BLUEPRINT FOR ACTION ON WOMEN AND GIRLS AND HIV/AIDS
2012 CANADIAN REPORT CARD BACKGROUNDER

CANADA - OVERVIEW

Overall, women in Canada have access to a significant number of opportunities. Their human rights tend to be protected, and there have been great strides in ensuring equality with men over the last decades. This said there is still significant work to be done for all women. Certain communities of women in Canada continue to experience severe challenges and barriers limiting their ability to fully enjoy their rights and opportunities.

HIV/AIDS & Women - Epidemiological Data:

It is estimated that women account for 17% of people living with HIV and 26% of all new HIV infections in Canada as of 2008[1] with heterosexual transmission representing 53.9% of cumulative HIV case reports among adult women over 15 years of age from 1985-2009.[2] Injection drug use accounted for 35.4% of HIV cases among women in 2009.[3] Aboriginal women are almost equally as affected by HIV as Aboriginal men, and women who come from countries where HIV is endemic represent more than half (54.2%) of the positive HIV test reports attributed to women. The rate of HIV infection for women in prisons is higher than the rate of HIV infection for men in prisons (4.7% as compared to 1.7%).[4] The 2007 National Inmate Infectious Diseases and Risk-Behaviours Survey conducted by Correctional Service of Canada (CSC) puts women's self-reported HIV rate at 7.9% versus the self-reported HIV rate for men in prison of 4.5%. Data on women in prison reveals that Aboriginal women in prison reported the highest rates of HIV infection (11.7%). Limited data indicate that trans women have particularly high HIV prevalence rates. A recent meta-analysis estimated an HIV prevalence rate of 27.7% for male-to-female transgender people in North America. A growing body of evidence shows that women who have sex with women are at increased risk of HIV.[5] Of the total number of perinatally HIV-exposed infants from 1984 to 2009 with reported ethnicity data, 16.2% were Aboriginal. This number is disproportionately high as Aboriginal peoples make up approximately 3.8% of the population of Canada.[6]

Among federally incarcerated women, one third is Aboriginal, 80% are survivors of physical and sexual abuse (a percentage that rises to 90% for Aboriginal women), a significant number are struggling with substance use, one in five is struggling with mental health problems, and many are single mothers with primary childcare responsibilities. While more than 80% of women in Canada have completed education beyond the ninth grade, the figure for women in prison is closer to 50%. A previous history of injection drug use is consistently found more frequently among female than male prisoners in Canada. Consequently, more than half of all charges that bring females in contact with police are non-violent, property and drug offences, as women often perpetrate income-generating crimes to support their drug use.[7] In a 2007 national survey, 1 in 4 women in federal prisons admitted using drugs in the past six months in prison, and 15% admitted injecting drugs. Of those women, 41% used someone else's used needle, and 29% shared a needle with someone who had HIV, HCV or an unknown infection status. In a 2003 study of women in federal prisons, 1 in 4 was tattooing.[8]

Determinants of Health – Education, Income, Housing:

Statistics reveal that women and men report having relatively equal levels of post-secondary education in Canada[9] with the important exception of Aboriginal people and immigrants who were educated outside of Canada and have difficulty having those credentials recognized in Canada. However, the Census reveals women earned an average employment income of $28,073 as compared to $43,869 for men in 2005. Data also show that some groups of women earn less than others. For example, Black women reported earning less than the overall immigrant women population, and Aboriginal women reported earning less than Black and immigrant women.[10]

According to research by the Canada Mortgage and Housing Corporation (CMHC), in 2001, 12.7 % of Canadian women lived in households with core housing need for increased affordability, suitability and adequacy as compared to 10.3 % of Canadian men. Occupants of households with core housing need are at risk of homelessness. The highest incidence of core housing need for women occurred in Northern areas, including Nunavut (46.6%), NWT (17.8%) and Yukon (17.8%), and in urban cities such as Toronto (18.3%), Vancouver (15.9%) and Ottawa (14.7%). Research by CMHC shows that women living alone (28.3%) and those living in lone-parent families (31%) had the highest incidence of core housing need. Among those living alone, 33.3 % of women over the age of 65 and 39.4 % of Aboriginal women had core housing need.[11] This has particular implications for people living with HIV, as HIV-positive people who face housing instability have significantly poorer physical and mental health and decreased health-related quality of life. Correspondingly, unstably housed individuals are two to four times more likely to have recently participated in high risk behaviors for HIV, including drug use, needle use or unsafe sex exchange.[12]

Census Changes:

The loss of the mandatory long-form census in Canada in 2011, including its questions on education and employment, leaves Canadians with less demographic data about changing lifestyle and statistical trends. This data is used by a range of stakeholders from public health and police departments to urban planners and school boards, from researchers and civil society to analysts and businesses in order to understand and develop programs that respond to the needs of Canada's diverse population.[13]

LEGAL ETHICAL AND HUMAN RIGHTS **D+ grade**

While Canadians continue to be protected by the *Charter of Rights and Freedoms*, the federal government in particular has taken steps to limit its scope, especially for marginalized communities. In March 2010, the federal government withdrew so much funding from the Canadian Human Rights Commission as to force the closure of its offices in Toronto, Vancouver and Halifax. In addition, the 2006 funding cut to Status of Women Canada led to the closure of the National Association of Women and the Law's office, which for more than 30 years had been involved in precedent-setting legal work on behalf of women, such as winning amendments to the *Criminal Code* regarding sexual assault laws, improvements to the *Divorce Act,* and adoption of equality rights in the *Canadian Charter of Rights and Freedoms*.[14]

Meanwhile, trans women are not currently protected under the existing *Canadian Human Rights Act*. While a federal gender identity bill, C-279, is presently going through readings in the House of Commons and will make its way to the Senate, due to harsh opposition from ruling party members, compromises are being made that may weaken trans women's protection. Some have called it a "bathroom bill" and have even gone as far as comparing trans people to sexual predators. There is concern the compromises, including further definitions being required within the *Act* may limit protections available to gender-variant persons in certain circumstances, for example persons living in "alternative" or "non-binary" gender identities.[15]

Incarcerated women continue to have their human rights violated. No prison system in Canada permits harm reduction measures such as needle and syringe programs and safer tattooing options, despite significant evidence of high-risk behaviours related to these practices and women's desire to access such measures. While bodies such as the Human Rights Commission[16] and officials such as the Correctional Investigator, the ombudsman for federal prisoners, have made strong recommendations for the provision of these health services based on scientific and medical literature, they remain inaccessible in all Canadian prisons.[17] It is anticipated that the passage of omnibus Bill C-10, the *Safe Streets and Communities Act*, will result in more women and more Aboriginal women, many of whom are mothers, being incarcerated and for longer periods of time.[18]

For newcomers to Canada, the federal government announced $53 million in cuts to immigration settlement programs in December 2010. The effect of the federal cuts to these programs has been so deleterious that, in February 2011, the Ontario government announced a one-time bailout fund of $500,000 to support the hardest-hit agencies and give them time to come up with long-term alternatives to federal funding.[19] Changes to the Interim Federal Health Program (IFHP), the federal health program for refugees, reduce health coverage available to refugees and restrict medical care to those services necessary to protect public health or public safety. These changes, publicly opposed by over 20 national health professional organizations including the Royal College of Physicians and Surgeons of Canada, Canadian Nurses Association, Canadian Psychiatric Association and Canadian Medical Association, came into effect on June 30, 2012.[20]

96.6 % of survey respondents indicated that the Canadian government has historically perpetrated forms of injustice, including colonialism, discrimination, and segregation. It is widely agreed that the gender role of Aboriginal women shifted dramatically as a result of the imposition of Eurocentric governance systems and social values, with the Indian Residential School Systems being one of the most damaging elements of colonial rule for Aboriginal peoples. Generations of children were separated from their families, communities, cultures and languages and placed in boarding schools, where many suffered mental, emotional, physical and sexual abuse.[21] The brutal legacy of Residential Schools and colonial practices live on through what the literature calls "intergenerational or historical trauma", a cycle of violence whereby survivors become perpetrators that lead to a host of social problems and negative coping behaviours within Aboriginal communities, including violence, sexual abuse, neglect and substance use. The reserve system's overcrowded and inadequate housing and the social and economic isolation of Aboriginal peoples have further led to increased exposure to HIV by reducing access to health and education resources. Damaged cultural identities, like loss of language,

tradition and family connection, result in poor mental health.[22] Aboriginal women are reported to be three times more likely than non-Aboriginal women to experience some form of intimate partner violence and are eight times more likely to be killed by their partners after separation. Results from the Nunavik Inuit Health Survey indicate that one in two women experienced sexual abuse or attempted sexual abuse in childhood and one in four women experience sexual violence in their adult lives. Statistics on sexual violence against women in the territories report rates from three to 14 times higher than the national average, with Aboriginal women being twice as likely as non-Aboriginal women to be sexually assaulted by their intimate partner.[23] Physical and sexual violence contribute to damaged self esteem, internalized blame, negative body image, suicidal thoughts and attempts, lack of self care, anger/resentment/sense of betrayal, and addictions/involvement in the sex trade.[24] Lack of adequate training for service and health care providers can contribute to additional racism, sexism and stigma and discrimination against HIV-positive people. These factors can contribute to increased vulnerability and exposure to HIV, as well as a distrust of systems that can lead to late diagnosis at the AIDS stage, to sub-standard health care, and, in some cases, to death without ever having been diagnosed. Finally, being HIV positive leads Aboriginal women to increased exposure to further violence, including legal threats, stalking, intimidation, and physical abuse. [25] Lastly, systemic racism has an immense impact on Aboriginal women. Many researchers attribute the higher levels of non-spousal violence against Aboriginal women to systemic racism and sexism. The perception of Aboriginal women as easy targets and as 'disposable' people — a view reinforced by socio-economic marginalization and sexist, discriminatory policing — has been linked to the increased risk of violence in and around urban centres.[26]

To compound matters further, provincial laws on matrimonial property cannot be applied on reserves because reserves fall under federal jurisdiction, often resulting in the denial of property rights to women living on reserves. This legal gap can mean a wife is forced off a reserve if a relationship breaks up or if her spouse dies. Moreover, perpetrators of abuse are rarely permanently or even temporarily removed from the home by the Band or police and victims of abuse are forced to flee, typically with their children.[27]

As a result of all of the above, while Aboriginal peoples in Canada account for one of the fastest growing segments of the Canadian population, First Nations, Inuit, and Métis lag behind national averages in all of the major indices for health and wellbeing. Aboriginal peoples face significantly shorter life expectancy rates compared to the national average. Health Canada reports that infant mortality rates among First Nations are twice the national average, while the mortality rate among Inuit newborns is four times the national average. In the field of education, 33% of adult Aboriginal peoples lack a high school education, compared to 13% for non-Aboriginal adults. When it comes to accessing post-secondary education, only 51.1% of Aboriginal people have received education beyond high school, compared to 75.4% of non-Aboriginal Canadians. There is a corresponding widening of the employment gap between Aboriginal and non-Aboriginal Canadians from 3.5 to 4.8 percentage points. A 2009 Library of Parliament statistical profile of poverty in Canada reports the gap in per capita annual income between Aboriginal and non-Aboriginal Canadians is $12,000.[28]

Meanwhile, budget cuts to Aboriginal health groups in Canada are curbing Aboriginal leadership in confronting epidemic levels of diabetes, hypertension, HIV/AIDS, substance use, depression, and suicide, while reasserting government power over Aboriginal health policies and services. In late March 2012, Canada's federal government announced the termination of funding for the First Nations Statistical Institute, the Pauktuutit Inuit Women of Canada, the National Centre for First Nations Governance, the Aboriginal Healing Foundation, and the National Aboriginal Health Organization (NAHO). Since then, the federal government has also cut health grants to the Native Women's Association of Canada, the Métis National Council, the Congress of Aboriginal Peoples, the National Indian & Inuit Community Health Representatives Organization, and Inuit Tapiriit Kanatami. While curbing Aboriginal leadership in health governance, the Canadian federal government is revising legislation to allow it to check Aboriginal economic and legal power, is aggressively expediting exploitation of oil and minerals on lands claimed by Aboriginal groups, and is increasing spending on military projects in the Arctic.[29] Oil extraction and pipelines everywhere not only degrade the environment, but also often precipitate increased rates of sexual violence, sexually transmitted infections including HIV, sex work, and human trafficking.[30]

Other groups impacted by historic and ongoing forms of injustice identified by online survey respondents are newcomers, including Japanese immigrants during World War II, Chinese immigrants, members of the African diaspora in Canada, including 19th century slave refugees; women generally; French Canadians; HIV-positive people through criminalization of non-disclosure; differently-abled people; LGBT community members; Canadians of lower economic

status; sex workers; drug users; and people with mental health issues. Respondents indicated that this has contributed to vulnerability and/or prevalence to HIV through marginalization, damaged self-esteem, loss of culture and stigma, leading to poor determinants of health, which contribute to poor health and poor health outcomes.

A landmark legislative ruling for people who use substances across Canada was rendered on September 30, 2011 when the Supreme Court of Canada, in a unanimous decision, opened the door to supervised drug injection clinics across the country in a decision that ordered the federal government to stop interfering with Vancouver's Insite clinic.[31] The eventual impact of this ruling on improved policies and programmes across Canada could be transformative for women who use substances.

> *"[W]ithout policies in place to protect these basic rights to healthcare and housing, treatment for addictions, many succumb to despair and addictions. As an example: we have very young women who lack all of above; lose their children to the child protection system, then those children begin the same life of poverty, lack of opportunity, disconnection from family and community; the cycle repeats and deepens as we fail one generation after another."*

As it relates to the protection of women engaged in sex work in Canada, the activities surrounding sex work remain illegal while sex work itself is legal. This has implications for sex workers' ability to negotiate and practice safer sex as well as access health services. While in early 2012 the Ontario Court of Appeal partially upheld a lower court ruling that struck down Canadian criminal provisions that place unconstitutional restrictions on sex workers' ability to protect themselves, the federal government has appealed that ruling, bringing the case to the Supreme Court of Canada.[32]

For Canadian women's protection from violence and provision of services to women affected by violence, survey respondents ranked the federal government's performance poorly. This is supported by our literature/media review findings. For example, the 2006 decision to cut funding to Status of Women Canada (SWC) also compelled the redrafting of the remaining SWC funding criteria to make women's service providers such as rape crisis centres ineligible for funding.[33] When the federal government renewed funding for the Native Women's Association of Canada's Sisters in Spirit project, which involved in large part a national database tracking cases of missing and slain Aboriginal women to expose this violence, the organization was forbidden from continuing to compile the database.[34]

> *"To date I still experience discrimination in the community I live. I feel a lot of frustration that it is not dealt with fairly by the government. I would like to see more programs that decolonize my perspective."*
>
> *"Inequality feeds vulnerability."*

Of the more than 130 people criminally charged for HIV non-disclosure before sex in Canada, 15 are women living with HIV. Although charges are often framed by prosecutors and the media as a way to protect women from 'predatory' men living with HIV, there are potentially dangerous ramifications for HIV-positive women, especially those in relationships involving domestic violence, who may fear leaving their partners for fear of retaliatory criminal prosecution — even when they have disclosed their HIV-positive status to their partners. A major HIV non-disclosure case is awaiting a Supreme Court of Canada decision.

> *"The criminalization of HIV has decreased the number of women testing for HIV."*

Online survey respondents gave a poor grade for ensuring access to female-initiated prevention methods like the female condom. Respondents gave better grades for respecting, protecting and fulfilling women's rights to make decisions about their bodies for HIV testing, initiating HIV treatment, and breastfeeding. However, as elucidated in the Diagnosis and Treatment section the evidence reveals a lot of variation in informed HIV testing across Canada and HIV treatment initiation remains a serious challenge for some marginalized communities of women. Also, First Nations women on reserves with boil water advisories, both HIV-positive and negative, are forced to breastfeed their children.

Survey respondents were also divided on performance related to women's choice for safe abortions. A factor influencing this split may be that, while abortions remain legal in Canada, in April 2012, Kitchener Member of Parliament (MP) Stephen Woodworth decided to ask for a special parliamentary committee to discuss the definition of a human being. The Conservative MP takes issue with Section 223 of Canada's *Criminal Code*, which states that human life begins when a child emerges from its mother's body.[35]

"Reinstate funding for the Status of Women. Reinstate the funding for refugee health. Reinstate funding for Planned Parenthood. Revise [the] policy which presently disallows any Canadian funds being used to support intentional organizations that support abortions."

Lastly, there were split grades on the topic of federal, provincial and territorial governments ensuring access to sexual and reproductive health information and services. The federal government has published since 1994 *Canadian Guidelines for Sexual Health Education* with revisions in 2003 and 2008 and in 2011 published "Questions & Answers: Sexual Orientation in Schools", as a result of feedback from a national evaluation of the sexual health guidelines. However, implementation at the provincial and territorial levels is likely uneven and unequal.

Recommendations from online survey respondents:

- Encourage more female political leadership by running more female candidates from diverse backgrounds
- Develop and implement women, young women, children, trans-positive policies and legislation
- Fund non-profit organizations that support diverse women's health
- Encourage and expand supervised injections sites to communities in need across Canada
- Re-instate funding for Aboriginal health organizations
- Expand free, anonymous sexual and reproductive health clinics with information and prevention tools, including condoms and female condoms
- Fund programs addressing mental health, addictions, trauma
- Support approaches that address underlying factors to prevent domestic violence and violence against women
- Develop prosecutorial guidelines to limit prosecution in cases of alleged HIV non-disclosure
- Decriminalize sex work and drug use
- Re-instate funding to organizations and research bodies addressing these issues
- Implement better access to existing harm reduction measures in corrections and across the country and expand access to harm reduction measures, such as needle and syringe programs and safer tattooing, which do not currently exist in prisons
- Improve determinants of health like national housing, child care and education strategies, support for more economic opportunities and skills development for diverse women, young women and trans people
- Fast-track treaty negotiations and land claims, while treating First Nations and Inuit as sovereign nations with control over water, mineral, oil rights

"ACTIONS SPEAK LOUDER THAN WORDS."

"Get women involved in developing programs that serve them accordingly which are also accessible and culturally appropriate. More funds should be allocated for the development of services for women, that are sustainable."

"Acknowledge the difference[s]."

"Listen to those living with it and their lived experience. Ensure HIV-positive women, women, [young women] and trans women are integral in the discussion."

RESEARCH **C grade**

Survey respondents gave better grades to federal funding and support for HIV/AIDS prevention, treatment, care and support research related to women, young women, girls and trans. This is supported by some, but not all, evidence. As the government agency responsible for funding health research, The Canadian Institutes of Health Research (CIHR) continue to carry out and support research initiatives that are of direct benefit to women and their communities. Since 2004, the CIHR HIV/AIDS Community-Based Research Program has been supporting "research that engages communities in all stages of research, from the definition of the research question, to capacity building and integration of community members in conducting research, to active participation in disseminating research results." CIHR also valorizes and promotes knowledge translation and exchange, by ensuring that research be made relevant and accessible to knowledge users through different funding opportunities. Since 2007, funding has been made available for the organization of "Café scientifiques," events that bring together researchers and the public to discuss health-related research in an informal setting.

One of CIHR's thirteen institutes, the Institute of Gender and Health (IGH) "is the first, and remains the world's only, health research funding institute with a specific focus on gender, sex and health." The IGH supports the integration of a gender lens in CIHR activities, while funding related research. In 2009, the IGH funded three Canadian Centres for Research Development in Gender, Mental Health and Addictions, and in 2011, it partnered with the CIHR Institute of Infection and Immunity's HIV/AIDS Research Initiative to fund six research teams to examine and address the links between gender, violence and HIV. The appointment of Dr. Nadine Caron to the Governing Council of CIHR in 2011 also deserves recognition, given "Dr. Caron's unique perspective and commitment to Aboriginal, rural, northern and remote health issues."[36]

According to the Public Health Agency of Canada's "Population-Specific HIV/AIDS Status Report – Women" released in spring 2012, 87 HIV/AIDS women-specific research projects were underway from 2006 to 2009.[37] 56.3 % focus on HIV prevention, interventions, and/or treatment strategies and their effects.[38] Four projects look at a specific intervention initiative, and nine others investigate HIV risks or barriers to prevention and/or treatment. 11 studies are biomedical, focusing on factors related to the physical transmission and susceptibility of women to HIV infection. Of the 87 projects identified in the research inventory, 79.3% study women from specific groups living in Canada, including women living with HIV (49), women involved in sex work (14), women from immigrant or ethnocultural communities (8), Aboriginal women (First Nations, Inuit and Métis) (8), women who use injection drugs (6), female youth (5), lesbian/two-spirit/and women having sex with women (3), trans people (2), and women in prisons (1).[39]

The Public Health Agency of Canada was a co-funder of Towards the Development of a Coordinated National Research Agenda for Women, Transwomen, Girls and HIV/AIDS in Canada: A Multi-Stakeholder Dialogue at the 2011 Canadian Association of HIV Research Conference (CAHR) and Gathering of Spirits: Canadian Women, Trans People and Girls' HIV Research Collaborative meeting at CAHR 2012. This should be highlighted as a positive step on the part of the federal government, with regard to supporting the participation of multiple stakeholders in research, including women who are living with HIV and their communities.

Devastatingly, Health Canada announced the end of the WHCP as of March 31, 2013. The WHCP supported Le Réseau québécois d'action pour la santé des femmes, the Canadian Women's Health Network, the Atlantic Centre of Excellence for Women's Health, the British Columbia Centre of Excellence for Women's Health, the Prairie Women's Health Centre of Excellence and the National Network on Environments and Women's Health.[40]

HIV research often neglects to consider the experiences of trans people. Trans women, for example, are lumped into the men who have sex with men category, despite the fact that they are women, and many of them do not necessarily sleep with men. This kind of research therefore obscures the realities of trans people.[41]

Survey respondents gave poor grades for inclusion of HIV-positive women on federal government-associated research ethics boards, and disseminating findings in a linguistically and culturally appropriate fashion. Respondents were divided on the grade for federal government support of research initiated and led by women.

Recommendations from Survey Respondents and PHAC's Women's Status Report:

"Research results need to be disseminated more widely. There may be some excellent research being undertaken by different institutions on women and HIV but we are simply not aware of it."

"More research should be funded and conducted that is women specific to address some of the challenges faced by aging HIV positive women and all the side effects faced by women of ART."

"Some research is happening which highlight all of the themes of participation above, however it is still underfunded and insufficient to the scope of need and the diversity of communities."

"[T]he process of applying for research grants in itself [is] a barrier…You need a masters degree before they will even look at you."

- Invest in capacity building and resources for community organizations generally and for Aboriginal communities specifically, including First Nations, Inuit and Métis from urban, rural and remote areas, to apply for and engage in research, and encourage greater flexibility to include culturally relevant expertise, such as Elders
- Improve community outreach that is meaningful and authentic, including to marginalized women
- Fund more research to address intersections between HIV and mental health

- Implement research results to improve responses
- Fund implementation research
- Involve more culturally and community-representative, academically fluent women in reviews
- Support young women's and girls' research involvement through academic settings
- Fund more research efforts initiated by and led by HIV-positive women and relevant communities
- Fund more research on cross-populations and heterogeneity within populations
- Fund more intersectionality research
- Fund more research on older women, both HIV-positive and negative
- Fund more research on sex work outside of Vancouver's Downtown Eastside
- Fund more research to identify and analyze gender and culturally appropriate approaches to HIV/AIDS prevention, care, treatment and support, specific to the needs of diverse groups of women

"As[k] us and us[e] the GIPA principles."

"More community-based research to include women who are positive as co-investigators."

"[S]tart putting things into action. You have researched things to death. Some people don't have time to wait."

STIGMA AND DISCRIMINATION **D- grade**

Respondents to the online survey gave poor grades to the federal government's addressing of stigma and discrimination faced by HIV-positive women and women from vulnerable groups including Aboriginal women, sex workers, female substance users, incarcerated women, female newcomers, trans women, co-infected women, women in rural/remote/isolated areas, women with disabilities, and female seniors living with HIV. They also graded poorly federal government stigma and discrimination campaigns and resilience programs; harm reduction services, including for incarcerated women; encouragement of workplace policies addressing stigma and discrimination; and resourcing programs to address stigma and discrimination resulting from historical and ongoing colonization of Aboriginal peoples in Canada.

Recommendations from Survey Respondents:

- Carry out public and stakeholder legal education and make legal services more accessible to promote the use of policies and laws that protect the rights of people living with HIV/AIDS who are discriminated against by health professionals
- Support effective programme development and promotion and effective dissemination of policies related to stigma and discrimination to all relevant stakeholders
- Increase HIV/AIDS education in First Nations and support for HIV-positive people and their families in First Nations
- Create safe homes/places in rural and remote Aboriginal communities
- Develop promotional materials and public education campaigns addressing stigma and discrimination using culturally and linguistically relevant, strengths-based approaches, which enhance inherent capacities of individuals and communities

"I am unaware of any promotion of policies that address discrimination and stigma for these groups. If it exists, it is plainly out of view for health workers like myself."

"I would say in all of the cases above the federal government has shown zero leadership in these areas. The only reason women and the issue of stigma is being addressed is because non-profit ASOs and women's organizations have done this themselves with little, to no, financial support from government."

"The stigma is still so huge many do not disclose their status, refuse to get tested, live their lives in secrecy and are reluctant to access appropriate care."

"The government cut ALL funding to the Aboriginal Healing Foundation...the only national body addressing healing from the effects of residential schools and this was done shortly after their 'apology'."

DIAGNOSIS AND TREATMENT **C− grade (Diagnosis) C− grade (Treatment)**

It is currently estimated that approximately 26% of HIV positive individuals in Canada are unaware of their status, a number that highlights the existence of continued barriers to HIV testing in the country.[42] Research reveals many cases of women not being offered or being denied an HIV test by their health-care provider, who assumed that they were not at risk for HIV.[43] In addition, there is significant variation across Canadian jurisdictions in accessing anonymous and rapid testing, as well as perinatal testing policy (opt-out or opt-in). Access to these types of testing is not universal in Canada.[44] Access is often limited or non-existent in smaller towns, rural or remote areas. Frequent examples have surfaced of

women being tested perinatally under the opt-out model without proper information, without understanding that they had the option to refuse testing, and in some cases, without knowing that they were being tested in the first place. The prenatal testing strategy in Ontario has revealed that the opt-in model can still reach a majority of pregnant women. In this province, various interventions have been used to increase the uptake of prenatal testing, including the development of counselling checklists for physicians, a multi-media campaign to educate the public, and memos sent to doctors when an HIV test had not been ordered.[45] In 2009, Ontario screened 97.6% of women perinatally using the opt-in strategy, while Alberta in 2006 tested 97% of women using the opt-out strategy.[46] This demonstrates that opt-in perinatal testing is not a barrier to testing, as many argue.

Service providers highlight the fact that testing is not always accompanied by adequate pre- and post-test counselling in Canada, if at all. When counselling is carried out, it may not be tailored to the linguistic, cultural and experiential specificities of the person being tested.[47] Recently, in Canada and internationally, there has been some movement away from the "three Cs" consensus [consent, counselling and confidentiality]. Calls for "routine testing" and "opt-out testing" have made reference to the need to "scale up" testing in order to get more people to know their HIV-positive status and onto treatment because HIV treatment both improves the health of people living with HIV and prevents new infections by reducing HIV risks of transmission.[48] The British Columbia Seek and Treat for Optimal Prevention of HIV/AIDS (STOP HIV/AIDS) program is an example of this approach in Canada. Human rights advocates have contended that this approach may lead to unintended rights violations, including the right to privacy in terms of one's medical records.[49] The federal government has been working on new testing guidelines to address many of these concerns, and they are due to be published soon.

Fears of confidentiality breaches and ensuing stigma and discrimination is worse in smaller urban centres, small towns, rural areas, and remote/isolated communities, as well as tight-knit ethno-cultural and Aboriginal communities.[50] While the majority of women in prison are voluntarily tested for both HIV and HCV, the provision of pre- and post-test counselling has been reported to be poor, and in some cases, non-existent.[51] Women in prison have concerns about the privacy and confidentiality of their HIV status. Survey respondents also felt that health care professionals needed compulsory training in HIV testing.

> *"[S]ome doctors call…people on the phone and tell them that way… "[Y]ou have it[,] your d[y]ing."*

The shame, stigma, and discrimination associated with the disease leads to the perception among some women that an HIV diagnoses is something they would be better off not knowing. This in turn can serve to limit access to and uptake of HIV testing services, timely diagnosis, and early access to treatment for those who are found to be infected. Some HIV-positive women indicate problems with male partners after an HIV diagnosis. Women describe verbal, psychological or physical abuse, which either followed or was aggravated by disclosure of their HIV status to their partners. Women also describe difficulties accessing HIV-related support services because of opposition from their partners.[52] Almost all of the participants mentioned the importance of a strong support system to assist HIV-positive individuals to adapt to and accept their diagnosis.[53]

Recommendations from Survey Respondents (Diagnosis):

- Institute compulsory education for health care providers about women, young women, girls, trans people and HIV
- Better enforce pre and post-test counselling for all women, young women, trans people
- Fund more support that address the range of needs for women, young women, trans people testing HIV-positive
- Develop and provide adequate training for mental health providers to work with HIV-positive women, young women and trans people
- Develop and provide culturally appropriate programs and cultural sensitivity programs in health care systems, for example access to Elders and traditional healers for the sick and dying needed for many Aboriginal peoples

Survey respondents gave poor grades to implementing treatment programs addressing the needs of women from marginalized communities including Aboriginal women, sex workers, substance users, incarcerated women, newcomers, trans people, women in remote/isolated communities, women with disabilities, seniors and cross-populations. Key issues were the lack of clean water and food security in remote/isolated communities; poor performance at addressing access and adherence issues caused by poor determinants of health; inadequate approach to addressing treatments for accelerated aging; the need to establish viable partnerships between First Nations, Inuit and Métis communities, governments and other stakeholders – both on and off-reserve - to ensure access to a range of

culturally and linguistically-appropriate health services; the need to establish regulations requiring pharmaceutical companies and researchers to demonstrate whether and how treatments differentially affect women and men as a condition for both market approval, and listing on government formularies. There was some division on whether HIV treatments and treatment programs are adequately funded, available and accessible because this varies between jurisdictions and drug plans since treatment access is not universal in Canada.

Women, particularly from marginalized communities, find few safe and nonjudgmental places for themselves and their children to access treatments and care. They struggle to cover basic needs and may be unable to afford treatments. They worry about and experience discrimination, as do their children, including from their families and communities. They need support systems, [54] yet there are only two women's-specific AIDS service organizations in Canada.

As of June 30, 2012, changes to the Interim Federal Health Program reduced health coverage for refugees, restricting medical care to services necessary to protect public health or public safety. In particular, refugees will lose treatment for angina, diabetes, psychoses and psychiatric disorders (unless they may harm others if untreated) and post-traumatic stress disorder.[55]

The majority of HIV-positive Aboriginal women in a study interpreted 'health services' as involving more than strictly physical or medical health needs, describing holistic visions of health and healing.[56] A lack of accessible, culturally sensitive care presents a significant barrier to obtaining health services for many Aboriginal people living with HIV/AIDS. Researchers argue that stigmatization and barriers to service experienced by Aboriginal women push them into a position of "extreme isolation." Community rejection, systemic racism, sexism, socio-economic marginalization, and a history of trauma and gender subordination related to colonialism have placed them in a position of extreme marginality.[57] As mentioned earlier, federal funding has cut dozens of Aboriginal health bodies.

> *"[O]n reserve, we are bound by the federal non insured health benefits program which conflicts with confidentiality needs; e.g. a woman must submit reason to travel to out of town medical appointments to get funding thus the clerk in the health center learns of her status."*

Lesbians with HIV continue to be a hidden and isolated population, and despite attempts to include greater numbers of HIV-positive lesbians in research, few come forward. Those who did, however, spoke poignantly about HIV-related stigma and the resulting social marginalization and isolation.[58] Trans people living with HIV/AIDS may face particular challenges and issues. Again, the scarcity of information is problematic. Little is known about the interactions between the hormones used by trans people and antiretroviral treatments. In addition, finding comprehensive health care is rendered more complicated for trans people living with HIV as it becomes harder to find doctors competent in both types of care. Lack of awareness of trans issues, lack of policies and administrative guides, uneasy relationships with health care systems due to inability to access needed care and/or stigma and discrimination by providers, barriers to accessing employment, racialization and intersecting marginalizations, violence and criminalization all negatively impact trans people.[59]

Globally, Canada's ability to promote treatment access to people in developing countries was hindered when a bill to streamline Canada's *Access to Medicines Regime* (CAMR) died on the Order Paper when Parliament was dissolved and the 2011 federal election was called. While the law was supposed to help get lower-cost, generic medicines to people in developing countries, developing countries and generic drug manufacturers have complained that the current regime is too cumbersome and difficult to use.

Recommendations from Survey Respondents (Treatment):

- Fund support services for women who are told they should start ARVs, including peer support groups, retreats, peer support staff
- Fund treatments that address side effects, including lipodystrophy
- Promote and enforce policies that ensure confidentiality, including for women living on reserves and needing to travel to access care, concerning HIV testing, diagnosis and treatment
- Create policies to address adherence and continuity of care issues for diverse women
- Fund on-reserve education, care and support programs
- Support the treatment access and adherence needs of those living with addictions
- Through meaningful consultation, develop and fund culturally appropriate services, including more information to

vulnerable populations such as women living on reserves, sex workers and substance users

- Support resources for the very isolated, rural and remote communities
- Reform Canada's *Access to Medicines Regime* to promote treatment access to those suffering and dying in developing countries

> *"Listen to the people, believe it or not the people have lots to say."*

PREVENTION & HIV EDUCATION **C– grade**

Survey respondents gave a better grade to ensuring access to information on healthy child development. However, poor grades were assigned to provision of cultural, linguistic and age appropriate HIV/AIDS education in school curricula; incorporation of women's sexual and reproductive health and rights into prevention and education programs; development of proactive strategies related to female-initiated prevention methods; ensuring prevention education and prevention methods are readily available and affordable for women, including those from the most vulnerable and marginalized communities; ensuring access to adequate housing; and developing and delivering culturally and linguistically appropriate prevention and education strategies and programs for Aboriginal peoples in Canada.

HIV prevention research must actively involve women living with or affected by HIV from diverse communities. HIV prevention policies need to be more inclusive of women's unique experiences. There is a need for greater recognition of the complexities of women's lives and identities and the cumulative impact of race, class, age, immigration and colonialism on the unequal distribution of HIV in Canada. There is also the need for a systematic, concerted effort in policy responses at the local, provincial and national level in a manner that will foster solidarity and cohesion. According to " HIV/AIDS Prevention for Women in Canada: A Meta-Ethnographic Synthesis", there is a lack of accessible and appropriate prevention information for diverse communities of women in Canada, and it is crucial that responses to the HIV/AIDS epidemic among women begin with an understanding of the unique social, cultural and economic issues facing them.[60] Safer sex education and HIV-prevention materials and resources often fail to address the needs and realities of trans people by using language that alienates and excludes trans bodies and lives. There are very few safer sex resources that are created by and for trans people and that address their unique experiences.[61]

Also, it must be noted that as the STOP HIV/AIDS Project proceeds, British Columba is simultaneously closing five sexual health clinics, leaving huge areas of the province without any sexual health services.[62]

> *"I comment only for ABORIGINAL WOMEN to the above statements as this is the community we serve; we have huge needs and remain grossly underfunded to provide assistance."*
>
> *"Very small non-profit orgs are going into communities and schools to educate on HIV/AIDS. Northern BC does not have adequate information/resources."*

Recommendations from Survey Respondents and "HIV/AIDS Prevention for Women in Canada":

- Adopt national standards for HIV prevention education in all Canadian schools
- Provide sustained investment and develop programs in rural, remote and isolated communities, including on-reserve
- Develop funding initiatives related to determinants of health such as housing, food security, and other prevention strategies that move beyond an individual, behavioural focus to include structural and environmental interventions
- Fund resource centres for women's health
- Enhance evaluations of what is working and what is not, with greater emphasis on the uniqueness and diversity of women's HIV prevention experiences and needs
- Move away from the use of generic prevention messages for 'women' and towards specific messages and vehicles understanding women as heterogeneous in HIV prevention programming and policy
- Capitalize on existing community institutions and strengths such as the church for women from the African diaspora
- Provide youth with accurate, practical information about sex from informed, non-judgmental teachers and service providers

> *"I think there should be standardized minimum HIV prevention education in all the schools. There is too much ignorance about HIV among high school students."*
>
> *"Education is needed at all levels and needs current education tools and resources. This is very lacking in the Aboriginal isolated, rural, and remote communities. We need to have activities to work on prevention. Youth need to do activities where there is nothing to do."*

CARE AND SUPPORT **D grade**

Survey respondents gave poor grades to the incorporation of the following into care and support programs: addressing the multiple and often competing roles of women; risk factors faced by diverse women when seeking care and support; cultural and linguistic approaches to care and support. They also gave poor grades to addressing voluntary care and support services provided by women to people living with HIV/AIDS (PHAs).

> *"Why should women volunteer to do this? Don't they deserve some income?"*
>
> *"Impossible to access mental health care, [zero] peer support funding."*

Many women require services in female-friendly environments where children are welcome. Larger social structural issues such as unemployment, lack of housing, poverty, childcare, lack of information and lack of support contribute to HIV-positive women's isolation and inability to access local resources for support. Women from diverse populations and cultures indicated experiencing various levels of social isolation. Isolation of caregivers is a consequence of the continuing stigma attached to HIV/AIDS in Aboriginal communities. Counselling and support for caregivers are almost nonexistent.[63] Meanwhile, the current federal government' $100-a-month universal child benefit is not an adequate substitute or a realistic alternative for impoverished mothers, especially single ones, who need to work to support their families.[64] While AIDS service organizations (ASOs) are funded to provide care and support, more women's programs are needed. In Canada, there are only two women-specific ASOs, one in British Columbia and one in Quebec.

Recommendations from Survey Respondents:

- Address the determinants of health, social services, peer support groups and women's unique needs like child care
- Fund care and support of diverse women that addresses multiple, competing roles, risk factors, culturally and linguistically appropriate care/support
- Develop better supports for women volunteering to provide services to PHAs
- Create safe environments for all women experiencing trauma, including and particularly Aboriginal women
- Provide more support resources to reach rural, remote and isolated communities

> *"[B]est practice is demonstrated by agencies like Positive Women's Network, Oak Tree Clinic, Chee Mamuk from BCCDC, Native Health Society Vancouver, having support groups, peer networks, retreats, funding support for rural women to participate, housing subsidies."*
>
> *"I often hear from Aboriginal people living with HIV about them feeling comfortable coming in to an Aboriginal organization [with] Aboriginal staff."*
>
> *"Re-fund Voices of Positive Women in Ontario."*
>
> *"Find out what their living situations are. Whether they are trapped in an abusive relationship, unable to eat themselves, to feed their family, unable to meet financial obligations. These all contribute to poor mental health for women. Mental health of HIV positive women is very much an unspoken problem."*

OVERARCHING DEMANDS **C grade**

Survey respondents gave poor grades to resourcing the domestic HIV response for Aboriginal women, sex workers, substance users, incarcerated women, newcomers, trans people, co-infected women, seniors, and young people. It is important to note that Health Canada renewed, at the same level of $72.6 million, the *Federal Initiative to Address HIV/AIDS in Canada*. However, the *Federal Initiative* has never been resourced to the full original $84.4 million commitment. Also, as mentioned previously, many other groups serving the needs of women vulnerable to, infected by and affected by HIV have had funding cut.

Recommendations from Survey Respondents:

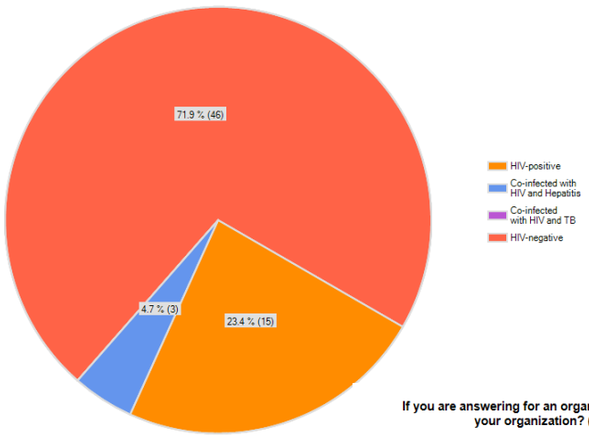
- Better resource harm reduction and support harm reduction policies, laws and programmes
- Develop Aboriginal health agreements
- Ensure that HIV issues remain important, requiring special focus
- Consult with stakeholders such as national and local AIDS organizations
- Resource and implement the *Federal Initiative to Address HIV/AIDS in Canada* as it stands and as it may be revised in future

> *"There needs to be a revisioning done to look at why these challenges still exist, and relook at the strategy itself to see what is working and where can we build on those successes."*

Appendix 1: Online Survey Overview of Respondents

TOTAL # OF RESPONDENTS WHO COMPLETED PART OF THE SURVEY = 86;
ALL OF THE SURVEY = 51

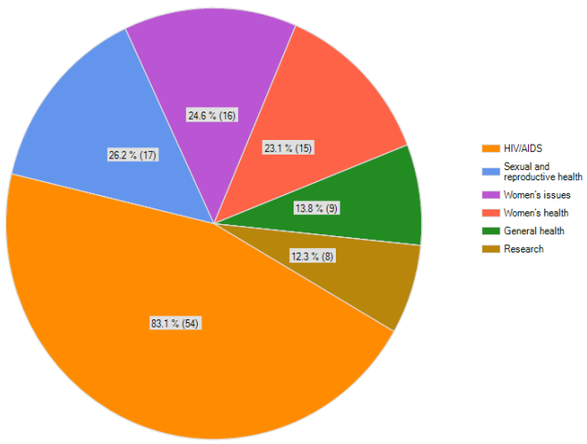
If you are answering as an individual, what is your HIV-status?



Other Answers to HIV-Status:

- Was Hep C+ but no longer am
- Was co-infected with Hepatitis C for many years, did treatment, cleared
- Negative, but lived with Hepatitis C and have been in the HIV movement for 13+ years

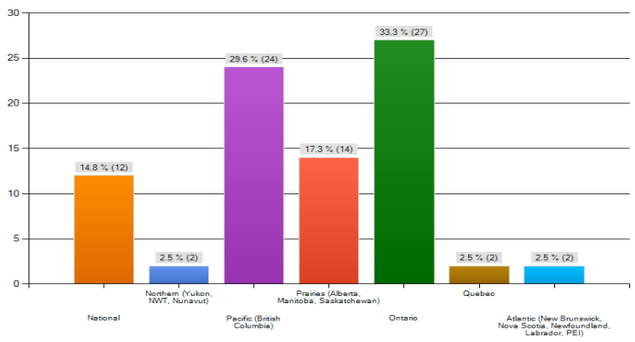
If you are answering for an organization, what is the principle mandate of your organization? (Please check all that apply.)



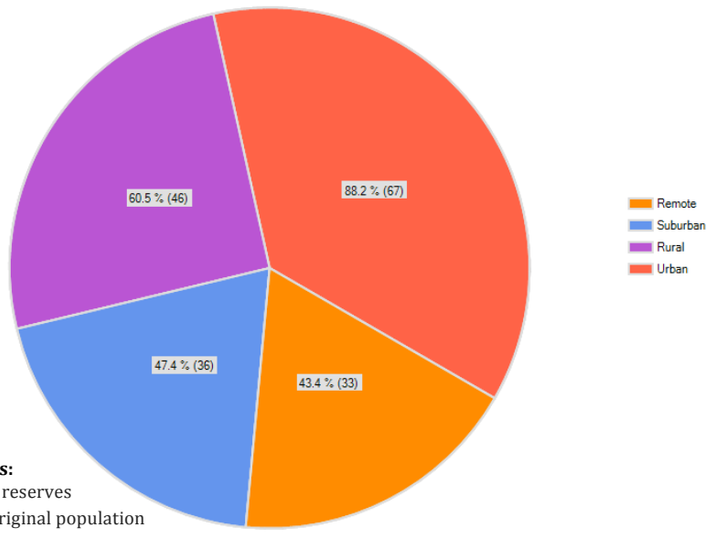
Other Answers to Mandate:

- Public health
- Harm reduction
- Community health from a harm reduction perspective
- First Nations and Aboriginal Community Health Centres
- Shelter; Shelter for Aboriginal women & children
- Aboriginal off reserve
- Hepatitis C
- Education
- Transgender/Transsexual health (primarily working with trans women)
- Human rights
- Pediatrician in HIV clinic

What region(s) of Canada does your organization serve? If you are an individual, what region do you live in? (Please check all that apply.)



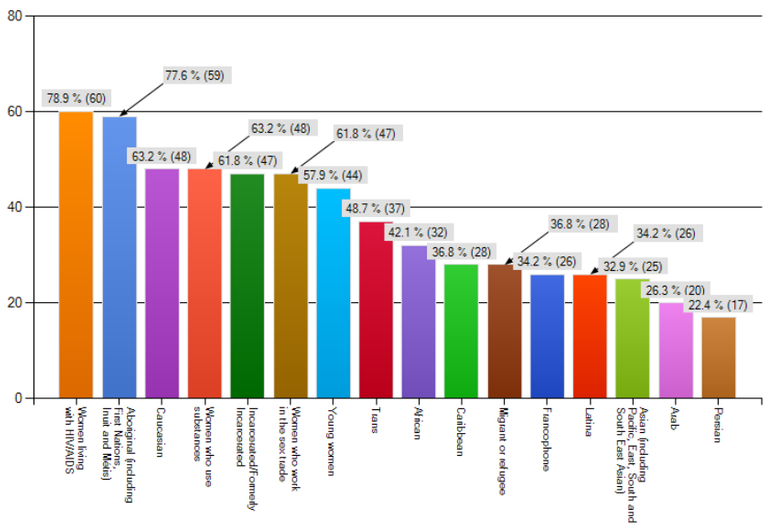
Which of the following populations does your organization serve? If you are an individual, where do you live? (Please check all that apply.)



Other Answers:

- First Nations reserves
- Isolated, Aboriginal population
- All
- Primarily urban, but as one of few trans specific resources, we are contacted by people throughout the province
- Downtown Eastside Vancouver
- Small town/city

Which communities does your organization serve? If you are an individual, which of the following communities do you identify with? (Please check all that apply.)



Other Answers:

- Health professionals, academics and researchers
- I work at a regional HIV/AIDS clinic that provides care to HIV-positive children and adults representing all communities listed above
- People that use drugs, and the community organizations that work with them
- All people living with HIV in Ontario
- Co-infected HIV/HCV, HIV/HBV community
- Street involved

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[34] Ibid.

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[37] Public Health Agency of Canada. Population-Specific HIV/AIDS Status Report – Women. 2012. Page 81.

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[39] Ibid. Pages 84-85.

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