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### HIV testing experiences of Aboriginal youth in Canada: service implications

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## HIV testing experiences of Aboriginal youth in Canada: service implications

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The objective of this study was to explore HIV testing experiences and service views of Canadian Aboriginal youth in order to provide information for HIV testing services. An exploratory, mixed-method, community-based research design was used for this study. Findings reported here are from 210 survey participants who had experienced an HIV test. Youth were recruited through 11 Aboriginal organizations across Canada, including AIDS service organizations, health centers, community organizations, and friendship centers. Youth who had tested for HIV ranged in age from 15 to 30 years of age (20% were <20), and came from First Nations (75%), Métis (14%), and Inuit (9%) backgrounds. Participants lived in all provinces and one territory. Over half (62%) were female. While the majority of survey respondents indicated at their last HIV test they had been treated with care (80%), respect (77%), or kindness (76%), some reported being treated with hostility (19%), fear (12%), discrimination (11%), avoidance (10%), or being treated in a bored way (15%). When asked about information they had received, 28% of survey respondents could not remember; 23% said they were not given any information, and 24% said their questions were not answered. Emotional reactions to testing ranged from anxiety/apprehension (64% of survey respondents) to being “calm” (19%). When asked for suggestions to improve testing services, participants indicated emotional support, compassion, professional yet personable services, and personalized HIV information were important. Study results suggest that to facilitate HIV testing for Aboriginal youth, testing services and counseling must be respectful, compassionate, non-judgmental, and culturally responsive in order to provide emotional support and HIV information that is meaningful and memorable.

**Keywords:** HIV/AIDS; Aboriginal; youth; HIV testing; service satisfaction

### Introduction

Aboriginal peoples (First Nation, Inuit, Métis) comprise only 3.8% of Canada’s total population (Statistics Canada, 2008), but in 2006 accounted for 27% of new HIV infections in provinces/territories that provide ethnicity data (Public Health Agency of Canada, 2007a). Almost one-third (32.4%) of the positive HIV test reports from 1998 to 2006 for Aboriginal persons were among those younger than 30 years of age, a rate higher than that of non-Aboriginal youth (21%) (Public Health Agency of Canada, 2007b). For Aboriginal youth, high rates of teenage pregnancy and sexually transmitted infections (Ontario Federation of Indian Friendship Centres, 2002; Shields et al., 2004), inconsistent condom use (Calzavara et al., 1998), along with feelings of invulnerability and the perception among youth that HIV happens to “other people” in “other communities” (Larkin et al., 2007; Public Health

Agency of Canada, 2007c) contribute to susceptibility to HIV infection. In addition, interactions with HIV prevention services may be influenced by historical inequality and social-structural conditions that promote Aboriginal youths’ understandings of HIV as a “death sentence” (Larkin et al., 2007); distinct cultural practices in health care engagement (Smylie et al., 2001); and Aboriginal peoples’ distrust of outsiders (Bucharski, Reutter, & Ogilvie, 2006).

The availability of voluntary, client-initiated testing and counseling is a key component of comprehensive HIV prevention programs (Public Health Agency of Canada, 2006; UNAIDS, 2004). Despite changes to HIV testing guidelines in some jurisdictions that may encourage less test counseling (Branson et al., 2006), HIV test counseling remains central to testing as it provides an opportunity to promote behavior change and potentially control the spread of HIV (Holtgrave & McGuire, 2007; Norton, Miller, & Johnson, 1997; Weinhardt, Carey, Johnson, &

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Bickham, 1999). It also provides an opportunity to link those who test HIV positive to treatment (Hult, Maurer, & Moskowitz, 2009; Obermeyer & Osborn, 2007).

From the test provider perspective, best practices in HIV test counseling include ensuring provision of information/education to support HIV risk reduction; individualization of risk assessment and need for psychological support; ensuring test results are given in person; providing HIV information and service referrals; and facilitating partner notification (Myers, Worthington, Haubrich, Ryder, & Calzavara, 2003). HIV test recipients desire convenient services in a private location where they can receive personalized information and decision-making support about the test in order to obtain appropriate information and allay anxiety and concern over the social consequences and stigma around HIV (Obermeyer & Osborn, 2007; Worthington & Myers, 2002, 2003). Although counseling is recommended there is evidence it is not always provided (Monette, Albert, & Waalen, 2001; Silvestre, Gehl, Encandadela, & Schelzel, 2000).

The most common reasons youth, including Aboriginal youth, seek an HIV test are because they have been advised by a health care worker; have engaged in a high risk behavior (i.e., injection drug use, unprotected sex); for prenatal screening; or because they are feeling sick (Bucharski et al., 2006; Grant et al., 2006; Mackellar et al., 2006; Rotheram-Borus, Gillis, Reid, Fernandez, & Gwadz, 1997; Samet & Winter, 1997). Very little information is available about youth perceptions on test counseling; however, one study of HIV testing sites in the USA reported that only 28% of youth said the counselor did a "good" job helping them identify their HIV risk behaviors (Schneir, Belzer, & Adivi, 1998).

While there is a growing body of work on Aboriginal youth and HIV risk (e.g., Larkin et al., 2007; Marsiglia, Nieri, & Stiffman, 2006; Mehrabadi et al., 2008), there is little literature that focuses on HIV testing and Aboriginal youth. Given the vulnerability of Aboriginal youth to HIV, the need to develop appropriate HIV testing services, and the lack of information in general on youth experiences and views of HIV testing and counseling, the purpose of this study was to examine the experience of Aboriginal youth in the test encounter and ascertain their views on improving HIV testing and counseling.

## Method

An exploratory mixed-method design was employed, including a cross-sectional survey and in-depth interviews (Mill et al., 2008). Here, we report on survey findings. Aboriginal health and friendship centers and

AIDS service organizations across Canada assisted with recruitment of participants. Aboriginal youth between 15 and 30 years of age, English or French speaking, were invited to participate. The term Aboriginal referred to youth who self-identified as First Nations (status or non-status), Métis, or Inuit.

A community-based research approach, incorporating the principles of community ownership, control, access and possession (OCAP) for research involving Aboriginal communities, which are consistent with Canadian Institutes of Health Research (CIHR) guidelines (2007), guided the study (Patterson, Jackson, & Edwards, 2006). In order to honor OCAP principles, a community advisory committee (CAC; including Aboriginal youth and Elders) guided the study design, implementation and dissemination of the findings, and a participatory decision-making model was used. The participatory process allowed the research partners (including Aboriginal and non-Aboriginal researchers) to jointly make research decisions and share results with community. While there is an emerging literature on the challenges of sharing results (e.g., Cooper, 2007, 2008), in this study we faced no difficulties in presenting results or other aspects of the research process. Ethics approval was obtained from all participating institutions.

## Survey instrument

A self-administered survey was developed based on the published literature (Calzavara et al., 1998; Rotheram-Borus et al., 1997; Worthington & Myers, 2002) in consultation with the CAC. The 49-question survey included items on the decision to test, the testing experience and, for youth living with HIV, experiences of HIV care. Questions related to the testing experience included a series of categorical response questions, three multiple response questions, three sets of Likert-scale questions, and two open-ended questions. The instrument was pre-tested with the CAC and recruiting organization members to enhance face and content validity; translated into French; and then pilot tested with two groups of Aboriginal youth, one English and one French speaking (total  $n = 19$ ).

## Data collection

Convenience and network sampling (Wood & Ross-Kerr, 2006) were used to recruit youth to complete the surveys at 11 Aboriginal and Friendship Centers and AIDS Service Organizations in eight provinces/territories between January 2004 and February 2005. Participants were provided with a private space to complete the survey, and a research assistant was available to answer queries. The number of surveys

collected at the 11 sites ranged from 14 (3%) to 60 (14%).

### Data analysis

Bivariate analyses (Pearson's  $\chi^2$ ) were used to compare selected test experiences by HIV test results. Open-ended survey item responses were listed verbatim, reviewed to establish categories, and then categorized according to the emergent categories. These categories were then tabulated, and representative quotations were selected for presentation.

## Results

### Participants

Four hundred and thirteen (413) Aboriginal youth completed the survey. Youth living in all 10 Canadian provinces and one territory participated in the study. Approximately half (51%) of the survey respondents (210 of 413 Aboriginal youth) reported that they had ever been tested for HIV. Of the 210 youth who had tested for HIV, 26 youth (12%) indicated they had tested HIV positive, and 21 (10%) said their results were not clear or they had not received the result. See Table 1 for characteristics for the 210 youth who had tested for HIV.

The majority of youth (61%) who had tested for HIV had their first HIV test in the five years prior to the survey (1999–2004), and only 13% (28) of those who had ever tested for HIV reported that they had not tested within the last two years. The large majority (81%) of youth had their most recent test in the community where they were currently living/had lived at the time of the test. The largest percentage (34%) reported they had gone to a physician for their most recent HIV test, 17% reported testing at a hospital, 14% at a community/public health center and 14% at a walk-in clinic.

### The HIV test counseling experience

#### Information

Survey participants were asked about types of information they received when they went for their most recent HIV test. Twenty-eight percent could not remember what information they were given, and almost one quarter (23%) indicated they were not given any information (Table 2). Only one-fifth or less remembered being given information about specific issues such as protecting sexual partners from HIV (20%). There were no significant differences in the types of information youth reported receiving by HIV test result (positive, negative or don't know/unclear).

Table 1. Characteristics of survey participants who had ever had an HIV test ( $n = 210$ ).

Variable <sup>a</sup>	N	Percent
Age ( Mean $\pm$ SD years) range	23.4 $\pm$ 4.2	
15–30 years		
Gender		
Male	79	38
Female	130	62
Transgender	1	0.5
Aboriginal background		
First Nations status	132	65
First Nations non-status	21	10
Métis	29	14
Inuit	15	7
Inuvait	3	2
Other	5	2
Languages spoken by youth (not mutually exclusive)		
English	205	98
Aboriginal language	42	20
French	32	15
Sexual identification		
Heterosexual or straight	162	77
Gay/lesbian/two-spirit/bisexual	44	21
Other	3	1
Marital status		
Single	126	61
Common-law relationship	53	26
Married	11	5
Separated/divorced/widowed	13	6
Education		
Grade eight or less	27	13
Some high school	100	48
Completed high school	27	13
College/university	2	11
Some post-secondary	33	16
Religion and spirituality		
Followed a religion	80	38
Followed traditional Aboriginal practices	74	35
Place of residence		
Living in urban centre, population > 10,000	157	76
Own home/apartment	94	36
Parents' home	34	16
Friend's home	24	12
Rooming house	5	2
Shelter or safe house	14	7
Hotel	11	5
Homeless	15	7
Other living arrangement	11	5
Income sources		
Had job	65	31
Social support/welfare	88	42
No income	37	18

<sup>a</sup>Certain variables do not add up to 100% as only some sub-variables are shown. Many variables have missing data as participants could choose not to answer the survey questions or answer more than once per question.

Table 2. Information provided at most recent HIV test ( $n = 210$ ).<sup>a</sup>

	Frequency (percent)
I don't remember	59 (28)
Not given any information	49 (23)
Prevention for IDU	46 (22)
Protecting sexual partners	42 (20)
Effects of HIV disease	42 (20)
Support/counseling	35 (17)
Treatment for HIV infection	29 (14)
HIV reporting obligations	22 (10)

<sup>a</sup>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 indicated "yes, all of them," 26% indicated "yes, some of them," and 23.5% indicated "no." Youth who were HIV negative were more likely ( $\chi^2(4, N = 197) = 14.7, p < 0.01$ ) to report they had their questions answered (56%) than those who were HIV positive (42%) or those who didn't know/results not clear (25%).

#### *Perceptions of how treated*

Youth were also asked a series of questions about how they were treated during their most recent HIV test (Table 3). Over three quarters of participants felt they had been treated well, including 77% who said they were treated with respect. However, there was a significant minority who reported less positive perceptions, including being treated in a hostile (19%) or bored (15%) manner (Table 3).

#### *Being asked about sexual behavior and alcohol and drug use*

Seventy-two percent of youth who had been tested indicated that at their most recent HIV test they were

asked about their past sexual behavior. The majority (63%) of these indicated they felt comfortable when asked about sexual behaviors; however, a sizable minority reported less positive feelings, such as being scared (39%) or embarrassed (35%; Table 4). Similarly, the majority (63%) of youth indicated they were comfortable when being asked questions about alcohol and drug use, but a significant minority reported more negative responses (see Table 5).

#### *Emotional reaction to HIV testing*

The survey included an open-ended question asking youth to describe their emotions when taking an HIV test. Seventy-nine percent of youth who had an HIV test responded. The majority of comments (106/166, or 64%) summarized feelings of apprehension about the possibility of testing HIV positive, ranging from brief comments such as "holy shit scared" or "terrified" to more elaborate descriptions. One youth 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 ... 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." Beyond anxiety, six youth indicated that they felt "lost," "confused," or that they felt "negative about life."

Twelve (7%) youth who responded to the survey question reported negative feelings about the HIV test experience itself. These youth indicated they were "embarrassed," "ashamed," or "uncomfortable," and one wrote "You wonder what the person who is testing you is thinking." One youth indicated, "I don't like being questioned by a white doctor." Two youth reported being upset because they had been tested without their knowledge.

Table 3. Perceptions of how youth were treated at their most recent test ( $n = 210$ ).<sup>a</sup>

Characteristic: "I was treated [with]..."	Strongly agree/agree	Neutral	Strongly disagree/disagree
	Frequency (percent)		
Care	159 (80)	31 (16)	9 (5)
Respect	153 (77)	37 (19)	8 (4)
Kindness	151 (76)	40 (20)	8 (4)
Hostility	37 (19)	39 (20)	119 (61)
In a bored, disinterested way	29 (15)	47 (24)	120 (61)
Fear	24 (12)	27 (14)	144 (74)
Discrimination	22 (11)	32 (16)	141 (72)
Avoidance	19 (10)	32 (16)	145 (74)

<sup>a</sup>Frequency and valid percent excludes missing cases (i.e., "No Response" and "Do Not Know," etc.). Percentages may not total 100% due to rounding.

Table 4. Comfort with questions regarding sexual behavior ( $n = 199$ ).<sup>a</sup>

Characteristic: "I felt..."	Strongly agree/agree	Neutral	Strongly disagree/disagree
	Frequency (percent)		
Comfortable	94 (63)	37 (25)	18 (4)
Scared	57 (39)	36 (25)	54 (37)
Embarrassed	52 (35)	42 (28)	55 (37)
Ashamed	35 (24)	31 (21)	83 (56)
Upset	29 (20)	32 (22)	87 (59)
Angry	20 (14)	32 (22)	96 (65)

<sup>a</sup>Frequency and valid percent excludes missing cases (i.e., "No Response" and "Do Not Know," etc.). Percentages may not total 100% due to rounding.

A smaller percentage (31/166, 19%) reported little if any negative feelings about HIV testing. These youth reported feeling "normal" or "relaxed" when they had an HIV test. Three youth were more specific about why they felt this way; one wrote, "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."

#### *Advice from youth on improving the HIV testing experience*

Fifty-seven percent (121) of survey respondents 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 question respondents (27%) used this space to encourage others to get tested for HIV despite the anxiety it may provoke, with comments like "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." Five respondents suggested that youth should consult an elder or bring a relative or friend with them for support ("Bring a close friend to ensure you that everything will be okay").

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 (McQueen, 2000). Fifteen youth described "respectful" and "friendly" interpersonal styles, and other comments included in this category included, "Ask them in a way they don't feel ashamed," and "Have doctors that don't judge; it's not a bad thing to get tested." Comfort and emotional support were also commented on by six youth, for example, "Just to make the person feel at home – comfortable," and one youth advised test providers, "not to discriminate against them (i.e., youth) or treat them as if you are afraid of them." Six youth also indicated that "more information," or "more pre- and post-test counseling" would be helpful, and one commented on the information needs of health professionals (e.g., "Doctors and nurses strongly need to be aware of the disease").

In addition to the three major professional relationship components, four youth expressed concerns about confidentiality of the test results, informing individuals that they were being tested for HIV, and availability of HIV testing services. Three also suggested that HIV test results should be available more quickly. Finally, eight used the space to comment on their satisfaction with HIV testing experiences, with comments like "Nothing – maybe it's okay for me because I go to street nurses, and they are unjudgmental."

Table 5. Comfort with questions regarding alcohol and drug use at most recent HIV test ( $n = 195$ ).<sup>a</sup>

Characteristic: "I felt..."	Strongly agree/agree	Neutral	Strongly disagree/disagree
	Frequency (percent)		
Comfortable	78 (63)	36 (29)	10 (8)
Scared	29 (24)	30 (24)	64 (52)
Embarrassed	26 (21)	36 (29)	61 (50)
Ashamed	25 (21)	33 (27)	64 (52)
Upset	18 (15)	32 (26)	73 (59)
Angry	15 (12)	28 (23)	79 (65)

<sup>a</sup>Frequency and valid percent excludes missing cases (i.e., "No Response" and "Do Not Know," etc.). Percentages may not total 100% due to rounding.



## Discussion and conclusions

Results from this study with Aboriginal youth are generally consistent with results from other studies in North America on test recipients' experiences with HIV testing. Aboriginal youth desire respectful, sensitive interactions in order to receive personalized information and allay anxiety over HIV and the social consequences of HIV; however, it appears that youth may not be receiving this information and support during HIV test counseling, or if they are, are not receiving it in a manner that helps them remember it (Obermeyer & Osborn, 2007; Silvestre et al., 2000; Worthington & Myers, 2002, 2003).

Other studies have found that test counseling can be a very useful tool for young clients to help ease their testing anxiety, especially if the counselor is reassuring (Michaels Opinion Research for the Kaiser Family Foundation, 1999). Unfortunately, some HIV test counselors are missing valuable opportunities to be emotionally supportive, and to provide useful information on HIV and how to reduce one's risk of becoming infected (Bucharski et al., 2006; Michaels Opinion Research for the Kaiser Family Foundation, 1999). Going for an HIV test may provoke anxiety, especially during the waiting period as clients worry whether their test will be HIV positive (Ransom, Siler, Peters, & Maurer, 2005; Worthington & Myers, 2003). At such an emotionally intense time, test providers need to be sensitive and ensure they are non-judgmental and communicate a sense of understanding. Youth who sense judgment have been known to conceal the truth or simply walk out (Bucharski et al., 2006; Michaels Opinion Research for the Kaiser Family Foundation, 1999). The principle of respect is particularly important within Aboriginal cultures (Smylie et al., 2001).

There is reason to believe that strategies that make the testing experience easier for youth will increase their likelihood of voluntarily seeking an HIV test. This would include offering the test via saliva or urine rather than extracting blood (Michaels Opinion Research for the Kaiser Family Foundation, 1999; Peralta, Deeds, Hipszer, & Ghalib, 2006), reducing wait times (Bucharski et al., 2006; Peralta et al., 2006), or providing more flexible hours. The move in many jurisdictions to rapid (point-of-care) testing may alleviate some of these concerns. Similarly, a study of high risk youth found that those who were given the option of telephone notification were more likely to receive their test results than those required to receive face-to-face notification (Tsu, Burm, Gilhooly, & Sells, 2002).

Our results also suggest that cultural responsiveness within HIV testing services would create a more

comfortable environment for Aboriginal youth. Comments from survey participants about needing to be treated with "respect," discomfort with "white doctors" and the desire to bring family or friends or consult an elder highlight important aspects of health care engagement for Aboriginal cultures (Smylie et al., 2001). Aboriginal people have suggested that incorporating more cultural (but not necessarily traditional) practices and spirituality would improve the testing process. Aboriginal women reported that they would find it helpful during the testing process to have the support of an Aboriginal elder, have native practices available (e.g., smudging), and be in a home-like environment (Bucharski et al., 2006). Cultural responsiveness to the many diverse Aboriginal cultures, and training in cultural competence for service providers are important components of HIV professional development and care (Barlow et al., 2008), as Aboriginal people in Canada may face significant stigma, discrimination, and misunderstanding from health care workers (Browne, 2007; Mill et al., 2009; Tang & Browne, 2008).

This study was exploratory, and findings should be understood with several limitations in mind. The sampling methods used were not probability-based, but rather participants were recruited from convenience and network sampling to achieve diversity. Thus, while we recruited a relatively large sample (413 youth), the sample cannot be considered representative, and care should be exercised in applying results. For example, our sample was largely urban, and thus this survey does not capture perspectives of on-reserve or rural youth, where HIV services access may be more limited (Wordsman, Quantz, & Clement, 2006). Nor was our sample size designed to allow for meaningful comparisons among First Nations, Métis, and Inuit youth. In addition, as this was a retrospective cross-sectional survey, participants reported on their perceptions of HIV testing experience a variable period after the test. Thus, recall effects and other factors will have influenced reported perceptions of the HIV test. Limitations aside, to the best of our knowledge, this is the first study to explore the HIV testing experience among Aboriginal youth in Canada.

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