codes of ethics or the law requires reporting. For example, if an individual under the age of 18 requires protection, this will be sought through the appropriate Child Protection agency.

The information you provide will be kept in a locked filing cabinet for at least 5 years after the study is done. The information that we learn from the interviews may be used for the teaching of others or for writing papers. It will be only used for future research if further ethical approval is obtained.

It is not expected that there will be any risk to you if you take part in the study. You may not receive any benefit from being in the study. By being in the study you may help other men and women in the future. If you become upset discussing your experiences, the interviewer will refer you to a counselor. You may ask questions about the study and you may choose not to take part in it. Participation in the study is voluntary. If you decide to be in the study and change your mind, you may withdraw from the study at any time. You may also decide not to answer any one of the questions in the interview. Your care and/or service will not be affected by these decisions.

B: Information letter for interview participants (cont'd)
 Project: **The Diagnosis and Care of HIV Infection in Aboriginal Youth**

If you have any questions about the study, you may contact any of the researchers listed below or Tracey Prentice at the Canadian Aboriginal AIDS Network. If you have any concerns during the study feel free to call Dr. Kathy Kovacs Burns collect. Dr. Kovacs Burns is not associated with the study.

Dr. Kathy Kovacs Burns
 Director, Research Planning and Development
 Faculty of Nursing
 Email: kathy.kovacsburns@ualberta.ca
 Phone: 780-492-3769

Tracey Prentice
 Project Coordinator
 Canadian Aboriginal AIDS Network
 Email: traceyp@caan.ca
 Phone: 1-888-285-2226

Initial of researcher reviewing letter

Initial of participant

Principal Investigator:
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 and Sexually Transmitted Diseases,
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 APHA Coordination Program
 Canadian Aboriginal AIDS Network
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Ted Myers
 Professor
 HIV Social, Behavioural and Epidemiological
 Studies Unit, Faculty of Medicine
 University of Toronto
 Phone: 416-978-8979

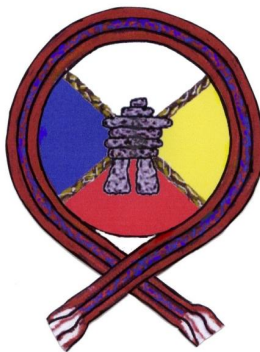
Catherine Worthington
 Assistant Professor
 Faculty of Social Work
 University of Calgary
 Phone: 403-220-8507

C: Informed consent for survey and interview participants
 Project: **The Diagnosis and Care of HIV Infection in Canadian Aboriginal Youth**

Part 1: Researcher Information		
Name of Principal Investigator: Dr. Judy Mill Affiliation: Faculty of Nursing, University of Alberta Contact Information: 780-492-7556		
Name of Co-Investigator: Mr. Randy Jackson Affiliation: Canadian Aboriginal AIDS Network Contact Information: 613-567-1817 (ext 106)		
Part 2: Consent of Subject		
	Yes	No
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached information sheet?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss the study?		
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care.		
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records/information?		
Part 3: Signatures		
This study was explained to me by: _____ Date: _____		
<i>I agree to take part in this study.</i> Signature of Research Participant: _____ Printed Name: _____		
Witness (if available): _____ Printed Name: _____		
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate. Researcher: _____ Printed Name: _____		
* A copy of this consent form will be given to each participant.		

Appendix B. Participant Survey

HIV Testing and Care in Aboriginal Youth



Participant Questionnaire

Thank you for agreeing to complete this survey. As you may be aware, HIV infection is a growing problem among youth in Canada. Therefore, we are interested in finding out how you feel about HIV testing and care. The survey will take about 20 to 30 minutes to complete. If you are not sure about any of the questions, please ask for help.

PART A: DEMOGRAPHIC INFORMATION

For all participants

We would like to start by asking a few questions about your background and where you live. Please answer as many of the following questions as you can.

Q-1 What year were you born?

19_____

Q-2 What language(s) did you first speak? (Circle **ALL** numbers that apply)

- 1 ENGLISH
- 2 FRENCH
- 3 ABORIGINAL (e.g. Cree, Inuktitut, Michif – please specify)_____
- 4 OTHER (please specify)_____

Q-3 What language(s) can you speak now? (Circle **ALL** answers that apply)

- 1 ENGLISH
- 2 FRENCH
- 3 ABORIGINAL (e.g. Cree, Inuktitut, Michif – please specify)_____
- 4 OTHER (please specify)_____

Q-4 Are you? (Circle number)

- 1 MALE
- 2 FEMALE
- 3 TRANS-GENDER
- 4 OTHER (please specify)_____

Q-5 What do you consider yourself to be? (Circle number)

- 1 HETEROSEXUAL
2 STRAIGHT
3 GAY
4 LESBIAN
5 HOMOSEXUAL
6 TWO SPIRIT
7 BISEXUAL
8 OTHER (please specify) _____
- Q-6** Are you? (Circle number)
1 SINGLE (never married)
2 MARRIED
3 LIVING COMMON LAW (shacking up)
4 SEPARATED, DIVORCED OR WIDOWED
5 OTHER (please specify) _____
- Q-7** What is the highest level of education that you have completed? (Circle number)
1 GRADE 8 OR LESS
2 SOME HIGH SCHOOL
3 COMPLETED HIGH SCHOOL
4 SOME VOCATIONAL TRAINING
5 COMPLETED VOCATIONAL TRAINING
6 SOME COLLEGE OR UNIVERSITY
7 COMPLETED COLLEGE
8 COMPLETED UNIVERSITY
- Q-8** Are you a student now? (Circle number)
1 YES, FULL-TIME
2 YES, PART-TIME
3 NO
- Q-9** a) Do you currently follow a religion? (Circle number)
1 YES →
2 NO
- Q-9** b) If **YES**, which of the following religions do you follow? (Circle **ALL** that apply)

1 CATHOLIC
2 UNITED
3 ANGLICAN
4 PENTACOSTAL
5 OTHER (please specify) _____

- Q-10** a) Do you currently follow traditional Aboriginal practices? (Circle number)
1 YES →
2 NO
- Q-10** b) If **YES**, please tell us what practice(s) you follow

- Q-11** What is your Aboriginal group? (Circle number)
1 FIRST NATIONS STATUS (Treaty)
2 FIRST NATIONS NON-STATUS (Non-Treaty)
3 METIS
4 INUIT
5 OTHER (please specify) _____
- Q-12** What province/territory do you currently live in? (Circle Number)
1 ALBERTA
2 BRITISH COLUMBIA
3 NUNAVUT
4 MANITOBA
5 NEWFOUNDLAND
6 ONTARIO
7 QUEBEC
8 N.W. TERRITORIES
9
10 PRINCE EDWARD ISLAND
11 QUEBEC
12 SASKATCHEWAN

6 NEW BRUNSWICK
7 NOVA SCOTIA

13 YUKON

- Q-13** Do you currently live in a First Nations rez/community, Métis settlement or Inuit community?
(Circle number)
1 YES
2 NO
- Q-14** What size of community do you currently live in? (Circle number)
1 A CITY (more than 10, 000 people)
2 A SMALL COMMUNITY (less than 10, 000 people)
3 A REMOTE COMMUNITY (less than 10, 000 people AND during part of the year I must fly out of my community)
- Q-15** What are the first three digits of your postal code?
_ _ _ XXX
- Q-16** Where do you live now? (Circle number)
1 HOME OF PARENT(S)
2 FRIEND'S HOME
3 OWN HOME/APARTMENT
4 SHELTER/SAFE HOUSE
5 ROOMING HOUSE
6 HOTEL
7 HOMELESS
8 OTHER (please specify) _____
- Q-17** What is your income each year? (Circle number)
1 NONE
2 \$5,000 OR LESS
3 \$5,001 – \$10,000
4 \$10,001 – \$20,000
5 \$20,001 or MORE
- Q-18** Where is your income from? (Circle **ALL** numbers that apply)
1 JOB
2 WELFARE/SOCIAL ASSISTANCE
3 UNEMPLOYMENT INSURANCE
4 SUPPORT FROM PARENTS
5 DISABILITY BENEFIT
6 MOTHER'S ALLOWANCE
7 FAMILY ALLOWANCE
8 GST CREDITS
9 'STREET' SOURCES
10 INCOME FROM COMMUNITY (e.g. royalty, distribution)
11 TRADITIONAL SOURCES (e.g. fishing, trapping)
12 OTHER (please specify) _____

Part B: SEXUAL HEALTH AND BEHAVIOUR

For all participants – In order for us to understand the reasons people use health services, it is important that we know about your sexual health and sexual experiences.

- Q-19** Have you ever been told by a doctor or nurse that you had a sexually transmitted disease (STD), other than HIV? (Circle number)
1 YES
2 NO
- Q-20** During the past 6 months have you done any of the following:
20.1 a) Had vaginal sex with any partner (Circle number)
1 YES →
2 NO
- 20.1b** If **YES**, did you use a condom? (Circle number)

1 NEVER
2 RARELY
3 SOMETIMES
4 ALWAYS
- 20.2 a)** Had oral sex (eg.

- 1 YES →
2 NO

20.2b If **YES**, did you use a condom/dental dam?
(Circle number)

- 1 NEVER
2 RARELY
3 SOMETIMES
4 ALWAYS

20.3 a) Had anal sex with any partner (Circle number)

- 1 YES →
2 NO

20.3 b) If **YES**, was a condom used? (Circle number)

- 1 NEVER
2 RARELY
3 SOMETIMES
4 ALWAYS

20.4 a) Used injection drugs (Circle number)

- 1 YES →
2 NO

20.4 b) If **YES**, did you share the needle/gear with someone else? (Circle number)

- 1 NEVER
2 RARELY
3 SOMETIMES
4 ALWAYS
5 DON'T KNOW

Q-21 Do you think it is a good idea to have an HIV test during pregnancy? (Circle number)

- 1 YES
2 NO
3 DON'T KNOW

For Females Only

If you are **FEMALE**, please continue with next question.
If you are **MALE**, please skip to Q-23.

Q-22 a) Have you ever been pregnant?

- 1 YES →
2 NO

If **YES**, please answer the following questions.

Q-22 b) Have you had an HIV test during pregnancy? (Circle number)

- 1 YES
2 NO, I DID NOT WANT AN HIV TEST
3 NO, I WAS NOT OFFERED AN HIV TEST
4 NO, OTHER REASON (please specify) _____

5 DON'T KNOW

Q-22 c) Would you have an HIV test if you were pregnant in the future? (Circle number)

- 1 YES
2 NO
3 DON'T KNOW

PART C: QUESTIONS RELATED TO HIV TESTING

This group of questions are about HIV testing. We would like to know what kinds of things influence your decision to have, or not have, an HIV test.

For All Participants

Q-23 Below is a set of statements about the health worker who gives HIV tests. Please circle the responses that come closest to your opinion.

I would have an HIV test if I knew the health worker.	STRONGLY AGREE	AGREE	DOES NOT MATTER	DISAGREE	STRONGLY DISAGREE
I would have an HIV test if the health worker were from the same cultural background (e.g. First Nation).	STRONGLY AGREE	AGREE	DOES NOT MATTER	DISAGREE	STRONGLY DISAGREE
I would have an HIV test if the health worker were a physician (doctor).	STRONGLY AGREE	AGREE	DOES NOT MATTER	DISAGREE	STRONGLY DISAGREE
I would have an HIV test if the health worker were a nurse.	STRONGLY AGREE	AGREE	DOES NOT MATTER	DISAGREE	STRONGLY DISAGREE
I would have an HIV test if the health worker were a nurse practitioner.	STRONGLY AGREE	AGREE	DOES NOT MATTER	DISAGREE	STRONGLY DISAGREE
I would have an HIV test if the health worker were of the same sex.	STRONGLY AGREE	AGREE	DOES NOT MATTER	DISAGREE	STRONGLY DISAGREE
I would have an HIV test if the health worker were from my home community.	STRONGLY AGREE	AGREE	DOES NOT MATTER	DISAGREE	STRONGLY DISAGREE
I would have an HIV test if the health worker were close to my age.	STRONGLY AGREE	AGREE	DOES NOT MATTER	DISAGREE	STRONGLY DISAGREE

Other (please specify) _____

Q-24 Have you ever had an HIV test?

- 1 YES →
2 NO

If YES , please skip to Q-27

For participants who have never had an HIV/AIDS test

Q-25 The following is a list of reasons why people decide not to get tested for HIV. Which of the following reason(s) apply to you? (Circle **ALL** numbers that apply)

- 1 I AM AT LOW RISK FOR HIV/AIDS
- 2 I AM HEALTHY SO I DON'T NEED TO BE TESTED
- 3 MY DOCTOR/NURSE DIDN'T RECOMMEND A TEST
- 4 I AM AFRAID THAT SOMEONE WILL FIND OUT
- 5 IF I TESTED POSITIVE, NOTHING CAN BE DONE
- 6 I DO NOT WANT TO KNOW
- 7 MY DOCTOR/NURSE SAID I WAS NOT AT RISK
- 8 I HAVE NEVER HAD SEX WITH AN INFECTED PERSON

- 9 I AM AFRAID OF HAVING MY NAME REPORTED
- 10 I AM WORRIED ABOUT THE ACCURACY OF THE TEST
- 11 I DO NOT LIKE NEEDLES
- 12 I AM WORRIED ABOUT BEING DISCRIMINATED AGAINST
- 13 IT COULD AFFECT MY RELATIONSHIPS
- 14 I ALWAYS HAVE SAFE SEX
- 15 I NEVER SHARE NEEDLES
- 16 THERE IS NO ONE IN MY COMMUNITY WHO HAS HIV/AIDS
- 17 I HAVE NEVER HAD SEX
- 18 IT TAKES TOO LONG TO GET THE RESULTS
- 19 OTHER (please specify) _____

Q-26 If you wanted to be tested for HIV/AIDS, where would you go for the test? (Circle **ALL** numbers that apply)

- 1 DON'T KNOW
- 2 DOCTOR'S OFFICE
- 3 HOSPITAL
- 4 COMMUNITY/PUBLIC HEALTH CENTRE
- 5 CLINIC FOR SEXUALLY TRANSMITTED DISEASES
- 6 ANONYMOUS TESTING CLINIC
- 7 BIRTH CONTROL CLINIC
- 8 WALK-IN CLINIC
- 9 NURSING STATION
- 10 RESEARCH STUDY
- 11 FRIENDSHIP CENTRE
- 12 MOBILE SERVICE
- 13 AIDS SERVICE ORGANIZATION
- 14 OTHER (please specify) _____

Additional Comments:

Please provide any other comments that you would like to make about the topic:

If you have never had an HIV test, please stop here. Thank you for participating in the survey.

PART D: THE TEST EXPERIENCE

For Participants who have had an HIV/AIDS Test

In the next questions, we ask you where and when you had your HIV test. We would also like to know why you decided to have a test and how you were treated when you went for the test.

Q-27 When was the first time that you were tested for HIV/AIDS?

YEAR _____
MONTH _____

Q-28 How many times have you had an HIV/AIDS test in the past 2 years?

Q-29 When was the last time you were tested for HIV/AIDS?

YEAR _____
MONTH _____

Q-30 What were the results of your most recent HIV/AIDS test? (Circle number)

- 1 I WAS HIV POSITIVE
- 2 I WAS HIV NEGATIVE
- 3 RESULTS WERE NOT CLEAR, I HAVE TO GO BACK FOR ANOTHER TEST
- 4 I DON'T KNOW – I HAVEN'T RECEIVED THE RESULT (please explain) _____
- 5 OTHER (please specify) _____

Q-31 Where did you go for your most recent test? (Circle number)

- 1 DOCTOR'S OFFICE
- 2 HOSPITAL
- 3 COMMUNITY/PUBLIC HEALTH CENTRE

- 4 CLINIC FOR SEXUALLY TRANSMITTED INFECTIONS
- 5 ANONYMOUS TESTING CLINIC
- 6 BIRTH CONTROL CLINIC
- 7 WALK-IN CLINIC
- 8 NURSING STATION
- 9 ALCOHOL/DRUG TREATMENT CENTRE
- 10 PRISON/DRUG TREATMENT CENTRE
- 11 RESEARCH STUDY
- 12 FRIENDSHIP CENTRE
- 13 MOBILE SERVICE
- 14 AIDS SERVICE ORGANIZATION
- 15 OTHER (please specify) _____

Q-32 a) In what community did you have your most recent HIV/AIDS test? (Circle number)

- 1 OUTSIDE THE COMMUNITY WHERE I AM NOW LIVING
- 2 IN THE COMMUNITY WHERE I AM NOW LIVING
- 3 OTHER (please specify) _____

Q-32 b) If you tested **outside** the community, what were your reasons? (Circle **ALL** numbers that apply)

- 1 NO ONE KNEW ME
- 2 I KNEW THE HEALTH WORKER
- 3 MY FAMILY WAS THERE TO SUPPORT ME
- 4 THERE WAS NO HIV TESTING IN MY COMMUNITY
- 5 OTHER (please specify) _____

Q-33 The following is a list of reasons why people decide to get tested for HIV. Which of the following reasons apply to you? (Circle **ALL** numbers that apply)

- 1 I AM AT HIGH RISK FOR HIV INFECTION
- 2 I WAS HAVING SYMPTOMS
- 3 A HEALTH PROFESSIONAL ADVISED ME TO
- 4 I WANTED TO CONFIRM THE RESULTS OF A PREVIOUS TEST
- 5 IT WAS PART OF THE SCREENING FOR SEXUALLY TRANSMITTED DISEASES
- 6 I HAD SEX WITHOUT A CONDOM
- 7 I HAD BEEN SHARING NEEDLES
- 8 I WAS PREGNANT OR THOUGHT I WAS
- 9 IT WAS REQUIRED FOR INSURANCE
- 10 I WANTED TO DONATE BLOOD
- 11 I WAS IN A NEW RELATIONSHIP
- 12 I WAS SEXUALLY ASSAULTED (e.g. raped)
- 13 IT WAS A REQUIREMENT FOR SUBSTANCE ABUSE TREATMENT
- 14 I GET TESTED REGULARLY
- 15 OTHER (please specify) _____
- 16

Q-34 Please describe the person who ordered your most recent HIV test. (Circle number)

- | | | |
|------------------------------------------------------------------------------|--------|----------|
| The person was | 1 MALE | 2 FEMALE |
| I knew him/her | 1 YES | 2 NO |
| He/she was a physician | 1 YES | 2 NO |
| He/she was a nurse | 1 YES | 2 NO |
| He/she was about the same age as me | 1 YES | 2 NO |
| He/she was from a similar background to me (e.g. First Nation, Métis, Inuit) | 1 YES | 2 NO |
| Other _____ | | |

Q-35 What topics were you given information about when you went for your most recent HIV test? (Circle **ALL** numbers that apply)

- 1 THE EFFECTS OF THE DISEASE ON MY BODY
- 2 TREATMENT FOR HIV INFECTION
- 3 PREVENTING THE SPREAD OF THE VIRUS WHEN USING IV DRUGS
- 4 PROTECTING MY PARTNER FROM HIV
- 5 SUPPORT AND COUNSELLING
- 6 REPORTING OBLIGATIONS
- 7 I WASN'T GIVEN ANY INFORMATION
- 8 I DON'T REMEMBER
- 9 OTHER (please specify) _____
- 10

Q-36 Were your questions answered when you went for your most recent HIV test? (Circle number)

- 1 YES, ALL OF THEM
- 2 YES, SOME OF THEM
- 3 NO

Q-37 Below is a list of statements about how people might be treated when they go for an HIV test. Please **circle** the response that comes closest to how you felt when you went for your most recent HIV test.

I was treated with care	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I was treated with respect	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I was treated in a bored, disinterested way	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I was treated with kindness	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I was treated with discrimination	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I was treated with hostility	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I was treated with fear	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I was treated with avoidance	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE

Other (please specify) _____

Q-38 a) When you went for your most recent HIV test, were you asked questions about your past sexual behaviour? (Circle number)

- 1 YES →
2 NO

Q-38 b) If **YES**, please answer the following question

Below is a set of statements people might use to describe how they felt when asked about their behaviour. Please **circle** the response that comes closest to describing how you felt when asked about your sexual behaviour the last time you were tested for HIV.

I felt comfortable	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I felt embarrassed	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I felt upset	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I felt angry	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I felt ashamed	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I felt scared	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE

OTHER (please specify) _____

Q-39 a) When you went for your most recent HIV test, were you asked questions about your past alcohol and drug use? (Circle number)

- 1 YES →
2 NO

Q-39 b) If **YES**, please answer the following question

Below is a set of statements people might use to describe how they felt when asked about their behaviour. Please **circle** the response that comes closest to describing how you felt when asked about your past alcohol and drug use the last time you were tested for HIV.

I felt comfortable	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I felt embarrassed	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I felt upset	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I felt angry	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I felt ashamed	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE
I felt scared	STRONGLY AGREE	AGREE	NEUTRAL	DISAGREE	STRONGLY DISAGREE

OTHER (please specify) _____

Q-40 People feel a variety of emotions when having an HIV test. Please tell us briefly how you felt when you had an HIV test.

Q-41 What advice do you have to improve the testing experience for others?

If your recent HIV test results were negative, please stop here. Thank you for participating in the survey.

PART E: QUESTIONS RELATED TO TREATMENT

For Participants who have received an HIV positive test

In this last group of questions, we would like you to tell us about how you have decided to treat your HIV. We are interested in knowing if you are taking any medications for your HIV and if you have used HIV services.

Q-42 Which of the following describes your health at the time a doctor first told you that you are HIV positive (HIV is the virus that causes AIDS)? (Circle number)

- 1 I DID NOT HAVE ANY SYMPTOMS
- 2 I HAD SYMPTOMS RELATED TO HIV OR AIDS
- 3 I DON'T KNOW

Q-43 The first time that a doctor told you that you are HIV positive, were you told you have AIDS? (Circle number)

- 1 YES
- 2 NO
- 3 I DON'T KNOW

Q-44 a) After a doctor told you that you are HIV positive, did you visit a doctor again to discuss your health and treatment options related to HIV? (Circle number)

- 1 YES →
- 2 NO

If **YES**, please answer the following questions.

Q-44 b) How long after a doctor told you that you are HIV positive did you visit a doctor again to discuss your health and treatment options related to HIV? (Circle number)

- 1 0 – 3 MONTHS
- 2 4 – 6 MONTHS
- 3 7 – 12 MONTHS
- 4 13 MONTHS – 2 YEARS
- 5 MORE THAN 2 YEARS

Q-44 c) At the time of that visit to the doctor were any HIV/AIDS medications recommended? (Circle number)

- 1 YES →
- 2 NO

If **YES**, please tell us what was recommended _____

Q-45 a) In the 3 months after a doctor told you that you are HIV positive, did you use any HIV-related services? (Circle number)

- 1 YES →
2 NO

Q-45 b) If **YES**, which of the following HIV-related services did you use? (Circle **ALL** numbers that apply to you)

- 1 PHYSICIAN
- 2 HIV OUTPATIENT CLINIC
- 3 AIDS SERVICE ORGANIZATION
- 4 ABORIGINAL COUNSELLING SERVICE
- 5 REMOTE NURSING STATION
- 6 COMMUNITY/PUBLIC HEALTH CLINIC
- 7 WALK-IN CLINIC
- 8 NEEDLE EXCHANGE
- 9 TRADITIONAL HEALER (please specify) _____
- 10 OTHER (please specify) _____

Q-46 a) Have you done anything to treat your HIV infection in the past? (Circle number)

- 1 YES →
2 NO

Q-46 b) If **YES**, please indicate all of the ways you have treated your HIV infection. (Circle **ALL** numbers that apply)

- 1 HIV DRUGS (e.g. anti-retroviral therapy)
- 2 STAYING HEALTHY (e.g. exercise, diet, sleep)
- 3 ALTERNATIVE THERAPIES (e.g. massage, meditation)
- 4 VISITING A PHYSICIAN, NURSE, COMMUNITY HEALTH REPRESENTATIVE
- 5 VISITING A HEALTH CENTER
- 6 SWEAT LODGES
- 7 TRADITIONAL HERBAL MEDICINE
- 8 VISITING A MEDICINE PERSON/TRADITIONAL HEALER
- 9 STOPPED SMOKING
- 10 STOPPED USING DRUGS
- 11 STOPPED USING ALCOHOL
- 12 OTHER (please specify) _____

Q-47 a) Are you currently taking any HIV/AIDS medication? (Circle number)

- 1 YES →
- 2 NO

Q-47 b) If **YES**, please indicate the reasons that you began medication for your HIV infection? (Circle **ALL** numbers that apply)

- 1 I BEGAN TO HAVE SYMPTOMS
- 2 MY CD4 COUNT WAS LOW
- 3 MY VIRAL LOAD WAS HIGH
- 4 A PHYSICIAN, NURSE, OR HEALTH WORKER RECOMMENDED IT
- 5 A FRIEND OR FAMILY MEMBER RECOMMENDED IT
- 6 AN INDIVIDUAL IN MY AIDS SUPPORT/SERVICE ORGANIZATION RECOMMENDED IT
- 7 READ AN ADVERTISEMENT ABOUT HIV MEDICATION
- 8 OTHER (please specify) _____

If you are currently taking HIV/AIDS medication, please stop here. Thank you for participating in the survey.

Q-48 There are many reasons for not taking medication for HIV infection. Please tell us which of the following reasons apply to you. (Circle **ALL** numbers that apply)

- 1 MY MEDICATION HAD BAD SIDE EFFECTS
- 2 MY LIFESTYLE GETS IN THE WAY
- 3 MY IMMUNE STATUS IS STILLGOOD
- 4 I DO NOT FEEL ILL
- 5 MY DOCTOR TELLS ME THAT I DON'T NEED HIV/AIDS MEDICATION
- 6 I DO NOT WANT TO TAKE PILLS
- 7 I AM AFRAID OF THE SIDE EFFECTS
- 8 I BELIEVE THAT THE MEDICATION IS BAD FOR ME
- 9 I DO NOT HAVE MONEY FOR MEDICATION
- 10 I AM SEEING A TRADITIONAL HEALER
- 11 OTHER (please specify) _____

Q-49 I plan to start HIV medication in the future if: (Circle **ALL** numbers that apply)

- 1 I BEGIN TO HAVE SYMPTOMS
- 2 MY CD4 COUNT IS LOW
- 3 MY VIRAL LOAD IS HIGH
- 4 A PHYSICIAN, NURSE, OR HEALTH WORKER RECOMMENDS IT
- 5 A FRIEND OR FAMILY MEMBER RECOMMENDS IT
- 6 OTHER (please specify) _____

Additional Comments:

Please provide any other comments that you would like to make about the topic:

THANK YOU, YOU ARE NOW FINISHED THE SURVEY

Appendix C. Sample Log Sheet for Participant Surveys

“Diagnosis and Care of HIV Infection in Canadian Aboriginal Youth”

LOG SHEET for participant surveys

Location: Bent Arrow

Interviewer(s): _____

Survey No.	Date Completed	Length of time to complete	Comments
1			
2			
3			
4			
5			
6			
7			
8			
9			
10			
11			
12			
13			
14			
15			
16			
17			
18			
19			
20			

Date returned to University of Alberta _____

Appendix D. Guiding Questions for In-depth Interviews with Aboriginal Youth



“Diagnosis and Care of HIV Testing Among Aboriginal Youth”



November 17th, 2004

Prior to interview: Overview of project and explanation of interviews leading to informed consent.

Preamble: Say something about the topic of the interviews and what we’re hoping to achieve. Are there any questions about the interview or the project?

Possible warm-up questions: How did you hear about these interviews? How long have you been associated with this centre? Where do you usually go for your health services?

1) Why do some Aboriginal youth decide to have an HIV test, while others do not?

- **Have you ever considered having an HIV test? Please explain.**
 - What are some reasons that young people would have an HIV test?
 - What stops youth from getting tested?
 - If you did something that you knew was risky, do you think you’d go get tested? Is there anything that would prevent you from getting tested?

2) How do Aboriginal youth view HIV testing?

- **When you and your friends talk about getting an HIV test, what kinds of things do you say/talk about?**
 - What was it like to get tested? How did you feel before you went in? During the test? After the test?
 - Where would you go if you wanted to get an HIV test? Please explain.
 - What would make you decide to have a test?

3) What is the experience of Aboriginal youth when they present for testing?

- **Have you ever had an HIV test? What was that like for you? (What have your friends said about getting tested?)**
 - Why did you get tested?
 - Where did you have it done?
 - Who did the test?
 - What did you talk about?
 - Were all your questions answered?
 - Would you change anything the test? Was there any part of it you didn’t like?

- What would have made that a better experience for you?

4) What is the relationship between HIV testing and the decision to initiate treatment?

- **Do you think that getting an HIV test will make people get treatment?**
- **How do you think youth feel when they find out they are HIV positive?**
 - Do you and your friends ever talk about HIV testing or treatment?
 - Has anyone ever talked to you about the various ways that HIV can be treated?
Please explain
 - Do you know anyone (eg yourself, friends, family) who has decided to start treatment?
 - Who did you talk to about your test result? Please explain

5) How do Aboriginal youth make decisions about the care and treatment of their HIV illness?

- **In your experience or the experience of your friends, how do young people make decisions about the care and treatment of their HIV infection?**
 - Why do you think that someone who is HIV positive would start treatment?
 - In your opinion (or experience) what are appropriate ways to treat HIV infection?
 - Why would someone not want treatment? Why would they stop?
 - Who would you talk to about beginning/continuing treatment?

6) Support Services (eg social, health, housing)

- What types of services do you currently use?
- How long have you been using these services?
- Why did you start to use these services?

Is there anything you'd like to add?

Appendix E. Demographic Questions for Interview Participants

(After tape is off)

INTERVIEW DATE AND NUMBER: _____

MALE/FEMALE: _____ AGE: _____

ABORIGINAL BACKGROUND?

First Nation

Métis

Inuit

Other _____

EVER HAD AN HIV TEST

Yes

No

HIV POSITIVE

Yes

No

IF YES, LENGTH OF TIME SINCE DIAGNOSIS: _____

WAY YOU WERE INFECTED (Do you know how you were infected?):

IV drug use

Blood or blood product transfusion

Sex with a man

Sex with a woman

Don't know

EDUCATIONAL BACKGROUND (last attained education level):

Grade school

Some high school

Finished high school

Some college/university

Finished college/university

Graduate degree

Appendix F. HIV Testing and Care Brochure (cover page)

Why are we doing this research?

- **To find out what you think about HIV testing and care in Canada.**
- If you've never had an HIV test, we'd like to know why. If you have had an HIV test, we'd like to hear about your experiences.

What are we hoping to achieve?

- **To make HIV testing and care more comfortable for Aboriginal youth.**
- We can only do this by understanding what you think about the way testing and care is delivered now, and the changes that you would like to see made.

FACTS ABOUT HIV & ABORIGINAL YOUTH

- Aboriginal youth are being infected by HIV at an earlier age than non-Aboriginal youth.
- 28.6% of Aboriginal Canadians who are infected with HIV/AIDS are under the age of 30.
- Very little is known about the HIV testing and care experiences of Aboriginal youth across Canada.

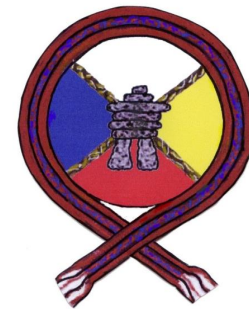
How can you contact us?

In Western Canada, contact Sonia Isaac-Mann (Project Coordinator) at (780) 492-8319 or sti@ualberta.ca.

In Eastern Canada, contact Tracey Prentice (Project Coordinator) at (613) 567-1817 ext. 113, or traceyp@caan.ca.

You can also see _____ at your local participating organization.

HIV Testing and Care in Aboriginal Youth



A Community-Based
Research Project

Testing and Care Brochure (inside page)

Who can participate in this project?

YOU CAN!

If you are:

- An Aboriginal Canadian
- Between 15-30 years old, AND
- able to communicate in English or French,

we'd like to know what you think about HIV testing and care in Canada.

You do not have to be HIV+.

You do not have to have had an HIV test.

What will you be asked to do?

- Spend 20-30 minutes filling out a survey about your thoughts and experiences of HIV testing and care.

What else do you need to know?

- No one, besides the researchers, will ever know that you filled out the survey, unless you tell them yourself.
- You may answer only the questions that you want to answer, and you may stop answering the questions at any time. Your services will not be affected by participating in the survey.
- Your name and your responses to the survey questions will not be identified in any way.
- You will receive a small gift for helping us with this research.
- The results of the survey will be made available to you through your participating organization.

Who are we?

- We are a research team concerned about HIV infection in Aboriginal youth.
- We are guided by an Aboriginal Advisory Committee made up of Elders, Youth, and spokespersons from Aboriginal communities all across Canada.
- We are researchers from various Aboriginal communities, from CAAN (the Canadian Aboriginal AIDS Network), from Health Canada, and from the Universities of Alberta, Calgary, Ottawa, and Toronto.

IMPORTANT:

Si vous avez besoin de compléter le questionnaire en Français, laissez savoir la personne qui fait passer l'entrevue dans votre organisation.

Appendix G. Participant Poster

This poster was placed in participant organizations to recruit interview participants.

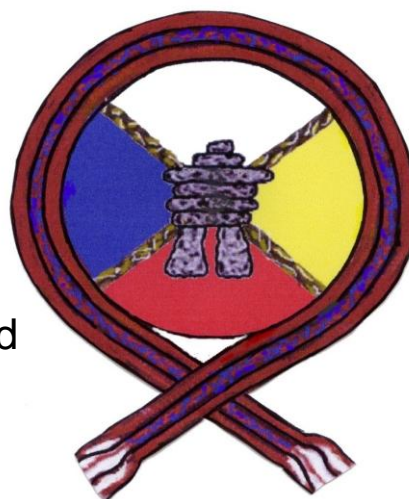
HIV TESTING AND CARE IN ABORIGINAL YOUTH

A Community-Based Research Project

If you are: an Aboriginal Canadian, between 15-30 years old,
AND able to communicate in English or French,
we'd like to know what you think about HIV testing
and care in Canada.

Things you need to know:

- You will spend 30 - 50 minutes to complete the interview.
- You or your responses to the questions, will not be identified in any way.
- You can do the interview in English or French.



For more information on how you can participate, please see


Appendix H. Business Card for Testing Project

This information card (actual size) was given to potential survey recruits. The colors on this card are consistent with the project colors as illustrated on the cover of this report.

HIV Testing and Care in Aboriginal Youth

A Community-Based Research Project

We'd like to know what you think about HIV testing and care in Canada.

<p>You can participate if you are:</p> <ol style="list-style-type: none"> 1. an Aboriginal Canadian; and 2. between 15-30 years old 		<p>How to contact us:</p> <ul style="list-style-type: none"> -Western Canada, Sonia Isaac-Mann (780) 492-8319 or sis@ualberta.ca -Eastern Canada, Tracey Prentice (613)567-1817 or traceyp@caan.ca
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Things you need to know:

You will spend 20-30 minutes filling out a survey.
 Your name and everything you tell us will be completely confidential.
 You can fill out the survey in English or French.

Appendix I. Advisory Committee Terms of Reference

The Diagnosis and Care of HIV Infection in Canadian Aboriginal Youth
May 2003

Mandate

The Advisory Committee will provide advice and guidance to the research team related to the project “The Diagnosis and Care of HIV Infection in Canadian Aboriginal Youth”. This guidance will attempt to reflect the diversity of First Nations, Métis and Inuit Communities.

Membership

The membership will consist of 8-10 Aboriginal community members with experience in one or more of the following areas: community-based research; HIV/AIDS programs/policies; Aboriginal health issues; or living with HIV/AIDS. Care will be taken to include elders and youth in this membership.

Meetings

Members are required to attend meetings that will take place two to three times a year in Ottawa for a two-year period from April 2003 to April 2005. Additional telephone conversations and correspondence may be required to provide ongoing guidance to the research team. Members of the Advisory Committee and the research team may chair meetings, or specific discussions within meetings. Members should inform the project coordinator if they are unable to attend a meeting.

Activities

The Committee will be responsible for the following activities:

To contribute to the overall vision of the research project.

To provide guidance and support to the research team and their activities.

- To identify and discuss emerging issues related to the research project.
- To review, evaluate and provide feedback on the research process as requested by the research team.
- To share relevant information and opportunities related to the research project and the framework for the research.
- To participate in the development of strategies to communicate research findings
- To review and assist in the interpretation of the research findings
- To assist in building awareness of the project within communities and organizations.

1. Reports

A record of discussions, major issues and advice given will be prepared by the project coordinator following each Advisory Committee meeting and will be made available to the Advisory Committee Members.

At each Committee meeting, a verbal or written report will be provided the Principal Investigator or designate to Advisory Committee members in order to update them on the progress of the research project.

2. Confidentiality

All members will sign an oath of confidentiality, which will be kept by the project coordinator.

3. Definitions

Aboriginal: The term Aboriginal as used in this study includes individuals who self-identify as Métis, First Nations, or Inuit, regardless of status.

Appendix J. Community Solutions Workshop Documents

A. Community Solutions Workshop Poster. Colors on Poster are consistent with project colors illustrated on the cover of report.

HIV TESTING AND CARE IN ABORIGINAL YOUTH

A Community-Based Research Project

You are invited to.....

a Community Solutions Workshop!


- Where research findings from the “HIV Testing and Care in Aboriginal Youth” study will be discussed.
 - More on why they should attend or what will go on??
- The work shop is two days before the Canadian Aboriginal AIDS Network General Meeting.

Details

When: October 4th & 5th, 2005

Where: Regina, Saskatchewan
Ramada Inn

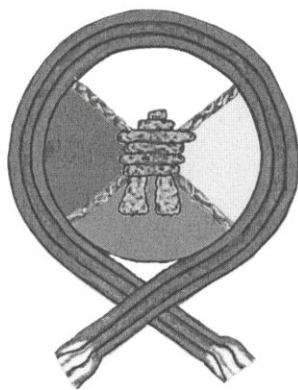
- Lunches will be provided but additional meals, transportation, & accommodation will be at your expense.
- Hope to see you there!!



For more information on how you can attend, please contact Tasha Pachal by phone: (403) 492-8319 or email: tpachal@ualberta.ca

B. Community Solutions Workshop Agenda. Colors on agenda are consistent with project colors illustrated on cover of report.

Community Solutions Workshop



**The Diagnosis and Care of
HIV**

**Infection in Canadian
Aboriginal Youth**

October 4th and 5th, 2005

October 4th, 2005

Time	Activity	Presenter
9:00 am	Opening Prayer	Elder
9:05-9:45 am	Introduction	Judy Mill & Randy Jackson
9:45-10:30 am	Sample and Participant Characteristics	Tracey Prentice
10:30-11:00 am	BREAK	
11:00-12:00 pm	The Decision to Test	Tom Wong & Judy Mill
12:00-1:00 pm	LUNCH	
1:00-2:00 pm	The Decision to Test	Tom Wong & Judy Mill
2:00-2:30 pm	BREAK	
2:30-4:30 pm	The Experience of HIV Testing	Cathy Worthington & Randy Jackson

Community Solutions Workshop Agenda continued.

Community Solutions Workshop

October 5th, 2005

Time	Activity	Presenter
9:00-10:30 am	Relationship Between Testing and Care	Chris Archibald, Judy Mill & Tracey Prentice
10:30-11:00 am	BREAK	
11:00-11:30 am	Main Themes/ Home Video	Tasha Pachal & Susan Sommerfeldt
11:30-11:55 pm	Closing Remarks	Judy Mill
11:55-12:00 pm	Closing Prayer	Elder
12:00 pm	LUNCH with CAAN	

Thanks for Coming!!!

Appendix K. Presentations

Oral and poster presentations:

Jackson, R. & Prentice, T. (2007, March). *“A little too cold”*: The diagnosis and care of HIV/AIDS infection in Canadian Aboriginal youth. Invited oral presentation at the annual conference of the Healing Our Spirit BC Aboriginal HIV/AIDS Society, Victoria, BC.

Jackson, R. & Worthington, C. (2007, February). *The diagnosis and care of HIV infection in Canadian Aboriginal youth*. Plenary session. Walking a Path to Wise Practices: First Aboriginal HIV/AIDS CBR Capacity Building Conference Vancouver, British Columbia, February 13-16, 2007

Archibald, C., Prentice, T., Mill, J. Jackson, R., Worthington, C., Wong, T., Sommerfeldt, S. & Myers, T. (2006, August). *HIV testing and access to care: The experience of Canadian Aboriginal youth*. Poster Presentation at the XVI International AIDS 2006 conference. Toronto, Ontario.

Wong, T., Prentice, T., Mill, J., Jackson, R., Sommerfeldt, S., Worthington, C., Archibald, C. & Myers, T. (2006, August). *The diagnosis and care of HIV infection in Canadian Aboriginal youth: Engaging the community in research*. Oral presentation at XVI International AIDS 2006 conference. Toronto, Ontario.

Masching R., Y. Allard, T. Prentice, R. Jackson, J. Mill & K. Barlow. (2006, August). *Aboriginal perspectives on knowledge translation in community-based HIV/AIDS research*. Oral presentation at XVI International AIDS Conference, Toronto, Ontario.

Masching, R., T. Prentice, Y. Allard, R. Jackson & J. Mill. (2006, May). *Walking the talk: One example of knowledge translation in Aboriginal community-based HIV/AIDS research*. Oral presentation at the 14th Annual Canadian Conference on HIV/AIDS Research, Quebec City, Quebec.

Worthington, C., Jackson, R., Mill, J., Prentice, T., Archibald, C., Wong, T., & Myers, T. (May, 2006). *“A little too cold”*: Aboriginal Youth speak about the experience of HIV testing. Poster presentation at the 14th Annual Canadian Conference on HIV/AIDS Research, Quebec City, Quebec.

Mill, J. & Jackson R. (2006, April) *“Totally blank to their mind”*: Aboriginal youth deciding to test for HIV. Plenary session. Canadian Association of Nurses in AIDS Care. Conference Montréal.

Mill, J., Jackson, R., Worthington, C., Archibald, C., Prentice, T., Wong, T. & Sommerfeldt, S. (2005, October). *Community solutions workshop: HIV testing and care among Aboriginal youth*. Two-day dissemination workshop presented in conjunction with Canadian Aboriginal AIDS Network Skills Building & Annual General Meeting, Regina, SK.

Mill, J., Jackson, R., Worthington, C., Myers, T., Archibald, C., Wong, T., Prentice, T., & Isaac Mann, S. (2005, May). *HIV testing decisions and experiences of Canadian Aboriginal youth*. Poster presentation at the 13th Annual Canadian Conference on HIV/AIDS Research. Vancouver, British Columbia.

Published Abstracts

Archibald C., Prentice, T., Jackson, R., Worthington, C., Wong, T., Sommerfeldt, S., Myers, T. & Mill, J. (2006, August). *HIV testing and access to care: the experience of Canadian Aboriginal youth*. AIDS 2006 - XVI International AIDS Conference, 2006. Abstract no. TUPE0237.

Masching R., Allard, Y., Prentice, T., Jackson, R., Mill, J. & Barlow, K (2006, August). *Aboriginal perspectives on knowledge translation in community-based HIV/AIDS research*. AIDS 2006 - XVI International AIDS Conference, 2006. Abstract no. THAD0305.

Wong T., Prentice, T., Mill, J., Jackson, R., Sommerfeldt, S., Worthington, C., Archibald, C. & T. Myers (2006, August). *The diagnosis and care of HIV infection in Canadian Aboriginal youth: engaging the community in research*. AIDS 2006 - XVI International AIDS Conference, 2006. Abstract no. THAD0303.

Masching, R., Prentice, T., Allard, Y., Jackson, R. & J. Mill (2006). *“Walking the talk”: An Aboriginal perspective on knowledge translation*. The Canadian Journal of Infectious Diseases and Medical Microbiology, Vol. 17 Supplement A May/June: 61A. [412].

Worthington, C., Jackson, R., Prentice, T., Mill, J., Archibald, C., Wong, T., Sommerfeldt, S. & T. Myers (2006). *“It’s a little cold”: Aboriginal youth speak about the experience of HIV testing*. The Canadian Journal of Infectious Diseases and Medical Microbiology, Vol. 17 Supplement A May/June: 68A. [437P].

Non Peer-Reviewed Publications & Monographs

Prentice, T., Jackson, R., Wong, T., Mill, J., et al. (2007, in press). *Diagnosis and care of HIV infection among Canadian Aboriginal youth: Engaging the community in research. Compass: A Community Resource in HIV/AIDS-Related CBR.*

Prentice, T., Archibald, C., Mill, J., Jackson, R. Wong, T., Worthington, C., Myers, T. & Sommerfeldt, S. (2006, Spring). *HIV testing and care among Aboriginal youth: A summary of findings related to the relationship between HIV testing and the decision to seek care. Canadian Treatment Action Council Newsletter, Volume 8, Issue 2: 4-5.*

Appendix L. Community Solutions Workshop Final Report

This report was prepared and submitted to CIHR on June 28, 2007

HIV Testing and Care for Aboriginal Youth
CIHR Final Report

*HIV/AIDS Community-Based Research Program – Aboriginal – Capacity Building
Workshop Grant # 74356*

Project Summary

This project, *Community Solutions Workshop*, was a two-day research dissemination workshop held in Regina, Saskatchewan in October 2005 during the preliminary data analysis phase of a larger study, *The Diagnosis and Care of HIV Infection in Canadian Aboriginal Youth*. The overall goal of the workshop was to discuss and verify findings from the research study, and to get community feedback on the next steps in the research process. This was also an opportunity to assist with the development of the research skills of the advisory committee and promote culturally relevant research with non-Aboriginal researchers.

The concurrent research project, *The Diagnosis and Care of HIV Infection in Canadian Aboriginal Youth* (“Diagnosis and Care Project”) used survey and interview data to explore HIV testing *decisions, experiences, and subsequent decisions about care*. The inquiry was assisted through a community advisory committee of Aboriginal youth and agency representatives as well as interested youth and elders from various Aboriginal backgrounds and locations. Using an exploratory, descriptive mixed methodology guided by community involvement, valuable information about HIV testing practices in the young Aboriginal population was obtained. The principles of ownership, control, access and possession (OCAP) directed the research project to ensure Aboriginal self-determination in the research.

The Diagnosis and Care project collected data from youth in British Columbia, Alberta, Manitoba, Ontario, Quebec, Northwest Territories, and Newfoundland-Labrador. Twenty eight youth were interviewed and surveys were completed by 413, facilitated by agencies utilized by Aboriginal youth in the various communities. Approximately half of the young people surveyed had received an HIV test. Key findings from this study revealed:

- *Decisions to test for HIV* – those who did have HIV testing sought it after high-risk behaviors or were pregnant or thought that they were. In addition a number of youth stated that HIV testing was part of their routine health care or screening for STDs. Those youth who had not had HIV testing done believed that their risk was low. Interviewed participants identified a common feeling of invulnerability in relation to their HIV risk as well as the notion that HIV/AIDS and sexuality is a taboo subject, particularly in small reserve communities.

- *Experience of having an HIV test* – the majority of youth were tested in the community where they were currently living and most had gone to a physician for a test. Half of the surveyed youth either did not receive or did not recall receiving any information about HIV offered at their most recent test. The majority of the youth described an emotional reaction to testing, most often anxiousness or apprehension about the possibility that the results would be positive. The youth offered advice for testing services centering on interpersonal style (respect), emotional support including confidentiality, and the availability of services and information relating to HIV.
- *Relationship between testing and decisions about care* – of the surveyed youth who tested positive for HIV, there appeared to be a tendency to delay seeking or initiating medical care. Explanations for the delay included fear, preoccupation with addictions, indifference or lack of information. This suggests that post-test counselling could be an important point of intervention for Aboriginal youth. Feeling healthy and the absence of symptoms were factors associated with delays in seeking care. Family and community support, particularly Aboriginal AIDS service organizations and community/public health clinics were identified as being key factors in managing care.

This CHIR funded capacity building Workshop brought together the advisory committee, research team and other key stakeholders (eg.

HIV TESTING AND CARE IN ABORIGINAL YOUTH
A Community-Based Research Project

You are invited to.....
a Community Solutions Workshop!

The purpose of the workshop is to:

1. Share research findings from the "HIV Testing and Care in Canadian Aboriginal Youth" study
2. Discuss strategies to disseminate the findings with Aboriginal communities and organizations

NOTE: This a pre-workshop of the Canadian Aboriginal AIDS Network Annual General Meeting, October 5th to 7th, 2005.

Details

When: October 4th, 2005—full day
October 5th, 2005—morning

Where: Regina, Saskatchewan
Ramada Inn

Cost:

- there is no fee for the workshop
- lunches will be provided
- participants responsible for meals, transportation, & accommodation
- hope to see you there!!

To register for the workshop, please contact Tasha Pachal by phone:
(780) 492-8319 or email: tpachal@ualberta.ca
by Friday September 23rd, 2005

research team and other key stakeholders (eg. APHAs, decision-makers, representatives from ASOs) to review preliminary findings from the larger study. The *Community Solutions Workshop* (“the Workshop”) was planned to coincide with the annual general meeting of the Canadian Aboriginal AIDS Network (CAAN) held in Regina, Saskatchewan on October 4th & 5th, 2005. Information about the Workshop was distributed to individuals and agencies through CAAN’s communication networks including newsletters and websites. The partnership with CAAN was instrumental to ensuring that a wide network of individuals and agencies were informed about the Workshop. Additionally, direct electronic posters (displayed at left) were distributed to participating agencies and others as requested. Advisory committee members were individually contacted and provided with registration information.

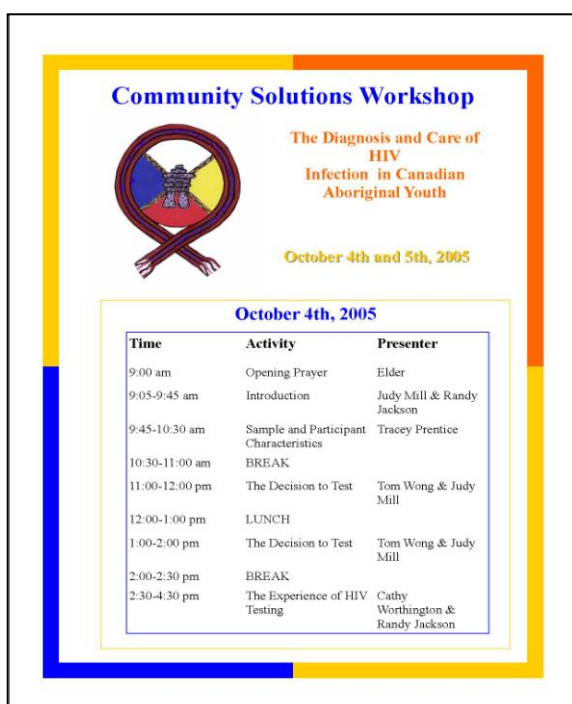
The format for the Workshop was closely aligned with the research questions and included in-depth discussion of: the decision to test; the experiences of HIV testing; and the relationship between testing and care. The cultural appropriateness of the workshop was enhanced through consultation with Aboriginal researchers, advisory team members and

CAAN personnel. Each day began with prayer offered by an Aboriginal Elder who was invited to the Workshop. Attendance ranged from 25-40 individuals in each session. At the beginning of the workshop the research methodology, description of the sample, and strategies to operationalize OCAP were summarized. The discussion of methodology helped to increase participants' knowledge of community-based research and research in Aboriginal communities. In each session two of the members of the research team introduced the topic, summarized the findings, and invited discussion and feedback. Written feedback was collected following each session and notes of the oral comments were taken. The final session in the Workshop focused on possible "next steps" to address issues related to HIV testing in Canadian Aboriginal youth. The closing session featured a *talking stick*, a traditional Aboriginal custom, during which participants were invited to individually speak freely and uninterrupted.

Objectives

CAAN had identified capacity building in the area of knowledge translation and research dissemination as an important focus for researchers working with community based organizations. The dissemination of the findings from the "Diagnosis and Care" project provided an excellent opportunity for the research team to work with community partners in the development of knowledge translation strategies. This was reflected in two specific objectives for the Workshop:

- to build research capacity among the Aboriginal community partners in relation to knowledge translation
- to engage Aboriginal community members in designing culturally and community-appropriate strategies for disseminating findings from the "Diagnosis and Care" project



Community Solutions Workshop

The Diagnosis and Care of HIV Infection in Canadian Aboriginal Youth

October 4th and 5th, 2005

October 4th, 2005

Time	Activity	Presenter
9:00 am	Opening Prayer	Elder
9:05-9:45 am	Introduction	Judy Mill & Randy Jackson
9:45-10:30 am	Sample and Participant Characteristics	Tracey Prentice
10:30-11:00 am	BREAK	
11:00-12:00 pm	The Decision to Test	Tom Wong & Judy Mill
12:00-1:00 pm	LUNCH	
1:00-2:00 pm	The Decision to Test	Tom Wong & Judy Mill
2:00-2:30 pm	BREAK	
2:30-4:30 pm	The Experience of HIV Testing	Cathy Worthington & Randy Jackson

These objectives were met during the Workshop. Many of the participants in the Workshop were involved in the initial stages of the "Diagnosis and Care" project. Youth members of the advisory committee who were able to attend expressed both interest and satisfaction in seeing the research process unfold and being able to participate in discussions about the findings. Discussion in the sessions was lively and free-flowing. Community agencies compared their own experience with the trends identified in the data.

Community Solutions Workshop		
October 5th, 2005		
Time	Activity	Presenter
9:00-10:30 am	Relationship Between Testing and Care	Chris Archibald, Judy Mill & Tracey Prentice
10:30-11:00 am	BREAK	
11:00-11:30 am	Main Themes	Tasha Pachal & Susan Sommerfeldt
11:30-11:55 am	Closing Remarks	Judy Mill
11:55-12:00 pm	Closing Prayer	Elder
12:00 pm	LUNCH with CAAN	

Thanks for Coming!!!

The research team received suggestions from several community partners regarding possible future phases to the research and further inquiry into some aspects of the findings. During the final Workshop session, strategies to ensure that community agencies and relevant governmental departments received the research findings were discussed. Participants felt that the findings were relevant to policy and program planning as well as to inform existing interventions and programs.

Key Findings from the Workshop

Participants in the Workshop offered feedback to the research team on the study findings. They shared anecdotes from their own experiences that confirmed the findings and suggested that the information that they had heard and learned during the Workshop would impact their work.

Summary of participants' recommendations to the research team:

Decision to test

- the data was startling and representative of information needed in planning interventions
- take the stories (qualitative data) to the community – stories “hit home”
- suggest comparing findings with those of Canadian Youth Sexual Health Study (sic) and Canadian Street Youth Study (sic)
- further inquiry needed in rural communities

Experience of testing

- reminders for front-line workers
- results should be shared with health care students to enhance their education related to HIV testing
- alarming information regarding the treatment of youth seeking testing services
- further study needed about the experience of having an HIV test

Relationship between testing and care decisions

- appreciate opportunity to give input to researchers
- instructional and informative

During the sessions of the Workshop, notes of the discussion and comments were recorded and later circulated to the researchers for their use in writing the final report.

Disseminations of Findings

The findings from the Workshop were integrated with the findings from the “Diagnosis and Care” project. A comprehensive final report will be completed in mid-2007 and will be circulated to the participating agencies and Workshop participants. The research team is developing an information sheet in paper format summarizing the research findings for distribution by ASOs and health care organizations. In addition, electronic information about the Workshop and “Diagnosis and Care” project will be made available through CAAN’s website.

Dissemination of the study findings has also been carried out through presentations at multiple community and academic conferences. Publications for peer-reviewed journals are in preparation.

Appendix M. Power Point Slides Presented at Workshop.

The following pages contain the power point slides presented at the Community Solutions Workshop. Presenters were Randy Jackson (Introduction), Tom Wong and Judy Mill (The decision to test).