

Women & HIV

This is one in a series of four info sheets on the human rights of women living with or vulnerable to HIV in Canada.

1. Women in Prison, HIV and Hepatitis C
2. Women and the Criminalization of HIV Non-Disclosure
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Women and HIV Testing

“I was given a requisition form with all manner of other tests on it. I recognized my test for thyroid, and I think maybe one or two other tests on it. And I did notice written in ‘HIV,’ which I didn’t question or ask why because I was just assuming it was mandatory at that point.”

— Testing experience of a pregnant woman in Canada¹

HIV testing for women in Canada

Since it was first realized that HIV could be transmitted from a mother to her child during pregnancy, labour and delivery, or through breastfeeding, women have been a central focus of HIV testing. If a woman is not pregnant or of childbearing age, however, she might not seek, or be offered, an HIV test. For many people, the perception remains that HIV predominantly affects men who have sex with men, people who use drugs, and newcomers from Africa and the Caribbean; therefore, other women may not be seen as at risk.

Yet many women are vulnerable to HIV infection and need access to high quality HIV testing and counselling that responds to their needs. HIV testing can and should be expanded, while promoting and protecting human rights in all aspects of the HIV testing process.

Early in the epidemic, it was recognized that HIV testing should be conducted in ways that took into account the widespread stigma and discrimination against people affected by HIV. Moreover, respecting and protecting people’s rights would be central to successfully implementing HIV testing programs.

A broad consensus therefore emerged that people should only be tested with their informed, voluntary and specific consent; counselling should be provided both before and after testing; and HIV testing should occur only when confidentiality can be guaranteed. Policies in Canadian jurisdictions generally reflected this consensus which came to be called “the three Cs” of HIV testing — consent, counselling and confidentiality.²

Recently, in Canada and internationally, there has been some movement away from the “three Cs” consensus.³ Calls for “routine testing” (i.e., including HIV testing in standard medical assessment without requiring specific consent) and “opt-out testing” (i.e., testing by default unless a person specifically refuses) 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). Calls for “routine testing” and “opt-out” testing also highlight the high resource-commitment required in order to provide pre- and post-test counselling to everyone who is tested, and that treating an HIV test differently from other tests may add to HIV-related stigma and hence deter people from being tested.⁴

However, models that respect the “three Cs” may still be more effective in the long-run response to HIV in Canada, and legal and ethical requirements favour ensuring informed consent, appropriate counselling and confidentiality. An effective HIV response requires more than just increasing the numbers of people who are tested. Moreover, HIV disproportionately affects marginalized people who face multiple barriers to accessing health services. A shift towards more coercive measures will not improve HIV testing among these communities and could hinder efforts to curb the spread of HIV by contributing to fear and stigma.

For women, this shift away from the “three Cs” can pose particular difficulties. Many women do not feel that they really can decline an HIV test when recommended by their health care provider, even if they would prefer to access a different type of testing (e.g., anonymous) or defer testing until they feel more ready to deal with the results and manage personal risks. The unequal power relationships between women and their doctors, as well as the desire to do what is best for their child (in the pregnancy context), limit many women’s ability to decline the test. Moreover, many women need time to consider it before consenting to an HIV test, which may not be possible in the short time allotted for a medical appointment. And if counselling in the pregnancy context focuses on the health of the child, not the woman’s own needs and risks, women may not be prepared for possible negative consequences of testing. As noted in one report, people “may agree to be tested because they are used to agreeing to health professionals’ requests, think that they will receive improved care, do not think they can decline, or have a diffuse sense that refusing would have adverse consequences.”⁵

While some research indicates that a proportion of women find HIV testing more accessible if it is routinized, similar to Pap tests,⁶ it is important to recognize that many women continue to face considerable barriers to testing, including many Aboriginal women, youth, women living in rural communities, women in prison, women from countries where HIV is endemic, and women in abusive or dependant relationships. HIV testing occurs in a social context marked by unequal gender and power relations and high levels of stigma. The public health objective of increasing testing cannot override the need to reduce women’s risks and vulnerabilities to HIV-related abuses.

A supportive and enabling environment is needed in order for many women to be able to make free and informed decisions about HIV testing. Negative consequences of HIV testing and fears of disclosure are more frequently documented for women and approaches to testing should prioritize addressing these gendered factors.⁷ If people are tested without being prepared, they may suffer negative outcomes (e.g., adverse psychological outcomes, inability to protect themselves from abuse if others discover their status), or lose confidence in the health care system, thus undermining their access to HIV prevention, treatment and care. Moreover, many women are tested for HIV during pregnancy, a time when they may require extra support. The significance of an HIV test is greater than the medical information that it provides. It can have a powerful impact on a person’s life and test results have meanings that are tied to relationships, faithfulness, trust, and specific roles such as mothering.⁸

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Stigma and fear remain important impediments to seeking HIV testing for some women. Aboriginal women and women from countries where HIV is endemic may be particularly concerned about HIV testing because of racism, insecure immigration status, fear of the reactions of members of their families or communities, unfamiliarity with the Canadian medical system, language barriers, fear that they will lose custody of or access to their children, distrust of government institutions, lack of information about HIV, and the inability to take time off from work and family responsibilities to attend to their own health needs. For some women facing these various challenges, alternative modes of HIV testing, such as anonymous or rapid testing, may be preferable.⁹

The “three Cs” of HIV testing: grounded in human rights principles

- HIV testing should only occur with specific **informed consent** voluntarily given. This requirement derives from the *right to security of the person*ⁱ — that is, to be able to control what happens to one’s body — as well as from the *right to information*,ⁱⁱ which is an integral part of the right to health.
- **Pre- and post-test counselling** of good quality gives effect to the *right to information* and is essential for both promoting the mental health of persons getting tested and protecting public health more broadly by helping to prevent onward transmission of HIV. Good-quality counselling is of particular importance for people who may not otherwise be able to get appropriate information on HIV.
- **Confidentiality** of results of medical tests, and of the fact of even seeking or having a test, derives from the *right to privacy*ⁱⁱⁱ and is a central element of ethical medical practice.

ⁱ *International Covenant on Civil and Political Rights*, 9999 U.N.T.S. 171, Article 9 [ICCPR]; *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act*, 1982, being Schedule B to the *Canada Act 1982 (U.K.)*, 1982, c. 11, at s. 7.

ⁱⁱ ICCPR, Article 19.

ⁱⁱⁱ ICCPR, Article 17; *Canadian Charter of Rights and Freedoms*, ss. 7 and 8.

HIV test results can also have important legal implications that may be of particular concern for women in dependant or abusive relationships or for those lacking confidence in governmental institutions. Positive HIV test results are reported to public health authorities. In most jurisdictions, public health laws give public health officials the power to inform the sexual and drug use partners of a person who has tested positive for HIV (known as “partner notification” or “contact tracing”). Certain coercive interventions may be implemented if deemed necessary to protect public health. People living with HIV can also be criminally prosecuted in Canada for not disclosing their HIV-positive status to sexual partners. Such serious consequences require women to be fully informed of the medical *and* legal implications of HIV testing.

Facts and figures:

- According to the most recent data available from the Public Health Agency of Canada, **11 403 women and 224 female children (less than 15 years of age) have tested positive for HIV in Canada.**¹⁰ Women represent an increasing proportion of the positive HIV tests performed in Canada, accounting for 26.2 percent in 2008.¹¹
- It is estimated that **26 percent of Canadians living with HIV are unaware of their infection** because

they have not been tested.¹²

- There are **three different methods of HIV testing** available in Canada: *nominal testing*, where the person’s name is associated with the test result and reported to public health authorities; *non-nominal testing*, where a unique code, rather than the person’s name is attached to the sample, which the health care provider who orders the test can use to match the result to the patient; and *anonymous testing*, where the test results are recorded and reported without revealing the name of the person who was tested. Non-nominal and anonymous testing, however, are not universally available.
- Standard HIV testing involves sending a blood sample to a laboratory for it to be tested for HIV antibodies. Results are available one to two weeks later. **A rapid HIV test can be done on a drop of blood from a finger prick. The testing is done at the testing site and the result is available in five to ten minutes.** If a rapid test returns a positive result, a second confirmatory test must be done to ensure accuracy of the results.
- HIV tests detect HIV antibodies, not the virus, in the blood. It takes time for a person’s body to produce antibodies to HIV, therefore there is a **“window period” of up to three months between the point at which a person is infected and the point at which the test will show an infection.** During the “window

period,” a person can test negative for HIV antibodies even though he or she is infected.

- All foreign nationals applying for permanent residence in Canada, and certain applicants for temporary residence, are required to undergo **an immigration medical examination**. The examination includes a question about whether the individual has ever tested positive for HIV. It also **includes an HIV antibody test for all persons over 15 years of age**.
- At least **five Canadian provinces have legislation** allowing certain people who may be exposed to bodily fluids from another person in the course of their employment (e.g., paramedics, police, firefighters) or in other specified circumstances to apply for **a legal order authorizing that the source person be forced to undergo testing for HIV** and other communicable diseases.

“*Though in some situations there may be benefits to health care providers more actively encouraging HIV testing, each patient’s human rights must be protected and HIV tests should not be “routine.”*”

Recommendations for policy and law reform

- **Enshrine “the three Cs” of HIV testing — informed consent, pre- and post-test counselling, and confidentiality — in all HIV testing policies.** While the availability of treatment has dramatically changed what it means to receive an HIV-positive diagnosis, HIV remains a serious medical condition that is highly stigmatized and can have serious legal implications. Though in some situations there may be benefits to health care providers more actively encouraging HIV testing, each patient’s human
- rights must be protected and HIV tests should not be “routine.”
- **Make anonymous and rapid HIV tests available throughout the country.** Currently, these types of tests are available in some locations but not in others. In order to meet the testing needs of diverse women, both types should be available irrespective of province or territory, and in both urban and rural areas.
- **Conduct research on women’s experiences of HIV testing and what testing approaches work best for women,** both in the context of pregnancy and outside of pregnancy. Special consideration should be given to the needs and experiences of adolescents and young women, women in prison, sexual assault survivors, women in abusive relationships, women from countries where HIV is endemic, lesbian and transgender women, Aboriginal women, and women living in small communities. Such research is essential to inform HIV testing policy and practice that is respectful of and effective for the full diversity of women.
- **Ensure that counselling for women who receive an HIV test during pregnancy focuses on the woman herself, not just as a “vessel” for the baby.** The availability of alternative testing methods, the benefits and risks of receiving a positive test result, and the right to accept or decline the test must be clearly communicated. This is particularly important in the context of rapid HIV testing offered to a woman who is in labour and was not screened for HIV as part of prenatal care.
- **Note on laboratory requisition forms that informed consent is required for an HIV test** following pre-test counselling suitable for the individual to make an informed decision.
- **Ensure that all efforts to increase HIV testing are linked to and coordinated with efforts to achieve universal access to prevention, treatment, care and support.** Referrals to services should be provided with all HIV testing (e.g., specialized health care, counselling and support services, etc.), including mandatory and compulsory testing. Sufficient resources must be put in place to ensure services are available.

References

- ¹ L. Leonard et al., “Pregnant women’s experiences of screening for HIV in pregnancy: What they have to say about what constitutes an appropriate policy for HIV testing of pregnant women in Canada (a pilot study),” in Health Canada, *Perinatal HIV transmission: Study results and implications for policy and program development* (Ottawa: Health Canada, 2001).
- ² See Canadian HIV/AIDS Legal Network, “Evolution of HIV testing policy and technology in Canada,” *HIV Testing*, info sheet 1. Available via www.aidslaw.ca/testing.
- ³ See for example Centers for Disease Control and Prevention, “Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings,” *MMWR* 2006; 55 (No. RR-14); Letter to Vancouver Coastal Health affiliated physicians, nurse practitioners and registered nurses from Dr. Reka Gustafson, Medical Officer of Health, June 30, 2011 [on file with author]; World Health Organization, *Guidance on Provider-Initiated HIV Testing and Counselling in Health Facilities*, 2007; and J. Csete and R. Elliott, “Scaling up HIV testing: human rights and hidden costs,” *HIV/AIDS Policy and Law Review* 11 (2006): pp. 1, 5–10.
- ⁴ See Canadian HIV/AIDS Legal Network, “Shifting HIV testing policies,” *HIV Testing*, info sheet 2. Available via www.aidslaw.ca/testing.
- ⁵ C.M. Obermeyer and M. Osborn, “The Utilization of Testing and Counseling for HIV: A Review of the Social and Behavioral Evidence,” *American Journal of Public Health* 97 (2007): 1762–1774 at 1769.
- ⁶ See for example, J. Gahagan et al. “Barriers to gender-equitable HIV testing: going beyond routine screening for pregnant women in Nova Scotia, Canada,” *International Journal for Equity in Health* 10 (2011), on-line: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3110558/?tool=pubmed>.
- ⁷ C.M. Obermeyer and M. Osborn at 1766.
- ⁸ Ibid.
- ⁹ On rapid HIV testing and anonymous testing generally, see Canadian HIV/AIDS Legal Network, “Anonymous HIV testing,” *HIV Testing*, info sheet 5; and “Rapid HIV testing,” *HIV Testing*, info sheet 9. Available via www.aidslaw.ca/testing.
- ¹⁰ Between 1985 and 2009. Public Health Agency of Canada (Surveillance and Risk Assessment Division, Centre for Communicable Diseases and Infection Control), *HIV and AIDS in Canada. Surveillance Report to December 31, 2009*, 2010, at table 4C, page 22.
- ¹¹ Public Health Agency of Canada, *HIV/AIDS Epi Update*, July 2010, chapter 5.
- ¹² Public Health Agency of Canada, *Summary Estimates of HIV Prevalence and Incidence in Canada, 2008*. Surveillance and Risk Assessment Division, Centre for Communicable Diseases and Infection Control, Public Health Agency of Canada, 2009.

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