

The  
**Current State** of the **HIV Epidemic** among

**Indigenous People** in Ontario 

May 2014

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# FOREWORD

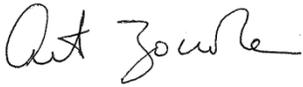
All of us who work with Indigenous people in Ontario to prevent and manage HIV, hepatitis C and other sexually transmitted and bloodborne infections (STBBIs) — including community-based agencies that serve Indigenous people, health programs in First Nations communities, Indigenous researchers, clinicians and our allies in the AIDS Bureau and the Hepatitis C Secretariat at the Ministry of Health and Long-Term Care and the Ontario HIV Treatment Network (OHTN) — have long been frustrated by the lack of data on HIV or other STBBIs among Indigenous people in this province. Although we all work with Indigenous peoples who are living with HIV and many who are at risk, we do not have a clear picture of the extent and the impact of HIV on their lives. How many Indigenous peoples have been diagnosed with HIV? How many are in care? How many are doing well on treatment? How many have died? What are the historical, social, structural and behavioural factors that put Indigenous peoples at risk or make living well with HIV more difficult? What are the strengths and resiliencies that help Indigenous peoples either avoid infection or cope well with HIV, and enjoy good physical, spiritual, emotional and mental health?

The main reason for the gap in our knowledge and understanding is that Ontario's HIV test requisition form does not collect information on the ethnicity of people being tested. It is also difficult to find ethnicity information on people in care. The test requisition form is now being revised, and we should have more complete information on Indigenous people who are diagnosed with HIV in the future.

But what about the past and the present — the people who are living with HIV now? Thanks to the leadership of people like LaVerne Monette, Executive Director of the Ontario Aboriginal HIV and AIDS Strategy (Oahas) until her death in 2010, the OHTN began structuring its studies to gather information on how HIV was affecting Indigenous people in Ontario. For example, with the Positive Spaces Healthy Places study on housing of people with HIV, the research team — which included LaVerne Monette — made a concerted effort to recruit Indigenous peoples to the study and to analyze the findings with the Aboriginal community. The OHTN also made a particular effort to strengthen the OHTN Cohort Study (OCS), adding questions about ethnicity and the social determinants of health, as well as conducting analyses that can help create a picture of Indigenous peoples who are receiving care in HIV clinics across the province. In OCASE, the electronic case management system that the OHTN manages for Ontario's dedicated community-based AIDS service organizations, agencies can now include information on client ethnicity and the services that people receive can be analyzed by ethnicity. We received permission from the agencies to include aggregate (non-identifiable) information on the number of Indigenous peoples being served and the services they are using.

Using these data as well as information from studies conducted with populations most at risk of HIV — such as the I-Track studies, which include people who use drugs, and the Lambda study which includes (but is not limited to) men who have sex with men — we have taken the first steps in trying to understand how the HIV epidemic is affecting Indigenous people in Ontario. We know there are still many gaps. Most of the data is for people who are receiving care — either at HIV clinics or community-based agencies — or who live in large urban centres. They do not capture the experience of Indigenous peoples living in First Nations communities or in more rural and remote areas. From the First Nations Regional Health Survey, we were able to include some information on the socio-economic and health status of Indigenous adults living in First Nations communities but we know that survey did not reach everyone.

This report is a beginning. We must continue to work together to understand HIV and other STBBIs among all Indigenous people in Ontario and develop effective, culturally appropriate prevention, support and care programs and services. In our work, we continue to be committed to the OCAP principles of Ownership, Control, Access and Possession, to community-based research principles, and to Indigenous and decolonizing methodologies. Indigenous people were intensely involved in guiding and preparing this report. We will continue to work with our allies to collect and share information that will help improve the health and well-being of Indigenous people in Ontario who are living with or at risk of HIV and other STBBIs.



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# EXECUTIVE SUMMARY

We know from analyses done by the Public Health Agency of Canada that Indigenous people are over-represented in the HIV epidemic in Canada. However, we also know that those analyses did not include Ontario data because they were based on information from HIV test requisition forms and, historically, the province did not collect information on ethnicity on those forms. Does the national picture hold true in Ontario or is the situation for Indigenous people different here?

Using existing sources of data, this report attempts to characterize the burden of HIV for Indigenous people in Ontario and identify the factors that put people at risk. We recognize that there are serious limitations to the data. For example, most Indigenous people who participated in the studies used to inform this report were living primarily in urban areas, so there is little HIV-specific information on Indigenous people who live in First Nations communities. Most of the information is from people accessing services (e.g. needle exchange services, community-based AIDS service organizations, HIV clinics) so we know little about Indigenous people with HIV who are not in care or using HIV-related services. Most of the data is from adults and may not represent the experience of Indigenous youth. Taking into account these limitations, we were able to identify the following trends:

- The gaps in socioeconomic status between Indigenous and non-Indigenous people in Ontario are narrowing. The number of Indigenous people with higher levels of education, higher incomes, and stable employment and housing has increased. However, the Indigenous population in Ontario still experiences significant health and social disparities that may increase their HIV risk and reduce their access to health services.
- Indigenous people in Ontario are more at risk of HIV than non-Indigenous people. The prevalence of HIV among Indigenous people (0.42%) is 1.7 times higher than among non-Indigenous people. Rates of HIV infection appear to be higher in Indigenous people in certain parts of the province, including Northern Ontario, Toronto and southwestern Ontario.
- Indigenous people in Ontario are less at risk of HIV than Indigenous people in other parts of Canada. The prevalence of HIV among Indigenous people in other parts of Canada was 3.6 times higher than among non-Indigenous people in Canada – compared to 1.7 times higher in Ontario.
- HIV risk in Indigenous people in Ontario is driven by the legacy of racism and colonialism as well as social, structural and systemic factors, and risk behaviours.

- Among Indigenous people in Ontario diagnosed with HIV from 2009 to 2011, the most commonly reported risk factors were sexual exposure (64%) and injection drug use (45%). Fifty-nine percent of Indigenous women and 48% of Indigenous men reported “sex with men” as a risk factor. Twenty percent of Indigenous men who reported having sex with men also reported using injection drugs, suggesting overlap in the drivers of the epidemic. About one-third of Indigenous people in Ontario with HIV are diagnosed later in the course of HIV disease.
- About one in three Indigenous people in Ontario who are living with HIV are also co-infected with hepatitis C (HCV) and, therefore, at higher risk of developing liver disease, liver cancer and other complications.
- Injection drug use is one of the key drivers of both HIV risk and HCV risk among Indigenous people in Ontario. Although we did not identify any substantial differences in drug-using behaviours between Indigenous and non-Indigenous people, Indigenous people were more likely to inject non-prescribed morphine, Ritalin, benzodiazepines, barbiturates, oxycodone/OxyContin, and the combination of Talwin & Ritalin. These drug preferences may be driven by prescribing patterns and/or by the cost or availability of these drugs.
- Indigenous women are more likely than Indigenous men to share drug equipment, which increases their risk of infection.
- Indigenous people with HIV report higher levels of psychological distress than non-Indigenous people with HIV or Indigenous people who are HIV-negative. They are less likely than non-Indigenous people with HIV to have used mental health services and more likely to report an unmet need for these services.
- In general, Indigenous people with HIV were more likely to report that their needs for a variety of health and social services – including having a family doctor – are not being met. The most commonly reported barriers that Indigenous people face accessing health and social services are lack of local availability and financial costs (e.g. transportation).
- Despite the barriers that Indigenous people with HIV face, they engage in care as frequently as non-Indigenous people. They are also highly successful in accessing antiretroviral therapy (ART) and adhering to treatment regimens.
- Despite the fact that Indigenous people experience serious health and social disparities overall, there is no substantial difference in health status, quality of life or HIV-related deaths between Indigenous and non-Indigenous people living with HIV – which is not the case in other parts of Canada. In fact, three of every four Indigenous people who are receiving HIV care in Ontario rated their health as “good” or better. We are aware that this may not be the experience of Indigenous people who are not in care.

## Recommendations

Based on our analyses of available data on Indigenous people in Ontario living with or at risk of HIV, we would recommend the following:

1. Improve the social determinants of health for Indigenous people.
2. Make Northern Ontario, Toronto and Southwestern Ontario priority areas for culturally appropriate, effective HIV prevention for Indigenous people.
3. Make concerted efforts to encourage Indigenous people at risk of HIV to test frequently so cases of HIV can be diagnosed as soon as possible.
4. Provide measures to reduce the risks and harms associated with injection drug use (e.g. sterile equipment, access to drug substitution and rehabilitation programs). Improve Indigenous people's access to harm reduction and addiction/mental health services and ensure these services have the capacity to work effectively with Indigenous people. Monitor the impact of the recent policy change related to OxyContin to ensure it does not have a serious negative impact on Indigenous people. Harm reduction services should focus on Indigenous women.
5. Make Indigenous men who have sex with men a priority population for HIV prevention. Expand Indigenous-focused HIV prevention programs and services to give more specific attention to Indigenous men who have sex with men.
6. Ensure Indigenous women with HIV who are pregnant have timely access to antiretroviral therapy, support to improve adherence and quality care during and after pregnancy.
7. Develop culturally appropriate healthy sexuality and safer sex programs for Indigenous people. These programs should include all sexual and gender orientations, as a focus on the heterosexual community may marginalize Indigenous men who have sex with men, two-spirit and trans people.

8. Take steps to help Indigenous people with HIV manage co-morbidities. Ensure high quality care is accessible for Indigenous people co-infected with HIV and HCV, including HCV teams and HIV clinics, and ongoing coordination of these services. Encourage health promotion efforts designed to prevent non-HIV co-morbidities, such as Indigenous-specific smoking cessation programs, to welcome people living with HIV. Support effective planning for prevention and care services, conduct ongoing research on non-HIV chronic conditions among people with HIV and, whenever possible, report on these conditions separately for Indigenous people.
9. Develop culturally-appropriate HIV and non-HIV care services for Indigenous people with HIV. Ensure federal and provincial policy makers experienced in Indigenous health, HIV and the provision of health services for Indigenous people – both in and outside First Nations communities – collaborate to identify and address systemic barriers to coordinated and timely health care services for Indigenous communities. Identify effective ways to improve access to care for Indigenous people in rural and remote communities, such as the Ontario Telemedicine Network.
10. Explore the best approaches to understand and build cultural resiliency as one way to improve the health and well-being of Indigenous people with HIV in Ontario.
11. Improve collection of health-related data from Indigenous people to ensure evidence-based health policy and practice.

## Introduction

The purpose of this report is to compile epidemiological evidence on the status of the HIV epidemic among Indigenous people in Ontario.

We hope this report will:

- help Indigenous people understand the HIV epidemic in their communities and advocate for their health care needs
- provide evidence for policy-makers, clinicians and community organizations to inform HIV prevention and care services among Indigenous people
- identify gaps to help researchers and research funders set research agendas.

## Why Develop this Report?

HIV is not a generalized epidemic in Ontario. It does not affect all Ontarians equally. It is concentrated in a small number of marginalized populations, including gay and other men who have sex with men; African, Caribbean and Black communities (i.e. people from parts of the world where HIV is endemic); people who inject drugs; and Indigenous people. The more we understand about HIV risk in each of these populations, the better able we are to develop effective prevention, support and care programs.

For a number of years, the Indigenous community (particularly the organizations involved in HIV prevention and support), policy makers and researchers have been concerned that Indigenous people are over-represented in both new and existing HIV infections in Ontario.

We know that this is the case nationally. According to the Public Health Agency of Canada, in 2011, an estimated 12% of newly diagnosed HIV infections were among Indigenous people (1) – even though Indigenous people make up only 4.3% of Canada's total population (2). At the national level, the epidemic among Indigenous people is largely driven by injection drug use, which is the risk factor for 66% of infections – compared to 17% of infections in non-Indigenous people. Nationally, HIV has a particular impact on Indigenous women: almost half (49%) of the Indigenous people in Canada infected with HIV are women while, in the non-Indigenous population, women account for about 20% of HIV diagnoses (1998-2009) (3).

The impact of HIV on Indigenous people is not limited to Canada: Indigenous people in Australia and New Zealand are also over-represented in their countries' epidemics (4).

However, **the national picture of HIV among Indigenous people may not necessarily reflect the situation in Ontario** because it does not include Ontario data. Historically, the province has not reported information on the ethnicity or Indigenous status of people diagnosed with HIV to the Public Health Agency of Canada because it does not collect that information on HIV test requisition forms (4,5). Ontario's HIV test requisition form is in the process of being revised to capture that information. In the meantime, we must look to other sources of information to help us understand how the HIV epidemic is affecting Indigenous people in Ontario.

## **How was the Report Developed?**

In 2010 and 2011, the AIDS Bureau, Ministry of Health and Long-Term Care hosted a series of meetings with key stakeholders – including the Ontario Aboriginal HIV/AIDS Strategy (Oahas), 2-Spirited People of the 1st Nations, the Ontario HIV Treatment Network (OHTN), the University of Toronto, the Public Health Agency of Canada, and First Nations and Inuit Health Branch Ontario Region, Health Canada – to talk about the need for a comprehensive overview of the epidemiology of the HIV epidemic among Indigenous people in Ontario.

The AIDS Bureau is responsible for providing leadership in HIV/AIDS policy development and program delivery for Ontario. Its mandate is to ensure effective and efficient use of provincial resources to address HIV/AIDS issues; prevent the spread of HIV; address the needs of people living with HIV/AIDS; and promote a humane, compassionate and knowledgeable societal response to the epidemic (6).

In 2012, in consultation with Aboriginal organizations, the AIDS Bureau commissioned this report. An editorial committee comprised of community members, ministry staff and epidemiologists was formed to lead the work. To ensure community involvement, community representatives were key members of the editorial committee. The committee also invited external researchers and community members to review and provide feedback on a draft version of the report.

## **What is the Focus of the Report?**

This report uses existing available data to characterize the epidemiology of HIV among Indigenous people.

We recognize that HIV risk is largely driven by social determinants of health. Several recently published reports have explored in-depth the social and cultural drivers that

increase HIV risk or help build resiliency among Indigenous people (7–17). Rather than duplicate those efforts, this report focuses on Ontario-specific epidemiologic statistics that — combined with the sociocultural work done by others — can inform next steps in HIV prevention, health care service planning and research.

## Terminology

**Indigenous peoples:** refers collectively to the original inhabitants of North America and their descendants; culturally distinct groups that have been affected by the processes of colonization; recognized in the Constitution Act (1982) as three distinct “Aboriginal” peoples — First Nations, Métis and Inuit — each with unique heritages, languages, cultural practices, land bases, and spiritual beliefs.

**First Nation(s):** refers to the largest collective group of Indigenous peoples and nations in Ontario. This term came into common usage in the 1970s to replace the word “Indian”, and has also been adopted by some First Nation communities<sup>1</sup> to replace the term “band” and the term “on reserve”. First Nations people include those who are registered under the Indian Act (Registered Indians or Status Indians) and those who are not (non-Status Indians). First Nations people may reside in or outside First Nations communities. These geographical distinctions have important implications because Canadian census data refer to those who self-identify as First Nations people (residing either in or outside First Nations communities) while other data (e.g. health information, the Aboriginal Peoples Survey [19]) usually refer to a specific group of First Nations people, such as Status First Nations people who live in First Nations communities or First Nations people — Status and non-Status — who reside outside First Nations communities (7).

**Inuit:** refers to the Indigenous people who have traditionally lived above the tree line in the area bordered by the Mackenzie Delta in the west, the Labrador coast in the east, the southern point of Hudson Bay in the south and the High Arctic islands in the north (20). Today, Canada’s Inuit population lives primarily in Nunavut, the Northwest Territories and northern parts of Labrador and Québec. Nunavut, meaning “our land” in Inuktitut, is the Inuit Homeland in Canada and was formed in 1999.

### Epidemiology

Epidemiology is the study of the occurrence and distribution of health-related states or events in specified populations, including the study of the determinants influencing such states, and the application of this knowledge to control the health problems (18).

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<sup>1</sup> The editorial committee decided to use the term “First Nations community” rather than the term “on-reserve”.

**Métis:** historically refers to children who were offspring of a First Nation and a European union. Today, the Métis population has grown into a distinct group with their own language, culture and diet. There is some controversy around the definition of Métis. The Supreme Court of Canada outlined three broad factors to identify Métis rights-holders: 1. self-identification as a Métis individual; 2. ancestral connection to a historic Métis community; and 3. acceptance by a Métis community. All three factors must be present for an individual to qualify under the legal definition of Métis, but there is still ambiguity and controversy.<sup>2</sup> The Canadian Constitution recognizes Métis people as one of the three Aboriginal peoples in Canada (20).

**Non-Indigenous people:** refers, in this report, to all other ethnicities combined. In our review of data for this report, we compared and contrasted findings from people reporting Indigenous ethnicity with persons of other ethnicities. The choice of comparison group depended to some degree on the data sources. For all comparisons, our underlying hypothesis was that Indigenous people, by virtue of historical events such as colonization and the residential school system and a tendency toward rural residency, may be underserved with respect to healthcare needs compared to other Ontario residents. Note: some data sources compare Indigenous people to the non-Indigenous population; some compare Indigenous people to the general population.

## Data sources

All data included in this report were collected and analyzed for purposes consistent with the Ontario Human Rights Code, which supports ethno-cultural data collection in order to monitor discrimination, identify and remove systemic barriers, address historic disadvantage, and promote substantive equality. To be included, a data source had to have adequately collected ethnicity information, as determined by a source's data custodians.

The Editorial Committee decided *not* to include:

- HIV statistics from Health Canada's First Nations and Inuit Health Branch, which is responsible for collecting data on First Nations communities. We were advised these data would not be significant because of the small numbers and were likely incomplete due to testing stigma. We note that information for First Nations people living in First Nations communities is a significant gap in this report.

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<sup>2</sup> For more details on the discussions around the definition of Métis citizenship, see <http://www.metisnation.ca/index.php/who-are-the-metis/citizenship>

- Notifiable disease case reports for HIV, bacterial sexually transmitted infections and hepatitis C because ethnicity information is not collected consistently and is rarely recorded on these reports.

The primary data sources are summarized in Table 1 (see Appendices for more detailed information.)

**TABLE 1: PRIMARY DATA SOURCES USED TO DESCRIBE THE CURRENT STATE OF THE HIV EPIDEMIC AMONG INDIGENOUS PEOPLE IN ONTARIO.**

Full descriptions are provided in the Appendices.

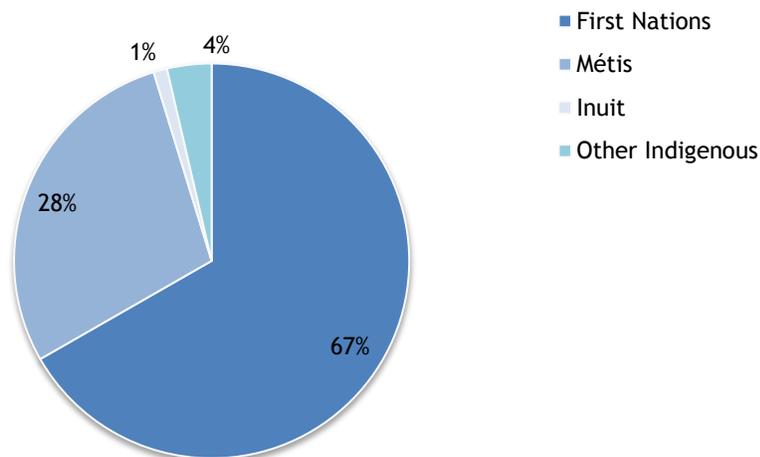
Data Source	Population	Indicators
<b>Canadian Perinatal HIV Surveillance Program (CPHSP)</b>	All identified infants born to mothers in Canada who are known to be infected with HIV. Only data from Ontario residents were analysed for inclusion in this report (5,21)	<ul style="list-style-type: none"> <li>• Race/ethnicity of mother-infant pairs</li> <li>• HIV exposure category of mothers</li> </ul>
<b>Enhanced Hepatitis Strain Surveillance System (EHSSS)</b>	People who have been newly diagnosed with hepatitis B and C at 11 sentinel sites across Canada. Data from three Ontario sites (Hamilton, London, and Ottawa) were included for analyses in this report (22)	<ul style="list-style-type: none"> <li>• Race/ethnicity</li> <li>• Cases of HCV</li> </ul>
<b>I-Track &amp; I-Track/SurVIDU</b>	People who inject drugs in urban and semi-urban centres and who participated in I-Track surveys in Kingston, London, Sudbury, Thunder Bay, and Toronto and in the Ottawa site of the I-Track/SurVIDU network (23)  <a href="http://www.phac-aspc.gc.ca/sti-its-surv-epi">http://www.phac-aspc.gc.ca/sti-its-surv-epi</a>	<ul style="list-style-type: none"> <li>• Prevalence of HIV &amp; HCV</li> <li>• Testing history</li> <li>• Race/ethnicity</li> <li>• Passing on a previously-used needle for someone else to use</li> <li>• Passing on an item of drug &amp; injection preparation equipment for someone else to use</li> <li>• Injecting with a needle previously used by someone else</li> <li>• Injecting with a previously-used item of drug &amp; injection preparation equipment</li> <li>• Age at first injection</li> <li>• Types of drugs used</li> <li>• Types of drug injected</li> <li>• Housing situations</li> <li>• Use of needle exchange services</li> <li>• History of incarceration</li> <li>• Condom use at last sex</li> </ul>

Data Source	Population	Indicators
<b>Lambda Study (M-Track)</b>	<p>Men who have sex with men in urban and semi-urban centres and who participated in surveys conducted in Ottawa and Toronto (24)</p> <p>(<a href="http://www.actoronto.org/home.nsf/pages/lambda">http://www.actoronto.org/home.nsf/pages/lambda</a>)</p>	<ul style="list-style-type: none"> <li>• Prevalence of HIV &amp; HCV</li> <li>• Unprotected anal intercourse</li> <li>• Delayed condom application</li> </ul>
<b>OCASE &amp; OCHART</b>	<p>People living with HIV accessing services through AIDS Service Organizations (ASOs) in Ontario (25)</p> <p>(<a href="http://www.ohtn.on.ca/Pages/Programs/OCASE-OCHART.aspx">http://www.ohtn.on.ca/Pages/Programs/OCASE-OCHART.aspx</a>)</p>	<ul style="list-style-type: none"> <li>• Indigenous clients of ASOs in Ontario</li> <li>• Programs &amp; services provided to Indigenous clients living with HIV</li> </ul>
<b>Ontario HIV Treatment Network Cohort Study (OCS)</b>	<p>People with HIV who are in specialty HIV care at clinic sites across Ontario (26)</p> <p>(<a href="http://www.ohtncohortstudy.ca">www.ohtncohortstudy.ca</a>)</p>	<ul style="list-style-type: none"> <li>• Race/ethnicity</li> <li>• Sexual behaviour</li> <li>• Smoking &amp; alcohol use</li> <li>• Psychological measures</li> <li>• Health-related quality of life</li> <li>• Clinical HIV status (e.g. CD4 cell count, HIV viral load)</li> <li>• AIDS-defining conditions</li> <li>• Hepatitis C virus co-infection</li> <li>• All-cause mortality</li> <li>• HIV care utilization</li> </ul>
<b>Positive Spaces, Healthy Places Cohort Study (PSHP)</b>	<p>People living with HIV in Ontario receiving services from community-based AIDS service organizations (27–31)</p> <p>(<a href="http://www.pshp.ca">www.pshp.ca</a>)</p>	<ul style="list-style-type: none"> <li>• Race/ethnicity</li> <li>• Sexual behaviour</li> <li>• Smoking &amp; alcohol use</li> <li>• Psychological measures</li> <li>• Health-related quality of life</li> <li>• Health care &amp; social service utilization</li> </ul>
<b>Public Health Ontario, HIV-testing Database</b>	<p>HIV antibody test reports and diagnosed cases of HIV in Ontario (32)</p> <p>(<a href="http://www.ohemu.utoronto.ca/doc/PHE/R02009_report_final.pdf">http://www.ohemu.utoronto.ca/doc/PHE/R02009_report_final.pdf</a>)</p>	<ul style="list-style-type: none"> <li>• Prevalence of HIV &amp; HCV</li> <li>• Race/ethnicity</li> <li>• HIV exposure category</li> </ul>

# SECTION I: INDIGENOUS PEOPLE IN ONTARIO

Ontario has the largest Indigenous population in Canada (2). In 2011, the estimated 301,430<sup>3</sup> Indigenous people living in Ontario represented about 2.4% of the total Ontario population and more than one in five of all Indigenous people in Canada. Most Indigenous people in Ontario self-identify as First Nations (67%) or Métis (28%) (Figure 1) (33).

**FIGURE 1: PERCENT OF FIRST NATIONS, MÉTIS, AND INUIT POPULATIONS AMONG INDIGENOUS PEOPLE IN ONTARIO, 2011 (33)**



Source: Statistics Canada, 2011 National Household Survey, Statistics Canada Catalogue no. 99-011-X2011026 (n=301,430)

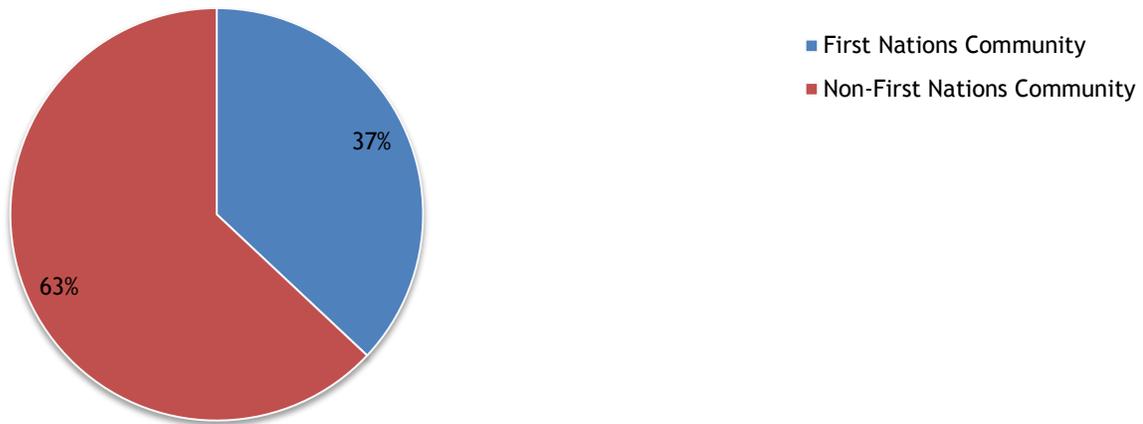
The Chiefs of Ontario identify 133 First Nations communities across Ontario – 127 of which are recognized by the Indian Act. According to the Ontario Ministry of Aboriginal Affairs, one quarter of the 133 First Nation communities are small and remote, accessible only by air or ice road in the winter. Compared to any other region in Canada, Ontario has the greatest number of remote First Nations communities (35).

**Most Indigenous people in Ontario do not live in First Nations communities.** Of the 125,560 First Nations peoples in Ontario with registered Indian Status in 2011, only 37% were living in a First Nation community (“reserve”) (Figure 2) (34). According to 2006 Census data, over

<sup>3</sup> Of the 22 inhabited First Nations communities (“reserves”) that were not completely enumerated by the NHS, six did not permit enumeration; three had enumeration interrupted and 13 experienced natural events such as forest fires that meant enumeration was not completed. As a result, this number undercounts the Indigenous population in Ontario.

three-quarters of Indigenous people who were not living in First Nations communities, were living in urban areas (77.5% vs. 22.5%) (35).

**FIGURE 2: PERCENT OF FIRST NATIONS PEOPLE WITH REGISTERED INDIAN STATUS BY AREA OF RESIDENCE IN ONTARIO, 2011 (34)**



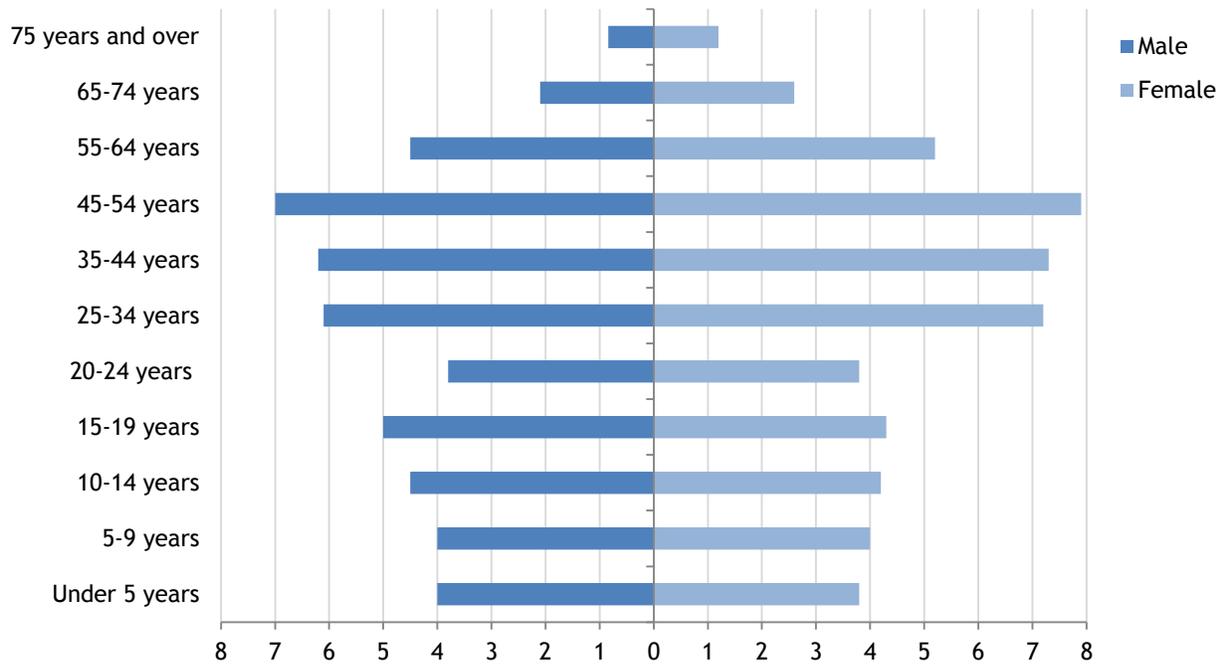
Source: Statistics Canada, 2011 National Household Survey, Statistics Canada Catalogue no. 99-011-X2011001 (n=125,560)

**Ontario's Indigenous population is young and growing.** The Indigenous population in Ontario is younger than the non-Indigenous population: by 10 years for males (median 29.4 years vs. 39.0 years), and by eight years for females (median age 32.7 years vs. 40.9 years). One in four Indigenous people in Ontario is younger than 15 and 42% are younger than 25 (compared to 17% and 31% in the non-Indigenous population) (34). Since 2006, the Indigenous population has grown by 24% – compared to a 4.8% increase in the non-Indigenous population (36). (See Figure 3.)

#### Age & HIV Prevention

Age is an important factor in sexual health and HIV prevention because most people begin to be sexually active and may initiate drug use in adolescence and young adulthood. Rates of most STIs are highest among youth.

**FIGURE 3: AGE DISTRIBUTION OF INDIGENOUS PEOPLE IN ONTARIO, 2011 (37)**



Source: Statistics Canada, 2011 National Household Survey, Statistics Canada Catalogue no. 99-011-X2011026 (n = 301,430)

# SECTION II: HIV, HCV AND HIV/HCV CO-INFECTION AMONG INDIGENOUS PEOPLE

## How Many Indigenous People have been Diagnosed with HIV?

In Ontario, all HIV diagnostic testing is performed at the Public Health Ontario HIV Laboratory and six regional HIV laboratories. HIV testing is provided free of charge to the patient and may be prescribed by any physician or at an anonymous HIV test centre. The HIV test requisition form sent to the HIV Laboratory with the serum specimen includes information on the age and sex of the person being tested, the location of the prescribing physician and any risk factors for HIV infection.

It is difficult to estimate the incidence<sup>4</sup> or prevalence<sup>5</sup> of HIV among Indigenous people in Ontario because the provincial HIV test requisition form does not ask for information on a person's race or ethnicity. In fact, we do not know how many Indigenous people in Ontario have been diagnosed with HIV since the beginning of the epidemic. However, the Laboratory Enhancement Program (LEP) – a program designed to collect more detailed data on a subset of HIV test requests each year – does provide some information (32,38). In January 2009, questions on race/ethnicity were added to the LEP questionnaire. Each year, the questionnaire is mailed to all physicians who ordered HIV tests that were positive as well as to a ~1:200 random sample of physicians who ordered tests that were negative.

We have race/ethnicity information on 1,573 diagnoses (i.e. completed LEP questionnaires) or 91% of 1,729 new HIV diagnoses from 2009 to 2011: **43 (2.7%) of those 1,573 HIV diagnoses were in Indigenous people.**

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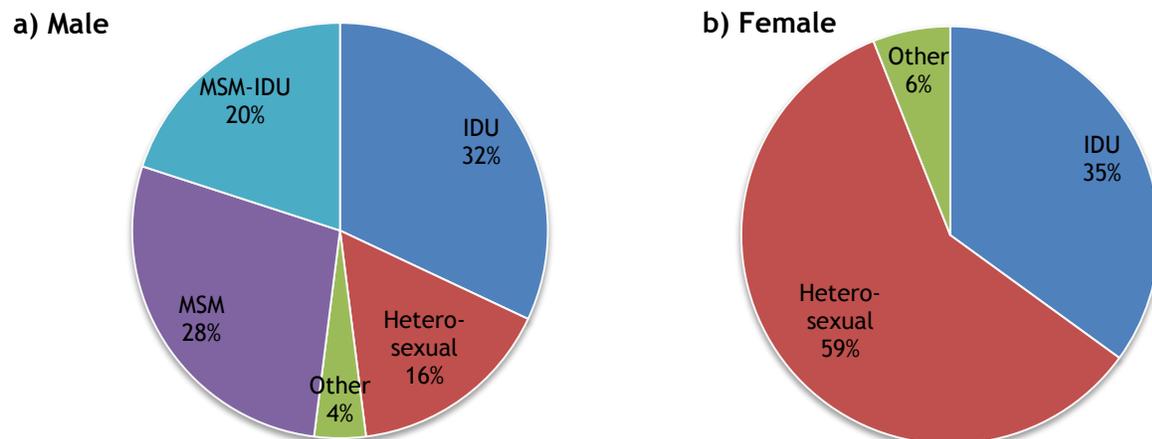
<sup>4</sup> Incidence is the number of new cases per population at risk in a given time period – usually a year.

<sup>5</sup> Prevalence is the proportion of the population infected (i.e. the measure of the burden of disease).

## Who Within the Indigenous Population is Most Likely to be Diagnosed with HIV?

Of the 43 diagnoses in Indigenous people from 2009 to 2011, 26 (60%) were in males and 17 (40%) were in females (Figure 4). According to the LEP data, 28 (64%) of the people diagnosed were exposed to HIV sexually while 15 (35%) were exposed through injection drug use. Among males, 8 (32%) reported being exposed through injection drug use, 7 (28%) through men having sex with men, 5 (20%) through both sex with other men and injection drug use, and 4 (16%) through heterosexual transmission. Among women, 10 (59%) reported being exposed through heterosexual transmission and 7 (35%) through injection drug use.

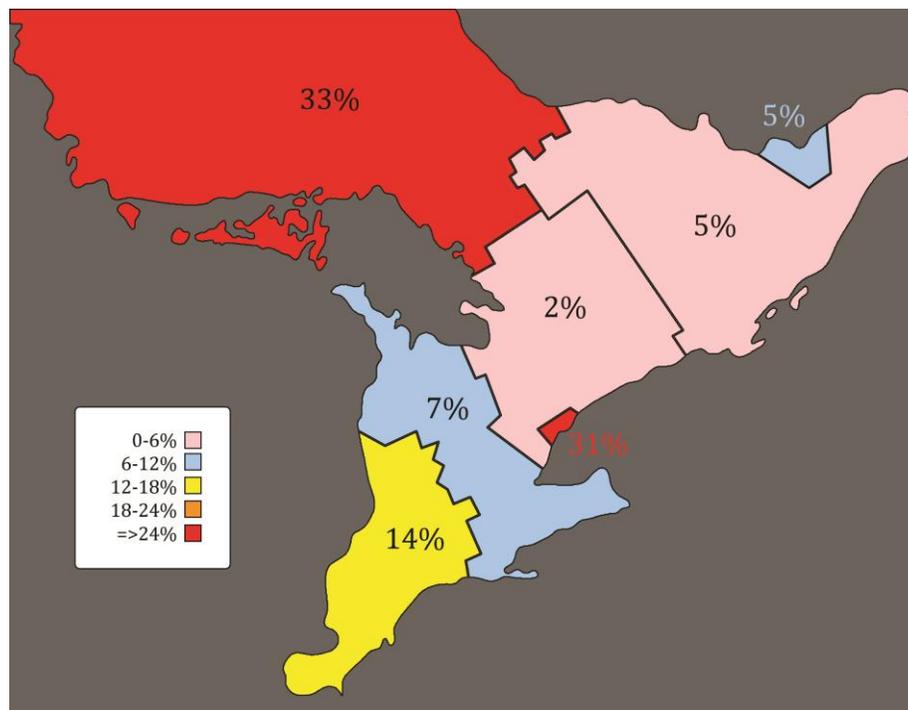
**FIGURE 4: PERCENT OF HIV DIAGNOSES AMONG INDIGENOUS A) MALES AND B) FEMALES BY EXPOSURE CATEGORY IN ONTARIO, 2009-2011**



Source: Sullivan AS, Remis RS. Laboratory Enhancement Program (LEP), HIV Laboratory, Public Health Ontario (males n=26, females n=17)

From 2009 to 2011, most HIV diagnoses in Indigenous people were concentrated in three regions of the province. Fourteen (33%) of the 43 HIV diagnoses were from the Northern region, 13 (31%) were from Toronto (31%) and 6 (14%) were from the Southwest region (Figure 5).

**FIGURE 5: DISTRIBUTION OF HIV DIAGNOSES AMONG INDIGENOUS PEOPLE BY ONTARIO HEALTH REGION, 2009-2011**



Source: Sullivan AS, Remis RS. Laboratory Enhancement Program (LEP), HIV Laboratory, Public Health Ontario (n=43)

### **Between 1984 and 2010, three Indigenous babies were diagnosed with HIV**

The Canadian Perinatal HIV Surveillance Program (CPHSP) Ontario region (5,21) has been collecting information on infants born to HIV-infected mothers since 1984. Of the 1,002 mother-infant pairs reported from 1984 to 2010 that included information about the mother's race/ethnicity, 23 (2.3%) were Indigenous and vertical transmission of HIV (mother to baby) occurred in three cases. The three Indigenous babies born with HIV represented 2.2% of the 142 infected babies born between 1984 and 2010. Compared to other mother-infant pairs, Indigenous mothers were more likely to have been infected via heterosexual activity; however, two of the three mothers of babies who acquired HIV were infected through injection drug use.

## What is the Prevalence of HIV in Ontario's Indigenous Populations?

Because we do not have information on the total number of Indigenous people in Ontario who are living with HIV, we must use other data to estimate prevalence.

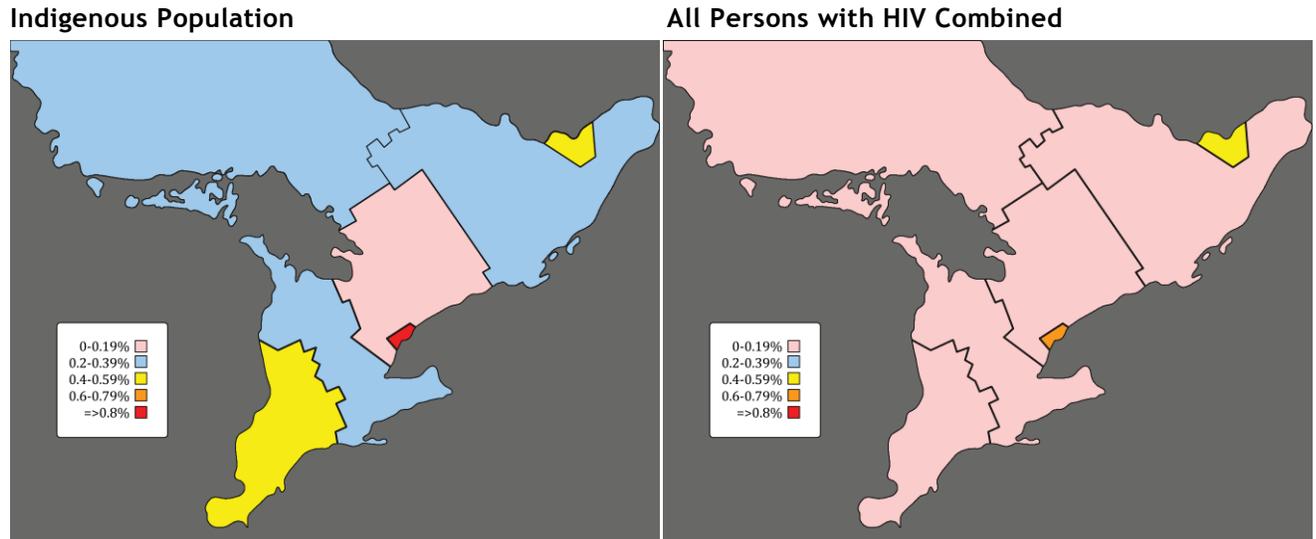
In 2008, the Public Health Agency of Canada (PHAC) independently modelled the number of people living with HIV Ontario and estimated that 625 Indigenous persons were HIV positive (39). In the same year, Ontario used data from several sources to estimate HIV prevalence (e.g. AIDS cases and HIV diagnoses by race/ethnicity, Indigenous population size estimates from Census data, the relative risk of all causes of mortality for urban Indigenous adults compared to urban non-Indigenous adults in Canada from 1991 to 2001, and the 2007 Ontario HCV report [40]). At that time, Ontario estimated that **Indigenous people, who made up 2.4% of Ontario's population, accounted for 3.2% (853) of the 26,628 people living with HIV in Ontario in 2008 – or a prevalence of 0.42%**. The Ontario estimate of 853 Indigenous people infected with HIV was at the upper bound of PHAC's range of uncertainty so the two prevalence estimates are similar.

**HIV prevalence varies by health region** (Figure 6). In 2008, we estimated that the highest HIV prevalence was in Toronto (2.82%), followed by Ottawa (0.57%), and the lowest prevalence was in the Central East Region (0.07%).

**Based on these estimates of prevalence, Indigenous people were 1.7 times more likely than the general population to be infected with HIV. While a rate that high is concerning, it is also significantly lower than the PHAC estimates for Indigenous people in other parts of Canada in 2008 (3.6 times more likely to be infected with HIV than the general population).**

Once again, that risk varies by region. Indigenous people in Toronto and Central West were 3.8 and 3.9 times more likely to have HIV than the general population in those regions – **rates similar to the PHAC national estimate**. On the other hand, Indigenous people in Central East were 1.2 times more likely to have HIV than the general population in that region.

**FIGURE 6: MODELED HIV PREVALENCE BY HEALTH REGION IN ONTARIO, 2008**



Source: Remis RS & Liu J. Ontario HIV Epidemiologic Monitoring Unit, University of Toronto (Indigenous n = 853, all persons with HIV n=26,630)

## Who is Most Affected by HIV?

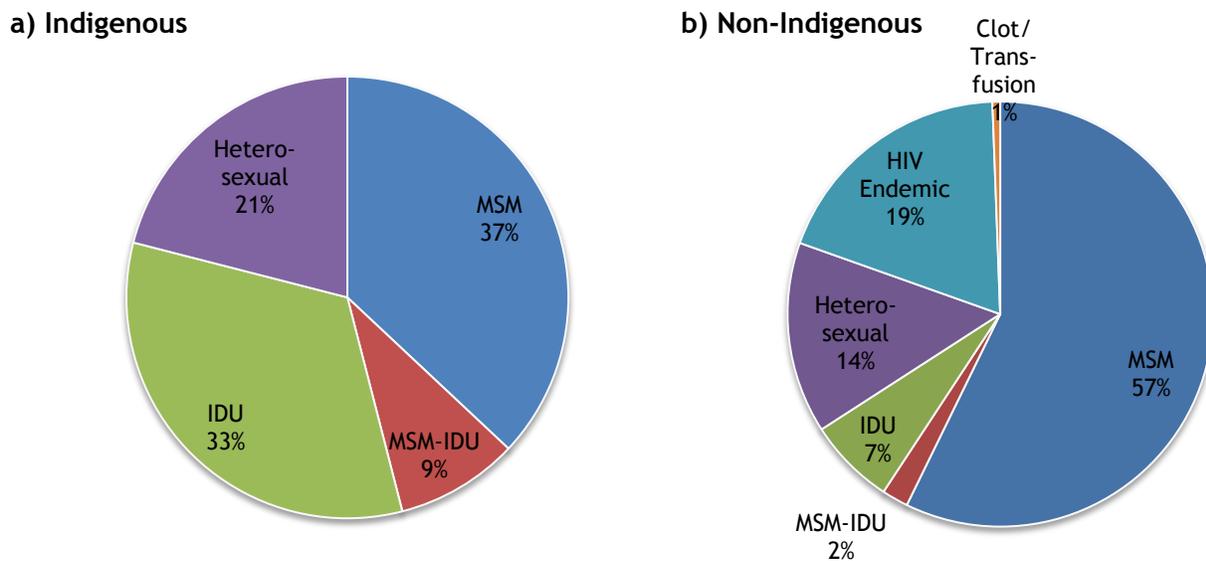
### HIV prevalence is higher in Indigenous males than females

In 2008, Ontario estimated that HIV prevalence was 0.66% among Indigenous males and 0.21% among Indigenous females – or 2.4 and 1.6 times higher than the general male and female population of Ontario.

Although HIV prevalence is higher in Indigenous males, Indigenous females account for one of every four diagnoses in Indigenous people (25.3%) – which is a much higher proportion than in non-Indigenous populations, where women account for just over one of every six diagnoses (17.8%).

Based on modeled estimates, Indigenous people were more likely than non-Indigenous people to be infected through injection drug use and heterosexual transmission. See Figure 7 for a comparison of exposure categories.

**FIGURE 7: MODELLED DISTRIBUTION OF HIV INFECTIONS BY EXPOSURE CATEGORY AMONG**



**A) INDIGENOUS AND B) NON-INDIGENOUS PEOPLE IN ONTARIO, 2008**

Source: Remis RS & Liu J. Ontario HIV Epidemiologic Monitoring Unit, University of Toronto (Indigenous n=853, non-Indigenous n=26,630)

**In some communities HIV prevalence is higher among Indigenous people who inject drugs than among non-Indigenous people who inject drugs**

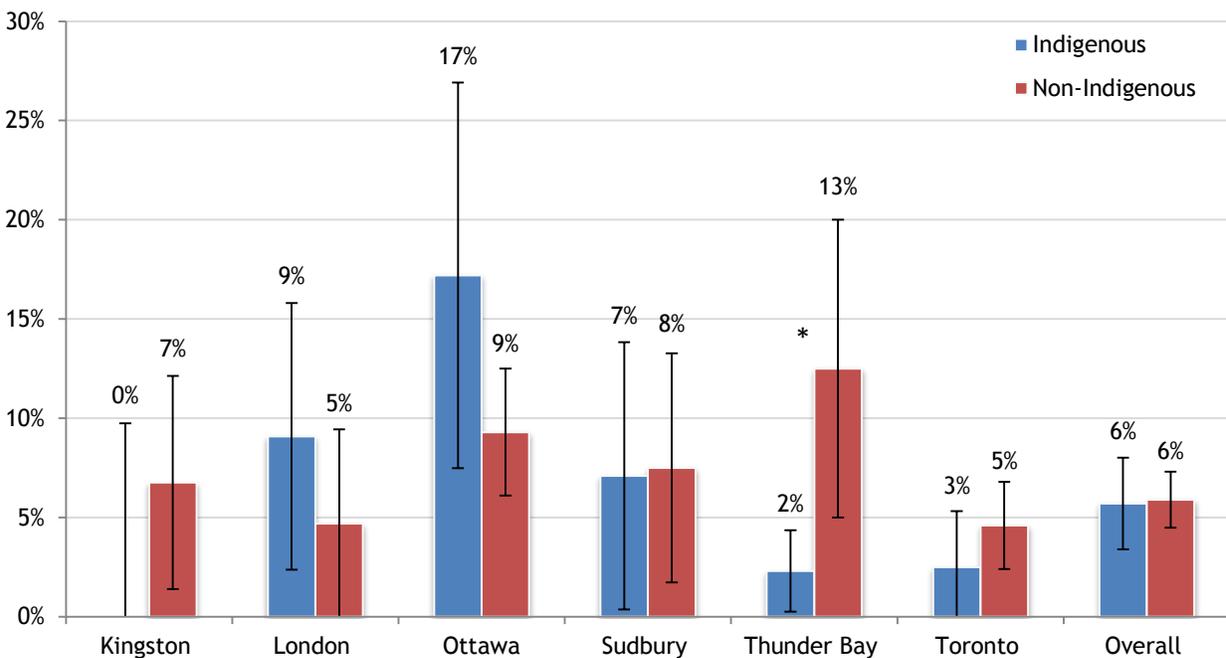
Because a significant proportion of Indigenous people diagnosed with HIV report being exposed through injection drug use, we looked at the prevalence of HIV among Indigenous people who inject drugs using results from laboratory testing of saliva or dried blood spot samples from Indigenous participants in the I-Track and I-Track/SurVIDU surveys.

When we looked at combined data from six Ontario cities, we saw little difference between the 5.7% HIV prevalence among Indigenous participants (95%CI 3.4, 8.0%) and the 5.9% prevalence among non-Indigenous participants (95%CI 4.5, 7.3%). However, when we looked at prevalence rates by city, we saw considerable variation (Figure 8). For example, there were no positive HIV test results among Indigenous participants in Kingston (95%CI 0, 9.7%). In Thunder Bay, HIV prevalence was significantly lower among Indigenous (2.3%, 95%CI 0.3, 4.4%) than non-Indigenous participants (13%, 95%CI 5.0, 20.0%). In Ottawa, on the other hand, 17.2% (95%CI 7.5, 26.9%) of Indigenous participants tested positive for HIV compared to 9.3% (95%CI 6.1, 12.5%) of non-Indigenous participants. Note that Toronto I-Track participants included some crack

smokers who were not current injectors and therefore could be expected to have a lower HIV prevalence than people who inject.

Among all Indigenous I-Track participants who used drugs, HIV prevalence was similar among women (5.8%, 95%CI 2.8, 10.5%) and men (5.5%, 95%CI 2.9, 9.5%).

**FIGURE 8: PREVALENCE OF HIV AMONG INDIGENOUS AND NON-INDIGENOUS PEOPLE WHO USE DRUGS, BY ONTARIO CITY, 2010**



Source: Millson P, Leonard L, White S, & Kohm E. Phase 3 I-Track surveys 2010-12 and Ottawa I-Track/SurviDU survey 2010-2011 (Indigenous n= 388; non-Indigenous n=1,076)

Asterisk (\*) indicates differences between Indigenous and non-Indigenous participants that were statistically significant ( $p < 0.05$ )  
 Bars indicate the 95% confidence interval. Longer bars indicate a larger margin of error and less precise estimates

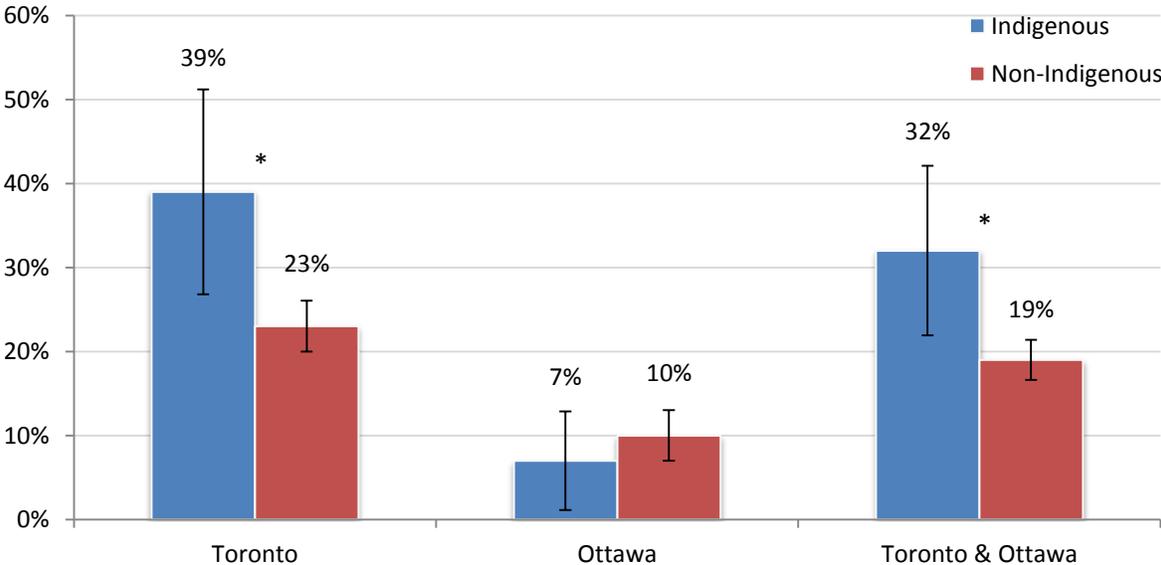
The relatively lower prevalence of HIV among Indigenous participants in some cities is encouraging. However, this information should be interpreted in the context of data on sociodemographics and injection locations. These data suggest that Indigenous people who use drugs may be part of injecting networks of friends and family members. As long as there is no HIV in these networks, the risk of contracting HIV stays low. However, if HIV were to be introduced into these networks, the risk of becoming infected would increase significantly. To prevent this increase, it will be important to work with Indigenous people who use drugs to develop culturally-appropriate harm reduction measures.

## HIV prevalence is higher among Indigenous men who have sex with men in Toronto

Because a significant proportion of Indigenous men diagnosed with HIV reported being exposed through sex with men, we used data from the Lambda study to estimate HIV prevalence among Indigenous men who have sex with men in the two cities covered by the study (Toronto and Ottawa) (24). As part of that study, participants were asked to provide a dried blood spot for HIV testing; 45% of all participants (1,095/2,438) and 53% of the Indigenous men (65/122) agreed to provide a specimen. Based on those specimens, HIV prevalence was higher among men who have sex with men in Toronto than Ottawa (24% vs. 12%,  $p < 0.01$ ). Differences were more extreme among Indigenous men who have sex with men: HIV prevalence was 39% (95%CI 27, 51%) in Toronto and 7% (95%CI 1, 13%) in Ottawa (Figure 9).

When these results were compared to the men's self-reported HIV status based on their HIV testing history, about 14% of men in Toronto and 23% in Ottawa did not know they were infected. However, the Indigenous men seemed more aware of their status: only 5% of Indigenous participants did not already know they had HIV.

**FIGURE 9: PREVALENCE OF HIV AMONG INDIGENOUS AND NON-INDIGENOUS MEN WHO HAVE SEX WITH MEN IN TORONTO AND OTTAWA, 2007**



Source: Remis RS, Myers T, Husbands W & Liu J. Lambda (M-Track) Survey (Indigenous n=65, non-Indigenous n=925)  
Asterisk (\*) indicates differences between Indigenous and non-Indigenous participants that were statistically significant ( $p < 0.05$ )  
Bars indicate the 95% confidence interval. Longer bars indicate a larger margin of error and less precise estimates

## What is the Prevalence of Hepatitis C among Indigenous People?

Because HIV and HCV share routes of transmission (i.e. bloodborne), behavioural risk factors (e.g. sharing drug equipment, unsafe tattooing, unprotected sexual practices especially if blood is present), and socioeconomic risk factors (e.g. poverty, homelessness), we also looked at the prevalence of HCV among Indigenous people in Ontario.

### Indigenous people may have higher rates of HCV than the general population

In 1998, the federal Enhanced Hepatitis Strain Surveillance System (EHSSS) was initiated to obtain a more accurate assessment of hepatitis B (HBV) and HCV infection in Canada. Initially, the EHSSS collected data from four localities in Canada, including Ottawa. In 2006, Hamilton and London joined the system and contributed data on newly identified acute and chronic infections, as well as risk factors associated with these infections. From 2007 to 2010, 71 new cases of HCV among Indigenous peoples in Ontario were reported to EHSSS: an incidence rate of 71.2 cases per 100,000 population per year, which was more than twice as high as the annual incidence of HCV in Canada of 33.7 per 100,000 in 2009 (40). Indigenous cases in these Ontario cities were evenly divided by gender (37 men, 34 women) and 20% (14/71) were diagnosed during acute infection.

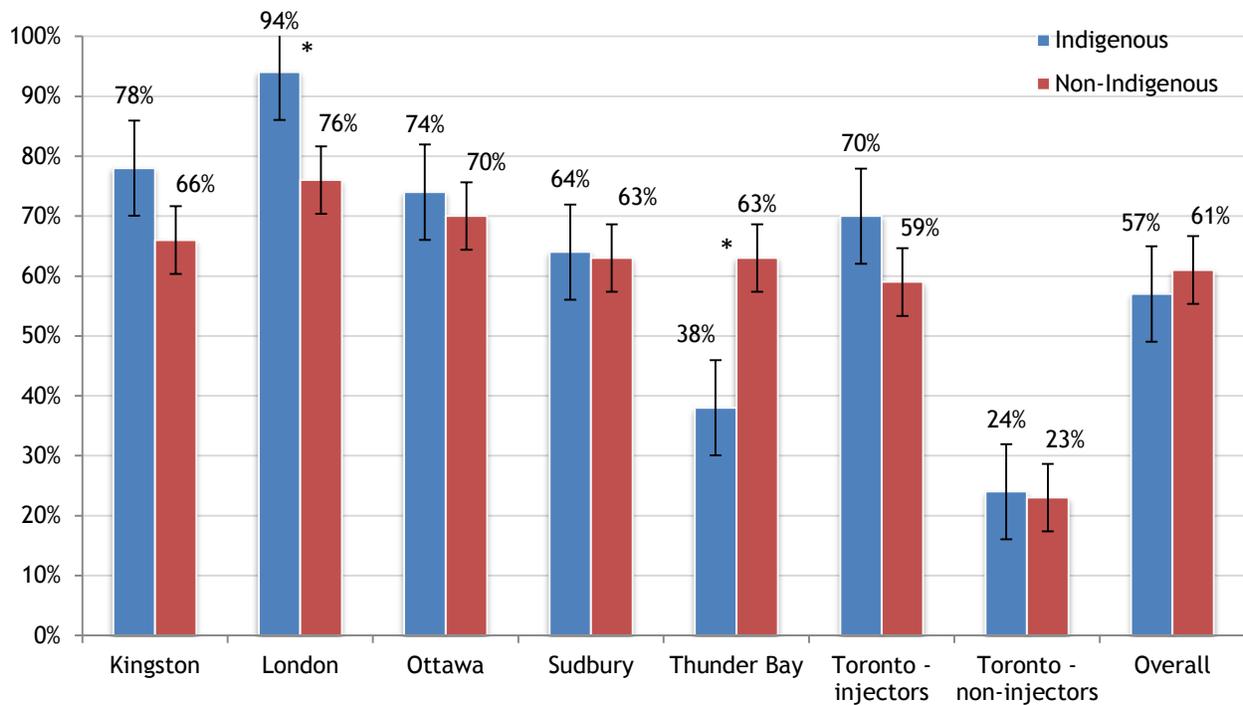
### Prevalence of HCV is 3.5 times higher in Indigenous people than in general population

Based on data on HCV diagnoses by race/ethnicity, Indigenous population size estimates from Census data and all-cause mortality, we estimate that, as of 2008, **7,194 Indigenous people in Ontario had HCV infection: an overall prevalence of 3.0%**. This is 3.5 times higher than the estimated 0.85% prevalence among all people in Ontario. HCV prevalence was higher among Indigenous men (4.1%) than Indigenous women (1.9%), a pattern that also holds true for non-Indigenous men and women (41,42).

**HCV is more prevalent than HIV among people who inject drugs, regardless of Indigenous status.** The I-Track studies found that HCV prevalence was higher than HIV prevalence among people who inject drugs at all recruiting sites. Among all participants, HCV prevalence was lower among Indigenous people (57.4%) than non-Indigenous people (60.7%).

However, this overall rate masks regional variations (Figure 10). HCV prevalence was higher among Indigenous participants than non-Indigenous participants in Kingston (77.8% vs. 66.0%), Ottawa (74.1% vs. 69.6%) and Sudbury (64.3% vs. 62.8%). In London HCV prevalence was significantly higher among Indigenous (93.8%) than non-Indigenous participants (75.9%) ( $p=0.02$ ). In Toronto, among current injectors, HCV prevalence was higher for Indigenous than non-Indigenous participants (70.0% vs. 58.8%); however, among people who smoke crack who were not current injectors, about half of whom were former injectors, HCV prevalence was similar among both Indigenous and non-Indigenous participants (24.2% vs. 23.0%). On the other hand, in Thunder Bay, HCV prevalence was significantly higher among non-Indigenous (62.5%) than Indigenous participants (37.7%,  $p<0.01$ ).

**FIGURE 10: PREVALENCE OF HCV AMONG INDIGENOUS AND NON-INDIGENOUS PEOPLE WHO USE DRUGS, BY CITY, 2010-2012**



Source: Millson P, Leonard L, White S, & Kohm E. Phase 3 I-Track surveys 2010-12 and Ottawa I-Track/SurVIDU survey 2010-2011 (Indigenous  $n=383$ ; non-Indigenous  $n=1,064$ )

Note that the Toronto non-injector group includes participants who formerly injected and a group who have never injected, all of whom smoke crack-cocaine

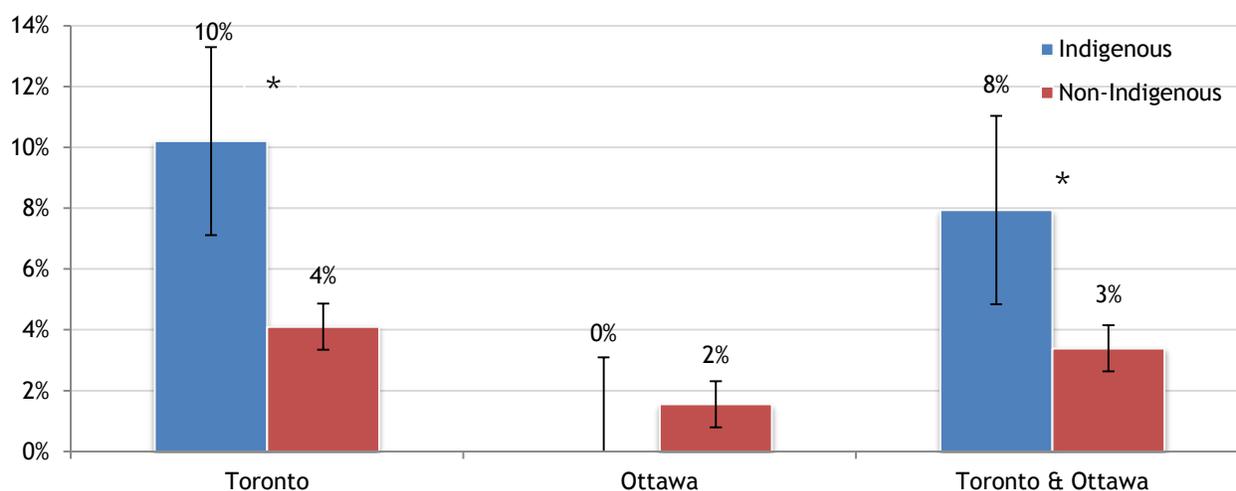
Asterisk (\*) indicates differences between Indigenous and non-Indigenous participants that were statistically significant ( $p<0.05$ )

Bars indicate the 95% confidence interval. Longer bars indicate a larger margin of error and less precise estimates

## HCV prevalence is high among Indigenous men who have sex with men

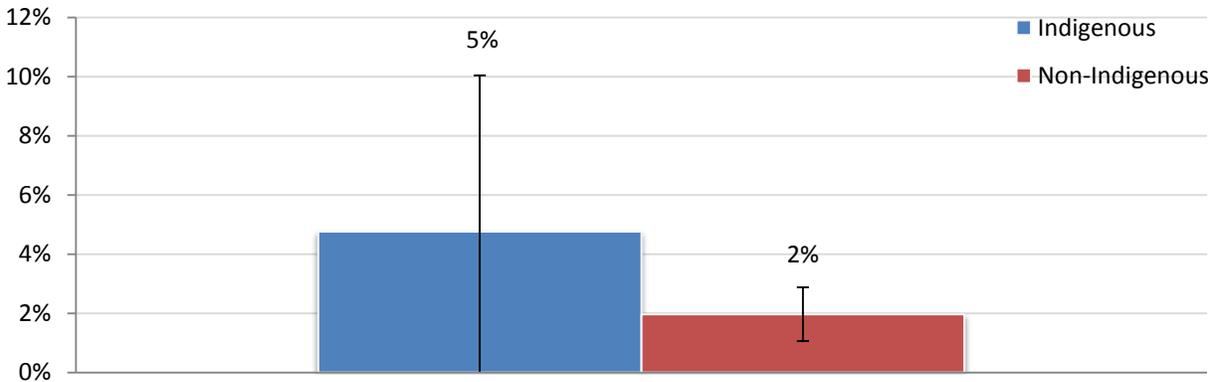
Men who have sex with men may be at higher risk of both HCV infection and HIV/HCV co-infection because some may also inject drugs and because of the possibility that HCV can be transmitted sexually, particularly among men who have sex with men who are HIV positive (43,44). **Indigenous men who have sex with men** who participated in the Lambda study in 2007 (24) and who provided a dried blood spot **had the highest HCV prevalence of any racial/ethnic group in the study (7.9%)** (Figure 11). The rate was even higher among Indigenous men in Toronto (10.2%). **Indigenous men who have sex with men also had the highest prevalence of HIV/HCV co-infection (4.8%)** although ethnic differences were not statistically significant (Figure 12).

**FIGURE 11: HCV PREVALENCE AMONG INDIGENOUS AND NON-INDIGENOUS MEN WHO HAVE SEX WITH MEN IN TORONTO AND OTTAWA, 2007**



Source: Remis RS, Myers T, Husbands W & Liu J. Lambda (M-Track) Survey (Indigenous n=63, non-Indigenous n=915)  
Asterisk (\*) indicates differences between Indigenous and non-Indigenous participants that were statistically significant ( $p < 0.05$ )  
Bars indicate the 95% confidence interval. Longer bars indicate a larger margin of error and less precise estimates

**FIGURE 12: PREVALENCE OF HIV/HCV CO-INFECTION AMONG INDIGENOUS AND NON-INDIGENOUS MEN WHO HAVE SEX WITH MEN IN TORONTO AND OTTAWA, 2007**



Source: Remis RS, Myers T, Husbands W & Liu J. Lambda (M-Track) Survey (Indigenous n=63, non-Indigenous n=914)  
Bars indicate the 95% confidence interval. Longer bars indicate a larger margin of error and less precise estimates

## What is the Prevalence of HIV/HCV Co-infection Among Indigenous People?

**In 2008, about 37% of Indigenous people with HIV in Ontario (~314 Indigenous persons) were co-infected with both HIV and HCV.**

Rates of HCV co-infection were higher among Indigenous women with HIV (44%) than Indigenous men (35%). Most co-infections were among people who injected drugs (74%) followed by men who have sex with men who also injected drugs (20%). To derive these numbers, we estimated the prevalence of HCV infection among HIV-infected persons for each exposure category from a previous extensive literature review (45). The proportion of people with HCV infection was then multiplied by the number of HIV-infected persons in each exposure category to estimate the number of HIV/HCV co-infected Indigenous persons in Ontario.

Our estimates were similar to the 31% (95%CI 26, 35%) of Indigenous people with HIV in the OHTN Cohort Study (OCS) (which represents

### HIV/HCV and HIV/AIDS

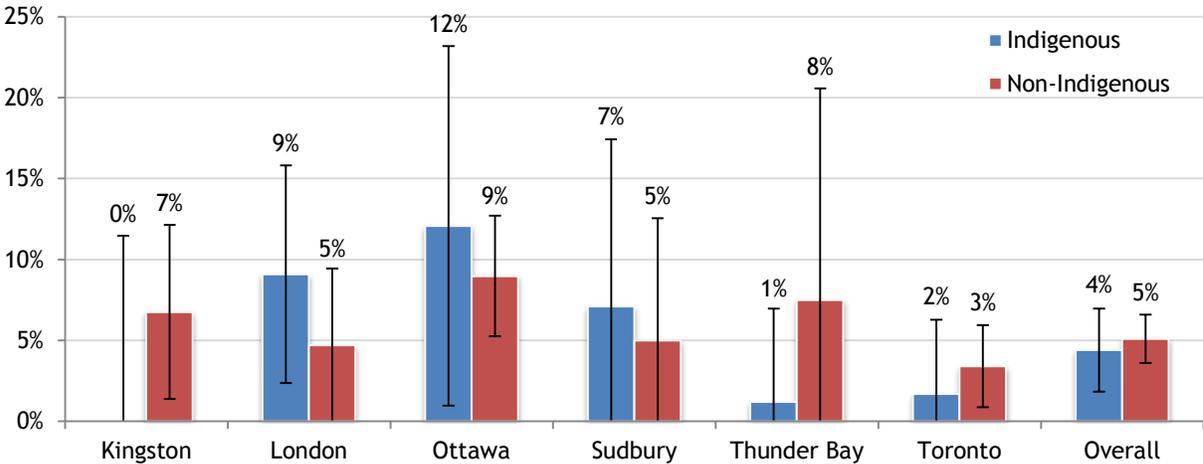
HIV/HCV co-infection complicates people's health and care. Being co-infected may lead to more rapid progression of liver disease compared to people infected with HCV alone, and as well as a poorer response to HCV treatment (46–48).

people in care at clinics across the province) who have been diagnosed with HCV. Slightly over half (53%) of HIV/HCV co-infected Indigenous people in the OCS used injection drugs; men who have sex with men-who also inject drugs, men who have sex with men and heterosexuals each accounted for about an equal number of the remainder. Similar to the modeled estimates above, HCV co-infection was more common among Indigenous women (56%, 95%CI 46, 66%) than Indigenous men (28%, 95%CI 24, 33%) in the OCS.

**The prevalence of HIV/HCV co-infection among Indigenous people who use drugs varies by region**

According to the I-Track studies, both Indigenous and non-Indigenous participants had similar rates of HIV/HCV co-infection: 4.4% (95%CI 2.6, 6.9%) and 5.1% (95%CI 3.9, 6.6%) respectively (based on laboratory results). Again, the overall rate masks regional differences (Figure 13). For example, Indigenous participants in Thunder Bay had a co-infection rate of 1.2% (95%CI 0, 7.0%), while the rate was 9.4% (95%CI 2.4, 15.8%) in London and 12.1% (95%CI 1.0, 23.2%) in Ottawa.

**FIGURE 13: PREVALENCE OF HIV/HCV CO-INFECTION AMONG INDIGENOUS AND NON-INDIGENOUS PEOPLE WHO USE DRUGS, BY CITY, 2010-2012**



Source: Millson P, Leonard L, White S, & Kohm E. Phase 3 I-Track surveys 2010-12 and Ottawa I-Track/SurVIDU survey 2010-2011 (Indigenous n=389; non-Indigenous n=1,078)  
 Bars indicate the 95% confidence interval. Longer bars indicate a larger margin of error and less precise estimates

# SECTION III: THE RISK FACTORS DRIVING INFECTIONS AMONG INDIGENOUS PEOPLE

Within populations in Ontario most affected by HIV, risk is driven by many factors including social determinants of health such as poverty, gender inequality and violations of basic human rights. Many of the root causes of the behaviours that allow the virus to spread (e.g. sharing drug equipment, unprotected sex) are social, structural and systemic. To understand HIV among Indigenous people in the province, we must have a clear picture of the socioeconomic features that may create disparities in health and access to health services, as well as the patterns of behavior that put people at risk.

## The Legacy of Racism and Colonialism Affects Indigenous People's HIV Risk

Although this report focuses on individual behaviours that can lead to HIV acquisition and transmission, we recognize that the legacy of racism and colonialism contributes to the risk environment for Indigenous people. A recent report by the Aboriginal Healing Foundation (2009) suggests that the residential school system has “played a role in the spread of HIV among certain segments of the Indigenous population, perhaps more indirectly than directly” (49). As the report outlines:

*It is a reasonable claim that the Legacy has been a factor in the spread of HIV/AIDS among the Aboriginal population. However, the real question is: to what extent? A study cited earlier on injection drug users revealed troubled homes and childhoods where physical, sexual, mental, and emotional abuse were common factors. This further confirms a relationship between troubled childhoods and homes and subsequent self-destructive patterns in adulthood. When this self-destructive pattern is injection drug use, there are high risks for HIV. Another study... that specifically targeted Aboriginal injection drug users also found physical and sexual abuse common to both male and female study participants. HIV/AIDS data clearly show the role of injection drug use as a risk factor among the Aboriginal population, which means that substance abuse is a common, yet negative, coping pattern being used. Finally, data from Health Canada confirm injection drug use as a key exposure category for Aboriginal people in regards to HIV/AIDS (49).*

## Socioeconomic Factors Increase Risk

A growing body of evidence reinforces that socioeconomic factors, such as income, housing stability, education and employment are determinants of health and influence the risk of HIV, HCV and HIV/HCV co-infection. Compared to non-Indigenous people in Ontario, Indigenous people still experience gaps in terms of income, education and employment – although many of these gaps are narrowing.

We would also like to stress that, faced with social and economic inequalities, Indigenous people are increasingly drawing on language, environmental connectedness and other cultural tools to promote and increase resiliency (7,50,51):

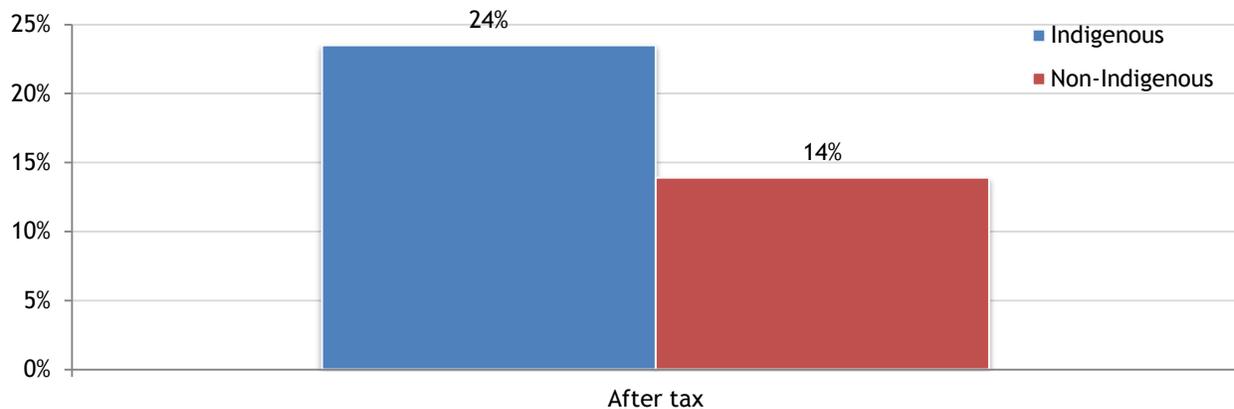
*Aboriginal Peoples in Canada have diverse notions of resilience grounded in culturally distinctive concepts of the person that connect people to community and the environment, the importance of collective history, the richness of Aboriginal languages and traditions, as well as individual and collective agency and activism. Narratives of historical identity and continuity along with revitalization of culture, language, and tradition can help repair the ruptures of cultural continuity that have occurred with colonization and the active suppression of indigenous cultures and identity (50).*

### Income/Poverty

**Indigenous people earn, on average, 26% less than non-Indigenous people.** The 2011 National Household Survey reported an \$11,200 (average) income gap between an Indigenous and a non-Indigenous person in Ontario (33,52). Although Indigenous people's incomes are lower, they are increasing at a faster rate than those of non-Indigenous people.

According to Statistics Canada data (2011), **a higher proportion of Indigenous people (24%) than non-Indigenous people (14%) in Ontario were considered low-income** based on Low Income Measure – After Tax (LIM-AT) criteria (33,52). These criteria indicate when people are spending a greater proportion of their income on basics like food, clothing and shelter than an average family of the same size (Figure 14).

**FIGURE 14: PERCENT OF INDIGENOUS AND NON-INDIGENOUS PEOPLE REPORTING LOW INCOME AFTER TAX IN ONTARIO, 2011 (33,52)**



Source: Statistics Canada, 2011 National Household Survey: Aboriginal Population Profile. Statistics Canada Catalogue no. 99-011-X2011007 (n=227,235) & Statistics Canada, 2011 National Household Survey: National Household Survey (NHS) Profile. Statistics Canada Catalogue no. 99-004-XWE (n=10,473,665)

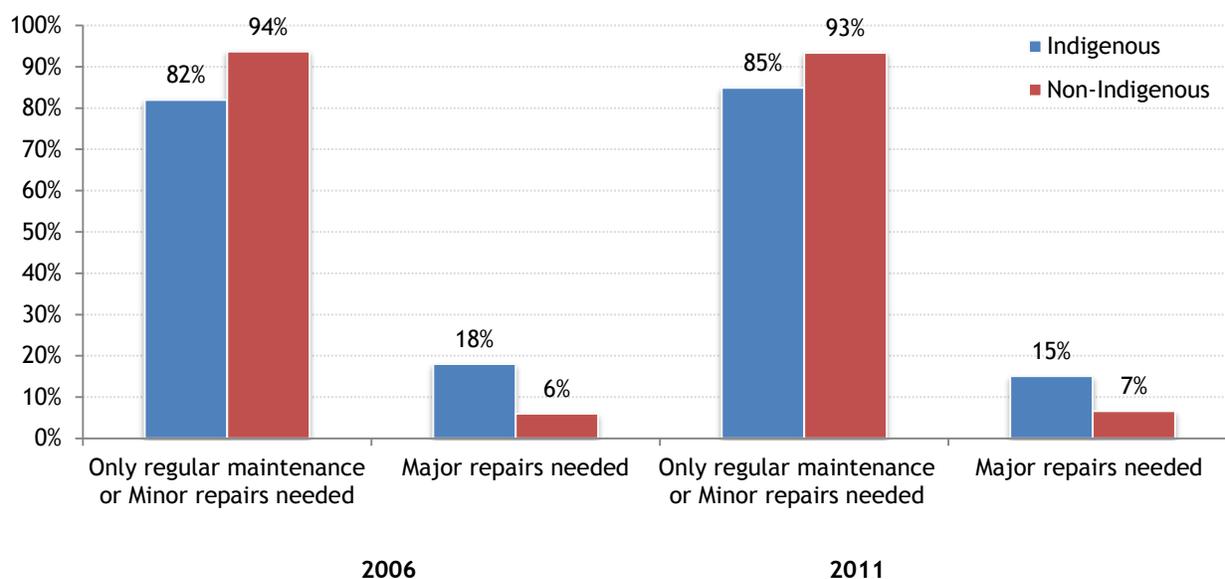
**Poverty may be more of an issue in First Nations communities.** In 2008-2010, the First Nations Regional Health Survey surveyed 1500 First Nations adults from select First Nations communities in Ontario and found that virtually all (99.9%, 95%CI 99.1, 100.0%) First Nations adults surveyed were part of low-income families (i.e. living below the Statistics Canada low income cut-off measure) and at risk of poverty (53).

## Housing

**Some Indigenous people continue to experience housing challenges, but the gaps are narrowing.** Substandard housing has been an issue for Indigenous people in Canada for many years (54). According to the Ontario Ministry of Aboriginal Affairs, in 2006, Indigenous peoples were four times more likely than non-Indigenous Canadians to be living in crowded housing (55). For urban areas outside of First Nations communities, affordability is a particular challenge. For Indigenous people, the risk of homelessness was as much as 10 times higher than for non-Indigenous people (56).

According to Statistics Canada, in 2006 18% of Indigenous people indicated that their household was in need of major repairs compared to 6% of the general Ontario population (57). However, by 2011, the National Household Survey indicated that the situation had improved: the proportion of Indigenous people requiring “only regular maintenance” or “minor repairs” to their homes had increased while the proportion requiring “major repairs” had decreased (Figure 15) (33,52).

**FIGURE 15: HOUSING CONDITIONS AMONG INDIGENOUS AND NON-INDIGENOUS PEOPLE IN ONTARIO, 2006 AND 2011 (33,52,57)**

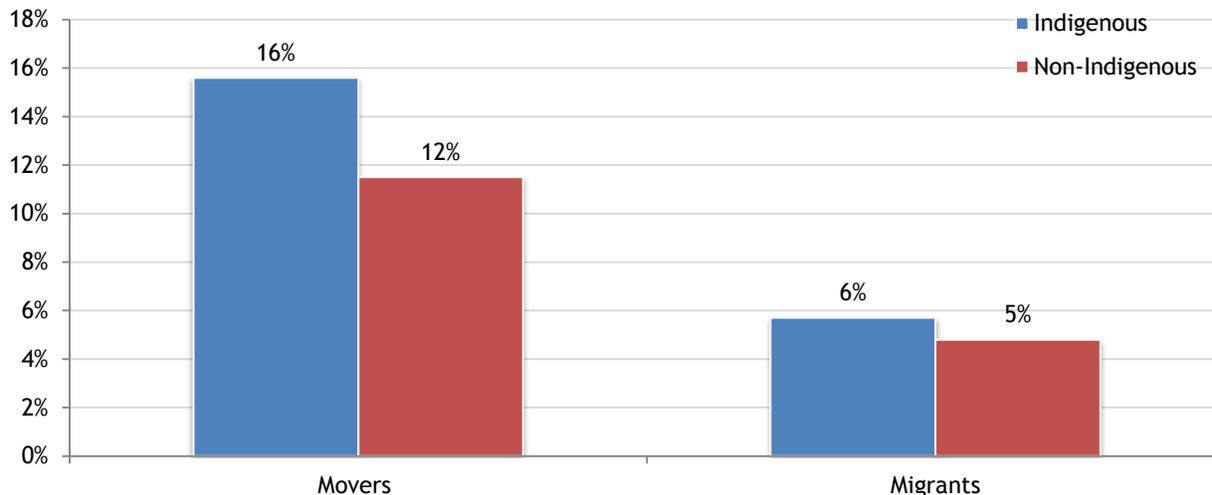


Source: Statistics Canada, 2006 Census: Indigenous Identity, Topic-based Tabulations & Statistics Canada, 2011 National Household Survey: Indigenous Population Profile. Statistics Canada Catalogue no. 99-011-X2011007 (n=156,405) & Statistics Canada, 2011 National Household Survey: National Household Survey (NHS) Profile. Statistics Canada Catalogue no. 99-004-XWE (n=4,886,655)

Housing instability is a risk factor for HIV and poor health outcomes. Frequent moves, especially during childhood, have been associated with poorer health outcomes, including greater risk of attempted suicide (58). When people are mobile or move often, it can affect their ability to develop strong social networks, maintain employment and schooling, and have continuity in the health care services they receive, all of which may influence HIV risk.

In 2011, a higher proportion of Indigenous people than non-Indigenous people moved from their place of residence within the previous year (Figure 16) (33,52). Among Indigenous people in Canada, young people, women and lone-parent families were most likely to move. Lone-parent families were found to be most likely to move to urban centres (59). Reasons for moving from First Nations communities to other locations included: employment, education and community-related issues. Reasons for moving to First Nations communities were: housing and family issues (53,59). Over two thirds of First Nations adults (67.5%, 95%CI 61.0, 73.3%) have lived outside their community at some point, and more than 10% reported moving back and forth more than once per year (53).

**FIGURE 16: ONE-YEAR MOBILITY STATUS AMONG INDIGENOUS AND NON-INDIGENOUS PEOPLE IN ONTARIO, 2011 (33,52)**



Source: Statistics Canada, 2011 National Household Survey: Indigenous Population Profile. Statistics Canada Catalogue no. 99-011-X2011007 (n=296,945) & Statistics Canada, 2011 National Household Survey: National Household Survey (NHS) Profile. Statistics Canada Catalogue no. 99-004-XWE (n=12,517,320)

As defined by Statistics Canada, mobility status refers to the relationship between a person's usual place of residence on Census Day and his or her usual place of residence one year earlier. A person is classified as a non-mover if no difference exists. Otherwise, a person is classified as a mover. Within the category of movers, a further distinction is made between non-migrants and migrants. 'Non-migrants' are those who have moved to a different dwelling but reside in the same Census Subdivision (CSD); migrants are those who have moved to a different CSD. In this figure, movers and migrants are not mutually-exclusive.

## Education

**Gaps in academic achievement are decreasing in Ontario.** Academic achievement among Indigenous people is improving (60,61). According to the 2011 National Household Survey (33,52): 69% of Indigenous people in Ontario (15 years and older) had secondary or post-secondary education; 9% had completed a university degree; and 43% had completed some type of post-secondary education (including apprenticeships, trades certificates, diplomas, and college and university degrees). However, these rates are still lower than in the non-Indigenous population (81%, 23% and 55% respectively).

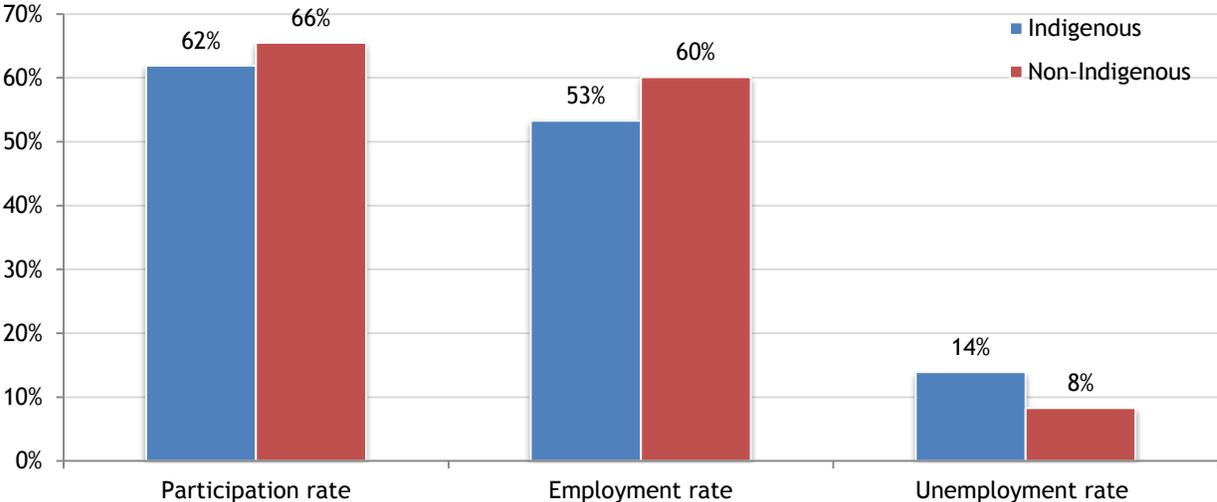
In the First Nations Regional Health Survey, 35.9% of First Nations participants ages 18 to 29 had completed a post-secondary degree, post-secondary diploma or some post-secondary education. This proportion increased dramatically to 61.1% in 30 to 39 year olds and 63% in 40 to 49 year olds (53).

With lower high school graduation rates than the non-Indigenous population, Indigenous people may face greater challenges participating in Ontario's knowledge economy, which may put them at greater risk of poor health outcomes.

### Employment

**More Indigenous people are employed but their employment rate is still lower than the rate in non-Indigenous people.** According to the Ontario Ministry of Aboriginal Affairs (36,62), employment rates for Indigenous people have increased over the past decade, but they still lag behind rates in the non-Indigenous population (Figure 17) (33,52).

**FIGURE 17: LABOUR FORCE ACTIVITY AMONG INDIGENOUS AND NON-INDIGENOUS PEOPLE IN ONTARIO, 2011 (33,52)**



Source: Statistics Canada, 2011 National Household Survey: Indigenous Population Profile. Statistics Canada Catalogue no. 99-011-X2011007 (n=227,235) & Statistics Canada, 2011 National Household Survey: National Household Survey (NHS) Profile. Statistics Canada Catalogue no. 99-004-XWE (n=10,473,670)

Rates calculated from those aged 15 years and older

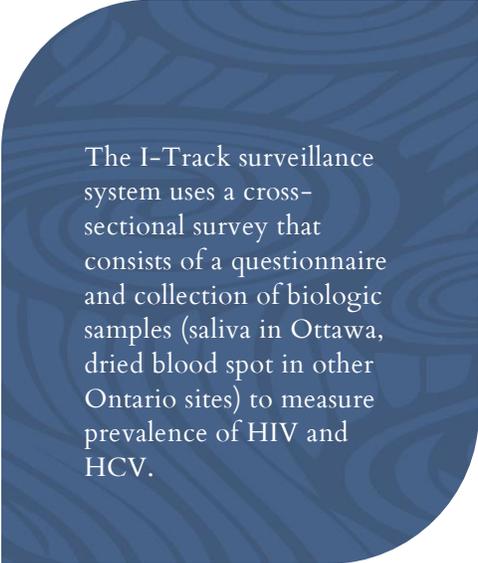
Unemployment rates are lower in urban areas than on First Nations communities (62). According to the First Nations Regional Health Survey, 55.6% of First Nations participants (95%CI 49.9, 61.2%) were working for pay and, of those, 85.0% (95%CI 77.8, 90.2%) were working in their First Nations community (53).

## The Role of Drug Use in Driving Risk

At the individual level, injection and non-injection use of illicit drugs are key drivers of HIV risk (63).

To understand patterns of drug use among Indigenous people in Ontario, we analyzed data from:

- the I-Track surveys administered to people who used injection drugs between 2010 and 2012 in Kingston, London, Sudbury, Thunder Bay and Toronto, as well as a sample of people who smoked crack cocaine in Toronto but were not concurrent injectors
- the I-Track/SurVIDU surveys carried out in Ottawa in July 2010, February 2011, and July 2011.



The I-Track surveillance system uses a cross-sectional survey that consists of a questionnaire and collection of biologic samples (saliva in Ottawa, dried blood spot in other Ontario sites) to measure prevalence of HIV and HCV.

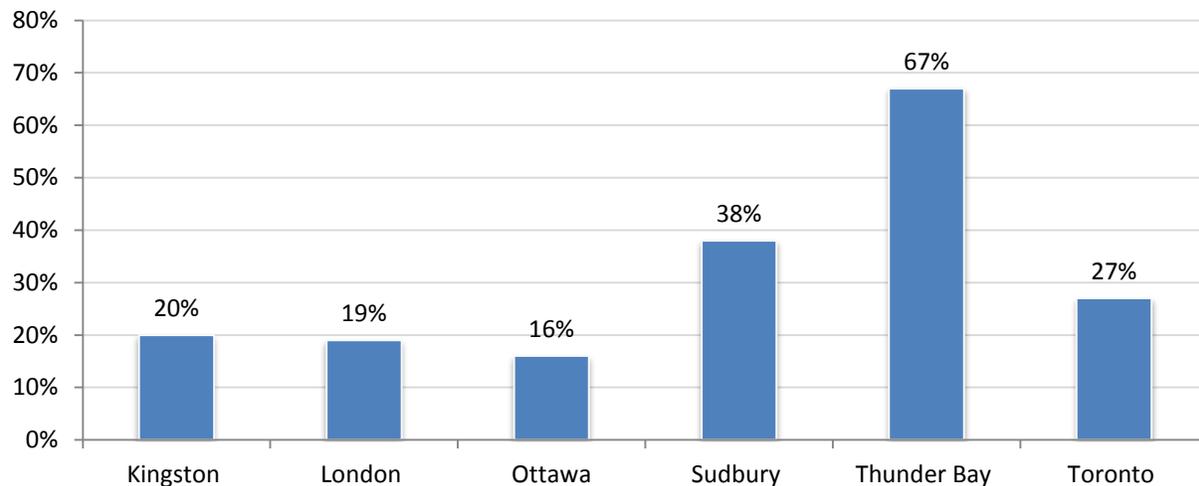
For our analyses, we compared Indigenous people who use drugs to non-Indigenous people who use drugs in each city and for the province overall. We also compared Indigenous men and women who use drugs in each city and overall. These analyses created a valuable snapshot of HIV- and HCV-related risk behaviours among Indigenous people who use drugs. (See Appendix 3 for more details about the I-Track surveys, their data collection methods, and the methods used for the analyses for this report.)

### What are the sociodemographic characteristics of Indigenous people who inject drugs?

The proportion of I-Track participants in each city who self-identified as Indigenous varied from 16% in Ottawa to 67% in Thunder Bay (Figure 18).

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**FIGURE 18: PERCENT OF INDIGENOUS PEOPLE AMONG PEOPLE WHO INJECT DRUGS, BY CITY, 2010-2012**



Source: Millson P, Leonard L, White S, & Kohm E. Phase 3 I-Track surveys 2010-12 and Ottawa I-Track/SurVIDU survey 2010-2011 (n=411)

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Compared to non-Indigenous people who use drugs, **Indigenous people who use drugs were more likely to be female and were slightly younger**. These differences were observed overall and in individual cities (see Appendix 3, Table 2).

Of the entire sample (n=1,553), 68% were male and 32% female. A significantly greater proportion of Indigenous participants (n=411) were female (44%) compared to non-Indigenous participants (27%;  $p < 0.01$ ).

Indigenous and non-Indigenous participants also varied substantially in terms of age distribution ( $p < 0.01$ ): 26% of Indigenous participants were under the age of 30 compared to 20% of non-Indigenous participants ( $p = 0.01$ ). Overall, Indigenous women participants (average age 36 years) were significantly younger than the Indigenous men (average age 40 years). These age differences were also statistically significant in Thunder Bay (31 years vs. 35 years,  $p = 0.02$ ) and Toronto (40 years vs. 44 years,  $p = 0.02$ ). Our analyses highlight the need for harm reduction policies and programs that are better tailored for Indigenous people, including Indigenous women.

## Lower education rates associated with drug use in both Indigenous and non-Indigenous people

Many Indigenous and non-Indigenous people who use drugs are socioeconomically disadvantaged, particularly in terms of housing and education. However, there are some significant differences between the two groups: 35% of Indigenous people who use drugs reported having obtained a high school education compared to 51% of non-Indigenous people ( $p < 0.01$ ). For both groups, high school completion rates are much lower than in the general Indigenous population (69%) and the non-Indigenous population (81%) (33,52).

## Less stable housing associated with drug use

Indigenous and non-Indigenous people who use drugs also differed in their living situation in the six months prior to their interview. A significantly greater proportion of Indigenous participants (12%) than non-Indigenous participants (4%) had lived with family members other than parents or with friends (27% vs. 20%,  $p \leq 0.05$ ) or were on the street or in squats (16% vs. 12%,  $p \leq 0.05$ ). Conversely, a significantly smaller proportion of Indigenous participants (13%) compared with non-Indigenous participants (16%) reported living in a boarding house ( $p \leq 0.05$ ).

When asked about their current living situation at the time of interview, Indigenous participants were again more likely to be living with friends or relatives other than their parents (4% vs. 2%,  $p \leq 0.01$ ), and less likely to be in a shelter (13% vs. 17%,  $p \leq 0.05$ ), rooming/boarding house (7% vs. 11%,  $p \leq 0.01$ ) or in rehab/detox (3% vs. 5%,  $p \leq 0.05$ ). These findings suggest that further attention to living conditions and social networks might help in providing better services to Indigenous people who use drugs.

In some regions, Indigenous people who inject drugs were more mobile. When asked whether they had lived in more than one city or community in the past six months, 17% of Indigenous and 13% of non-Indigenous participants responded “yes” ( $p = 0.03$ ). In some individual cities (e.g. Toronto, London) there was no difference in mobility between Indigenous and non-Indigenous people who use drugs; however, in Sudbury, Kingston, and Thunder Bay the difference was substantial: 24% vs. 16% in Sudbury; 26% vs. 14% in Kingston and 18% vs. 11% in Thunder Bay. In some cities, particularly those with First Nations communities relatively close, mobility may be a particularly important factor for Indigenous people who use drugs.

Among Indigenous participants, Indigenous women were significantly more likely to report living in their own place and less likely to be living in shelters. Sixty-three percent

of Indigenous women compared to 51% of men ( $p < 0.01$ ) reported currently living in their own place at the time of interview. Indigenous women were also less likely than Indigenous men to have lived in shelters (24% vs. 37% of men,  $p < 0.01$ ) or rooming/boarding houses (8% vs. 17%,  $p < 0.01$ ) in the six months before the interview.

### **High incarceration rates increase risk**

Overall levels of incarceration were high among I-Track participants: 14% of Indigenous and 11% of non-Indigenous participants had spent some time in jail in the preceding six months, but the differences were only statistically significant in Sudbury, where 22% of Indigenous and 10% of non-Indigenous participants reported being incarcerated within the preceding six months ( $p \leq 0.05$ ). High rates of incarceration are a concern because of the increased risk of disease transmission in prison environments where inmates may not have access to harm reduction materials. For people who use drugs – and particularly for Indigenous people who use drugs – there is an urgent need for programs and policies to reduce high levels of incarceration and the associated risks.

### **What are the patterns of drug use that put Indigenous people at risk?**

In terms of patterns of drug use, we looked at age of initiating drug use, frequency of drug use and location of drug use. I-Track asks detailed questions about use of both injection and non-injection drugs to understand patterns of use and risk.

## **In some communities, Indigenous participants started injecting at a younger age than non-Indigenous**

On average, I-Track participants were 23 years old when they first injected drugs, with no significant difference between Indigenous and non-Indigenous participants (average age 23 and 24 years of age). However, in Kingston and Toronto, Indigenous participants reported first injecting at a much younger age (20 in both communities) than non-Indigenous participants (23 and 24 respectively,  $p \leq 0.05$ ). There is a relationship between younger age of first injection and other HIV risk factors or behaviours such as homelessness, binge drug use, childhood sexual abuse and sex work (64–66). Given the younger age of first injection among Indigenous participants in certain cities (Kingston and Toronto) and the higher proportion of youth in the Indigenous population as a whole, there is a need for youth-focused programs aimed at preventing injection initiation and reducing harm for young people who have begun to inject.

## **Indigenous people are more likely than non-Indigenous people to inject at a relative's place**

For Ontario overall, Indigenous participants did not differ significantly from non-Indigenous people in their frequency of injecting, but there were some significant differences in the locations where they injected.

## **Depressants versus stimulants and how they affect HIV risk**

Drugs that affect the brain (“psychoactive” drugs) can vary broadly and are often simplistically categorized as depressants or stimulants.

Opiates as a group can be considered depressant drugs and are generally used for pain control. With repeated use, the body becomes habituated to them and requires larger doses to achieve the same effect. People who use opiates usually become physically dependent on them and experience a variety of physical effects such as nausea and diarrhea when these drugs are withdrawn. To prevent withdrawal symptoms, opiate users can be maintained on oral replacement therapy with methadone or buprenorphine.

Stimulants such as cocaine and amphetamines affect different receptors in the brain and do not cause the same type of longer term physical dependence. In the immediate withdrawal period, people who used stimulants may experience unpleasant psychological effects that lead them to seek more drugs to return to a more pleasant state. There is no approved substitution therapy for stimulants.

*(Continued on next page)*

A higher proportion of Indigenous people reported injecting at a family member's place (other than their parents') (14% vs. 5% for non-Indigenous participants,  $p < 0.01$ ), a hotel/motel (20% vs. 14%,  $p \leq 0.01$ ), a vehicle (17% vs. 12%,  $p \leq 0.05$ ) or a dealer's place/shooting gallery (17% vs. 11%,  $p \leq 0.01$ ). When asked where they had injected most in the previous six months, Indigenous participants were significantly more likely to report injecting at a relative's (other than their parents') place (4% vs. 1%,  $p < 0.01$ ); for all other locations, there was not a significant difference between Indigenous and non-Indigenous participants overall.

### **Indigenous people are more likely to inject morphine, oxycodone/OxyContin and Ritalin**

There were differences between Indigenous and non-Indigenous people in terms of which drugs were injected. When asked to list all drugs injected in the six months prior to interview, **Indigenous participants were significantly more likely to report injection of morphine (65% vs. 58%,  $p \leq 0.05$ ), oxycodone/OxyContin<sup>6</sup> (64% vs. 53%,  $p \leq 0.01$ ), Ritalin (34% vs. 20%,  $p \leq 0.01$ ), benzodiazepines (12% vs. 7%,  $p \leq 0.01$ ), barbiturates (9% vs. 4%,  $p \leq 0.01$ ), and a combination of Talwin & Ritalin (10% vs. 5%,  $p \leq 0.01$ ).**

When asked which drugs they had injected most, Indigenous participants were significantly less likely to report injection of heroin (6% vs. 10%,  $p \leq 0.01$ ), crack (4% vs. 8%,  $p \leq 0.01$ ) or dilaudid (9% vs. 12%,  $p \leq 0.05$ ), and significantly more likely to report

### **Depressants versus stimulants and how they affect HIV risk (continued)...**

Use of drugs in combination, either together or sequentially, is fairly common. This is often done, for example, to even out the effects of a stimulant with a depressant. Combining drugs may increase risk of adverse effects, particularly when the strength and purity of the drugs are uncertain.

Patterns of use tend to differ for different drugs, affecting HIV and HCV risk. For example, people who have developed a strong physical dependence on opiates may typically inject several times a day in order to avoid withdrawal symptoms. If sterile injection equipment is not readily available, their urgent need to inject can lead to reuse of unsterile equipment, including equipment borrowed from others.

People who use stimulants may have a binge pattern of drug use, injecting repeatedly over a few hours or days. This pattern of use requires large quantities of sterile equipment if each injection is to be done with new equipment.

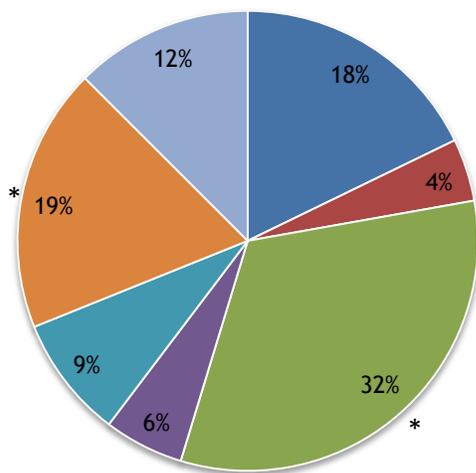
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<sup>6</sup> The 2010-2011 I-Track survey preceded changes in oxycodone/OxyContin formulation and availability.

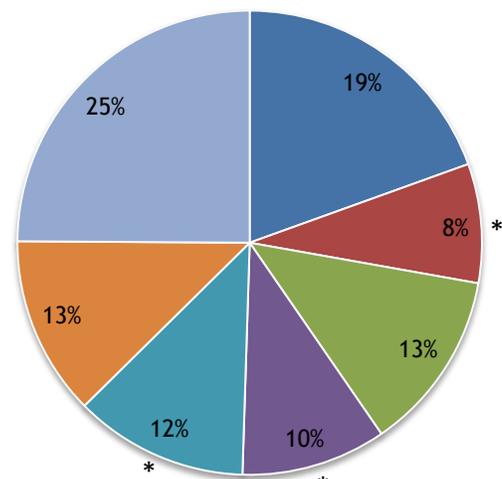
morphine (33% vs. 23%,  $p \leq 0.01$ ) or oxycodone/OxyContin (19% vs. 13%,  $p \leq 0.05$ ) (Figure 19).

**FIGURE 19: DRUGS MOST COMMONLY INJECTED AMONG A) INDIGENOUS AND B) NON-INDIGENOUS PEOPLE WHO INJECT DRUGS IN ONTARIO, IN THE SIX MONTHS PRIOR TO**

**a) Indigenous people who inject drugs**



**b) Non-Indigenous people who inject drugs**



- Cocaine
- Crack
- Morphine
- Heroin
- Dilaudid
- Oxycodone/contin
- Other

**INTERVIEW, 2010-2012**

Source: Millson P, Leonard L, White S, & Kohm E. Phase 3 I-Track surveys 2010-12 and Ottawa I-Track/SurVIDU survey 2010-2011 (Indigenous n = 340; non-Indigenous n=978)

Asterisk (\*) indicates differences between Indigenous and non-Indigenous participants that were statistically significant ( $p < 0.05$ )

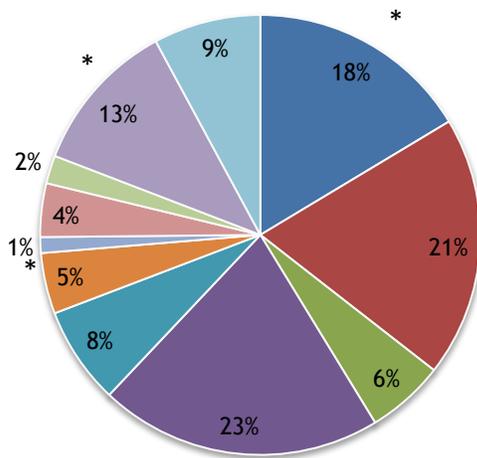
**Indigenous and non-Indigenous participants differed in their use of non-injection drugs**

Compared to non-Indigenous participants, a significantly higher proportion of Indigenous participants reported: use of alcohol (69% vs. 62%,  $p \leq 0.05$ ); non-injection use of barbiturates (10% vs. 6%,  $p \leq 0.01$ ), combination of Talwin and Ritalin (14% vs. 10%,  $p \leq 0.05$ ), MDA (3,4-methylenedioxyamphetamine) (5% vs. 2%,  $p \leq 0.01$ ), codeine (36% vs. 24%,  $p \leq 0.01$ ), morphine (43% vs. 27%,  $p \leq 0.01$ ), and oxycodone/OxyContin (47% vs. 34%,  $p \leq 0.01$ ); and drinking of solvents (2% vs. 1%,  $p \leq 0.01$ ).

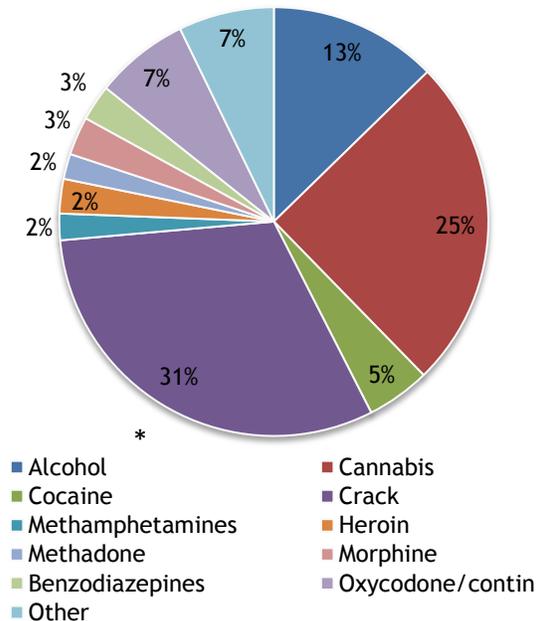
injection drug they had used most in the past six months, Indigenous participants were significantly more likely to report alcohol (18% vs. 13%,  $p \leq 0.01$ ) and non-injection oxycodone use (13% vs. 7%,  $p \leq 0.01$ ) and significantly less likely to name crack (23% vs. 31%,  $p \leq 0.01$ ) or heroin (1% vs. 3%,  $p \leq 0.01$ ) (Figure 20).

**FIGURE 20: NON-INJECTION DRUGS MOST COMMONLY USED AMONG A) INDIGENOUS AND B) NON-INDIGENOUS PEOPLE WHO USE DRUGS IN ONTARIO, IN THE SIX MONTHS PRIOR TO INTERVIEW, 2010-2012**

**a) Indigenous people who use drugs**



**b) Non-Indigenous people who use drugs**



Source: Millson P, Leonard L, White S, & Kohm E. Phase 3 I-Track surveys 2010-12 and Ottawa I-Track/SurVIDU survey 2010-2011 (Indigenous  $n=439$ ; non-Indigenous  $n=1,137$ )

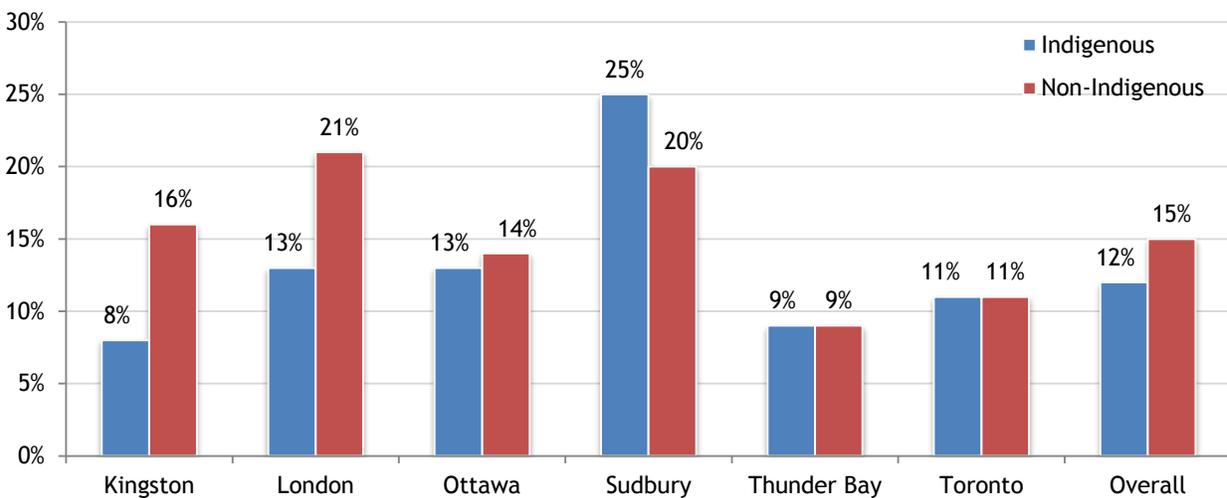
Asterisk (\*) indicates differences between Indigenous and non-Indigenous participants that were statistically significant ( $p < 0.05$ )

With both injection and non-injection drugs, Indigenous people appear to be more likely than non-Indigenous people to use certain prescription opiates such as morphine, oxycodone/OxyContin, codeine and barbiturates. In addition to understanding differences in drug preferences, efforts should be made to determine modifiable factors in the use of the drugs preferred by Indigenous people, such as health care provider prescribing patterns, cost or availability, and alternative approaches to addressing chronic physical and psychological pain. The I-Track surveys were conducted before the recent changes in policy related to oxycodone/OxyContin and suggest a serious potential impact for Indigenous people from these policy changes.

## Patterns in use of injection equipment

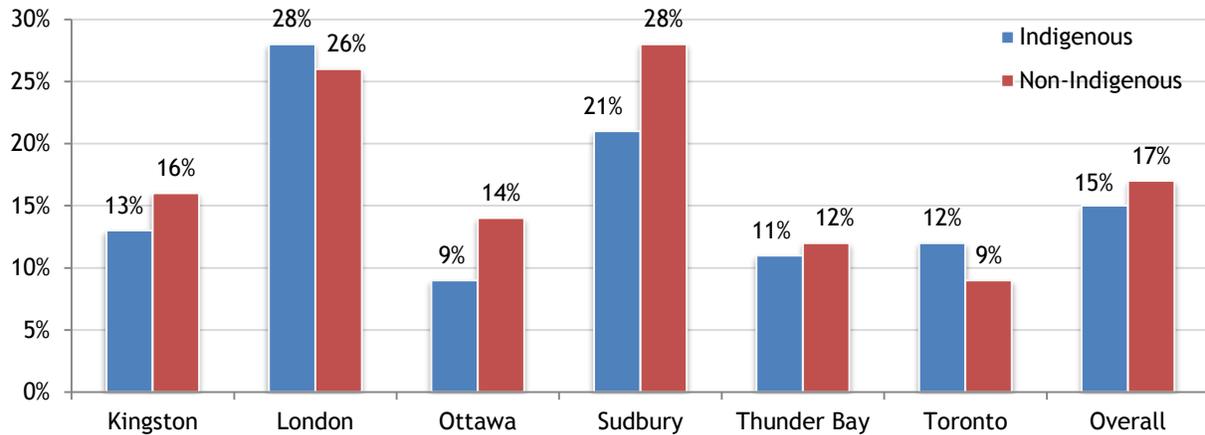
Overall, Indigenous and non-Indigenous people did not differ in: their use of needles or other drug injection equipment previously used by someone else; passing used needles or equipment to others; or smoking with a crack pipe used by someone else (Figures 21, 22 and 23). Both groups were more aware that there is a risk of HIV transmission when sharing needles than sharing other used equipment. The Ontario Harm Reduction Distribution Program, which provides access to sterile injection equipment for harm reduction programs to distribute, is seeking to address this issue, which is especially concerning for HCV transmission risk.

**FIGURE 21: PERCENT OF INDIGENOUS AND NON-INDIGENOUS PEOPLE WHO USE DRUGS WHO REPORT INJECTING WITH NEEDLES ALREADY USED BY SOMEONE ELSE, IN THE SIX MONTHS PRIOR TO INTERVIEW, BY CITY, 2010-2012**



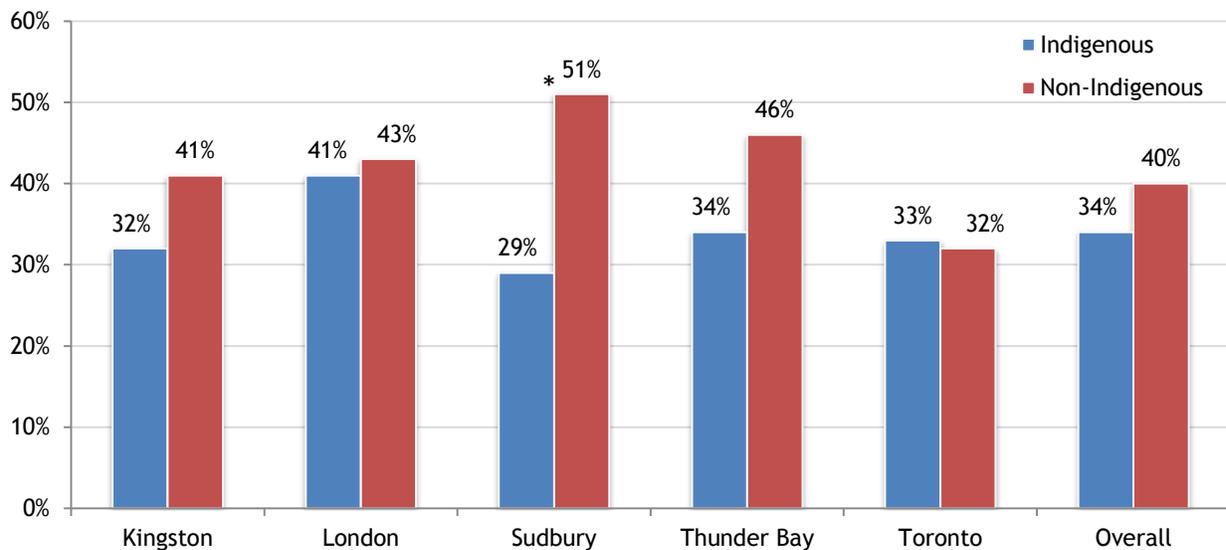
Source: Millson P, Leonard L, White S, & Kohm E. Phase 3 I-Track surveys 2010-12 and Ottawa I-Track/SurvIDU survey 2010-2011 (Indigenous n=338; non-Indigenous n=978)

**FIGURE 22: PERCENT OF INDIGENOUS AND NON-INDIGENOUS PEOPLE WHO USE DRUGS WHO REPORT PASSING ON NEEDLES THEY HAD ALREADY USED TO SOMEONE ELSE, IN THE SIX MONTHS PRIOR TO INTERVIEW, BY CITY, 2010-2012**



Source: Millson P, Leonard L, White S, & Kohm E. Phase 3 I-Track surveys 2010-12 and Ottawa I-Track/SurVIDU survey 2010-2011 (Indigenous n=333; non-Indigenous n=968)

**FIGURE 23: PERCENT OF INDIGENOUS AND NON-INDIGENOUS PEOPLE WHO USE DRUGS WHO REPORT INJECTING WITH ANY INJECTION EQUIPMENT OTHER THAN NEEDLES THAT HAD ALREADY BEEN USED BY SOMEONE ELSE, IN THE SIX MONTHS PRIOR TO INTERVIEW, BY CITY, 2010-2012**



Source: Millson P & White S. Phase 3 I-Track surveys 2010-12 (Indigenous n=282; non-Indigenous n=667)  
 Asterisk (\*) indicates differences between Indigenous and non-Indigenous participants that were statistically significant ( $p < 0.05$ )

There were no differences between Indigenous and non-Indigenous people with respect to those used needles they injected with when receiving used needles from others; however, Indigenous people were significantly more likely than non-Indigenous people to report lending used needles to family members (13.6% vs. 3.5%,  $p=0.027$ ).

**Indigenous people were significantly less likely than non-Indigenous people to report injecting alone** (44% vs. 32%,  $p=0.001$ ). This pattern of drug use may mean that they are at lower risk for an unwitnessed drug overdose.

### **Indigenous women are more likely than Indigenous men to share used equipment**

Among Indigenous participants, there were significant differences between men and women in terms of injecting with used equipment or passing their equipment to others. Indigenous women were significantly more likely than Indigenous men to report passing on used needles and acidifiers to someone else, and significantly less likely to report passing on used water. Indigenous women were significantly more likely than Indigenous men to report injecting with previously used water, but not needles or other equipment.

More Indigenous women than men reported using drugs with a regular sex partner (54% vs. 30%,  $p<0.001$ ) and passing their used needles to a regular sex partner (64% vs. 26%,  $p=0.01$ ). Although more Indigenous women than men reported taking used needles from a sex partner, the difference was not statistically significant. Significantly more Indigenous men than women reported passing on used needles to a friend or someone they knew well (53% vs. 20%,  $p=0.03$ ).

**Indigenous and non-Indigenous people did not differ in their use of needle exchange services, but Indigenous people used the services more frequently.** Given that recruitment for I-Track mainly occurs at needle exchange venues, most – but not all – participants are likely to be needle exchange clients. There was no significant difference in the proportion of Indigenous and non-Indigenous participants who used needle exchange services; however, Indigenous people used them more frequently. Among Indigenous participants, 22.2% reported using a needle exchange at least three times a week or more compared to 15.8% of non-Indigenous participants ( $p\leq 0.05$ ).

## **The Role of Sexual Behaviours in Driving Risk**

Among both Indigenous men and women in Ontario, sexual intercourse is a significant route of HIV transmission. When people who inject drugs become infected, it is often assumed that they acquired HIV from sharing injection drug equipment but, if they are sexually active, it is difficult to rule out the possibility of sexual transmission. Sexual

behaviours that put people at risk of acquiring HIV transmission also facilitate the spread of other sexually transmitted infections which, in turn, make someone without HIV more susceptible to infection and someone with HIV more infectious.

In this part of the report, we explore patterns of sexual behaviour among groups of Indigenous people at risk of or living with HIV, particularly men who have sex with men and people who inject drugs. To do these analyses, we used Ontario-specific data from two national surveillance systems (M-Track and I-Track) as well as data from two provincially-based cohorts of people with HIV – the OHTN Cohort Study (OCS) and the Positive Spaces Healthy Places study.

### **What are the general patterns of sexual behaviour among Indigenous people in Ontario**

The First Nations Regional Health Survey in 2008-2010 (53) reported the following findings about sexual behaviours:

- Most First Nations adults are sexually active (68.8%, 95%CI 65.3, 72.0%).
- Sexually activity decreased with age: 82.3% (95%CI 78.1, 85.9%) of First Nations adults who were between the ages of 18 and 39 reported being sexual active, 66.5% (95%CI 61.4, 71.2%) of those between 40 to 59 were sexually active, and 27.2% (95%CI 17.9, 39.0%) of those 60 years and older were sexually active.
- Among First Nations adults who said they were sexually active, 80.6% had one partner in the 12 months preceding the survey (95%CI 76.6, 84.0%), 7.9% had two sexual partners (95%CI 6.1, 10.2%), 6.1% had three partners (95%CI 4.3, 8.5%), and 5.0% had four or more partners (95%CI 3.3, 7.4%).
- When asked about condom use, over half of respondents indicated that they never use condoms (53.1%, 95%CI 49.2, 57.0%). Most said that the reason was because they were with a steady partner (59.3%, 95%CI 54.3, 64.2%).

## What are the patterns of sexual behaviour and risk for Indigenous men who have sex with men?

Gay and other men who have sex with men are the population most affected by HIV and AIDS in Ontario. In 2008, nearly half of all newly diagnosed cases of HIV in Ontario were among men who have sex with men (32). Indigenous men who have sex with men, some of whom may identify as “two-spirit” peoples, face unique vulnerabilities to HIV/AIDS due to the combined impact of homophobia and racism (67).

To understand the sexual risk facing Indigenous men who have sex with men, we reviewed data from the Lambda study (24), the Ontario component of M-Track (an ongoing national second generation surveillance system that monitors HIV infection and risk behaviours in men who have sex with men). The Lambda study, a venue-based cross-sectional survey conducted in Toronto and Ottawa in 2007, included a questionnaire and collection of biologic samples (dried blood spots) to measure prevalence of HIV, HCV and syphilis. It also included tests designed to detect recent HIV infection, which would help calculate HIV incidence.

Among Lambda participants who provided information on their race/ethnicity, 5.8% in Toronto (101/1,753) and 4.6% in Ottawa (21/460) were Indigenous. The Indigenous men had a similar age distribution as men of European/North American descent, but they were older than men in other ethnic groups (see Appendix 4, Table 3). Like the general Indigenous population in Ontario, Indigenous men who have sex with men had lower levels of education than all other ethnic group at both sites (all  $p < 0.05$ ). The Indigenous men in Toronto also had lower incomes.

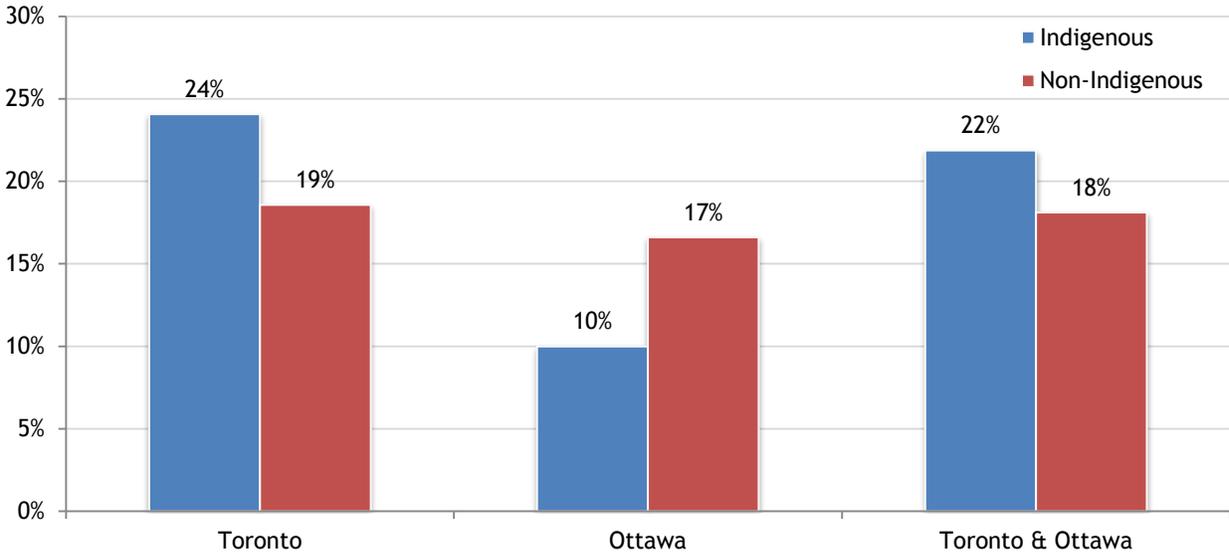
Despite these differences in their characteristics, **Indigenous and non-Indigenous men reported generally similar patterns of sexual behaviour.**

### Two-spirit Indigenous peoples

In some Indigenous cultures, before the Europeans settled in North America, “two-spirit” or “2-Spirit” referred to people who carried two spirits: that of male and female (67). Traditional gender roles did not limit their social activities as they embodied both male and female qualities. Women married other women and men married other men. In many cases, two-spirit people were considered to be a third gender and were honoured and revered in almost all cultures. In the current environment of racism and homophobia, two-spirit people may experience abuse, violence and sexual assault/rape, which can put them at disproportionate risk of HIV, HCV and other sexually-transmitted and blood-borne infections (8,9,67).

Unprotected receptive anal sex with an HIV-positive partner or a partner of unknown status is the sexual behaviour that poses the greatest risk for sexual HIV acquisition (68). Among Lambda participants overall, 19.0% in Toronto and 16.6% in Ottawa reported this behavior at least once in the previous six months. As Figure 24 illustrates, a higher proportion of Indigenous men in Toronto reported this activity, but the difference was not statistically significant.

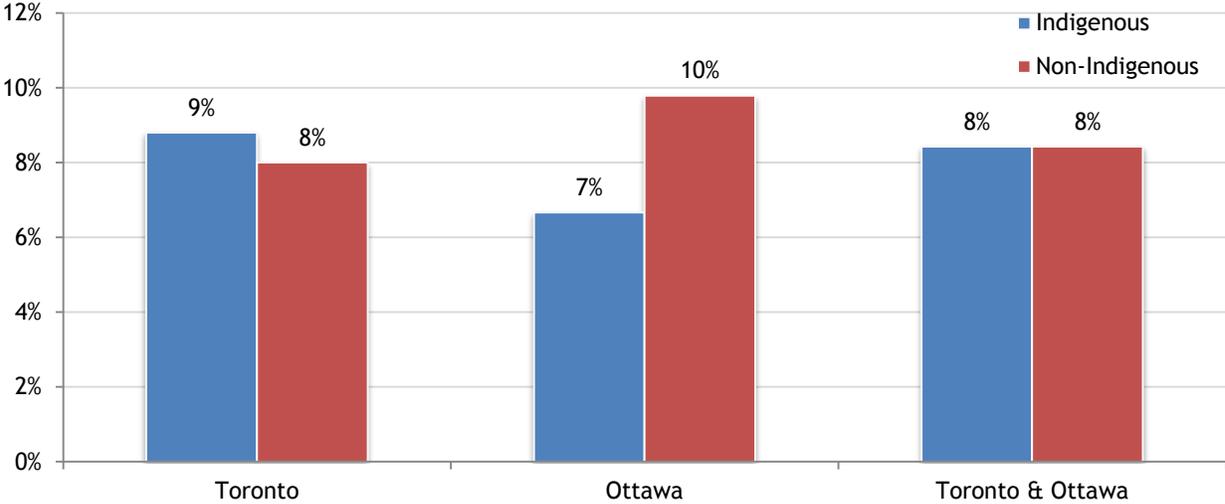
**FIGURE 24: PERCENT OF MEN WHO HAVE SEX WITH MEN (SELF-REPORTED HIV-NEGATIVE OR UNKNOWN STATUS) WHO REPORT UNPROTECTED RECEPTIVE ANAL SEX WITH A CASUAL PARTNER OR REGULAR PARTNER WITH HIV-POSITIVE OR UNKNOWN STATUS, TORONTO AND OTTAWA, 2007**



Source: Remis RS, Myers T, Husbands W & Liu J. Lambda (M-Track) Survey (Indigenous n=64, non-Indigenous n=1,281)

Lambda participants were also asked about delayed application of condoms (i.e. did they engage in unprotected sex before putting on a condom?). This behavior could increase HIV risk because of the potential exposure to pre-ejaculate that may contain HIV (69). Overall, 8.1% of Toronto participants and 9.9% of Ottawa participants reported that they had delayed condom application during receptive anal sex with an HIV-positive or unknown status partner in the previous six months, with no differences by ethnicity (Figure 25).

**FIGURE 25: PERCENT OF INDIGENOUS AND NON-INDIGENOUS MEN WHO HAVE SEX WITH MEN (SELF-REPORTED HIV-NEGATIVE OR UNKNOWN STATUS) WHO REPORTED DELAYED CONDOM APPLICATION WITH AN HIV-POSITIVE OR UNKNOWN STATUS PARTNER, TORONTO AND OTTAWA, 2007**



Source: Remis RS, Myers T, Husbands W & Liu J. Lambda (M-Track) Survey (Indigenous n=83, non-Indigenous n=1,507)

**What impact does drug use have on sexual risk?**

Sex or involvement in the sex trade is a risk factor for HIV acquisition among people who use injection drugs (70–73). To understand the impact of drug use on the sexual behaviour of Indigenous people, we analyzed data from the I-Track cohorts.

Compared to non-Indigenous participants (55%), a greater proportion of Indigenous people (67%) reported having any oral, vaginal or anal sex the month prior to the interview ( $p < 0.01$ ); however, there was no significant difference between the two groups in condom use at last sexual encounter (40% vs. 37%;  $p = 0.29$ ).

Significantly more Indigenous people than non-Indigenous people reported having client sex partners in the past six months (21% vs. 15%,  $p < 0.05$ ), but the small number of people involved in this activity precluded any analysis of sex work among Indigenous people by gender.

## What are the patterns of sexual behaviour among Indigenous people living with HIV?

Healthy sexuality is an important part of the lives of many people living with HIV. Safer sex practices are important for people living with HIV – both to protect them from becoming infected with other sexually transmitted or blood-borne infections which can complicate their care and threaten their health, and to prevent HIV transmission to their partners.

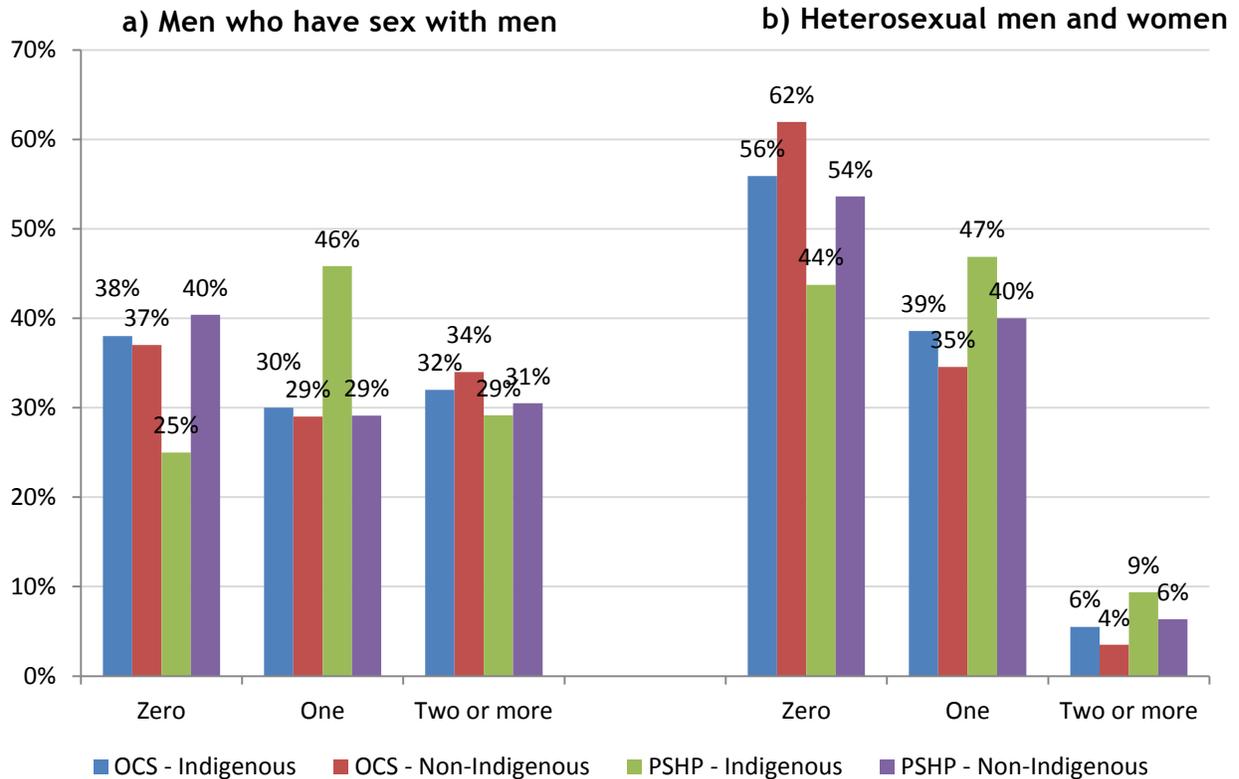
To understand sexual behaviours among people living with HIV, we looked at data from participants of:

- the OHTN Cohort Study (OCS), which follows people in specialty HIV care at clinics across Ontario
- the Positive Spaces Healthy Places (PSHP) study, which recruited people with HIV at clinical sites and AIDS Service Organizations across Ontario.

We found similar sexual behaviours among Indigenous and non-Indigenous participants in both studies.

**Most people with HIV either report no or one sexual partner.** However, gay, bisexual and other men who have sex with men were far more likely to report sexual activity than heterosexual men and women, regardless of ethnicity (Figure 26). Men who have sex with men were also more likely to report having had two or more sex partners.

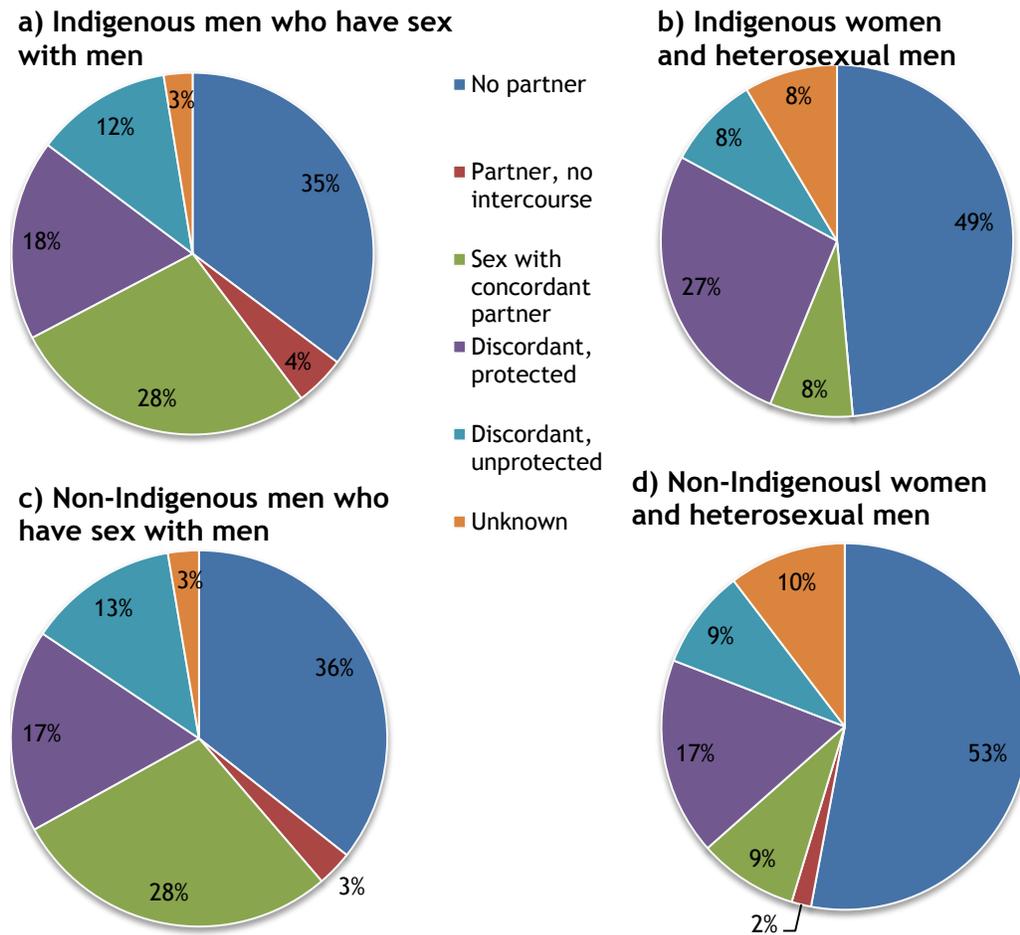
**FIGURE 26: PERCENT OF INDIGENOUS AND NON-INDIGENOUS A) MEN WHO HAVE SEX WITH MEN B) HETEROSEXUAL MEN AND HETEROSEXUAL WOMEN LIVING WITH HIV WHO REPORT ZERO, ONE, OR TWO OR MORE SEXUAL PARTNER(S), THREE MONTHS PRIOR TO INTERVIEW IN ONTARIO, 2009-2011**



Source: Burchell A & Warren L. OHTN Cohort Study (OCS), 2011, and Rourke S & Bekele T. Positive Spaces, Healthy Places (PSHP) study, 2009-2010 (**Men who have sex with men**: OCS-Indigenous n=154, OCS-Non-Indigenous n=1,711, PSHP-Indigenous n=24; PSHP-Non-Indigenous n=213; **Heterosexual men and women**: OCS-Indigenous n=127, OCS-Non-Indigenous n= 796, PSHP-Indigenous n=32, PSHP-Non-Indigenous n=110)

There was little difference in specific sexual behaviours by ethnicity (Figure 27). In the OCS, 12% of Indigenous and 13% of non-Indigenous men who have sex with men reported unprotected intercourse with an HIV-negative or status unknown (“discordant”) partner in the preceding three months while 9% of women and 9% of heterosexual men reported this behaviour, with no difference between Indigenous and non-Indigenous participants.

**FIGURE 27: SEXUAL BEHAVIOURS REPORTED BY A) INDIGENOUS MEN WHO HAVE SEX WITH MEN, B) INDIGENOUS WOMEN AND HETEROSEXUAL MEN, C) NON-INDIGENOUS MEN WHO HAVE SEX WITH MEN, AND D) NON-INDIGENOUS WOMEN AND HETEROSEXUAL MEN WITH**



## HIV IN ONTARIO, 2011

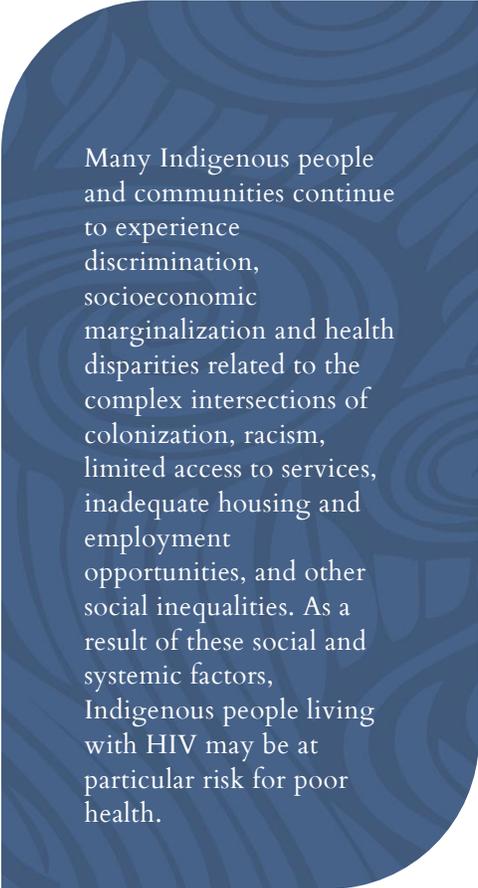
Source: Burchell A & Warren L. OHTN Cohort Study (**Men who have sex with men:** Indigenous n=156, non-Indigenous n=1,731; **Women and heterosexual men:** Indigenous n=105, non-Indigenous n=696)

Participants were classified according to the behavior that posed greatest risk for HIV transmission. For example, if a participant reported sex with an HIV-concordant partner and unprotected sex with a discordant partner, they were placed in the latter category.

# SECTION IV: THE HEALTH STATUS OF INDIGENOUS PEOPLE LIVING WITH HIV AND THEIR USE OF HIV-RELATED SERVICES

This section of the report pulls together available data about the health status of Indigenous people with HIV. Are they being tested and diagnosed early in their infection so they can receive timely treatment? Are they receiving appropriate consistent care? Are they successfully controlling the virus? Are they experiencing other conditions or co-morbidities? What are the factors that influence their health? This information will help community-based agencies, health care providers and policy makers develop effective care and support programs that meet the needs of Indigenous people living with HIV.

In this section, we explore available data to determine what differences currently exist (if any) between Indigenous and non-Indigenous persons living with HIV in Ontario in terms of their socio-demographic characteristics, clinical and treatment status, health-related quality of life, and utilization of health care, HIV care and social services.

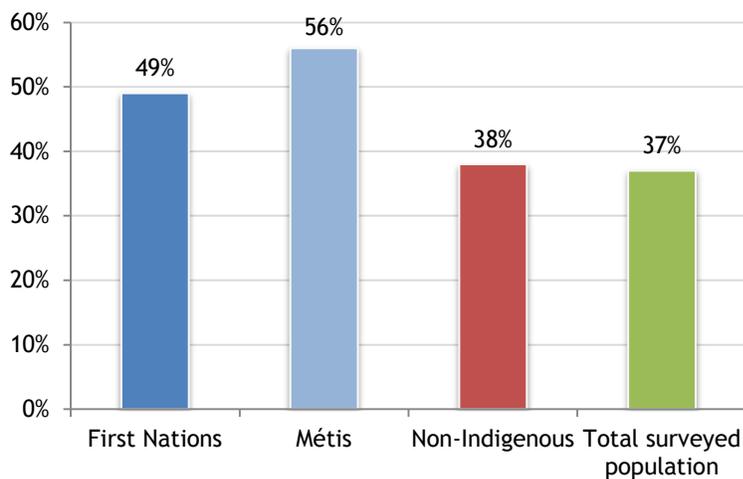


Many Indigenous people and communities continue to experience discrimination, socioeconomic marginalization and health disparities related to the complex intersections of colonization, racism, limited access to services, inadequate housing and employment opportunities, and other social inequalities. As a result of these social and systemic factors, Indigenous people living with HIV may be at particular risk for poor health.

## Are Indigenous People being Tested for HIV?

In the 2012 Public Health Agency of Canada national attitudinal survey, 49% of respondents who reported being First Nations and 56% of respondents who reported being Métis had had an HIV test (Figure 28) (74, unpublished data).

**FIGURE 28: PERCENT OF FIRST NATIONS, MÉTIS AND NON-INDIGENOUS PEOPLE WHO HAVE PREVIOUSLY TESTED FOR HIV (EXCLUDING TESTING FOR INSURANCE, BLOOD DONATION OR RESEARCH PARTICIPATION) IN CANADA, 2012 (74)**



Source: EKOS Research Associates Inc. HIV/AIDS Attitudinal Tracking Survey, 2012

Percent of Inuit who have previously tested for HIV not reported due to small sample size

The total population surveyed included 2% reporting a "don't know/no response"

According to the national Indigenous People's Survey conducted in 2001, 42% of Indigenous participants who lived off-reserve in Canada had had an HIV test and almost one-third of that group (32%) had been tested within the last year. In the year prior to the survey, more females (33%) than males (29%) had been tested (75). Rates of HIV antibody testing appear to be lower in Ontario First Nations communities than in other parts of Canada. In the First Nations

Estimates vary about the number of people infected with HIV who have not been tested and, therefore, do not know they have HIV. In 2011, the Public Health Agency of Canada estimated that about 25% of people in Canada with HIV are unaware of their infection. (1) However, more people are being tested. In a 2012 national attitudinal survey on HIV/AIDS of Canadians 16 years of age and older, 37% of Canadians reported having been tested for HIV (excluding testing for insurance, blood donation and participation in research – up from 27% in 2003 and 32% in 2006. Canadians who know someone with HIV, who are sexually active and who report having casual sexual partners are all more likely to have been tested for HIV. Respondents who identified themselves as lesbian, gay, bisexual or transgender are significantly more likely to have been tested for HIV (66%) (74).

Regional Health Survey of First Nations communities (2008-2010) (53), 37% (95%CI 32.1, 42.2%) of First Nations adults reported having ever been tested for sexually transmitted infections and 31.5% (95%CI 27.1, 36.2%) reported having ever been tested for HIV. Recent findings from the 2011-2012 Indigenous-focused A-Track surveillance system pilot survey in Regina, Saskatchewan, indicated that 70% of participants had been tested for HIV in their lifetime, and 68% of those who had been tested, had had an HIV in the preceding six months (17).

**Indigenous people who are at higher risk of HIV (e.g. people who inject drugs and men who have sex with men) are more likely to have been tested.**

Based on the I-Track and I-Track/SurVIDU surveys of people in Ontario who inject drugs, only 9% of Indigenous participants and 8% of non-Indigenous participants had *never* tested for HIV (non-significant difference). Among those who reported being tested at least once, a significantly higher proportion of Indigenous people (56%) than non-Indigenous people (49%) had been tested within the past six months ( $p \leq 0.05$ ). Findings were similar in the 2007 Lambda survey of men who have sex with men in Toronto and Ottawa: only 12% of Indigenous and 11% of non-Indigenous participants had *not* been previously tested for HIV (24).

Despite relatively high levels of testing, Indigenous people at high risk of HIV may not be tested frequently enough to detect HIV early in the course of infection. In I-Track, when participants' self-reported HIV status was compared with laboratory test results, about one-third of Ontario I-Track participants who tested positive (33% of Indigenous and 31% of non-Indigenous participants) had been unaware of their HIV infection.

With the advent of antiretroviral treatment and prophylaxis for major opportunistic infections, the clinical course of HIV has changed. People with HIV are now more likely to die from non-HIV conditions — such as co-infections, cardiovascular disease, cancer, lung disease and kidney disease — than from complications due to HIV/AIDS. HIV must now be managed alongside these other conditions, which are thought to occur at a higher rate than among HIV-negative persons because of the inflammation and frailty caused by HIV. The number of AIDS-related deaths has declined appreciably, but they remain higher among Indigenous people than in the general population.

## What are the Sociodemographic Characteristics of Indigenous People Living with HIV?

### Compared to non-Indigenous people with HIV, Indigenous people with HIV are generally younger and a larger proportion are female

Indigenous women experience a number of social and structural factors that increase both their risk of acquiring HIV and of having poor health status with HIV. For example, they are more likely to experience poverty, often have lower levels of education, and poorer overall health than Indigenous men or non-Indigenous women. Indigenous women are also more likely to live in environments with widespread heavy alcohol use, substance use and violence, and they are less likely to have access to HIV prevention or education programs (76,77).

### Compared to non-Indigenous people with HIV, Indigenous people with HIV tend to have less education and lower socioeconomic status.

According to OCS data, over half of Indigenous women with HIV (52%) had not completed high school compared to 21% of non-Indigenous women. Although a larger proportion of Indigenous male OCS participants were better educated than their female counterparts (75% had a high school diploma or greater), the proportion was still lower than among non-Indigenous men (79%) men. The PSHP study identified similar patterns of educational achievement: 61% of Indigenous participants had completed high school compared to 78% of non-Indigenous participants.

Income and employment gaps also exist. In the OCS, Indigenous participants reported lower incomes than non-Indigenous participants: nearly half (45%) had a household gross yearly income of \$20,000 or less, an income level reported by only 28% of non-

Data on sociodemographic characteristics were gathered from: the OHTN Cohort Study, which follows people in specialty HIV care at clinics across Ontario, and the Positive Spaces Healthy Places study, which recruited people with HIV throughout clinical sites and AIDS Service Organizations across Ontario. The OCS includes a fairly diverse representative sample of people with HIV in care in urban centres in Ontario, whereas PSHP included more vulnerable people with HIV who seek services from community-based AIDS organizations — many of whom experienced unstable housing.

Indigenous participants. In the PSHP study, the average annual personal income of Indigenous people with HIV was \$13,560 and 70% reported their main source of income was disability pension. In the OCS, 35% of Indigenous participants were working (full- or part-time) compared to 49% of non-Indigenous participants. In the PSHP study, which specifically recruited people with housing issues, unemployment was higher among Indigenous participants (89%) than non-Indigenous participants (79%). The relationship between education, income, employment and health is complex, but people who have less income may lack access to food, housing, and safe and fulfilling work, which can have a negative impact on their health. Income and employment related gaps are particularly important for people living with HIV whose health may fluctuate between periods of wellness and disability and who may experience periods of great financial strain due to their illness.

For more detailed information on differences in age, gender, education, socioeconomic status, income and employment, see Appendices 6 and 7, Tables 5 and 6.

### **Indigenous people with HIV were more likely to reside in rural areas and experience inadequate housing.**

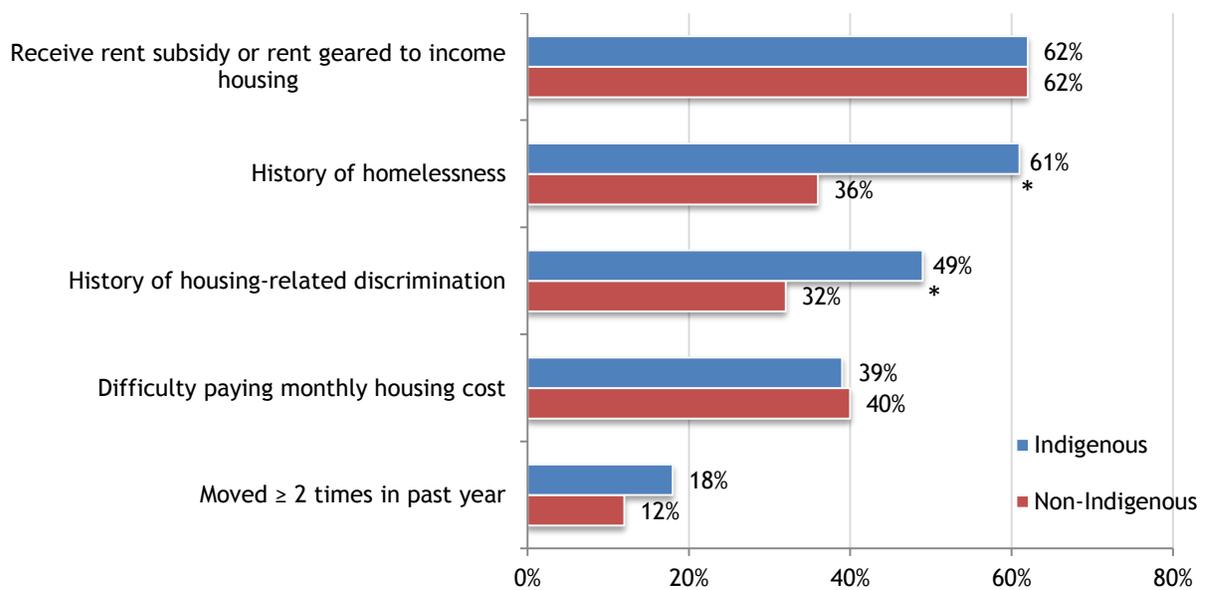
In the OCS, both Indigenous males (12%) and females (19%) were more likely than non-Indigenous males (6%) and females (3%) to have a rural postal code. As OCS participants are recruited from specialty HIV care clinics in urban centres, it is likely that an even greater proportion of Indigenous people living with HIV in Ontario are rural residents. Distance itself can be a barrier to health care, treatment and support services; rurality can also influence and intensify other factors that affect overall health status, such as distance to and from services, service limitations, and concerns about patient confidentiality and discrimination (7,78).

### **Indigenous people with HIV are more likely than non-Indigenous people with HIV to report living in an unstable housing situation (e.g. shelter, outdoors, street, park, car, housing facility, hotel, motel, boarding house, self-contained room in a house, couch surfing).**

Although unstable housing is not that common a problem, 6% of Indigenous OCS participants and 8% of PSHP Indigenous participants had housing issues – compared to 4% and 2% of non-Indigenous participants in the OCS and PSHP. In the PSHP study, Indigenous people reported more housing-related issues overall (Figure 29), including a higher prevalence of homelessness and discrimination when trying to access housing-related services related to their source of income, race/ethnicity, sexual orientation,

employment status or HIV status. Homelessness was more common among Indigenous than non-Indigenous participants in PSHP – even when all other determinants of inadequate housing were taken into account (29,30). Homeless persons, like vulnerable groups, are typically under-represented in research, even in studies that, like PSHP, focus on this population; therefore, it is likely that the proportion of Indigenous people with HIV with inadequate housing may be higher than the studies suggest.

**FIGURE 29: HOUSING CHARACTERISTICS OF INDIGENOUS AND NON-INDIGENOUS PEOPLE WITH HIV IN ONTARIO, 2006-2007**



Source: Rourke S & Bekele T. Positive Space Healthy Places Study, baseline visit (Indigenous n=79; non-Indigenous n=441)  
 Asterisk (\*) indicates differences between Indigenous and non-Indigenous participants that were statistically significant ( $p < 0.05$ )  
 "Rent geared to income housing" is a term used to describe a housing subsidy based on a percentage of a recipient's monthly income

## What Factors Put Indigenous People with HIV at Risk of Co-morbidities?

A number of risk factors may increase the risk of co-morbidities in people with HIV, including smoking, heavy alcohol use, ongoing substance use, and mental health difficulties (79–82).

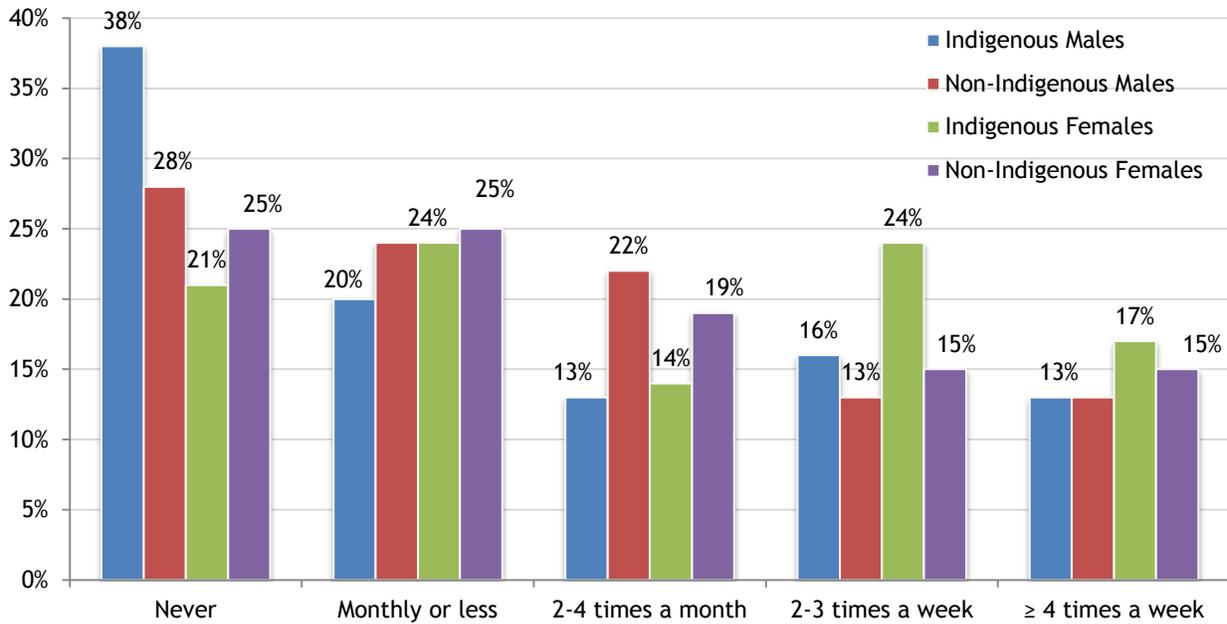
### **Smoking is widespread among Indigenous people living with HIV.**

Traditionally, Indigenous communities use tobacco for cultural and ceremonial activities. However, the non-traditional use of tobacco products has become a widespread health issue among Indigenous people in and outside First Nations communities (53,83). In the general population of Ontario, cigarette smoking is significantly more common among both Indigenous males (39%) and females (37%) than non-Indigenous males (25%) and females (19%) (84). Among people with HIV participating in the OCS, smoking rates were even higher. Most Indigenous women (88%) and nearly two-thirds of Indigenous men (61%) who are in the OCS smoke. High rates of smoking among Indigenous communities may be due to several factors, including tradition (e.g. the connection to Indigenous spiritual ceremony and spirituality), addiction, access to tobacco products and poverty (85). While public health approaches such as placing high taxes on cigarettes serve as effective disincentives to smoke, on-reserve tobacco is tax exempt, making smoking more financially accessible for some Indigenous people (86).

### **Alcohol use varies among Indigenous people with HIV**

Among OCS participants, Indigenous men were more likely than non-Indigenous men to report not having a drink in the previous year (38% vs. 28%,  $p=0.05$ ). There were no statistically significant differences in drinking frequency between Indigenous and non-Indigenous females (Figure 30).

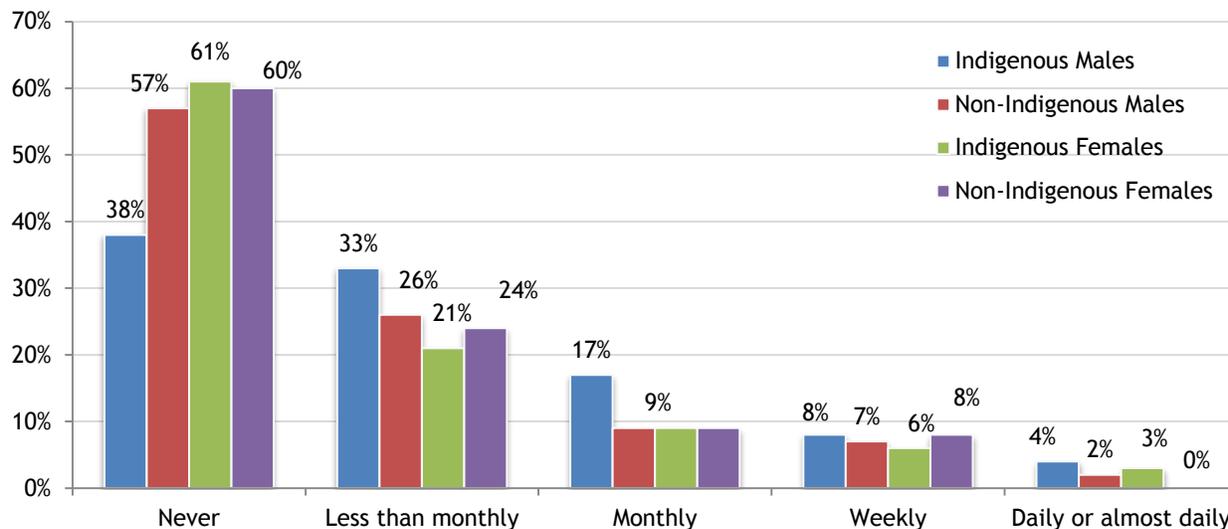
**FIGURE 30: FREQUENCY OF DRINKING AMONG INDIGENOUS AND NON-INDIGENOUS PEOPLE WITH HIV IN CARE IN ONTARIO, BY SEX, 2011**



Source: Burchell A & Warren L. OHTN Cohort Study (Indigenous male n= 126; non-Indigenous male n= 1,420; Indigenous female n= 42; non-Indigenous female n= 259)

Among drinkers, more Indigenous men (28%) than non-Indigenous men (17%,  $p < 0.01$ ), reported binge drinking monthly or more often (defined as six or more drinks on one occasion). Among women, rates of binge drinking did not vary based on ethnicity (Indigenous 18%; non-Indigenous 17%) (Figure 31).

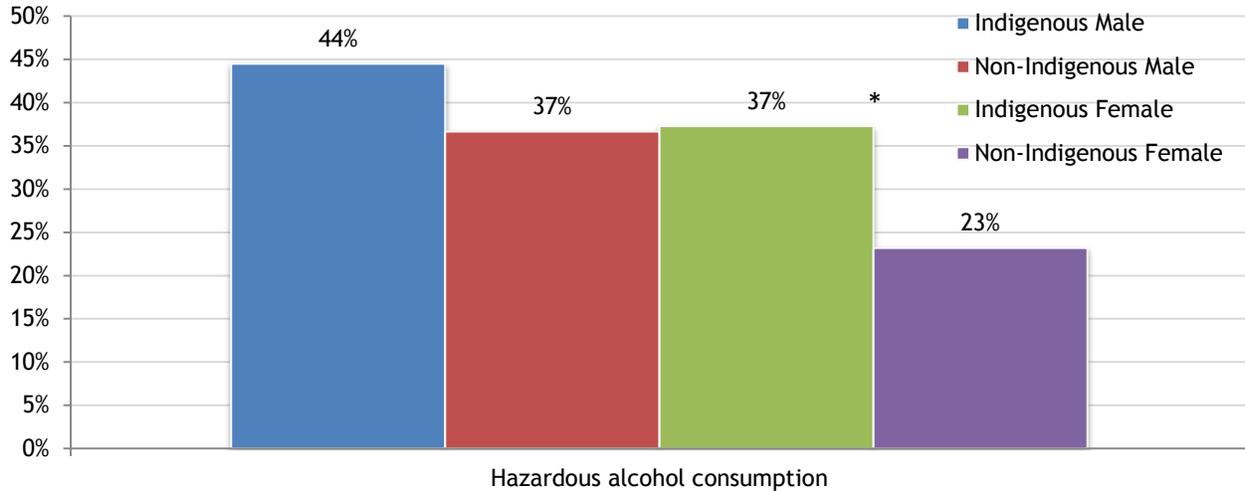
**FIGURE 31: FREQUENCY OF BINGE DRINKING ( $\geq 6$  DRINKS ON ONE OCCASION) AMONG INDIGENOUS AND NON-INDIGENOUS PEOPLE WITH HIV IN CARE IN ONTARIO WHO DRANK AT LEAST OCCASIONALLY, 2011**



Source: Burchell A & Warren L. OHTN Cohort Study (Indigenous male n= 78; non-Indigenous male n= 1,023; Indigenous female n= 33; non-Indigenous female n= 193)

A subset of OCS participants who reported drinking at least occasionally also completed the 10-item AUDIT scale to determine whether their drinking was potentially harmful (87). Items include measures of the frequency and quantity consumed, signs of dependence (e.g. lack of control over drinking) and signs of harm due to drinking (e.g. black-outs, alcohol-related injuries). A score of 8 or higher suggests “hazardous” drinking that increases the risk of harmful consequences for the user or others and could indicate alcohol dependence (87). Based on their scores, more Indigenous men and women had potentially hazardous alcohol use than non-Indigenous men and women (Figure 32).

**FIGURE 32: PERCENT OF INDIGENOUS AND NON-INDIGENOUS PEOPLE WITH HIV IN CARE IN ONTARIO WHOSE DRINKING PATTERNS SUGGEST HAZARDOUS ALCOHOL CONSUMPTION, AMONG THOSE WHO DRANK AT LEAST OCCASIONALLY, 2010**



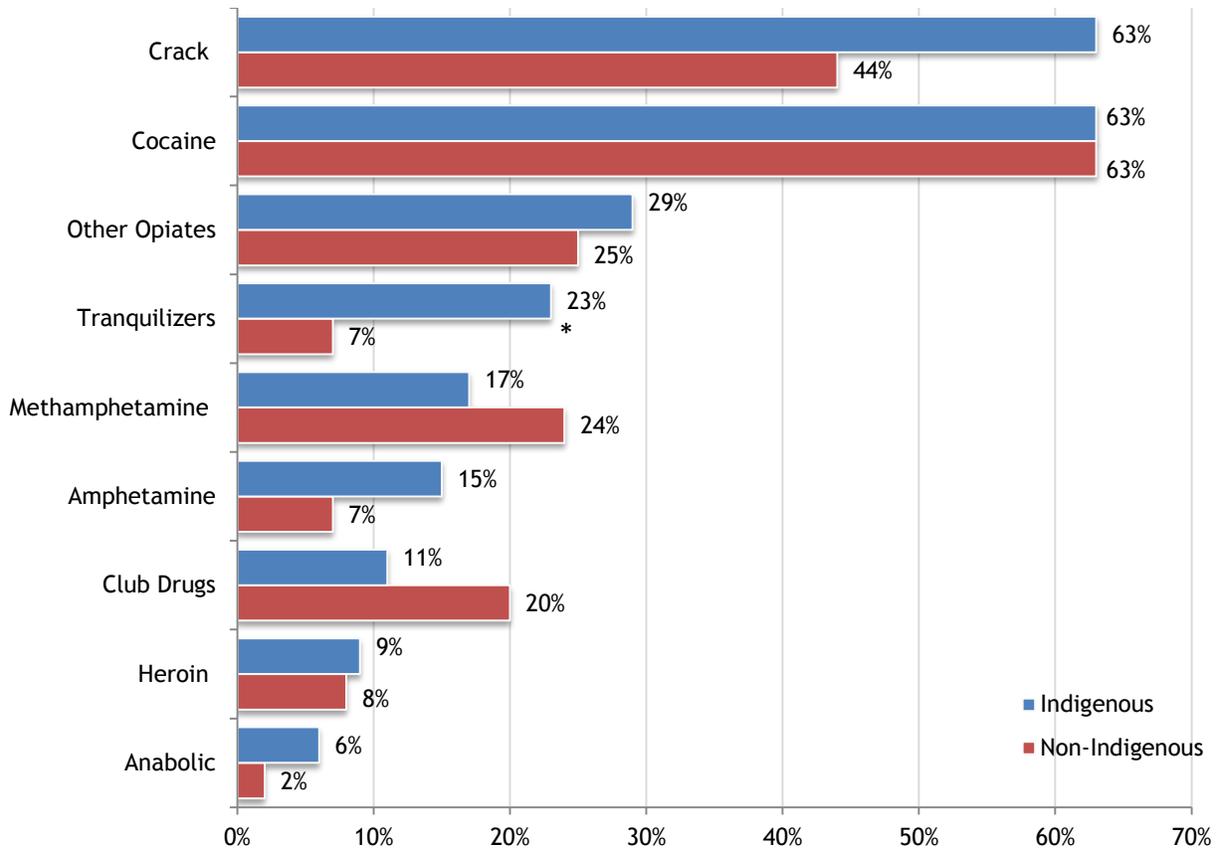
Source: Burchell A & Warren L. OHTN Cohort Study (Indigenous male n= 264; non-Indigenous male n= 2,623; Indigenous female n=59; non-Indigenous female n= 521)

Asterisk (\*) indicates differences between Indigenous and non-Indigenous participants that were statistically significant ( $p < 0.05$ )

### **There were no significant differences in drug use patterns**

Compared to I-Track participants, who include both HIV+ and HIV- people who inject drugs, OCS participants who use drugs are all living with HIV. Among OCS participants, there are no significant differences in drug use patterns (e.g. recent injection, types of drugs injected) based on Indigenous status (Figure 33). The most common drugs for OCS participants who inject were cocaine and crack — as opposed to morphine which was the most common drug of choice for Indigenous respondents in I-Track). The reasons for the difference may be that people who inject cocaine are at particularly high risk of acquiring HIV because the drug must be injected frequently (88).

**FIGURE 33: MOST COMMONLY INJECTED DRUGS AMONG INDIGENOUS AND NON-INDIGENOUS PEOPLE WITH HIV IN CARE IN ONTARIO WHO REPORTED INJECTION DRUG USE IN THE PAST SIX MONTHS, 2010**



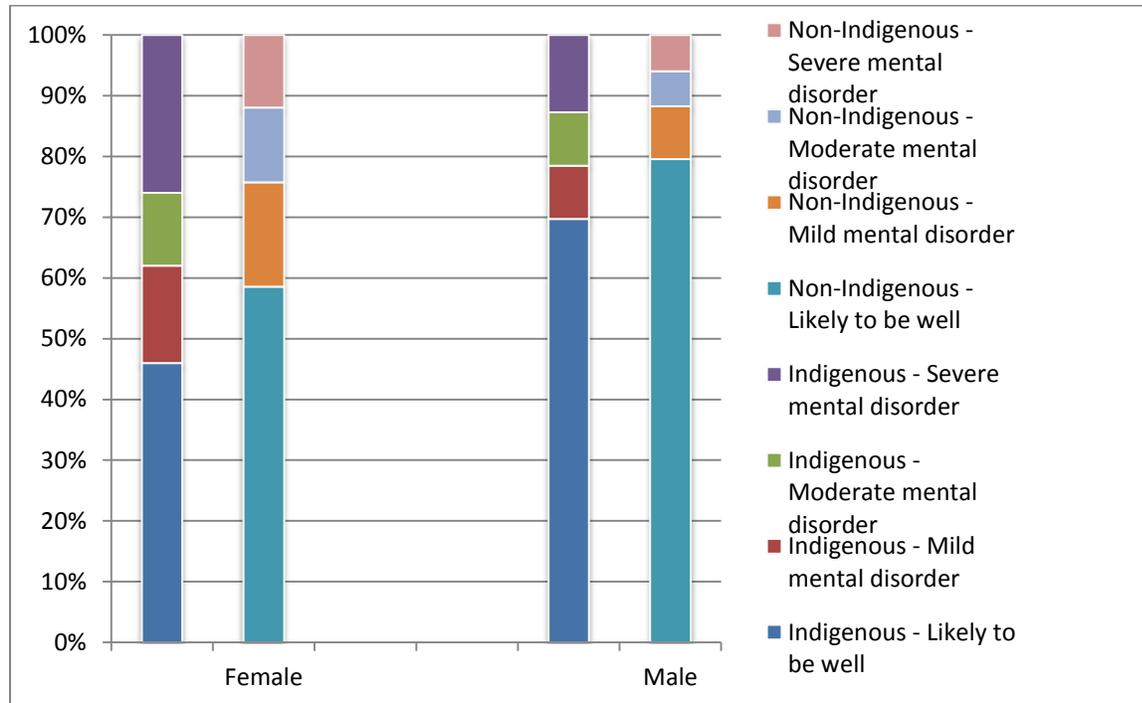
Source: Burchell A & Warren L. OHTN Cohort Study (Indigenous n= 35; non-Indigenous n= 134)  
 Asterisk (\*) indicates differences between Indigenous and non-Indigenous participants that were statistically significant (p<0.05)

**Indigenous people with HIV, particularly women, may experience higher levels of psychological distress than non-Indigenous people with HIV or other Indigenous people who are HIV-negative**

OCS participants completed the Kessler Psychological Distress scale (K10), which measures the level of distress based on 10 questions related to symptoms of anxiety and depression (89). Scores range from 10 to 50: the higher the score, the greater the levels of psychological distress (90). Among OCS participants, both Indigenous males and females had higher levels of psychological distress than non-Indigenous participants (Figure 34). According to findings from the First Nations Regional Health Survey, Indigenous people with HIV, especially women, had a much greater burden of psychological distress than HIV-negative Indigenous people based on the K10. Less than  
 Page | 64

half of Indigenous females and approximately 65% of Indigenous males in the OCS (all HIV+) scored between 0 and 10 (likely to be well) compared to 71% of HIV-negative participants in the First Nation Regional Health Survey (53).

**FIGURE 34: LEVEL OF PSYCHOLOGICAL DISTRESS AMONG INDIGENOUS AND NON-INDIGENOUS PEOPLE WITH HIV IN CARE IN ONTARIO, 2010**



Source: Burchell A & Warren L. OHTN Cohort Study using the Kessler Psychological Distress Scale (K-10) (Indigenous male n= 211; Indigenous female n= 50; non-Indigenous male n= 1,655; non-Indigenous female n= 268)

### Depression affects all people living with HIV

The PSHP study measured depression using the Center for Epidemiological Studies Depression scale (CES-D) (91). Approximately half of PSHP participants – both Indigenous (46%) and non-Indigenous (51%,  $p=0.41$ ) – had clinically significant levels of depressive symptoms (CES-D score  $\geq 16$ ). When the CES-D was administered to OCS participants who live in Toronto, Indigenous and non-Indigenous people also had similar scores with 36% and 33%, respectively. Where the CES-D was administered, Indigenous people had similar depression scores, with 36% scoring  $\geq 16$  ( $p=0.59$ ).

## What is the Health Status of Indigenous People Living with HIV?

### Indigenous women with HIV have higher viral loads than others in care.

Among people with HIV in care in Ontario, there are few substantial differences in clinical status based on Indigenous status. However, there is one significant exception: Indigenous women on treatment tend to have higher viral load and lower CD4 cell counts than non-Indigenous women.

### One third of Indigenous people are diagnosed late in HIV disease.

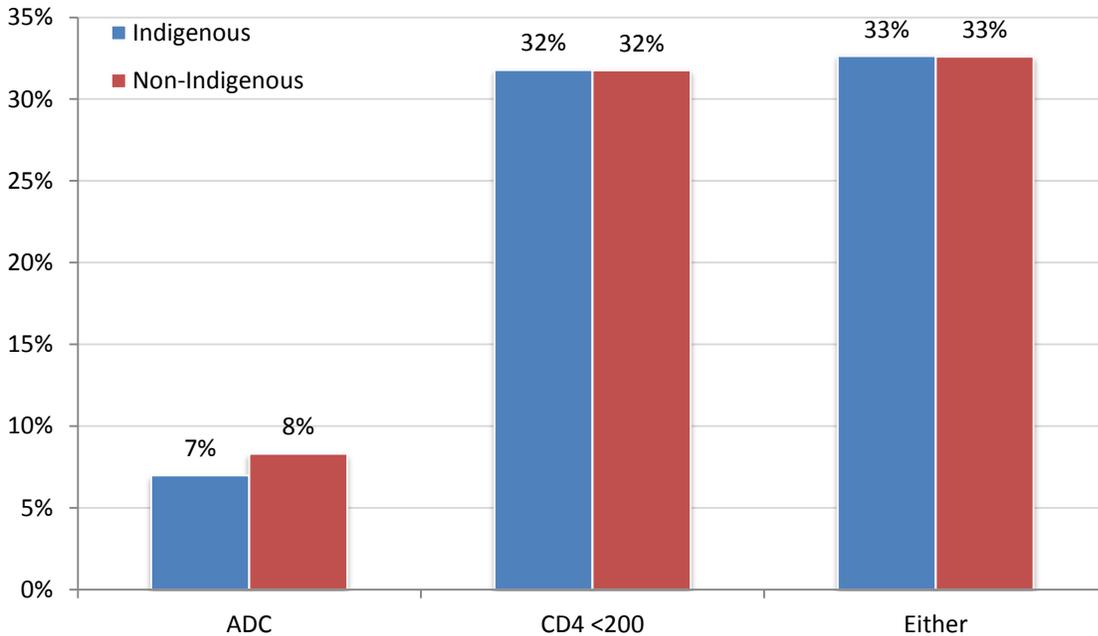
One of the greatest threats to the health of someone with HIV is being diagnosed late — when CD4 counts are already low and the person may be experiencing some serious symptoms of immunodeficiency and opportunistic infections. Late diagnosis is common among Indigenous people with HIV in some parts of Canada. For example, in studies conducted in northern Alberta and British Columbia, Indigenous people had higher viral load counts and lower CD4 counts at diagnosis than non-Indigenous people (92–95). Within the OCS, there was no significant difference between the proportion of Indigenous and non-Indigenous people diagnosed late (33%) (Figure 35) or the proportion diagnosed with an AIDS-defining condition before or within three months of their first HIV diagnosis (5.2% vs. 6.3%;  $p=0.40$ ) (96); however, being Indigenous

### Natural history of HIV/AIDS

Two key clinical HIV measures are CD4 cell count and HIV viral load. CD4 cell count is a measure of immune system function. Viral load is a direct measurement of viral activity: higher “loads” indicate greater viral activity. Virus weakens the immune system by attacking CD4 cells, making the body more susceptible to other infections and/or illnesses. A healthy HIV-negative person has CD4 cell counts in the range of 500 to 1,000 cells/mm<sup>3</sup>. When a person’s cell count falls below 250 cells/mm<sup>3</sup>, there is an increased risk of serious opportunistic infections. To monitor the health of people with HIV who are in care, clinicians routinely measure viral load and CD4 count at diagnosis and then approximately every three to four months thereafter. The rate of disease progression, including viral load and CD4 cell count, are affected by a variety of factors including age, genetic makeup and the infectiousness of the particular strain of HIV (97). Typically, as viral load increases, the CD4 cell count decreases. If left untreated, HIV will progress to AIDS, in which the immune system is severely damaged, resulting in potentially fatal opportunistic infections. Immunosuppression may be prevented or greatly reduced if antiretroviral treatment is started before the onset of immunodeficiency (98).

was modestly associated with having a CD4 cell count  $<200$  cells/mm<sup>3</sup> at the time of HIV diagnosis when controlling for age and HIV risk factors (OR=1.55; p=0.04).

**FIGURE 35: PERCENT OF LATE DIAGNOSES AMONG INDIGENOUS AND NON-INDIGENOUS PEOPLE IN CARE IN ONTARIO, AS DEFINED AN AIDS-DEFINING CONDITION OR LOW CD4 CELL COUNT ( $<200$  CELLS/MM<sup>3</sup>) AT DIAGNOSIS, 2011**



Source: Burchell A & Warren L. OHTN Cohort Study  
(Indigenous n= 472; non-Indigenous n= 5,508)

### **Indigenous people with HIV who are in care enjoy the same health as non-Indigenous people in care.**

For Indigenous people with HIV who are in care, there are no substantial differences in their clinical status once they begin antiretroviral treatment (ART). Among Indigenous and non-Indigenous OCS participants who started treatment between 2006 and 2010, there was no statistically significant difference in CD4 cell counts (Indigenous: mean 371 cells/mm<sup>3</sup>; non-Indigenous: mean: 368 cells/mm<sup>3</sup>; p=0.93). There was also little difference in the time from HIV diagnosis to starting treatment. Although Indigenous people started ART an average of 8 months after diagnosis (compared to 14 months among non-Indigenous people), this difference was no longer statistically significant after accounting for sex and CD4 cell count (p=0.28). For all ethnic groups in the OCS, there was a general trend over time for treatment to be initiated earlier: people diagnosed with

HIV more recently tended to initiate ART sooner than those diagnosed many years ago. These findings reinforce that, once Indigenous people with HIV are in care, they receive the same health benefits as non-Indigenous people; however, we cannot make the same assumption about people who are not in care. For example, a study conducted in British Columbia between 1995 and 2001 found approximately one of three people with HIV who died had never received ART, and Indigenous people were more likely than non-Indigenous people to die without having received ART (99). In another British Columbia study, Indigenous people with HIV took longer than non-Indigenous to initiate ART (100); the difference persisted even when controlling for potential confounding variables such as injection drug use.

### **Indigenous people with HIV appear to have equitable access to ART.**

Despite having lower socioeconomic status than non-Indigenous people with HIV, Indigenous people in Ontario with HIV do not appear to experience disparities accessing ART. In theory, any inequities in ART access for those without drug coverage through private insurance should be mitigated by publically-funded programs such as the *Ontario Drug Benefit Program*, the *Trillium Drug Program*, and the *Non-Insured Health Benefits* program offered by Canada's First Nations and Inuit Health Branch (106–109). As of their last clinic visit, virtually all OCS participants had initiated ART, and there was little difference based on ethnicity. Among Indigenous participants, 96% of men and 91% of women had started ART.

Findings from the PSHP study were somewhat different. At baseline, two-thirds (65%) of 79 Indigenous PHAs reported that they were currently receiving ART, compared

### **Guidelines for starting antiretroviral therapy**

With the advent of combination antiretroviral therapy (ART) in 1996, HIV has become a more manageable disease, and AIDS-related mortality has declined (101). Earlier initiation of ART is associated with lower morbidity and mortality rates and improved quality of life and longevity (102). There is also growing evidence that successful ART treatment can reduce the risk of transmitting the virus to others (103,104).

Nevertheless, the decision to begin ART is a personal one between patient and health care provider (104) which must take into account potential complications, including the possible development of drug resistance (104). Over the past decade, the critical CD4 cell count at which to initiate treatment has changed over the past decade, moving from <350 cells/mm<sup>3</sup>, regardless of symptoms, (102,105) to between 350 cells/mm<sup>3</sup> and 500 cells/mm<sup>3</sup>. US guidelines now recommend initiating treatment regardless of CD4 cell count, with a strong recommendation to initiate at any counts <500 cells/mm<sup>3</sup>.

to 76% of non-Indigenous people with HIV ( $p=0.03$ ). However, by the three-year follow-up interview, this disparity had vanished: 77% (43/56) of Indigenous participants reported having initiated ART. The increased percentage of participants receiving treatment may be because individuals less likely to initiate ART may also be less likely to return for subsequent study visits. The differences in ART use between the OCS and the PSHP study are likely a result of differences in the study populations. The OCS recruits people who are currently in HIV care, whereas the PSHP study did not have this eligibility criterion and included people who were not in regular care.

### **Indigenous people with HIV adhere well to treatment.**

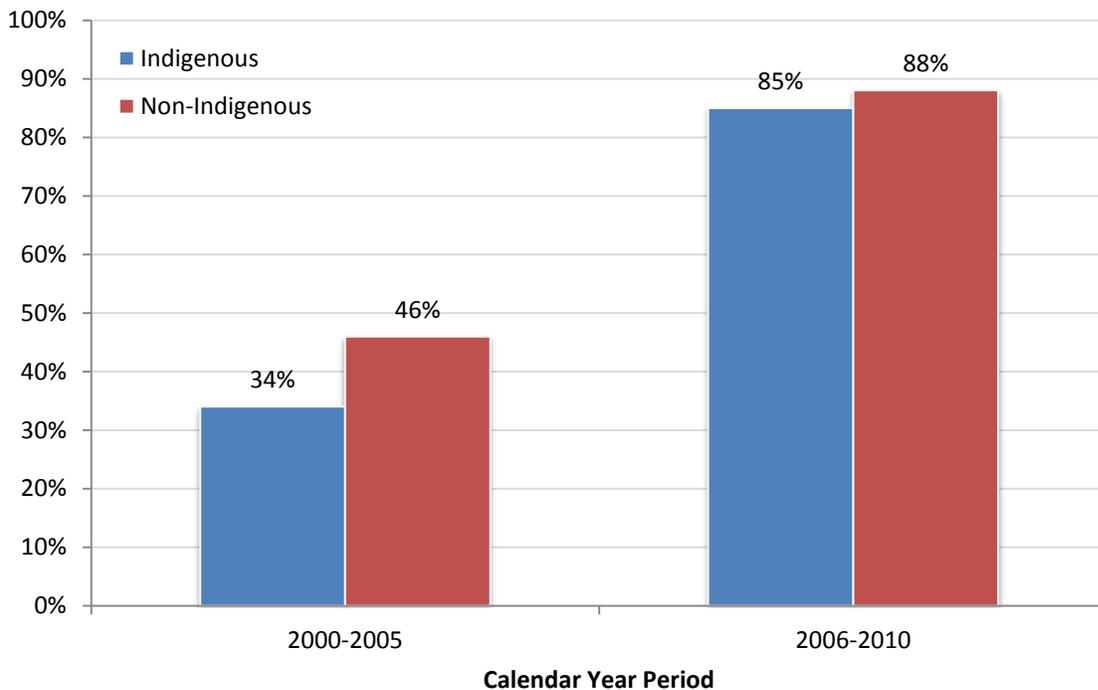
Once ART is initiated, it is vital for patients to adhere to treatment; that is, taking all medication doses as instructed. Good adherence is essential to successfully suppress viral load and avoid drug resistance or treatment failure. A number of Canadian studies have found lower rates of ART use and adherence in Indigenous than non-Indigenous people (94,110), particularly among females. Differences were attributed to lower incomes, poorer access to care and treatment, and higher proportions of people using injection drugs. However, we have not seen this pattern in Indigenous people in Ontario. Among OCS participants, adherence, defined as no missed doses in the previous four days, was slightly higher for Indigenous than non-Indigenous participants, although the difference was not statistically significant (91% vs. 86%,  $p=0.37$ ). In the PSHP study, adherence at the 3-year follow-up visit was slightly lower (74%) for Indigenous than non-Indigenous people with HIV (83%) but, because of small numbers, the difference may be due to chance ( $p=0.15$ ).

### **The proportion of Indigenous people with HIV who achieve viral suppression has improved over time.**

The goal of ART is to achieve viral suppression (i.e. undetectable viral load). To successfully suppress the virus, people must adhere consistently to ART and be monitored for drug resistance. With improvements in ART regimens, formulations and dosing (e.g. once-daily dosing), it is now easier for people with HIV to successfully suppress the virus (111). As a result, a much higher proportion of people with HIV — including Indigenous people with HIV — are achieving viral suppression, with no evidence of any disparity by ethnicity (Figure 36).

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**FIGURE 36: PERCENT OF INDIGENOUS, AND NON-INDIGENOUS PEOPLE WITH HIV RECEIVING ANTIRETROVIRAL TREATMENT WHO HAD UNDETECTABLE HIV VIRAL LOAD (<50 COPIES/ML) IN ONTARIO, 2010**



Source: Burchell A & Warren L. OHTN Cohort Study (Indigenous n= 312; non-Indigenous n= 3,485)  
Participants were classified according to their last viral load in the period

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**Indigenous women on ART, on average, have lower CD4 cell counts and higher viral loads than non-Indigenous women.**

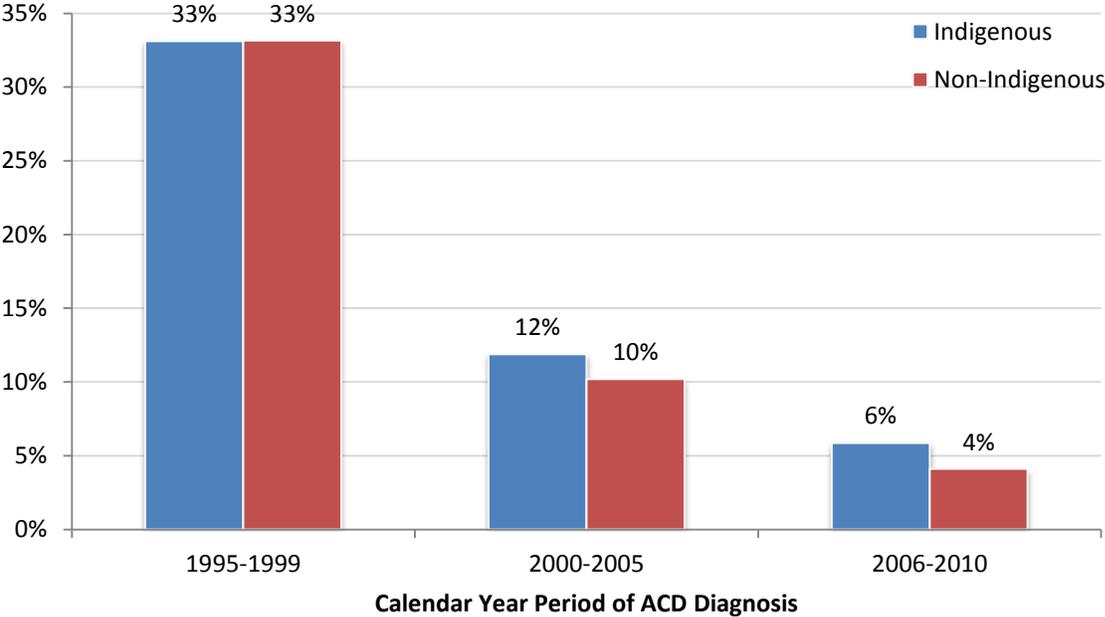
In the OCS, we did not observe such differences between Indigenous and non-Indigenous men on ART. However, we did observe statistically significant differences between Indigenous and non-Indigenous women. The average last recorded viral load was significantly higher for Indigenous females on ART (9,688 copies/mL) than for non-Indigenous females on ART (1,842 copies/mL,  $p < 0.01$ ). We explored whether this difference was related to injection drug use which has been associated with higher viral load counts (112,113); however this was not the case. Even after accounting for injection drug use, the difference remained statistically significant (viral load: 9,464 vs. 888 copies/mL for Indigenous versus non-Indigenous women;  $p < 0.01$ ). Similarly, Indigenous women's most recent CD4 cell count tended to be lower, on average (435 cells/mm<sup>3</sup>) than non-Indigenous females (mean 548;  $p < 0.01$ ), and these differences

could not be explained by other factors, including urban vs. rural residency, geographic region of residency, housing situation, injection drug use, HIV risk category, time period of CD4 cell test, age at HIV diagnosis, time since HIV diagnosis, HCV co-infection, alcohol use or history of cigarette smoking. Studies in western Canada have also seen higher viral load and lower CD4 counts in Indigenous populations; (92,94) however, these differences were explained by higher rates of injection drug use, unstable housing, lower incomes, and poorer access to care and experienced HIV physicians.

### **Both Indigenous and non-Indigenous people have seen a dramatic decline in AIDS-defining conditions.**

Acquired immunodeficiency syndrome, or AIDS, is the most advanced stage of HIV infection. AIDS-defining conditions are specific conditions, such as opportunistic infections and certain types of cancers, which do not normally occur in individuals who have strong immune systems. These conditions are less common now than they were before the availability of ART (114,115). As expected, the percentage of OCS participants – both Indigenous and non-Indigenous – diagnosed with an AIDS-defining condition has decreased markedly over time (Figure 38). Over all years, the proportion of Indigenous participants in the OCS diagnosed with an AIDS-defining condition was slightly higher than among non-Indigenous participants for all years; however, the difference was not statistically significant. In the PSHP study, about half the participants reported ever being diagnosed with an AIDS-defining condition at baseline (48% of Indigenous and 52% of non-Indigenous participants). Although Ontario data do not suggest a substantial difference among Indigenous and non-Indigenous people living with HIV in terms of AIDS-defining conditions, Alberta studies have shown that Indigenous people were more likely to develop HIV-related tuberculosis (116). As the HIV health burden shifts from AIDS-defining conditions to other co-morbidities, it will be important to remain vigilant and be aware of any disparities in long-term health outcomes for Indigenous people with HIV.

**FIGURE 37: DIAGNOSES OF AIDS-DEFINING CONDITIONS AMONG INDIGENOUS AND NON-INDIGENOUS PEOPLE WITH HIV IN CARE IN ONTARIO, BY CALENDAR YEAR, 1995-2010**



Source: Burchell A & Warren L. OHTN Cohort Study (Indigenous n= 358; non-Indigenous n= 3,682)  
No differences between Indigenous and non-Indigenous participants were statistically significant ( $p>0.05$ )

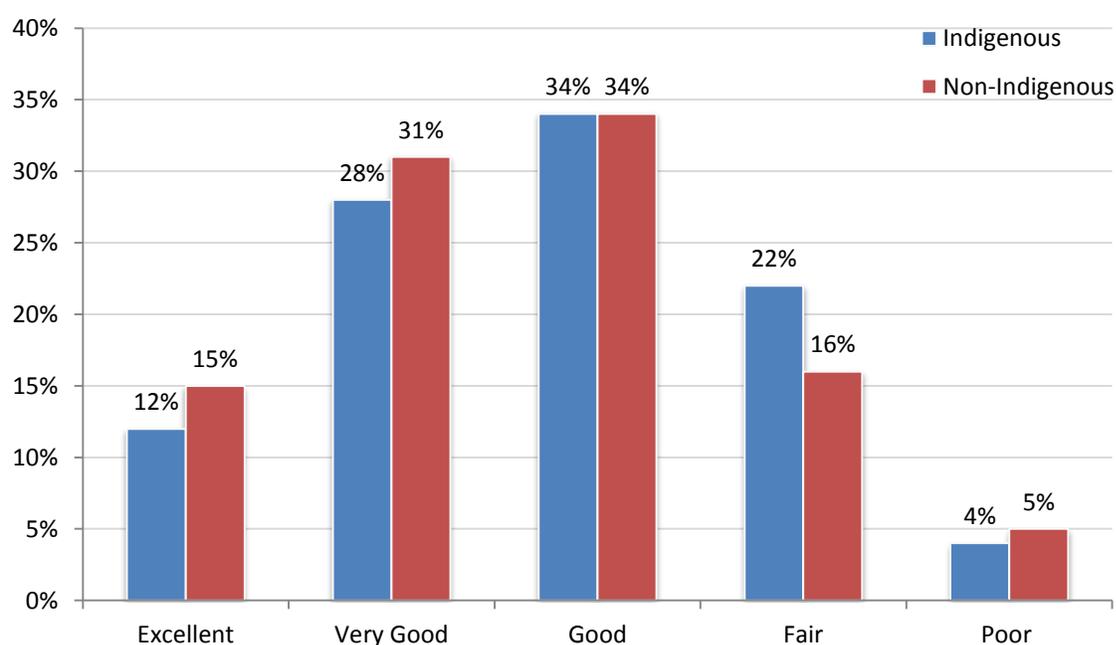
**Indigenous people in Ontario with HIV who successfully link to care have no greater risk of death than non-Indigenous people in HIV care.**

There are no marked differences in mortality between Indigenous and non-Indigenous people in Ontario who are living with HIV and in care. Based on the OCS data, crude mortality from 2000 to 2010 was similar for Indigenous and non-Indigenous participants (at 129 [95%CI 90, 186] vs. 158 [95%CI 143, 175] per 100,000 person-years). Even after accounting for differences between Indigenous people and non-Indigenous people with HIV that affect the risk of death (i.e. age, injection drug use and CD4 cell count at diagnosis), we did not observe ethnic differences in mortality (hazard ratio = 1.3 [95%CI 0.7, 2.6];  $p=0.40$ ). Our findings differ from those in Alberta, where mortality rates are higher among Indigenous HIV patients (93); it should be noted that injection drugs use has been a stronger driver of the HIV epidemic in Alberta than in Ontario (117). With the advent of ART, HIV-associated mortality has decreased significantly yet it remains higher than in the general population.

## Health-related Quality of Life

According to OCS data, most Indigenous people in HIV care (74%) rate their health as excellent, very good or good. However, a slightly higher proportion of Indigenous (26%) than non-Indigenous people (21%) in care rate their health as fair or poor (26%) (Figure 38).

**FIGURE 38: SELF-REPORTED HEALTH STATUS AMONG INDIGENOUS, AND NON-INDIGENOUS PEOPLE WITH HIV IN CARE IN ONTARIO, 2011**



Source: Burchell A & Warren L. OHTN Cohort Study  
(Indigenous n=386; non-Indigenous n=3,640;  $P < 0.01$ )

### **There are no substantial differences in health-related quality of life between Indigenous and non-Indigenous people with HIV.**

In the PSHP study, Indigenous people scored as well as non-Indigenous people on measures of physical health-related quality of life (MOS-HIV physical health summary mean score 43.6 vs. 41.8,  $p=0.15$ ) and mental health-related quality of life (MOS-HIV mental health summary mean score 44.8 vs. 43.0,  $p=0.23$ ), and they scored higher on role functioning (43.5 vs. 40.0,  $p=0.004$ ). Using data from Indigenous and non-Indigenous OCS participants, there were no statistically significant differences between

mental component scores for either men or women (data not shown). However, Indigenous OCS male participants tended to score lower on physical health-related quality of life measures than non-Indigenous men (mean score: 46.7 vs. 49.3,  $p < 0.01$ ). Although we cannot make direct comparisons between OCS and PSHP health-related quality of life measures because of the different scales used, it is interesting to note that Indigenous participants in the OCS scored slightly lower than non-Indigenous participants in both mental and physical component scores, whereas Indigenous participants in PSHP scored higher than non-Indigenous participants. A northern Alberta study had similar findings as the OCS: Indigenous people living with HIV had overall poorer health-related quality of life than non-Indigenous people with HIV (92).

Despite differences in socioeconomic status, there were **no dramatic differences in self-rated health-related quality of life between Indigenous and non-Indigenous people with HIV**. These findings suggest that many Indigenous people are resilient despite the burden of HIV as well as the long-term impacts on their lives of colonization and health/social disparities. Ontario should explore the most effective ways to build on and support resiliency and improve quality of life among Indigenous people with HIV in Ontario.

### Measures of health-related quality of life

Health-related quality of life is often measured using the internationally-validated Medical Outcomes Study (MOS) questionnaires, including the 12-item short form (SF-12) and the MOS-HIV questionnaire, which was developed in 1987 specifically to measure self-reported well-being and functional status among people living with HIV. Both questionnaires begin by asking, “In general, would you say your health is excellent, very good, good, fair or poor?” They also include items that measure quality of life features including physical functioning, vitality and mental health (118). With the mental and physical component scores (range from 0 to 100), a higher score represents better health.

## What Health Services do Indigenous People with HIV Use?

According to data from PSHP, **84% of Indigenous people with HIV — compared to 87% of non-Indigenous people — had visited their family doctor at least once over a 12-month period** (Figure 39, panel A). Most Indigenous participants (90%) visited an HIV care specialist at least once annually. As Figure 39 shows, there were few differences between Indigenous and non-Indigenous participants in their patterns of using other

health care providers. However, Indigenous people were significantly less likely to receive dental care, eye care or mental health care services, and these differences were consistent across all geographic regions.

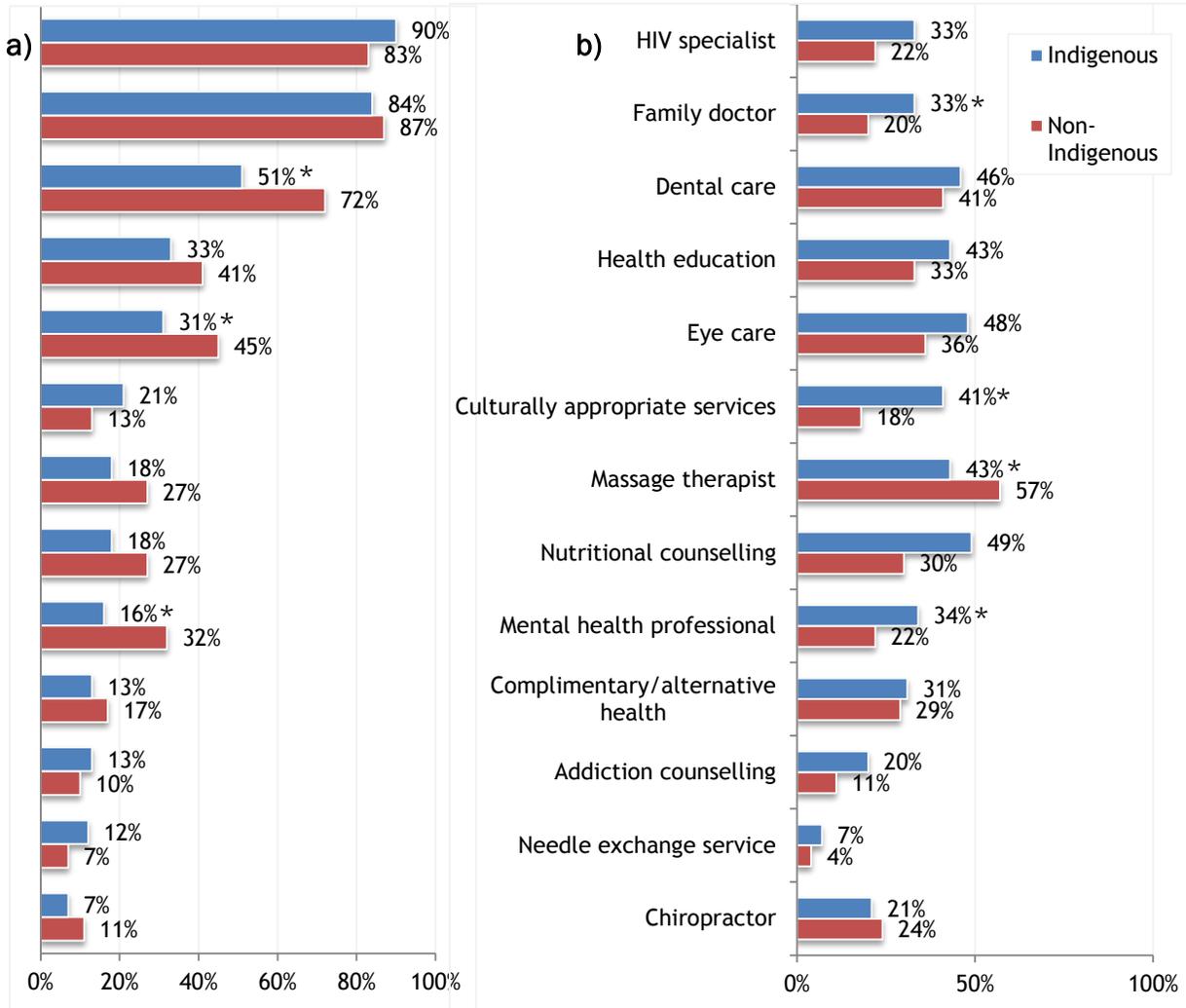
**Indigenous people with HIV report having many unmet health care service needs** (Figure 39). As part of the PSHP study, participants were asked: “How much of the service do you feel you need?” Panel B shows the proportion who reported needing more than they received. Compared to non-Indigenous participants, Indigenous people reported more unmet needs for family doctor, mental health professional and nutritional counselling services. They were also nearly twice as likely to report needing more addictions counselling services, although this difference was not statistically significant ( $p=0.05$ ). Once again, reports of unmet needs were consistent across geographic regions.

While Indigenous people with HIV are receiving a range of services, only one in five PSHP respondents reported receiving culturally appropriate services (e.g. traditional Indigenous healers or faith based support services) and 41% reported having unmet needs for these services. This finding is consistent with several Canadian studies, which reported that Indigenous people living with HIV need more traditional and culturally-based services to manage their illness in a more holistic fashion (7).

The lack of culturally appropriate services may be related to the challenges faced by Indigenous people living in urban centres rather than in First Nations communities. According to the First Nations Regional Health Survey, most adults in Ontario living on reserve (73.4%, 95%CI 68.4, 77.9%) reported having no difficulties accessing traditional medicines (53).

The challenges Indigenous people face accessing high quality health care services are well documented, including ineffective and/or insufficient primary care (119–121). Based on data collected from 56 Indigenous people with HIV who completed the three-year follow-up PSHP interview, **the most common barriers to accessing health care services were lack of availability locally and financial costs** (e.g. cost of service or transportation). In particular, service and transportation costs were a particular barrier to accessing the services of a mental health counselor or psychologist. The First Nations Regional Health Survey also identified financial and access barriers in Ontario. For adults living on reserve, the most common barriers were waiting lists (33.8%, 95%CI 30.1, 37.8%) and lack of coverage by Non-Insured Health Benefits (26.9%, 95%CI 23.4, 30.6%) (53).

**FIGURE 39: A) UTILIZATION OF AND B) UNMET NEEDS FOR HEALTH SERVICES OVER THE PREVIOUS 12 MONTHS AMONG INDIGENOUS AND NON-INDIGENOUS PEOPLE WITH HIV IN ONTARIO, 2007-2008**



Source: Rourke S & Bekele T. Positive Spaces, Health Places Study (Indigenous n=61; non-Indigenous n=377)  
 Asterisk (\*) indicates differences between Indigenous and non-Indigenous participants that were statistically significant (p<0.05)

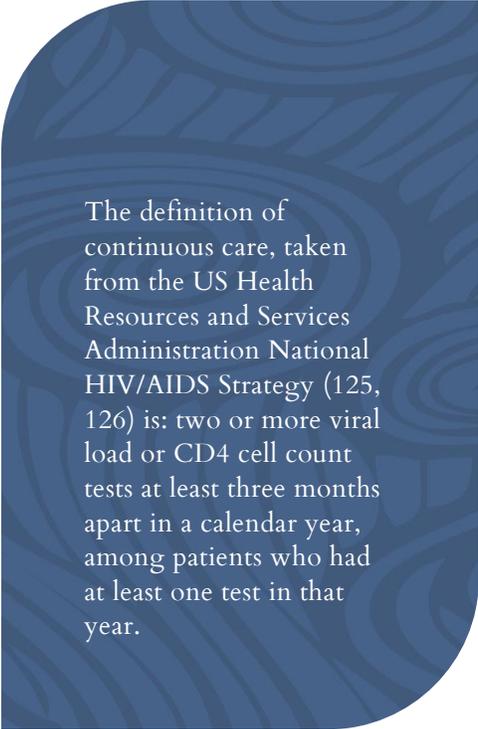
## Do Indigenous People with HIV in Ontario Receive Good Continuity of HIV Care?

Once people are diagnosed with HIV and enter HIV care, they should be seen regularly to help them adhere to ART medications and manage any co-morbidities or other health/social issues (122). A number of factors influence people’s desire and ability to access regular HIV care. For example, for people who suffer from addiction or who have

difficulty meeting their basic survival needs (e.g. food, shelter, water), managing HIV may not be a priority (123). Stigma and discrimination can also prevent people from accessing care consistently.

For people with HIV who are part of the OCS, we saw little difference based on Indigenous ethnicity. From 2006 to 2009, the vast majority of Indigenous people ( $\geq 94\%$ ) had at least one viral load or CD4 cell test per year – similar to non-Indigenous people. On average, Indigenous people had a viral load or CD4 cell count done three times a year, which is the recommended frequency.

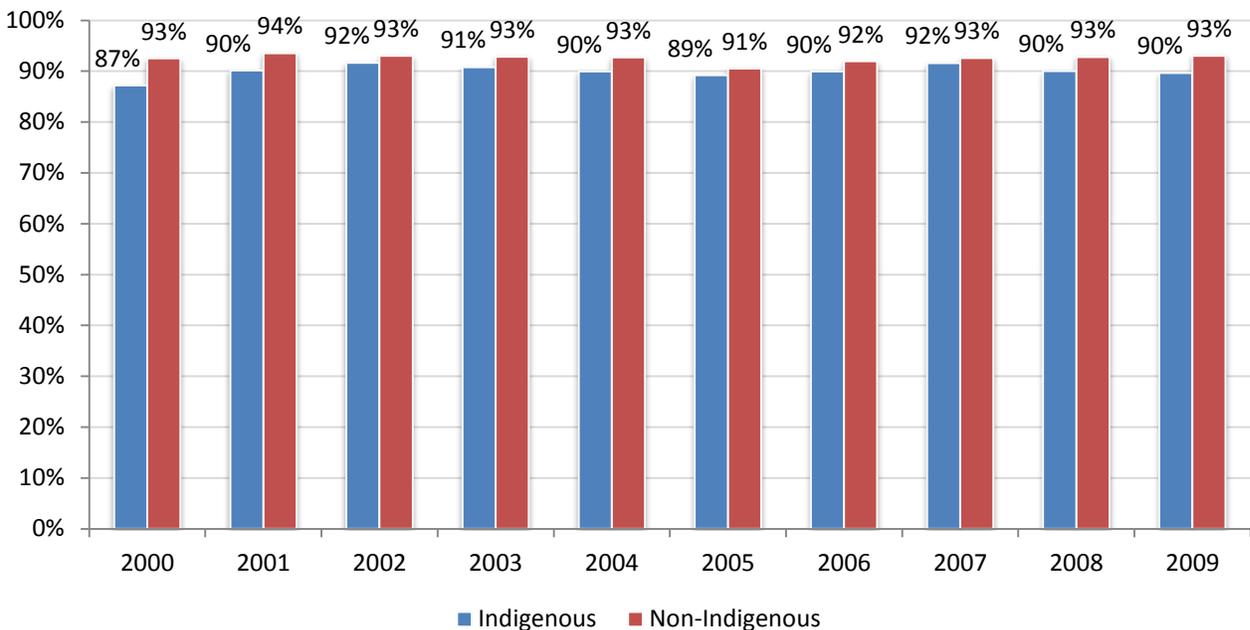
Looking specifically at participants from the Sudbury clinic, where Indigenous people make up a high proportion of patients in care, there were no apparent differences in linkage to HIV care based on Indigenous status. In the course of an investigation of HIV drug resistance, the proportion of Indigenous people with HIV (96% [22/23]) who attended the local HIV treatment program at least once was slightly but not significantly higher than the proportion of non-Indigenous persons who attended the program (87% [54/62]) (124).



The definition of continuous care, taken from the US Health Resources and Services Administration National HIV/AIDS Strategy (125, 126) is: two or more viral load or CD4 cell count tests at least three months apart in a calendar year, among patients who had at least one test in that year.

**Most Indigenous people in specialty HIV care in Ontario are receiving continuous HIV care.** Continuity of HIV care – or retention in care – is an important indicator of health services use among people with HIV. From 2000 to 2009, 91% of Indigenous people with HIV in the OCS were engaged in continuous care compared to 93% of non-Indigenous participants (93%;  $p=0.01$ ; Figure 40).

**FIGURE 40: PROPORTION OF INDIGENOUS AND NON-INDIGENOUS PEOPLE IN HIV CARE WHO WERE IN CONTINUOUS CARE IN ONTARIO, 2000-2009**



Source: Burchell A & Warren L. OHTN Cohort Study (Indigenous n= 290; non-Indigenous n=3,019)  
The differences between the mean proportion of Indigenous and non-Indigenous people in continuous care were statistically significant ( $p<0.01$ )

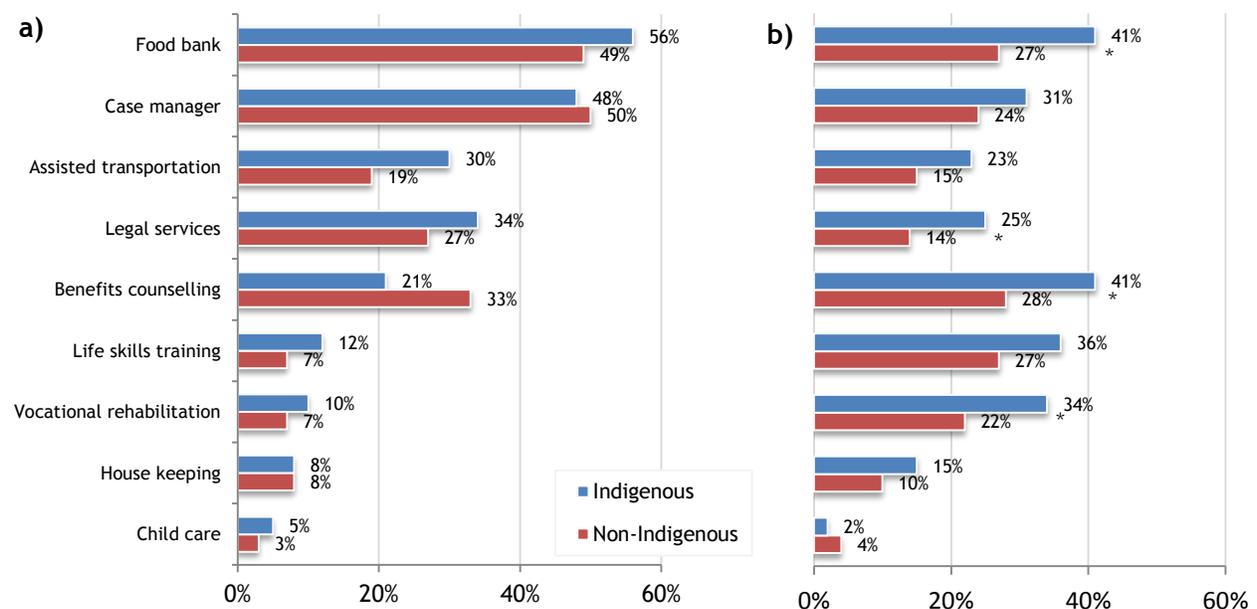
OCS participants are more likely to be engaged in continuous care when they are older and have a high CD4 count ( $\geq 500$  cells/mm<sup>3</sup>) (which is concerning for Indigenous women as they tend to have lower CD4 cell counts), and if they live in southwestern Ontario. Among people with HIV who did not inject drugs, non-Indigenous people were 30% more likely to be in continuous HIV care than Indigenous people ( $p=0.02$ ). However, among people with HIV who inject drugs, there was no difference in continuity of HIV care between Indigenous and non-Indigenous people.

## Are Indigenous People with HIV Using Social Services?

Indigenous people with HIV commonly report using social services, such as food banks and case managers, and many report having unmet needs for such services (Figure 41, panel A). Among Indigenous people with HIV participating in the PSHP study, 56% reported accessing food banks and 48% were seen by a case manager during the preceding 12 months. Indigenous people with HIV also reported using transportation assistance, legal services and benefits counselling. The patterns of social service use

among Indigenous people did not differ greatly from that among non-Indigenous participants. However, Indigenous participants were significantly more likely than non-Indigenous participants to report that they had unmet needs for services from a food bank, benefits counselling, legal services and vocational rehabilitation (Figure 41, panel B), and these differences could not be explained by geographic region of residence.

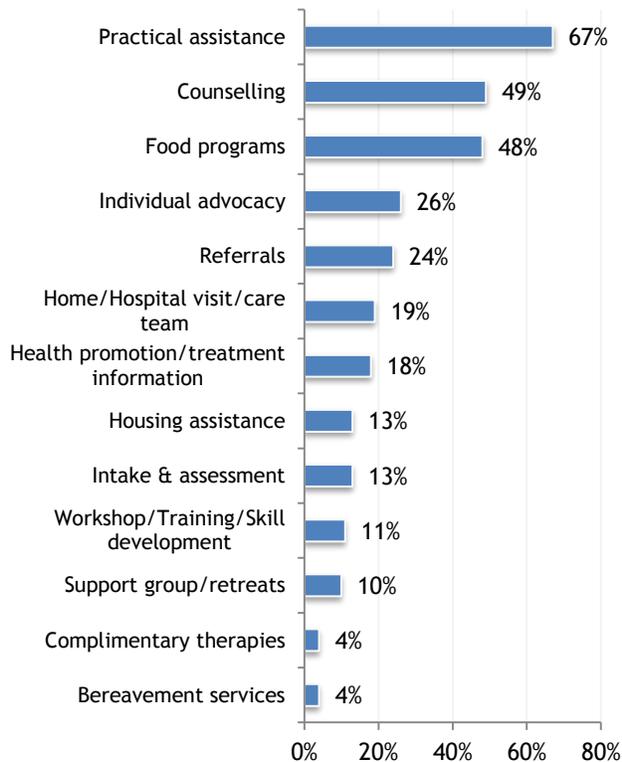
**FIGURE 41: A) UTILIZATION OF AND B) UNMET NEEDS FOR SOCIAL SERVICES IN THE PREVIOUS 12 MONTHS AMONG INDIGENOUS AND NON-INDIGENOUS PEOPLE WITH HIV, 2007-2008**



Source: Rourke S & Bekele T. *Positive Spaces, Health Places Study*, Indigenous n= 61; non-Indigenous n=377  
 Asterisk (\*) indicates differences between Indigenous and non-Indigenous participants that were statistically significant (p<0.05)

According to OCASE, the client management system used by community-based HIV/AIDS agencies funded by the AIDS Bureau, Indigenous people with HIV who receive ongoing services from support workers at community-based HIV/AIDS programs in Ontario commonly use services such as practical assistance, counselling, food programs, individual advocacy and home/hospital visits/care teams (Figure 42). Many clients also receive general case management services, which could include meetings or phone calls to discuss client issues, ongoing need assessment and service planning, implementation, coordination, monitoring and follow-up. See Figure 42 for specific services.

**FIGURE 42: PERCENTAGE OF INDIGENOUS PEOPLE WITH HIV ACCESSING SERVICES AT 24 COMMUNITY-BASED HIV/AIDS AGENCIES IN ONTARIO, BY SERVICE TYPE, APRIL 2010 TO SEPTEMBER 2011**



Source: Ontario Community-Based AIDS Services and Evaluation (OCASE), Evidence-Based Practice Unit (EBPU), Ontario HIV Treatment Network (OHTN), with the permission of AIDS Service Organizations (ASOs) in Ontario (n= 264)

Five community-based HIV/AIDS programs are funded specifically to serve the Indigenous community. From October 2011 to March 2012, these agencies served 134 Indigenous clients living with HIV. There was no significant difference in the type of services used by Indigenous men or women. The services used by Indigenous clients were similar to those used by clients of other ethnicities accessing services from programs that were not Indigenous specific. Note: the five Indigenous specific agencies regularly offer traditional services, such as Full Moon Ceremonies, Talking Circles, Naming Ceremonies, Sweat Lodge Ceremonies and

Services commonly provided by community-based agencies for people living with HIV

**Practical assistance:** includes financial assistance, bus tickets, legal advice, insurance/tax information, help with transportation, and help with accessing financial assistance and drug coverage programs.

**Counselling:** includes one-on-one sessions with a client (in person or over the phone) about employment, financial matters or other counselling/support.

**Food programs:** includes food vouchers, food banks, food hampers, community kitchen, hot meal programs, meal replacement supplements and cooking classes.

**Individual advocacy:** Some programs advocate and intervene on behalf of clients to make sure they get the services and entitlements they need. Others focus on empowering clients, through training and support, to act as advocates for themselves and others.

**Home and hospital visits/care teams:** includes any home and hospital visit to provide support to the client, partner or family and friends.

drumming; however, the use of these traditional services are not recorded separately so it is not possible to estimate the proportion of Indigenous clients who use these services.

## SECTION V: GAPS AND LIMITATIONS

The HIV epidemic among Indigenous people living in Ontario is extremely complex. This report attempts to describe the current state of the HIV epidemic among Indigenous people, but there are still many gaps and a dearth of information that is specific to Indigenous people and sub-groups within the Indigenous population in Ontario.

To date, the main obstacle has been the fact that the HIV test requisition form does not include information on ethnicity. This challenge is not limited to HIV or Ontario; it exists across the health sector. When information on ethnicity is available, it is often non-standardized or incomplete. Although Indigenous people are a heterogeneous group, it is rare to have data disaggregated for First Nations, Inuit and Métis and, when these data are available, small numbers preclude reporting and interpretation. Misreporting and under-reporting of ethnicity is a potential concern. In most data sources used to develop this report, the number of Indigenous people in each city was relatively small, limiting our ability to interpret geographic differences. Even though Indigenous participants tend to be younger, the average age of participants in most of the data sources suggests that they do not include a sizable number of youth.

For a number of reasons, it is difficult to present a complete, accurate picture for all Indigenous people in Ontario. First, we were unable to report HIV surveillance data from First Nations communities, as we were advised by Health Canada's First Nations and Inuit Health Branch that these data are unreliable due to very small numbers and suspected under-reporting related to stigma. Second, there is also no mechanism to determine whether people living in First Nations communities are accessing services such as HIV antibody testing and HIV care outside their communities. Third, research conducted among Indigenous peoples living outside First Nations communities is primarily done in urban areas, which severely limits our ability to present a fulsome picture of Indigenous people living in rural and remote communities.

The main data sources for this report are population-specific studies focusing on men who have sex with men, people who use drugs and people living with HIV. None focus predominantly on Indigenous people vulnerable to or living with HIV. As a result, sub-populations of Indigenous people, such as women or youth, are likely underrepresented in the findings. Several of the main data sources used to inform this report (e.g., I-Track, OCS, OCHART & OCASE) also include primarily people who are already accessing services (e.g. needle exchanges, specialty HIV care, ASOs), which may limit the generalizability of our findings because these data exclude people who are not seeking or receiving services.

Specifically for Indigenous people with HIV, we do not know the degree to which there are ethnic differences in clinical status for people who are not in care; however, we do know that people who are not in care are at greatest risk of HIV-related complications and death. Future efforts should focus on Indigenous people who are not in care so we can learn how best to support them to enter and remain in ongoing care and promote their long-term health.

# SECTION VI: CONCLUSIONS AND RECOMMENDATIONS

## **1. Improve the social determinants of health for Indigenous people.**

Demographic data suggest that gaps in socioeconomic status between Indigenous and non-Indigenous people in Ontario are narrowing. Despite these positive changes, Indigenous people in Ontario continue to experience disparities in education, employment, income and housing that contribute to HIV risk and reduce access to health services. These disparities tend to be observed in the larger community of Indigenous people as well as among subpopulations such as men who have sex with men, people who inject drugs and people living with HIV. To improve Indigenous health and well-being, it is essential to reduce these disparities.

## **2. Make Northern Ontario, Toronto and southwestern Ontario priority areas for culturally appropriate, effective HIV prevention for Indigenous people.**

Although the prevalence of HIV is lower among Indigenous people in Ontario than in other parts of Canada, it is still 1.7 times higher than in non-Indigenous Ontarians. An estimated 0.42% of Indigenous people in Ontario have HIV. At the time they were diagnosed, Indigenous people with HIV were most likely to live in northern Ontario, Toronto and the southwest region of the province.

## **3. Make concerted efforts to encourage Indigenous people at risk to test frequently so cases of HIV can be diagnosed as soon as possible. In addition, ensure Indigenous women with HIV who are pregnant have timely access to ART, support to improve adherence and quality care during and after pregnancy.**

One-third of Indigenous people with HIV were diagnosed late in HIV disease. Every effort should be made to diagnose people early and to prevent vertical (mother to child) transmission.

- 4. Provide measures to reduce the risks and harms associated with injection drug use (e.g. sterile equipment, access to drug substitution and rehabilitation programs). Improve Indigenous people's access to harm reduction and addiction/mental health services and ensure these services have the capacity to work effectively with Indigenous people. Monitor the impact of the recent policy change related to oxycodone/OxyContin to ensure it does not have a serious negative impact on Indigenous people. Harm reduction services should focus on Indigenous women.**

Nearly half (45%) of Indigenous people newly diagnosed with HIV reported injection drug use. Injection drug use is a key driver in the HIV epidemic among Indigenous people in Ontario. Although there were no substantial differences in drug-using behaviours based on ethnicity, Indigenous people who inject drugs were more likely than non-Indigenous people to inject non-prescribed morphine, Ritalin, benzodiazepines, barbiturates, oxycodone/OxyContin, and a combination of Talwin & Ritalin. The choice of drugs may be influenced by different prescribing patterns, cost or availability of these drugs, as well as possible differences in preference.

Almost half (44%) of Indigenous people who responded to the I-Track survey in Ontario are women. There are distinct gender differences between Indigenous men and women who inject drugs. Indigenous women were younger than men and more likely to report living in their own place, whereas men were more likely to live in shelters or on the street. Although engagement in the multi-person use of injection and drug preparation equipment was low (15% or less), these behaviours were significantly more common among Indigenous women than men.

- 5. Make Indigenous men who have sex with men a priority population for HIV prevention. Expand Indigenous-focused HIV prevention programs and services to give more specific attention to Indigenous men who have sex with men.**

Among Indigenous men, having sex with men is a major risk factor for HIV infection. Nearly half of Indigenous men newly diagnosed with HIV reported sex with other men. There is also a considerable overlap between HIV epidemics among Indigenous men: 42% of men who have sex with men who are newly diagnosed with HIV also reported injection drug use. Indigenous men who have sex with men and inject drugs may face extensive marginalization related to their ethnicity, sexual orientation and drug use.

**6. Ensure Indigenous women with HIV who are pregnant have timely access to ART, support to improve adherence and quality care during and after pregnancy.**

Effective prenatal and postnatal care are essential to safeguard the health of Indigenous women who are pregnant and to prevent vertical transmission. The number of infected babies born to Indigenous women born HIV in Ontario since the beginning of the epidemic is extremely small (3) and every effort must be made to prevent any other infections in babies.

**7. Develop culturally appropriate healthy sexuality and safer sex programs for Indigenous people. These programs should include all sexual and gender orientations, as a focus on the heterosexual community may marginalize Indigenous men who have sex with men, two-spirit people and trans people.**

Most Indigenous people newly diagnosed with HIV (64%) report sexual activity as a risk factor. Because the Indigenous population is younger than other ethno-cultural groups in Ontario and STIs rates are highest among youth, it will be important to conduct more sexual behaviour research with Indigenous youth.

**8. Take steps to help Indigenous people with HIV manage co-morbidities. Ensure high quality care is accessible for Indigenous people co-infected with HIV and HCV, including HCV Teams and HIV clinics, and ongoing coordination of these services. Encourage health promotion efforts designed to prevent non-HIV co-morbidities, such as Indigenous-specific smoking cessation programs, to welcome people living with HIV. Conduct ongoing research on non-HIV chronic conditions among people with HIV and, whenever possible, report on these conditions separately for Indigenous people to support effective planning for prevention and care services.**

Among Indigenous people with HIV, preventing and managing co-morbidities is crucial for long-term health and well-being. At least one in three Indigenous people with HIV is co-infected with HCV and, therefore, at higher risk of developing liver disease, liver cancer and other complications. Smoking is widespread among Indigenous people with HIV, which increases their risk of developing cancer as well as cardiovascular and respiratory diseases. The burden of non-HIV chronic conditions is thought to be high among Indigenous people with HIV; however, no data were available for Indigenous people living with HIV Ontario at the time of publishing this report.

**9. Develop culturally-appropriate HIV and non-HIV care services for Indigenous people with HIV. Ensure federal and provincial policy makers experienced in Indigenous health, HIV and the provision of health services for Indigenous people —both living in and outside First Nations communities and with and without status — collaborate to identify and address systemic barriers to coordinated timely health care services for Indigenous communities. Identify effective ways to improve access to care for Indigenous people in rural and remote communities, such as the Ontario Telemedicine Network.**

Indigenous people with HIV report higher levels of psychological distress, but were less likely to report use of a mental health professional and more likely to report an unmet need for mental health services. Among people with HIV recruited in community settings, Indigenous people were more likely to report unmet needs for a variety of health and social services, including a family doctor, mental health services and addictions counselling. The most common barriers to accessing health and social services were lack of local availability and financial costs. Among Indigenous people recruited from HIV clinics, there was no evidence that they had less frequent HIV care or less access to antiretroviral therapy. These findings suggest that, once people are in HIV care, they do well. The key place to focus is on linking Indigenous people to care. Because many Indigenous people in these regions live in rural and remote communities, including First Nations communities, it is critical to identify effective ways to facilitate access to services, such as telehealth.

**10. Explore the best approaches to understand and build cultural resiliency as one way to improve the health and well-being of Indigenous people with HIV in Ontario.**

Unlike the findings from western Canada, data from Ontario do not suggest that there are substantial differences in clinical status or mortality rates between Indigenous and non-Indigenous people living with HIV, nor did we find large differences in terms of self-rated health-related quality of life — despite pronounced differences in socioeconomic status. Given that Indigenous people of current generations have known only the intergenerational effects of colonization and residential school survival, they may have learned resiliency and see HIV as but one of a series of challenges that they ‘live with’. Health research and interventions are increasingly acknowledging the positive impact that cultural resiliency and resilience-building have on well-being. Greater integration of these concepts would be helpful for Indigenous research and health interventions.

## **11. Improve collection of health-related data from Indigenous people to ensure evidence-based health policy and practice.**

It is important that Indigenous leaders, policy makers, researchers and custodians of surveillance data at all levels of government consider ways to improve data collection. In particular, to fully characterize the current HIV epidemic among Indigenous people in Ontario, it is crucial to address the under-representation of Indigenous people living in rural and remote areas in HIV-focused research and the lack of availability of recent HIV statistics for Indigenous people who live in First Nations Communities.

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# APPENDIX 1: CANADIAN PERINATAL HIV SURVEILLANCE PROGRAM (CPHSP)

The Canadian Perinatal HIV Surveillance Program (CPHSP) is administered by the Canadian Pediatric AIDS Research Group (CPARG), and provides data on perinatal HIV to the Public Health Agency of Canada for national reporting. The surveillance program collects data on all identified infants and children born to mothers who are known to be infected with HIV in Canada. The Ontario region surveillance program was initiated in 1992. Data are extracted from medical charts by staff at participating hospitals.

The program includes infants identified as exposed to HIV during pregnancy, older infants and children not identified in the perinatal period, and those born outside Canada who are receiving care for HIV infection.

We obtained data from the CPHSP Ontario region for infants born to HIV-infected mothers from 1984 to 2010. We examined the number of HIV-infected mother-infant pairs and infants infected by perinatal transmission, by race/ethnicity and year/period. We also examined the number of Indigenous HIV-infected mother-infant pairs and infected infants by period of birth and mother's exposure category.

## **Acknowledgments:**

We would like to acknowledge Dr. Lindy Samson, Children's Hospital of Eastern Ontario, Ottawa, for providing perinatal data collected by the Ontario region of the Canadian Perinatal HIV Surveillance Program and Dieter Ayers, Canadian HIV Trials Network, University of British Columbia, for providing Dr. Remis with the data extraction.

## APPENDIX 2: ENHANCED HEPATITIS STRAIN SURVEILLANCE SYSTEM (EHSSS)

In partnership with local, provincial and territorial public health departments, the Public Health Agency of Canada coordinates the Enhanced Hepatitis Strain Surveillance System (EHSSS), a sentinel surveillance system that collects data on viral genotype and patient risk factors for newly diagnosed cases of hepatitis B (HBV) and hepatitis C (HCV), expanding upon the hepatitis information available through the Canadian Notifiable Disease Surveillance System. There are 11 sentinel sites across Canada, of which three are in Ontario (Hamilton, London and Ottawa).

We used Ontario-based data from the EHSSS from 2007-2010 to estimate the rate (per 100,000) and prevalence of HCV among Indigenous peoples. Census data from Statistics Canada and all cause-mortality data were used to develop population estimates. Methods have been previously described in the report, *Epidemiology of Hepatitis C Infection in Ontario, 2010* (42).

### **Link:**

Public Health Agency of Canada, Enhanced Hepatitis Strain Surveillance System:  
<http://www.phac-aspc.gc.ca/sti-its-surv-epi/hcv-epi-eng.php>

## APPENDIX 3: I-TRACK

I-Track is a periodic survey of people who inject drugs in a number of cities across Canada which is funded and supported by the Public Health Agency of Canada, and carried out in co-operation with researchers and local public health authorities in each participating city/region. In Ontario some participating cities have also recruited crack smokers who are not current injectors in order to examine their demographic characteristics, service use, and risks.

In Ontario, six cities currently participate in I-Track: Kingston, London, Ottawa, Sudbury, Thunder Bay, and Toronto. Ottawa's surveys are conducted through a partnership between Dr. Lynne Leonard, University of Ottawa, and the SurVIDU network in Québec, with a somewhat different survey organization but most of the same questions as the other sites. The other five cities involve a partnership between Dr. Peggy Millson of the University of Toronto, the local public health units, and their community harm-reduction program partners in each city. For purposes of this report, data from surveys conducted between 2010 and 2012 are included, depending on the city: Sudbury – 2010; Ottawa – 2010-2011; Kingston, Thunder Bay, and Toronto – 2011; and London – 2012.

Each participant interview consists of an interviewer-administered survey as well as the collection of a saliva sample (Ottawa) or a dried blood spot sample (other cities) for laboratory testing for infection with HIV and HCV. Participants are eligible to complete an interview if they are at least 16 years of age, have injected drugs in the six months prior to their interview and are able to give their informed consent to participate. Sampling is primarily, but not exclusively, conducted at harm reduction program sites. The interviewer-administered survey contains questions on demographics, injecting and non-injecting drug use, sexual behaviour, service use and previous HIV and hepatitis C testing. Participants have been identified as “Indigenous” if they self-identified as an Indigenous person. For the purposes of this report, all other responding participants have been classified as “non- Indigenous”.

### Link:

Public Health Agency of Canada, I-Track: <http://www.phac-aspc.gc.ca/sti-its-surv-epi>

## Acknowledgments:

The I-Track surveys and analyses are funded and supported by the Public Health Agency of Canada, and carried out with the assistance of staff of the following organizations in each city:

- Toronto: Toronto Public Health, and Harm Reduction teams from The Works, Queen West Community Health Centre, South Riverdale Community Health Centre, Street Health/Regent Park Community Health Centre, Parkdale Community Health Centre
- Sudbury: Sudbury and District Health Unit, Sudbury Action Centre for Youth, The Point Needle Exchange Programme
- Kingston: North Kingston Community Health Centre, Streethealth Needle Exchange Programme
- Thunder Bay: Thunder Bay District Health Unit, Superior Points Needle Exchange Programme, AIDS Committee of Thunder Bay
- London: Middlesex-London Public Health Unit, Regional HIV/AIDS Connection
- Ottawa: The Site Needle Exchange Programme

We thank all the research staff and study interviewers for their assistance with the study, and we particularly acknowledge the willing contributions of the research participants.

**TABLE 2: DEMOGRAPHIC INFORMATION AMONG INDIGENOUS AND NON- INDIGENOUS I-TRACK PARTICIPANTS IN ONTARIO, 2010-2012**

Variable	Category	All cities combined			
		Non-Indigenous	Indigenous	Overall	p-value
<b>Gender</b>	<b>n</b>	<b>1142</b>	<b>411</b>	<b>1553</b>	
	Male	72.8	56.0	68.3	$\leq 0.001$
	Female	27.2	44.0	31.7	
<b>Age</b>	<b>n</b>	<b>1144</b>	<b>411</b>	<b>1555</b>	
	Mean	40.5	38.3	39.9	$\leq 0.001$
	Range	16-76	17-62	16-76	
<b>Education Level</b>	<b>n</b>	<b>1144</b>	<b>411</b>	<b>1555</b>	
	Less than High School	48.5	64.7	52.8	$\leq 0.001$
	Completed High School	24.1	17.3	22.3	
	More than High School	27.4	18.0	24.9	
<b>Personal Income</b>	<b>n</b>	<b>826*</b>	<b>346*</b>	<b>1172*</b>	
	> \$500	11.1	15.6	12.5	$\leq 0.05$
	\$500 - \$999	30.3	35.6	31.8	
	\$1000 - \$1999	41.3	34.4	39.3	
	> \$2000	17.3	14.5	16.5	
<b>Previously in Jail</b>	<b>n</b>	<b>830*</b>	<b>351*</b>	<b>1181*</b>	
	No	18.0	16.5	17.5	NS
	Yes	82.1	83.5	82.5	

Variable	Category	All cities combined			
		Non-Indigenous	Indigenous	Overall	p-value
Living Situation(s) 6 months prior to interview	N	1144	411	1555	
	Own Apartment/ House	66.5	70.3	67.5	NS
	Parents' Home	7.3	8.0	7.5	NS
	Other Relative's Home	4.4	12.2	6.4	≤0.001
	Friend's Home	19.6	26.5	21.4	≤0.01
	Hotel/Motel Room	10.3	10.0	10.2	NS
	Rooming/Boarding House	16.4	12.9	15.5	≤0.05
	Shelter/Hostel	29.0	31.1	29.6	NS
	Transition/ Halfway House	2.7	4.1	3.1	NS
	Detox./Rehab. Centre	4.8	3.6	4.5	NS
	Public Place/Streets	12.4	15.8	13.3	≤0.05
	Correctional Facility	11.4	14.1	12.1	NS
	Psychiatric Institution	1.3	0.7	1.2	NS
	Other	1.5	2.4	1.7	NS

Variable	Category	All cities combined			
		Non-Indigenous	Indigenous	Overall	p-value
<b>Current Living Situation</b>	<b>n</b>	<b>1136</b>	<b>410</b>	<b>1546</b>	
	Own Apartment/ House	53.8	56.1	54.4	NS
	Parents' Home	3.0	2.2	2.8	NS
	Other Relative's Home	1.6	3.7	2.1	≤0.01
	Friend's Home	6.7	9.5	7.4	≤0.05
	Hotel/Motel Room	1.6	1.7	1.6	NS
	Rooming/ Boarding House	10.6	6.6	9.5	≤0.01
	Shelter/Hostel	17.1	13.4	16.1	≤0.05
	Transition/ Halfway House	1.5	2.2	1.7	NS
	Detox./Rehab. Centre	5.1	2.7	4.5	≤0.05
	Public Place/Streets	3.1	3.9	3.3	NS
	Correctional Facility	0.1	0.2	0.1	NS
	Psychiatric Institution	0.0	0.0	0.0	N/A
	Other	0.5	0.2	0.5	NS
<b>Currently Lives in</b>	<b>n</b>	<b>831*</b>	<b>353*</b>	<b>1184*</b>	
<b>City/Locally</b>	No	3.5	3.4	3.45	NS
	Yes	96.5	96.6	96.5	
<b>Lives On-Reserve (if Indigenous)</b>	<b>n</b>		<b>352*</b>		
	No		95.2		N/A
	Yes		4.8		

## APPENDIX 4: LAMBDA SURVEY (M-TRACK)

The Lambda study was conducted in Toronto and Ottawa in 2007. Lambda represents the Ontario component of an ongoing, national second generation surveillance system (M-Track) that monitors HIV infection and risk behaviours related to HIV infection among men who have sex with men in Canada.

The Lambda study was an anonymous venue-based cross-sectional survey that consisted of a self-administered behavioural questionnaire and the collection of a biologic sample (dried blood spots) to measure HIV, HCV and syphilis antibodies. Lambda used tests designed to detect recent infection of HIV to assess HIV incidence among men who have sex with men. Lambda sought to collect information about risk behaviours associated with HIV and sexually-transmitted infections and general issues relevant to sexual health and sexual behaviour among men who have sex with men.

Participants were recruited and data were collected from March-July in Toronto and April-June in Ottawa (2007). Self-identification as gay or bisexual was not a requirement for participation; however, as recruitment was venue-based and took place at gay bars, bathhouses and community groups, it was assumed that participants were likely to have had some connection with the gay community. To be eligible to participate, respondents were required to 1) be a biologic or self-identified man who has sex with biologic or self-identified men; 2) be at least 16 years of age; and, 3) have not previously completed a questionnaire in this study. Indigenous ethnicity was determined by self-reported ethnicity status. For the purposes of this report, participants who reported an ethnicity other than Indigenous have been classified as “non- Indigenous”. Unknowns were excluded from analyses.

### **Link:**

Ontario HIV Epidemiologic Unit, Lambda Survey:

[http://www.ohemu.utoronto.ca/doc/Lambda\\_SpecialReport\\_Ethnicity.pdf](http://www.ohemu.utoronto.ca/doc/Lambda_SpecialReport_Ethnicity.pdf)

## **Acknowledgments:**

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**TABLE 3: DEMOGRAPHIC INFORMATION AMONG INDIGENOUS AND NON- INDIGENOUS LAMBDA (M-TRACK) PARTICIPANTS IN ONTARIO, 2010-2012**

	Toronto		Ottawa		Toronto & Ottawa	
	Indigenous	Non-Indigenous	Indigenous	Non-Indigenous	Indigenous	Non-Indigenous
<b>Total</b>	101 (6%)	1,652 (94%)	21 (5%)	439 (95%)	122 (6%)	2,091 (94%)
<b>Age (years)</b>						
<30	12 (12%)	320 (21%)	6 (30%)	107 (26%)	18 (15%)	427 (22%)
30-45	51 (53%)	686 (45%)	6 (30%)	161 (39%)	57 (49%)	847 (44%)
>45	34 (35%)	516 (34%)	8 (40%)	142 (35%)	42 (36%)	658 (34%)
<b>Education</b>						
Did not complete college/university	53 (52%)	595 (36%)	13 (62%)	140 (32%)	66 (54%)	735 (36%)
Completed college/university	48 (48%)	1,038 (64%)	8 (38%)	294 (68%)	56 (46%)	1,332 (64%)
<b>Personal income</b>						
<\$20,000	29 (29%)	308 (19%)	6 (30%)	85 (20%)	35 (29%)	393 (19%)
\$20,000 - \$49,999	35 (35%)	622 (39%)	7 (35%)	134 (31%)	42 (35%)	756 (37%)
≥\$50,000	36 (36%)	675 (42%)	7 (35%)	208 (49%)	43 (36%)	883 (43%)
<b>Unprotected receptive anal sex<sup>z</sup></b>						
Yes	13 (24%)	182 (19%)	1 (10%)	50 (17%)	14 (22%)	232 (18%)
No	41 (76%)	798 (81%)	9 (90%)	251 (83%)	50 (78%)	1049 (88%)
<b>Delayed condom application<sup>y</sup></b>						
Yes	6 (9%)	94 (8%)	1 (7%)	33 (10%)	7 (8%)	127 (8%)
No	62 (91%)	1076 (92%)	14 (93%)	304 (90%)	76 (92%)	1380 (92%)

<sup>z</sup> - Participants who self-reported being HIV-negative or of unknown HIV status and had information on unprotected receptive anal sex with a casual partner or a regular partner of HIV-positive or unknown status

<sup>y</sup> - Participants who self-reported being HIV-negative or of unknown HIV status and had information on delayed condom application with an HIV-positive or unknown status partner

## APPENDIX 5: OCHART AND OCASE

Twice each year, the 88 community-based HIV/AIDS programs in Ontario funded by the Ontario Ministry of Health and Long-Term Care, AIDS Bureau and the Public Health Agency of Canada's AIDS Community Action Program are required to report their program outputs. The data and information provided give funders the information they need to review the range of HIV services provided in Ontario, identify emerging issues and trends, inform planning, and account for the use of public resources. Analysis and reporting of the data also give community-based programs information about services, trends, and client needs that they can use to improve existing services and plan new ones. Results are reported annually in the publication called [View from the Front Lines](#) based upon data submitted by the programs (25).

The analysis in this report focused on Indigenous clients living with HIV and their usage of provided services.

### OUCHART

OUCHART (Ontario Community HIV and AIDS Reporting Tool) is a web-based reporting tool that the 88 programs use to prepare their semiannual report. To identify Indigenous clients of community-based HIV/AIDS programs, the tool asks two questions specific to Indigenous peoples; 1) if the catchment area served by the agency contains Indigenous populations; and 2) the approximate percentage of their total clients who are of Indigenous ethnicity. This question is often answered based upon their understanding and experience working in their community and not necessarily on statistical data they have captured on clients. How a program defines who is a client depends on the type of service offered and this generally ranges from people living with HIV, those affected (i.e. family members or partners of people living with HIV), and those at-risk of HIV for whom they provide HIV prevention services.

OUCHART captures aggregate data on client visits by organization, but cannot determine whether a single client has visited multiple service organizations. Therefore, the total number includes clients who may use several ASOs, including Indigenous-specific ones, in regions where they have access to more than one agency. For example, a client may access services in Guelph and also receive services through the regional Ontario Aboriginal HIV/AIDS Strategy worker. As well, a client could be housed with Fife House in Toronto and also use services at 2-Spirits or another ASO in Toronto.

In October 2011-March 2012, five Indigenous-specific agencies served 134 Indigenous clients living with HIV. The largest number of clients was in the Toronto area followed by the southwest, northern and eastern regions of the province. Thirty-four percent of clients were female and 54% were male. The proportion of clients reported as transgendered and accessing support was slightly higher in the Indigenous population (12%) than in the general population (11%). Females and trans-women account for 47% of Indigenous PHA clients accessing support services. The median age range of Indigenous PHA clients was 40-54 years.

## **OCASE**

OCASE (Ontario Community-Based AIDS Services and Evaluation) is the electronic client management system provided to all AIDS Service Organizations (ASOs) and other community-based programs by the AIDS Bureau (Ontario Ministry of Health and Long Term Care). The system enables ASOs to collect and store client and service information, as well as inform reporting back to the AIDS Bureau in a secure and consistent fashion using the OCHART tool. A total of 30 programs use the OCASE system.

For the analysis for this report, clients were considered to be Indigenous if they self-reported as such, or if they were clients at the two ASOs that serve the Indigenous community specifically. There are 24 ASOs in OCASE which have data related to Indigenous PHA. Anonymous and aggregate data from April 2010 to the end of September 2011 were examined to describe service usage among Indigenous peoples with HIV.

According to OCASE, the number of Indigenous PHAs recorded as clients at the 24 ASOs ranges from 1 to 56, with a total of 355 individuals across the province. There are very likely more than that number but we have based this data only on clients with a confirmed HIV status in the OCASE system. Table 5 shows the geographic distribution and break-down by health region, sexual orientation, gender and age among Indigenous clients recorded in OCASE. The gender breakdown may be closer between males and females than in the general PHA population though it is difficult to determine the prevalence of HIV by gender due to limited reporting of HIV cases by ethnicity. The breakdown by gender in OCASE shows males at 56% (198), females at 39% (136) and trans-females at 5% (18). In terms of sexual orientation, 35% are heterosexual, 23% gay, 5% bisexual and 2-spirit and 2% are lesbian. Finally, 28% have trans-sexual or unrecorded sexual orientation. Among the 90% of Indigenous PHAs with recorded age, 33 (9%) were 30 or younger, 233 (66%) were 31-50 and 53 (15%) were 50 or older.

**Link:**

Ontario HIV Treatment Network & AIDS Bureau, Ontario Ministry of Health and Long-Term Care, *View from the Front Lines*:

<https://www.ochart.ca/documents/2011/The%20View%20From%20the%20Front%20Lines%20March%2021%202011-%20FINAL.pdf>

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**TABLE 4: CHARACTERISTICS OF INDIGENOUS PEOPLE WITH HIV WHO WERE CLIENTS OF COMMUNITY-BASED HIV/AIDS AGENCIES THAT USE OCASE, 2010-2011**

	Number (%) of Indigenous people with HIV recorded as clients (n= 355)	Number (%) of Indigenous people with HIV who received one or more services in 2010-11 (n=264)
<b>Region</b>		
Central East	14 (4%)	12 (5%)
Central West	25 (7%)	16 (6%)
Ottawa & Eastern	33 (13%)	24 (9%)
Northern	54 (15%)	48 (18%)
South West	10 (3%)	8 (3%)
Toronto	219 (62%)	156 (59%)
<b>Gender</b>		
Female	136 (39%)	98 (37%)
Male	198 (56%)	152 (58%)
Trans-Female	18 (5%)	12 (5%)
Unreported	-	2 (1%)
<b>Sexual Orientation</b>		
Heterosexual	126 (35%)	90 (34%)
Gay	81 (23%)	64 (24%)
Bisexual	17 (5%)	14 (5%)
2-Spirit	17 (5%)	13 (5%)
Trans-sexual	7 (2%)	6 (2%)
Lesbian	7 (2%)	3 (1%)
Other/Unrecorded	100 (28%)	74 (28%)
<b>Age</b>		
≤ 30 years	33 (10%)	24 (9%)
31-40 years	98 (31%)	82 (31%)
41-50 years	135 (42%)	94 (36%)
> 50 years	53 (17%)	64 (24%)

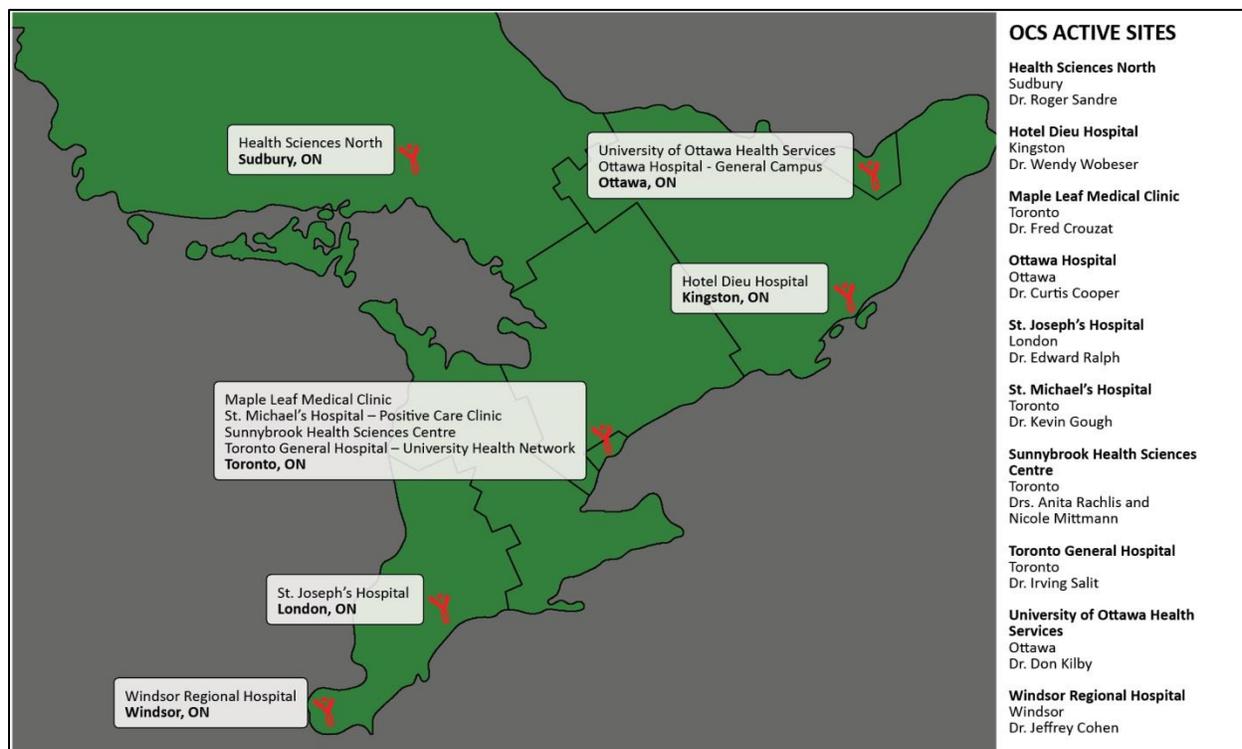
# APPENDIX 6: ONTARIO HIV TREATMENT NETWORK COHORT STUDY (OCS)

The Ontario HIV Treatment Network Cohort Study (OCS) is an ongoing observational, open dynamic cohort of adults aged 16 years and older with documented HIV infection who are patients at specialty HIV clinics across Ontario. It is a collaborative and community-driven study, including a Governance Committee made up of people with HIV and other stakeholders that evaluates each analysis project proposal for community relevance and ethics.

From 1995 to 2010, a total of 5,644 participants were enrolled and just over 27,000 person-years of observation were accumulated. Participating clinics serve over three-quarters of HIV-positive patients undergoing viral load testing provincially. Eligible patients were invited to enroll in the study by a clinician or interviewer during a routine clinic visit.

Data collection includes extensive de-identified information on clinical, laboratory and psychosocial and behavioural measures based on medical chart abstractions, interviews using a standardized questionnaire and linkage with external administrative health databases in Ontario (26).

**FIGURE 43: MAP OF ONTARIO HIV TREATMENT NETWORK COHORT STUDY (OCS) SPECIALTY HIV CLINICS, 2010**



For the current report, we identified Indigenous participants as individuals who self-reported Indigenous ethnicity and the United States of America (USA) or Canada as their country of birth and contrasted them to non-Indigenous participants, defined as all individuals who reported an ethnicity other than Indigenous. A total of 166 OCS participants were excluded from all our analyses due to missing information on race/ethnicity.

**Link:**

OHTN Cohort Study: <http://www.ohtncohortstudy.ca>

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**TABLE 5: SOCIO-DEMOGRAPHIC CHARACTERISTICS\* FOR INDIGENOUS AND NON-INDIGENOUS PARTICIPANTS IN THE ONTARIO HIV TREATMENT NETWORK COHORT STUDY (OCS), 2010**

Characteristic		Indigenous (n=418) <sup>a</sup>	Non-Indigenous (n = 4,951) <sup>a</sup>	P-value
Age (years) at HIV diagnosis (mean±S.E.)		31.5±0.9	34.1±0.3	<0.01
Age (years) as of 2010 <sup>b</sup>		45.5±1.1	48.0±0.4	<0.01
Sex	Male	344 (82%)	4240 (86%)	0.06
	Female	74 (18%)	711 (14%)	
Sexual Orientation <sup>c</sup>	Heterosexual	138 (41%)	1032 (33%)	<0.01
	Gay/Lesbian/ Bisexual/Two-Spirit	195 (59%)	2121 (67%)	
Education – Did not complete highschool <sup>d</sup>	Male	69 (25%)	285 (11%)	<0.01
	Female	31 (53%)	111 (21%)	<0.01
Employment <sup>e</sup>	Working for pay <sup>f</sup>	114 (35%)	1495 (49%)	<0.01
	Unemployed/ disability/	210 (65%)	1584 (52%)	
Household Gross Yearly Income <sup>g</sup>	<\$20,000	140 (45%)	843 (28%)	<0.01
	\$20,000 - \$49,999	77 (25%)	877 (29%)	
	\$50,000-\$79,999	44 (14%)	519 (17%)	
	\$80,000+	48 (16%)	768 (26%)	
Geographic Region <sup>h</sup>	Greater Toronto Area	130 (34%)	2425 (52%)	<0.01
	Eastern Ontario	89 (23%)	1011 (22%)	
	South-western Ontario	89 (23%)	1033 (22%)	
	Northern Ontario	77 (20%)	156 (3%)	
Rural Residency <sup>i</sup>	Male	38 (12%)	251 (6%)	<0.01
	Female	13 (19%)	22 (3%)	<0.01
Housing Situation <sup>j</sup>	House/Apartment/Cond	162 (94%)	2170 (97%)	0.07
	Other <sup>k</sup>	10 (6%)	72 (3%)	
Currently Smoke <sup>l</sup>	Male	167 (61%)	1008 (38%)	<0.01
	Female	52 (88%)	146 (28%)	<0.01

\* Unless otherwise noted, the number (and percentage) of participants in each category are shown. P-values are based on Pearson Chi Square (or Fisher's Exact Tests for cell sizes <5) for categorical variables and on t-tests for continuous variables.

<sup>a</sup> There were fewer observations for questionnaire related data (employment status, household gross income, education, housing situation, sexual orientation, and smoking status; Indigenous n = 324, Non-Indigenous n = 3,040)

<sup>b</sup> Based on participants enrolled in OCS as of January 1<sup>st</sup>, 2010; Indigenous n = 298, Non-Indigenous n = 3,003

<sup>c</sup> Based on last questionnaire. Indigenous n = 333; non-Indigenous n = 3,153

<sup>d</sup> Based on last questionnaire. Indigenous n = 333; non-Indigenous n = 3,166

<sup>e</sup> Based on Indigenous n = 324; non-Indigenous n = 3,079

<sup>f</sup> Includes both part- and full-time employment

<sup>g</sup> Based on last questionnaire. Indigenous n = 309; non-Indigenous n = 3,007

<sup>h</sup> Based on site location

<sup>i</sup> Determined by the second digit of the patient's FSA (forward sortation area); 0=rural, 1-9=urban

<sup>j</sup> Based on last questionnaire. Indigenous n = 172; non-Indigenous n = 2,242

<sup>k</sup> Other includes shelter; couch surfing; outdoors; street; park; car; housing facility; self-contained room in a house, hotel, motel or boarding house

<sup>l</sup> Participant smoked within the 30 day period prior to the completion of the last questionnaire. Based on Indigenous n = 333; non-Indigenous n = 3,164

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# APPENDIX 7: POSITIVE SPACES

## HEALTHY PLACES

Positive Spaces Healthy Places is an observational cohort of 602 adults living with HIV in Ontario, Canada designed to evaluate the health effects of housing. The study surveys and questionnaires included comprehensive social and behavioural measures (taking 60–90 min to complete) and were administered in face-to-face interviews by trained peer research assistants living with HIV. Participants were recruited through community-based AIDS service organizations and were eligible if they were HIV-positive adults (18 years or older) living in Ontario and able to provide informed consent. To achieve as representative a sample as possible, the recruitment strategy used a wide range of access points throughout the province, including: homeless shelters; agencies serving women, families, and youth; Indigenous organizations; transitional housing providers; and supportive housing agencies. Efforts were made to include harder-to-reach populations such as injection drug users and street-involved communities (i.e. individuals who live in and out of hostels and homeless shelters) (28).

To define Indigenous participants, all participants were asked which ethnic group they belonged to (e.g. English, Italian, and Jamaican) and whether they were members of an Indigenous group (i.e. First Nations, Inuit or Métis). For this report, individuals who reported being a member of an Indigenous group, regardless of ethnicity, are classified as Indigenous. The comparison group was respondents who reported European origin (list follows) as well as respondents who reported being “Canadian” with no other ethnic identity: English, Scottish, Irish, Other British, Croatian, Danish, Dutch, Finnish, French, German, Greek, Hungarian, Italian, Lebanese, Norwegian, Polish, Portuguese, Swedish, Ukrainian, or Yugoslavian.

### Link:

Ontario HIV Treatment Network Positive Spaces Healthy Places Study:  
<http://www.pshp.ca>

## Acknowledgments:

The Positive Spaces, Healthy Places (PSHP) study is a longitudinal community-based research that examines housing instability and housing outcomes among people living with HIV. It is supported by grants from the Canadian Institutes of Health Research, the Ontario Ministry of Health and Long Term Care, the Ontario AIDS Network, the Wellesley Institute, and the Ontario HIV Treatment Network.

The PSHP study team includes Dr. Sean Rourke (Ontario HIV Treatment Network; St. Michael's Hospital; University of Toronto), Ruthann Tucker (AIDS Hamilton), Dr. Saara Greene (Fife House, McMaster University), Doris O'Brien Teengs (Ontario Aboriginal HIV/AIDS Strategy) Jay Koornstra (Bruce House), Keith Hambly (Fife House), Glen Walker (AIDS Niagara), Michael Sobota (AIDS Thunder Bay), Dr. James Dunn (St. Michael's Hospital; McMaster University), Dr. Dale Guenter (McMaster University), and Dr. Stephen Hwang (St. Michael's Hospital; University of Toronto).

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**TABLE 6: BASELINE DEMOGRAPHIC CHARACTERISTICS OF INDIGENOUS PARTICIPANTS IN THE POSITIVE SPACES, HEALTHY PLACES (PSHP) STUDY, 2006–2007**

	Indigenous (n=79)	Non-Indigenous (n=441)	p-value
Age in years (mean ± SD)	41.7 ± 7.8	44.3 ± 8.6	0.016
<b>Gender</b>			
Female	22 (28%)	74 (17%)	
Male	52 (66%)	365 (83%)	0.001
<b>Sexual Orientation</b>			
Gay/Lesbian/Bisexual	43 (54%)	316 (72%)	
Heterosexual	36 (46%)	125 (28%)	<0.001
<b>Highest level of education</b>			
< HS completion	31 (39%)	99 (22%)	
≥ HS completion	48 (61%)	342 (78%)	0.002
<b>Employment</b>			
Working for pay	9 (11%)	91 (21%)	
Unemployed/retired/on disability	70 (89%)	350 (79%)	0.054
Annual Income (mean ± SD)	13,560 ± 660	19,020 ± 1,503	0.009
<b>Ever been to jail or prison</b>			
Yes	41 (52%)	143 (32%)	
No	38 (48%)	298 (68%)	0.001
<b>Region of residence</b>			
Greater Toronto Area	40 (51%)	266 (60%)	
Eastern Ontario	20 (25%)	68 (15%)	
South-western Ontario	7 (9%)	79 (18%)	
Northern Ontario	12 (15%)	28 (6%)	0.002

# APPENDIX 8: PUBLIC HEALTH ONTARIO, HIV-TESTING DATABASE

## **Modelling HIV Prevalence among the Indigenous population in Ontario**

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We wished to estimate the prevalence of HIV infection in the Indigenous population in Ontario by exposure category, sex and health region for 2008. To accomplish this, we obtained and analyzed data from multiple data sources about HIV cases and populations. The primary data sources for this analysis included: the HIV diagnostic database, the Laboratory Enhancement Program from 2009 to 2011, the Lambda Study (carried out among gay men in Toronto and Ottawa in 2007) and reported AIDS cases. In addition, the Toronto and Ottawa public health units provided us with data on HIV and AIDS cases by race/ethnicity from 1981 to 2004. The Indigenous population was estimated from census data for 1991 through 2006 and extrapolated to 2008.

A spreadsheet was created using the same approach as that for Ontario as a whole (32) for each exposure category and gender for each year from 1977 to 2008. The exposure categories included men who have sex with men, men who have sex with men and injection drug use, injection drug use and heterosexual. The parameters in the model included the incidence, cumulative incidence and prevalence of HIV infection, HIV diagnoses, AIDS cases and HIV-related and other cause mortality.

Data from the above data sources was adjusted and triangulated to obtain plausible for HIV prevalence in 2008 consistent with available data. Prevalent cases for 2008 were then interpolated to each of the seven health regions in Ontario using the LEP data. We also carried out analyses to compare original Indigenous and non- Indigenous rates by health region and overall.