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HIV/AIDS, Colonialism and Aboriginal Youth in Canada: Implications for HIV Prevention Work

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ABSTRACT

In this paper we report on the results of a community-based participatory research (CBPR) study conducted as part of the Gendering Adolescent AIDS Prevention (GAAP) project to provide insight into the ways colonialism is connected to issues of HIV risk faced by Aboriginal youth in Canada. The research took place in urban and on-reserve settings in two Canadian provinces: Ontario and Quebec. To obtain our results, we put out a call for youth facilitators who were responsible for convening a focus group in their community and recruiting youth participants. Prior to conducting the focus groups, the youth facilitators had one-on-one training with the GAAP coordinator. In total, six focus groups were completed: three groups in urban settings and three groups on-reserve. The data were coded using Nud*ist qualitative data management software and collaboratively analyzed for themes. In their focus group discussion, youth made links between ongoing colonialism and problems in their community today and discussed the relevance for HIV vulnerability. They talked about the stigma and fear associated with HIV/AIDS and stressed the importance of Elders taking a leadership role in educating their communities about HIV/AIDS. We discuss the relevance of these findings for Aboriginal communities and we stress the importance of recognizing Aboriginal youth as a powerful resource for HIV prevention work.

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INTRODUCTION

Key findings from the Canadian Aboriginal AIDS Network (CAAN) report, *HIV Prevention Messages for Aboriginal Youth*, state that there are not enough Aboriginal specific messages for youth (Canadian Aboriginal AIDS Network (CAAN), (2004). Aboriginal people are overrepresented in Canadian HIV/AIDS statistics. Although Aboriginal Peoples represent 3.8% of the Canadian population, their new infection rate was about 3.6 times higher than non-Aboriginal people in 2008 (Public Health Canada, 2010). Aboriginal Peoples who are diagnosed with HIV tend to be younger than their non-Aboriginal counterparts (Isaac-Mann, 2004; Public Health Canada, 2010) and the proportion of positive HIV test reports among Aboriginal youth has shown an increasing trend (Public Health Agency of Canada, 2010). Aboriginal youth are more likely to be diagnosed late, more likely to have an earlier onset of acute illness, less likely to receive optimal medical care, and have shorter survival rates (Mill, Jackson, Worthington, Archibald, Wong, Myers et al., 2008).

However, being Aboriginal is not what puts youth at risk of HIV infection. Compared to non-Aboriginal youth, Aboriginal youth deal with a number of socioeconomic and systemic factors that increase their vulnerability to HIV. These factors are rooted in a colonial legacy that compromises the health and well-being of Aboriginal youth today (Barlow, 2003; Mill, Archibald, Wong, Jackson, Worthington, Myers et al., 2008). In general, Aboriginal Peoples in Canada have lower education levels, employment rates and income than the national average and are more likely to live in conditions of isolation with inadequate housing, unhealthy water supplies and higher levels of contaminants (CIHI, 2004). Individually, each of these factors can contribute to risk. Taken together, they comprise a package of systemic discrimination that increases HIV vulnerability for Aboriginal youth.

To stop the spread of HIV among Aboriginal youth, HIV prevention and education programs must address the socioeconomic and systemic issues that put Aboriginal youth at risk in the first place. Aboriginal scholars have argued that "understanding HIV-related vulnerability must begin with a consideration of the historical legacy of colonization, including forced removal from traditional and spiritual connection to the lands, cultural genocide and, in particular, the history of the residential school system" (For the Cedar Project Partnership, Pearce, Christian, Patterson, Norris, Moniruzzaman et al., 2008, p. 2186). In this paper we report on the results of a study that provides insights into the ways colonialism is connected to issues of HIV risk faced by Canadian Aboriginal youth in urban and on-reserve settings today. We consider the relevance of our findings for HIV prevention programming for Aboriginal youth. This research is a follow-up to a study in which we conducted four focus groups with urban Aboriginal youth in the Toronto area (Larkin, Mitchell, Flicker, Dagnino, Koleszar-Green, & Mintz, 2004) as part of a larger project that also included rural youth in Ontario. The findings of this previous research were used to revise the survey and focus group guide used in this study that focused solely on Aboriginal youth. Overall, the questions focused more specifically on HIV/AIDS education, risk and prevention strategies in Aboriginal communities (see Appendix A).

Colonialism and HIV Risk

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Colonialism has had a devastating effect on Aboriginal Peoples. AIDS is one chapter in a long history of health disasters that have plagued Aboriginal Peoples since European conquest (Irwin, Millen & Farrows (2003). AIDS activists today increasingly identify colonialization as a key condition of HIV risk and are organizing transnationally with the goal of changing the conditions that produce the global pandemic (Moregenson, 2009). The International Indigenous People's Summit at the 2006 International AIDS Conference in Toronto issued a policy stating that Indigenous people share a history of marginalization by settler states that produces factors that increase their HIV vulnerability. Moregenson (2009) notes that Aboriginal scholars are "marking how the material effects of colonization on Indigenous health contextualize the spread of AIDS" (p. 46) and the disproportionate rates for Aboriginal Peoples.

The Indian Act; first passed in Canada in 1876; was designed to promote coercive assimilation by forcing Aboriginal Peoples to adopt European culture and values through the dismantling of Aboriginal social and political institutions (Henry, Tator, Mattis & Rees, 2000). It regulated legal status, land rights and outlawed Indigenous cultural practices (Trépanier, 2008). One of the most powerful assimilation strategies was residential schools. In Canada, residential school legislation forced over 100,000 Aboriginal children out of their homes and communities into foreign educational systems (Sinclair, 1997). Students who dared to speak their native language were punished (Llewellyn, 2002). Chronic underfunding meant that many children were hungry, malnourished, and even forced into labour to support the costs of running the schools (Llewellyn, 2002). It has recently been revealed that Aboriginal children in Canadian residential schools were deliberately starved so researchers could study the effects on malnutrition on human subjects. In other words, the health of Aboriginal children was deliberately compromised in the name of science (Livingstone, 2013).

The legacy of residential schools has affected all Aboriginal Peoples in Canada. The disruption in family unity and child rearing practices has meant that survivors are often unable to care adequately for their children (For the Cedar Project et al., 2008; Hamilton, 2001; Richmond & Ross, 2008). In addition, the widespread sexual abuse that occurred in residential schools makes it difficult for many to have a healthy view of sexuality. Instead, sexuality has become a source of shame and pain (McLeod, 1997) and, at the same time, intergenerational traditional teachings on sexuality have been lost (Yee, 2009). Recognizing how such forms of historical and on-going colonial practices continue to "impact negatively on the physical, mental-emotional, social, and spiritual health of Aboriginal peoples, families and communities" (Ship & Norton, 2001, p. 25) is key to understanding conditions of HIV/AIDS vulnerability.

Aboriginal communities have much work to do to heal the harm done by strategies of assimilation (Yee, 2009). The imposition of western ideologies and systems on Aboriginal Peoples has threatened Indigenous survival by eroding the very foundation of Indigenous culture, values, and worldview (Alfred, 1999; Nudler, 1990). This erosion destabilizes communities in ways that increase HIV vulnerability. This is particularly so when Aboriginal communities are marked by poverty, trauma, substance abuse and a bleak future. In these conditions youth, without some creative intervention, are unlikely to have the healthy and nurturing social networks

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they need to thrive (Richmond & Ross, 2008). In the national project *Taking Action! Art and Aboriginal Youth Leadership in the Arts*, members of the research team are currently working with Aboriginal youth and communities across Canada to use traditional and contemporary art forms as tools for resistance, HIV prevention and health promotion. Such initiatives draw on the strength of Aboriginal youth, culture and the creative arts to raise awareness about HIV/AIDS and mobilize action (Flicker & et al., 2012).

METHODOLOGY

The Gendering Adolescent AIDS Prevention (GAAP) project adopts a community-based participatory research (CBPR) approach to building youth leadership and activism for HIV prevention (Israel et al., 1998). Participatory approaches acknowledge that a community's local knowledge is crucial to understanding and addressing their own needs. Active community participation is particularly important in research with Aboriginal communities given the historical human rights violations inflicted on Aboriginal populations in the name of research (Tuhiwai Smith, 1999). In addition, CBPR has been found to be particularly effective in health research with young people (Grossman et al., 2004; Smyth, 2001; Society for Adolescent Medicine, 2003).

In this study, we conducted six focus groups with Aboriginal youth in urban and on-reserve settings in two Canadian provinces: Ontario and Quebec. Aboriginal members of the research team who have contacts in various Aboriginal communities initiated the focus group arrangements. Individuals were approached who work with Aboriginal youth in Ontario and Quebec in schools, friendship centres, youth councils and other locations. Ultimately, we were able to conduct three focus groups in urban locations and three groups in on-reserve locations within Ontario and Quebec.

In keeping with our commitment to CBPR, we put out a call for youth facilitators to convene the focus groups that were to be held in their community. Training youth in local communities builds the capacities of young people to engage in research and promote dialogue about HIV prevention, with multiple benefits: the youth acquire confidence and skills that can lead to long-term opportunities (Flicker, 2006; Jarrett, Sullivan, and Watkins, 2005) and the communal social capital is strengthened by keeping knowledge and resources in the community after the project is completed (Hawe et al., 1997). Youth facilitators gain valuable job experience and the project benefits because young people engage more freely with a known facilitator.

Youth facilitators who had a strong connection with a school and/or community group were selected. Facilitators were at least 16 years of age, and had some experience working with youth and facilitating small group discussions. Generally, facilitators were responsible for recruiting youth participants in their community, finding an appropriate space, facilitating the group and subsequent follow-up. Before the focus groups, facilitators had a one-on-one training session in person or over the phone with the GAAP Coordinator. The GAAP Coordinator attended each focus group to tape the sessions, co-facilitate and provide support to youth facilitators when necessary.

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Youth facilitators were provided with a facilitation package including consent forms, questions, protocol and survey tools. In the focus groups, the youth participants completed a survey using a scale of 1-5 (1 being strongly agree and 5 totally disagree), to answer 17 statements related to HIV/AIDS (see Appendix A). The survey was revised based on the findings of our previous study with particular attention to the issues identified by Aboriginal youth themselves. The survey was used as a tool to prompt the focus group discussion rather than as an instrument for collecting quantitative data. After completing the survey, the youth then shared their thoughts in a group discussion led by the youth facilitator and GAAP research coordinator. Overall, we trained 6 peer facilitators, held 6 focus groups and spoke with 61 Aboriginal youth (50% female and 50% male in the urban settings and 76% female and 24% male in on-reserve locations). (See Table 1)

Table 1: FOCUS GROUP DEMOGRAPHICS

General Descriptor	#	Average Age	Age Range	Gender Ratio Female	Gender Ratio Male
Urban Youth		20 yrs	14-27	50% Female	50% Male
Ontario 1	8	16 yrs	15 – 17	60%	40%
Quebec 1	14	21 yrs	14 – 25	50%	50%
Quebec 2	6	23 yrs	20 - 27	30%	70%
On-Reserve Youth		16 yrs	14-24	76% Female	24% Male
Ontario 2	9	18 yrs	17 – 20	70%	30%
Ontario 3	10	17 yrs	16 – 20	70%	30%
Quebec 3	14	16 yrs	14 - 24	86%	14%

This chart shows the breakdown of the six focus groups (3 urban and 3 on-reserve), the average ages of the youth participants, age range and gender ratio.

The Youth Participants (YPs) in the focus groups were young people (ages 14-27 years) who went to school/lived in the schools/communities the GAAP project had targeted for data collection. The age range for each group represented the age of youth serviced by the organizations in which the focus groups were held. The large age span in some groups (e.g. 14-25) reflected the diverse ages of the youth in various activities within the organizations. In these focus groups, the participants appeared to be both comfortable and familiar with each other. The adult contact/service worker for each group attended the sessions to act as a resource for the facilitators and to deal with disclosures or other personal issues that might arrive from the discussions. Youth were provided with an honorarium for their time, as well as food and

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beverages. Demographic data were obtained from the forms the YPs filled out at the beginning of the focus groups.

Although we tried to include as many Aboriginal groups (First Nations, Métis and Inuit) as possible in all our surveys, the majority of the focus group participants were First Nations youth as this was the largest group in the rural areas, reserves and community centres where we conducted the surveys. Informed consent was sought from all participants. Parental consent was sought for youth under the age of 18. At the beginning of each session, the consent form was read aloud and there was time for questions from group participants. All consent forms were collected prior to the beginning of the focus group. The facilitator described the process for completing the survey and the post-survey discussion. Participants were reminded that the focus group conversations were confidential. All discussions were audio-taped and then professionally transcribed after the focus group was completed.

A team made up of the Principal Investigator, two co-investigators, the Research Coordinator, one graduate student and an undergraduate student developed the coding framework and subsequent data analysis. In total, three of the data analysis team members were Aboriginal (50%), including one Aboriginal youth.

An inductive approach guided the analysis. A sub-sample of transcripts was offered to the data analysis team for preliminary analysis. Based on emerging themes, a preliminary coding framework was developed. Each transcript was coded separately by two team members for clarity and to minimize discrepancies. The coding scheme was revised to accommodate new themes as they emerged. After this step the codes were entered into Nud*ist qualitative data analysis software. Coded data were returned to the larger team for analysis. Weekly meetings were held to go over the coded data and discuss the main themes, relevance and implications for each code. Summary documents were constructed to capture the most common themes, gaps and issues. Although youth from the focus groups did not join the data analysis meetings due to travel and funding limitations, a draft of the final report was sent to the contact person at each site with an invitation to forward any feedback to the research team.

In this paper we provide an analysis of the comments of urban and on-reserve Aboriginal youth that make reference to colonialism as generated through a discussion of survey statements, particularly questions 13-17 (see Appendix A). As our sample was by no means representative or random, the findings are not meant to be generalized to all Aboriginal youth populations. Our goal was to explore the relationship between colonialism and HIV risk to raise issues that warrant further attention and investigation in research and prevention work with Aboriginal youth.

RESULTS

Youth who participated in the focus groups had varied reactions about whether or not the high rates of HIV/AIDS in Aboriginal communities were related to colonialism. Some youth did not link colonialism or other systemic factors to HIV risk:

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I don't think colonialism has anything to do with it, their coming here. (Female urban)

I think poverty has nothing to do with it. Personally, I think it depends on the individual. (Male urban)

We always had problems before the great confederacy; people will always have problems. (Female on-reserve)

These comments may reflect the heightened individualism of a neo-liberal economy where health and well-being are considered an individual responsibility (Lupton, 1999). For Wexler (2006) such comments may also reflect our tendency to focus on historical patterns of mistreatment so that colonialism is seen as a thing of the past rather than an ongoing practice that continues to impact Aboriginal communities.

However, a number of youth did make a link between ongoing colonial practices and problems in their community today:

It's still all happening to us today; everyone thinks it's over but it's not. (Female on-reserve)

We didn't have AIDS or HIV before. I guess it is the fact that they put us in a really bad position and they stuffed us on reserves and stole our land and told us that we don't have the right to do this. And I guess that affected the community that there is no clean water and there are lots of drugs and alcohol. That makes the risk higher because when one person gets a sickness the whole community becomes unbalanced. (Female urban)

Some youth discussed intergenerational trauma, a psychological cost of colonialism that continues to plague communities so that the health enhancing benefits of family and community support are seriously compromised:

I think it goes back to being ashamed of all the things that we've gone through, we don't feel we can be involved and our parents are alcoholics and don't attend to problems, cause you carry that back to yourself. (Male on-reserve)

Most Aboriginal youth who participated in the groups were aware of the impact of colonization on their families, especially their parents. Many connected the traumatic effects the Residential School System to the overall health and well-being of Aboriginal families today.

It stems from the lack of culture when kids were away in residential schools and came back and didn't have their language and traditions. Drinking and all that stuff go way back and gets deeper and harder to

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deal with for generations. (Female on-reserve)

Some youth provided personal accounts of this cycle and made connections to unsafe sexual practices, behaviour that can increase HIV risk:

> *From my understanding, from seeing my mother's generation and being taken away from her mother and with her having children and not knowing how to be a mother, then raising children is hard, ...They didn't know the teachings and the things about culture. They were taken away from them. I think the whole residential schools [system] had a huge effect on self-esteem. Safe sex has a lot to do with self-esteem. Like saying the way you want to respect yourself and it has to do with social problems. (Female urban)*

When urban Aboriginal youth spoke about how non-Aboriginal people see them in the cities, their comments illustrated issues connected with racist stereotypes of Aboriginal people:

> *I get that people refuse to believe that I'm Aboriginal. It's either that or it's oh God, she's Aboriginal. They always go "do you drink a lot?" One of my names growing up was Pocahontas because the movie had just come out and they're like "hey Native girl." And they're like "Oh, it's her, it's Pocahontas." (Female urban)*

> *There are so many misconceptions, because nobody understands, nobody knows. So people think "Oh you are Indian," well maybe you don't pay taxes, or this, that, or I thought Indians are gone. (Male urban)*

It seems from the comments by the youth participants that urban youth deal more with racism while on-reserve youth deal more with issues of isolation and its consequences. Youth on reserves spoke about feeling disconnected and disregarded from the rest of society:

> *We need Canadians to understand our issues, they are ignorant about our problems and our issues and they think we have it so good. (Female on-reserve)*
> *What about our land rights, and what they are doing to mother earth? They don't care. (Female on–reserve)*

On-reserve youth, in particular, felt that non-Aboriginal Canadians do not understand their situation and that the government does not provide enough support or respect.

> *Like our water, the government doesn't care about that and all the other health problems we have in our communities: diabetes, suicide, alcoholism. The government doesn't do enough to help our communities. (Male on-reserve)*

Racism, isolation and poor living conditions are products of the ongoing colonialism that impact the health and wellness of Aboriginal Peoples in ways that increase HIV vulnerability.

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Many youth participants expressed dismay at the ways Aboriginal Peoples with HIV/AIDS are treated as outcasts by their own people. On-reserve youth, in particular, talked about the poor treatment of HIV positive people in their community:

> *Yeh, the person who has HIV would be shunned because they'll be seen as dirty and bad. (Male on-reserve)*

> *And they'd blame the person who had it, no compassion, just judgment and punishment. (Female on-reserve)*

The fear and stigma associated with HIV/AIDS prevents the community from dealing effectively and openly with the disease. As a consequence, the virus has a better chance of spreading. According to some youth, prejudice against people with a positive HIV status stemmed from misunderstandings or lack of knowledge about HIV/AIDS:

> *They know, that the infections or HIV is something bad that kills you and can be transmitted and they take that information and they go further with [it]. (Male urban)*
> *I guess they're just afraid of getting it. For them, those kinds of sicknesses are a death sentence. (Male urban)*

Many youth thought that Elders should learn more about HIV/AIDS so they could work with the community to reduce stigma. They were concerned, however, that the Elders were not equipped to take on this role or were hesitant to do so:

> *The Elders don't know enough about HIV/AIDS… In my community the Elders say they didn't have HIV/AIDS when they were young and they are afraid if one person has it the whole community will get it. (Male on-reserve)*

The historical onslaught of European diseases and the outlawing of traditional medical systems (Waldram, Herring & Young, 2000) may play a role in why many Elders do not know or do not want to learn how to deal with HIV/AIDS in their communities. Given the history of devastation by diseases in Aboriginal communities as well as new chronic illnesses, the difficulty of facing another potential killer is probably understandable. For the youth, however, the leadership of Elders was crucial to their HIV/AIDS education:

> *I know that school's not the best way to learn because that's not the traditional way. I think it should be through the Elders. Some will talk about it but some wouldn't. If they were informed than they might really get into it. (Male urban)*

DISCUSSION

The findings of this study provide evidence that many Aboriginal youth see a link between colonialism and the disproportionately high HIV rates in their communities today. While it is

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beyond the scope of this paper to offer a full analysis of how best to address the issues of HIV/AIDS amongst Aboriginal youth, there are several key recommendations that come out of this study.

First, HIV prevention strategies should engage explicitly with connections to colonialism, racist histories, and the impact of residential schools. It may be productive to situate HIV prevention within large discussions of the social determinants of health and make connections to the issues affecting Aboriginal communities and individuals. Being aware of the issues that Aboriginal Peoples and communities face historically, on a daily basis and in regards to HIV/AIDS may lead to more culturally safe prevention options. By "culturally safe" we are referring to services that go beyond the concept of cultural sensitivity to address "power imbalances, institutional discrimination, colonization and relationships with colonizers, as they apply to healthcare" (NAHO, 2006).

Second, Elders can play a key role in HIV prevention work. The youth noted that many older people in their communities were too ashamed to talk about sex due to Residential Schools and Christianity. Elders could open up discussions about HIV/AIDS by teaching the traditional values around sexuality and illness. In particular, many youth emphasized they would like Elders to play a major role in their education about sexual health and HIV/AIDS. Health care workers could collaborate with Elders and offer supports such as sharing circles, traditional ceremonies, traditional medicines, etc. within programs that service Aboriginal populations. These activities may help increase Aboriginal participation in HIV/AIDS prevention and treatment and create more openness about HIV/AIDS within the community.

The strategies mentioned above would also address another issue that emerged from the data: a need for greater community support. In the focus groups, both urban and on-reserve youth expressed this need in regards to HIV/AIDS prevention. A focus on the community as opposed to the individual is part of the worldview of many Aboriginal Peoples (Nudler, 1990). A community approach could enhance the cultural relevance of HIV prevention work and help to eliminate HIV/AIDS stigma.

The youth also pointed out that the messages need to address the environment in which the youth live: urban messages for urban youth and relevant messages for on-reserve youth and rural youth. These comments are an important reminder that Aboriginal youth are not a homogenous group and providing messages that have a pan-Aboriginal approach is unlikely to work.

CONCLUSION

Considering the impact of colonialism on Aboriginal communities is an essential component in dealing with HIV/AIDS. A decolonizing approach to HIV prevention education is one that acknowledges the history of colonialism and works to undo its effects (Barndt, 2010). Developing culturally appropriate, participatory approaches that engage youth, Elders and community members in HIV prevention work is an important first step. Our work has shown that Aboriginal youth have many creative and intelligent suggestions in regards to preventing HIV/AIDS in their communities. GAAP is currently participating in *Taking Action: Art and*

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Aboriginal Youth Leadership for HIV Prevention, a national project with Aboriginal youth and communities across Canada. The initiative is led by Indigenous youth who use the arts (e.g., digital storytelling, wood carving, painting, drama) to talk about HIV/AIDS with youth in their communities and to mobilize action (see http://www.takingaction4youth.org/). Recognizing youth as a powerful resource for stopping the spread of HIV/AIDS is an important strategy for curbing the HIV rates in Aboriginal communities.

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Appendix A

Discussion Guide
After the youth participants had filled out the following form individually, the youth facilitator guided a discussion through the questions.

GAAP Focus Group Discussion

Gender: _____

Age: _____

Location: _____

First Nation ___ Métis ___ Inuit ___ Non-Status ___

On a scale of 1 to 5 describe how you feel about the following questions

1) I strongly agree
2) I some what agree
3) No feeling
4) I some what disagree
5) I totally disagree

1) Men have a higher chance of getting HIV because of biology.

1 2 3 4 5

2) When someone has a Sexually Transmitted Infection (e.g. Chlamydia, Herpes, Gonorrhoea or Syphilis) they are more at risk for HIV infection.

1 2 3 4 5

3) Globally, women and girls are more at risk of HIV infection than men and boys.

1 2 3 4 5

4) Being poor puts people more at risk for HIV infection.

1 2 3 4 5

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5) HIV is a gay disease.

1 2 3 4 5

6) Most youth (two-spirited and straight) use condoms when they are having sex.

1 2 3 4 5

7) Young women and young men are equally willing to use condoms.

1 2 3 4 5

8) Most sexually active youth get HIV tests every time they change sex partners.

1 2 3 4 5

9) Young people worry about contracting HIV/AIDS.

1 2 3 4 5

10) Some youth are more at risk for contracting HIV than others.

1 2 3 4 5

11) You can tell by looking at someone whether they are HIV positive.

1 2 3 4 5

12) Sex education in schools is where most youth get information about HIV/AIDS.

1 2 3 4 5

13) HIV/AIDS is a problem for people in my community.

1 2 3 4 5

14) Aboriginal communities are more at risk for HIV than other Canadians.

1 2 3 4 5

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15) There are things that Aboriginal communities can do to help protect youth from HIV.

1 2 3 4 5

16) Youth from Aboriginal communities are well informed about HIV risk.

1 2 3 4 5

17) Youth in my community know where to go to get an HIV test.

1 2 3 4 5

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