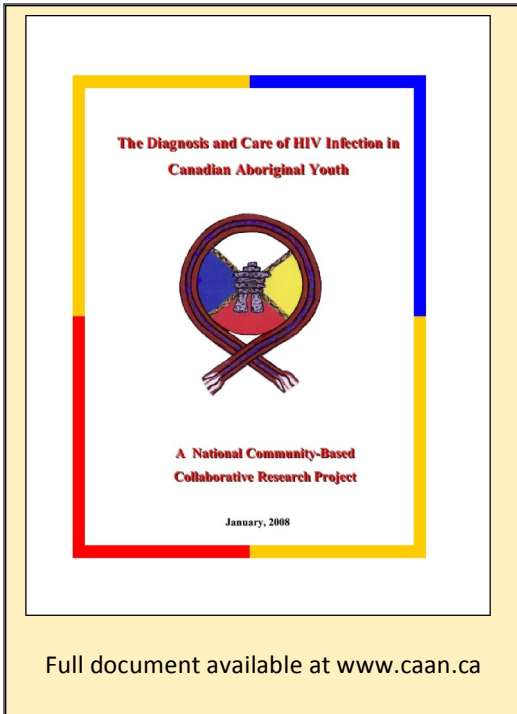


## RESEARCH REPORT SUMMARY

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

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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. **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.** An advisory committee included Elders, family members of persons diagnosed with HIV, and Aboriginal youth. This study explored HIV testing and care decisions in Canadian Aboriginal youth. **Three main question areas were: *the decision to test; the testing experience and the relationship between testing and care.***

**Design and Methods:** The project used a community-based research (CBR) approach guided by Ownership, Control, Access and Possession (OCAP) principles for research involving Aboriginal communities. **The research team developed the research questions and the design of the study with guidance from a community advisory committee.** An exploratory descriptive design was selected for the study because there was limited knowledge about HIV testing in Aboriginal youth in Canada.

#### Survey Participants

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 as being First Nations (56.2%).
- Most survey participants spoke English (92.3%).
- The majority identified 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%).
- 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.

**Sample:** 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. Youth from all ten provinces and one territory contributed to the data set.

#### Interview Participants

**Twenty-eight interviews with Aboriginal youth selected from the survey participants were conducted.**

- Interview participants were ages 16-30 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.

**Analysis and Findings:** Survey responses were coded and entered into a statistical software program for quantitative data analysis. The interviews were audio taped and transcribed verbatim. Analysis of the qualitative data was completed by members of the research team using an inductive approach.

### **The decision to test**

The most common reasons 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, told the interviewer 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.

### **Reasons for delaying 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.

### **The testing experience**

Fifty-one percent of the survey respondents (210 of 413 youth) had been tested for HIV at least once. Most (86.5%) received their 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 said they were treated with fear (12.3%), discrimination (11.2%) or avoidance (9.7%)**. Survey respondents expressed feelings of anxiety and apprehension about the possibility of testing HIV positive.

**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 at the time of diagnosis, including 6 (23.1%) who were told they had AIDS at the time of diagnosis. This suggests that **a large number of HIV diagnoses among Aboriginal youth are not made until late in the course of the disease**.

Also, only 12 of 25 (48.0%) indicated they had seen a physician after the positive HIV test result, and overall, only 38% of Aboriginal youth who had a positive HIV test had seen a physician within one year of their diagnosis. Interview participants stressed the importance of stable housing, family support, and support services such as AIDS service organizations in helping them manage their HIV. Better counselling after diagnosis and community and street outreach may be effective means of connecting more Aboriginal youth to care.

**Aboriginal youth need supportive health policy and models of service provision which encourage testing in youth who engage in high-risk behaviours.**

### **Suggested reference:**

Mill, J., Archibald, C., Wong, T., Jackson, R., Worthington, C., Myers, T., Prentice, T., & Sommerfeldt, S. (2008). *The Diagnosis and Care of HIV Infection in Canadian Aboriginal Youth: A national community based collaborative research project*. Edmonton, AB: University of Alberta.

