

Women and HIV Testing in Canada:

Barriers and Recommendations as Identified by Service Providers

A summary of key research findings

This document is available in French, titled: *“Les femmes et le dépistage du VIH au Canada: Obstacles et recommandations selon les prestataires de services: Un sommaire des principaux résultats de recherche.”* An extended version of the research report is also available in English.

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Table of Contents

1. Acknowledgments.....	4
2. Introduction: Women and HIV Testing in Canada.....	5
3. HIV Testing in Canada: A cursory Review.....	6
4. Barriers to HIV Testing for Women.....	9
5. Recommendations.....	13
6. Bibliography: Women and HIV Testing in Canada.....	16

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2. Introduction: Women and HIV Testing in Canada

HIV testing and early diagnosis offer several benefits. Research and experience have demonstrated that:

People who know they are HIV seropositive are more likely to adopt safer sexual and/or injecting drug practices in order to protect their partners from becoming infected. When people know their serostatus and have access to care and information, they are better able to cope with the diagnosis; manage their illness; prevent transmission to others; and live satisfying and healthy lives.”¹

This being the case, 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.²

Women face particular concerns when it comes to accessing and experiencing HIV testing, including “discrimination, fear of violence, stigmatized views of HIV/AIDS, and cultural barriers around sexuality.”³ Although these issues have the potential to impact all women in Canada (and elsewhere), there is great diversity to women’s backgrounds, identities, opportunities and experiences throughout and within the different provinces, territories and regions of the country. In turn, these factors play an important role in shaping women’s ability to protect themselves from HIV infection, to undergo testing, and to access care, treatment and support once diagnosed.

This document provides a cursory review of some of the barriers that affect women’s access to HIV testing in Canada, from the perspective of service providers. It draws from a community-based research project carried out between October 2009 and May 2010, by a Programs Consultant at the Canadian AIDS Society, working in consultation with a Steering Committee that represented various organizations and communities in Canada. The project used a mixed-methodology approach, comprised of an academic and grey literature review, an online survey with 75 respondents and 15 key informant interviews. Service providers who participated in the research worked with diverse communities across Canada, and included representatives of AIDS service and other community-based organizations, sexual health clinics and specialized HIV testing centers.

¹ Public Health Agency of Canada, 2006, p.1

² Public Health Agency of Canada, 2010, p.1

³ Gahagan and Sharman, 2009, p.8

3. HIV Testing in Canada: A cursory Review

If there is one overarching statement that can be made about HIV testing in Canada, it is that access and services vary immensely from one area to another. This diversity can be attributed in part to the fact that HIV testing is regulated at the provincial and territorial level. However, even within a same province or territory, large discrepancies can exist, based on varied factors including the types of testing available, the location of testing sites, whether the test is being conducted at a family doctor's office or a sexual health clinic, in a city, a small town, a remote or a rural area. The HIV testing technologies currently available in Canada are as follows:⁴

- **The Standard Test:** Blood is tested in a laboratory to detect the presence of HIV antibodies, through an enzyme-linked immunosorbent assay (or ELISA) test. If the initial ELISA test is positive, a second ELISA test is carried out and followed by a confirmatory Western Blot test.⁵ Because many testing sites are not equipped with their own laboratory facilities, blood-work is often sent away for testing. As a result, there is a delay between the time when a person is tested, and when they return to receive their result. While this time-period changes from one testing site to another, it tends to vary between 1-4 weeks.
- **The Rapid Test:** This test uses a drop of blood to detect the presence of HIV antibodies, within approximately 60-120 seconds. It is used as a screening procedure, so if a rapid test is initially reactive, blood will be sent to a laboratory for confirmation, using the standard approach described above. The rapid test reduces the stress associated to the period spent waiting for results, it can be carried out in a broad range of locations and contexts (as a Point-of-Care test), and allows for continuity in the pre- and post-test counselling experience. For these reasons, it has been touted as a very helpful HIV testing tool.⁶ Despite its many benefits, rapid testing remains largely unavailable in most of Canada, with the exception of a few specialized clinics and pilot projects.
- **The HIV p24 Antigen Test:** This test detects the p24 protein associated with HIV, within 1 to 2 weeks of infection. Because p24 levels peak after 3 to 4 weeks and may be undetectable after 5 to 6 weeks, this test is useful in the context of early diagnosis. When used in combination with an antibody test (as an AG + AB test, or antigen + antibody test), this option offers the most effective approach to HIV detection. Combination tests are only available in select locations in Canada.

⁴ For a comprehensive examination of the different testing technologies available in Canada, see Tooley, August 2010.

⁵ Public Health Agency of Canada, 2000, p.5

⁶ For a discussion of rapid testing in Canada and its benefits, see Canadian HIV/AIDS Legal Network, 2000; Public Health Agency of Canada, 2000; Saskatchewan Ministry of Health, 2010; Tooley, January 2010.

- **The HIV Nucleic Acid Amplification Test (NAT):** The NAT test detects HIV RNA in the blood, as early as 7 to 14 days after infection. Currently, it is only available in 6 clinics in British Columbia, as part of a study on acute HIV infection.

The forms of testing below vary in how the test is tracked and reported:⁷

- **Anonymous Test:** The name or identity of the person being tested is not required, nor is any identification or proof of medical coverage. The test is ordered using a code known only to the person being tested. If the result is positive, epidemiological data (including age, sex and risk factor for HIV infection) may be collected and reported, depending on the province where the test was carried out. Because test results are not written on the record of the person being tested, they can decide whether or not to give their name and include the HIV test result in their medical record. If and when a person who has been diagnosed as HIV positive anonymously decides to seek treatment, their status is recorded and becomes associated to their identity.

In Canada, anonymous testing is provided in specialized centers like sexual health clinics and AIDS Service Organizations. Anonymous testing is usually free, and because it is delivered in specialized centres, it tends to be associated to high caliber pre- and post-test counselling. Positive results tend to be higher with anonymous testing, which indicates the benefits of this method in reaching individuals at higher risk for infection.⁸ While it offers clear benefits, anonymous testing is still unavailable in certain provinces and territories, and in the Canadian prison system (see Table 1). Furthermore, anonymous testing tends to be difficult to access in smaller towns, rural or remote areas.

- **Nominal Test:** The service provider ordering the test uses the person's full name. If the test is positive, the laboratory is required to report the result to the local medical officer of health, for data collection and partner notification. Nominal testing, which is provided by family doctors, clinics and other health facilities, is available throughout the country.
- **Non-nominal Test:** This test is similar to the nominal test, except the test is ordered using a code or the person's initials, so only the person being tested and the health-care provider or tester know the result. If the test is positive, it is recorded in the person's medical files and reported to the local medical officer of health for data collection and partner notification. This test is available throughout the country.
- **Prenatal Test:** In Canada, prenatal testing is regulated at the provincial and territorial level and falls under two models, the "opt-in" and "opt-out" strategies. Under the opt-in strategy, a woman must consent to receive an HIV test specifically, whereas under the opt-out strategy, HIV testing is included as one of the routine prenatal tests, which a woman has the right to refuse. Frequent examples have surfaced of women being tested 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. Furthermore, given the power dynamics involved in the health-care provider and patient encounter, women may not always feel themselves able to

⁷ For additional information about these different types of testing, see Canadian HIV/AIDS Legal Network, 1999, 2007; Federal/Provincial/Territorial Advisory Committee on HIV/AIDS, 2004; Public Health Agency of Canada, 2004.

⁸ Public Health Agency of Canada, 2006, p.24

decline an HIV test, even though the opt-out model stipulates that this is a woman's right. While the opt-in model leaves more room for the health professional to decide whether or not HIV testing will be offered, it also provides a better guarantee that informed consent will be sought, and that pre- and post-test counselling will be offered.^{9 10}

Table 1: HIV Testing in Canada, as of March 2011

Province or Territory	Anonymous Testing Available (in select locations)	Nominal Testing Available	Non-nominal Testing Available	Rapid Testing Available (in select locations)	Prenatal Testing Policy
Newfoundland and Labrador	No	Yes	Yes	No	Opt-out
Prince Edward Island	No	Yes	Yes	No	Opt-in
New Brunswick	Yes	Yes	Yes	Yes	Opt-out
Nova Scotia	Yes	Yes	Yes	No	Opt-in
Quebec	Yes	Yes	Yes	Yes	Opt-out
Nunavut	No	Yes	Yes	No	Opt-out
Ontario	Yes	Yes	Yes	Yes	Opt-in
Manitoba	Yes	Yes	Yes	Yes	Opt-out
Saskatchewan	Yes	Yes	Yes	Yes	Opt-in
Alberta	Yes	Yes	Yes	Yes	Opt-out
Northwest Territories	No	Yes	Yes	Yes	Opt-out
British Columbia	No	Yes	Yes	Yes	Opt-in
Yukon	No	Yes	Yes	No	Opt-in

⁹ 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 counseling checklists for physicians, a multi-media campaign to educate the public, and memos sent to doctors when an HIV test had not been ordered. As a result of this multi-faceted approach, rates of HIV testing rose from 34% prior to the routine opt-in policy to 88% in 2005. (See Federal/ Provincial/ Territorial Advisory Committee on AIDS, 2004, p.37; Leonard, 2001; and Public Health Agency of Canada, 2006, p.26)

¹⁰ For additional information about prenatal testing in Canada, see Canadian HIV/AIDS Legal Network, 1999, 2007; Canadian Paediatric Society, 2008; Katz, 2001; Gruslin et al., 2001; Guenter, 2003; Jayaraman, 2003; Leonard et al., 2001, 2002; Margolese, 2009; Mehes et al., 2009; O'Connor and MacDonald, 2002; O'Connor et al., 2002; Ogilvie et al., 1997; Public Health Agency of Canada, 2010, "What Mothers Say"; Walmsley, 2003; Wang et al., 2005; Women's College Hospital, 2010.

4. Barriers to HIV Testing for Women

The service providers who participated in the research identify a number of barriers to women's access to HIV testing in Canada. As outlined in the introduction, these barriers coalesce differently in individual women's lives, affecting their desire and ability to access and undergo HIV testing. These barriers can be classified into five categories:

- **Access**

We need to be able to provide women with testing options and there are no options in our region. [Online Survey Respondent]

At a very basic level, the ability to undergo an HIV test depends on the ability to access a site where testing is provided. A key informant who worked in northern British Columbia noted that some of the Aboriginal communities served by her organization lacked access to basic health care, let alone HIV testing services. Beyond access to a nurse, doctor or other health-care professional licensed to provide an HIV test, service providers also highlight the lack of access to diverse forms of testing –particularly anonymous testing—as an important barrier. A participant based in Prince Edward Island noted that because anonymous testing is unavailable in the province, certain individuals choose to travel to neighboring provinces to seek anonymous testing. This option can prove very costly and time-consuming, and may not be available to women who are struggling to make ends meet while caring for children and other dependents. The location of a testing venue in a city, town or community, and its physical appearance can also play a role in influencing access to services. A key informant who worked with youth noted that young people, and members of street-involved and substance-using communities (among others), may feel more comfortable receiving an HIV test in a colorful, friendly and relaxed atmosphere, as opposed to a highly institutional medical facility.¹¹

- **The Testing Process**

One of my friends came to me, she was pregnant, and that's how she found out. She said: "When the doctor called me to tell me 'You tested positive for HIV,' I didn't even know what he was talking about. HIV? I only knew AIDS. I asked how he knew this.

¹¹ For additional information about access to HIV testing, see Blueprint for Action on Women and Girls and HIV/AIDS, 2010; Canadian HIV/AIDS Legal Network, 1999; Federal/Provincial/Territorial Advisory Committee on HIV/AIDS, 2004; Gahagan et al., 2010; Leibowitz, 2007; Orchard et al., 2010; Robertson, 2007.

'When I did your prenatal exam.' 'But you didn't tell me.' He said 'It's part of prenatal testing.' Yes, it's part of prenatal testing, but there's a difference between telling a woman who's pregnant that she's diabetic, or that she is HIV positive. [Key Informant Interview]

Pre- and post-test counseling are essential to the testing process and can greatly facilitate a woman's experience in the case of a positive diagnosis. However, service providers highlight the fact that testing is not always accompanied by adequate pre- and post-test counseling in Canada, if at all. This point surfaces frequently in reference to testing carried out in pre-natal care or immigration contexts, or by family physicians, who may not have the time to go through the counselling process. When counselling is carried out, it may not be tailored to the linguistic, cultural and experiential specificities of the person being tested. Service providers also identify a judgmental attitude on the part of the tester as an important barrier to testing, as women may not want to ask for information, ask to be tested, or return for results if they feel judged.¹²

• **Perceptions of Risk**

Even myself going to my family doctor and asking for an HIV test, it was like "Oh, you're a good girl, don't worry about that." And I really don't think that that should be. There should be no talk like that. You have to say "Okay, yeah, we can do that for you" and let them know what it's about, that type of stuff and do the test and then the post-test counseling. [Key Informant Interview]

The women who are in relationships, with their families, etc, it's harder [to reach them]... Hypothetically, if the woman is in a relationship and she suspects her partner may have other partners, she won't necessarily go for the test. It's as though she's in denial, you understand? Especially when they are older. They have learned to live with it, without realizing that they are more vulnerable than others. [Key Informant Interview]

The 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 great risk for HIV. Women's own assumptions and beliefs around HIV risks can also contribute to this pattern. Though it has long been determined that HIV is transmitted through behaviors, not identity, knowledge of HIV continues to be premised around assumptions and stereotypes, with many still believing that only gay men, sex workers or people who inject drugs are affected by the virus. Consequently, health-care professionals and women may not realize that they are engaging in activities that

¹² For additional information about the HIV testing process, including the importance of pre- and post-test counselling, see Canadian HIV/AIDS Legal Network, 2007; Committee for Accessible AIDS Treatment, 2005; Dorval et al., 2007; Myers et al., 2003; Tharao et al., 2006; Worthington and Myers, 2002, 2003.

could put them at risk for infection, let alone identify as requiring or benefiting from an HIV test. While this issue applies to women in general, it appears frequently in reference to lesbians and women who have sex with women (WSW), women who believe themselves to be in monogamous relationships, as well as divorced, widowed and older women, who are seldom targeted in HIV prevention interventions.¹³

- **The Emotional Dimensions of Testing**

If it was just her who had been positive, her concerns would have been different...I mean, she was absolutely petrified that this information would get out, because of the potential for harassment of her children and all that stuff. [Key Informant Interview]

And now with criminalization, especially women who are involved in risky behaviors, they are going to be even less likely to get tested. At least that's what we think, right now, we don't really know, but we think women are going to be less likely to get tested because they'll be concerned about repercussions. [Key Informant Interview]

Accessing an HIV test can be a difficult decision. In the first place, there is the anxiety and fear associated with the period between the time when the test is administered and the time when the results are given. Though a standard test is still required in the case of an initially reactive result, rapid testing offers a very useful tool in minimizing this particular stress-factor. Service providers also identify women's fear of being judged or experiencing partner, family or community violence as other important barriers to the process of being tested. The potential ramifications of a positive test result also constitute a significant source of concern for women, including the fear of sickness and death, the fear of losing one's children, partner, family, community, home or job, and the fear of experiencing violence, stigma and discrimination. The increasing trend towards the criminalization of HIV non-disclosure also presents another significant concern for women, and is likely to create an important barrier to HIV testing, since individuals who know their status may be at risk for criminal charges.¹⁴

- **Confidentiality**

And that's why a lot of people don't get tested here. Because for people to get tested, we don't have anonymous testing, so going to your family doctor that you've had since you

¹³ For additional information about perceptions of HIV risk and their influence on HIV testing, see Dorval et al., 2007; Hansen et al., 2005; O'Connor et al., 2002; Ogilvie, 1997; Positive Women's Network, 2010.

¹⁴ For additional information about the emotional dimensions of HIV testing, see Canadian Aboriginal AIDS Network, 2009; Katz, 2001; Ransom et al., 2005; Worthington and Myers, 2002, 2003.

were a child, and everybody in the office knows you and your family, it's very hard to go there, and worry that people are going to know. [Key Informant Interview]

Stigma and discrimination continue to play a key role in limiting access to HIV testing. The inability to receive confidential or anonymous testing, the fear of being seen at a testing site or of being discovered as having received an HIV test, and the possibility of having one's status known, all present important barriers to HIV testing. Confidentiality therefore constitutes a fundamental concern when it comes to women and HIV testing in Canada, and elsewhere. The issue of confidentiality surfaces frequently in reference to the experiences of women living in rural and remote areas, as well as smaller urban centers, where women may be known to the health-care providers and testers, or seen accessing services by friends and family members. This point also surfaces in relation to tight-knit communities living in urban areas, including women from ethno-cultural and Aboriginal groups. As a result, women may prefer to avoid seeking support in an agency that serves their community or their neighborhood, lest they run the risk of running into friends, acquaintances and family members. In some cases, they may avoid accessing services altogether.¹⁵

¹⁵ For an in-depth examination of issues around confidentiality and testing, see Canadian HIV/AIDS Legal Network, 2007, 1999, 1998.

5. Recommendations

The service providers who participated in the study also offer recommendations to help minimize barriers and increase women's access to HIV testing.

• Accounting for Women's Competing Roles and Priorities in Service Delivery

You're not going to find people 9-5. It's something that we know from our injection drug use outreach program. We have to go to all the places they are. [Online Survey Respondent]

For HIV testing services to be accessible to women, they must be structured around the recognition of women's multiple roles, priorities and responsibilities. Key amongst these are women's duties as parents and caregivers. Provisions like childcare and travel subsidies must therefore be included within service delivery. Additionally, women who are working one or more jobs, caring for their families and/or dealing with issues like substance abuse require flexible service hours. Finally, services should be trans-friendly, fully accessible to women who are living with disabilities, and cater to women's diverse cultural and linguistic backgrounds.

HIV testing programs should also be structured in a manner that recognizes women as members of romantic and sexual partnerships, families and communities. Pre- and post-test counselling must include a discussion of these issues and provide women with tools to be able to address them in their lived experiences. Testing options for partners and couples and awareness-raising activities in communities could greatly enhance women's access to HIV testing.

To prove most effective, testing services and programs should be developed in close consultation with women, since women are best positioned to identify the barriers they face and the tools they require to mitigate them.

• Raising Awareness and Educating Women and the General Population

There's not enough information going out to the general population about HIV, how it's transmitted, how people are living longer healthier lives, having healthy babies. And that comes right back to the testing issue. People don't think they're at risk unless they have a history of drug injection or prostitution or a heavily active sexual life. So it is a problem and that's why so many people in Canada don't know they're infected....To me that's a big problem. And I believe that affects the testing experience. Again, it boils down to you don't think you're at risk, so you practice risky behavior and you don't seek a test. [Key Informant Interview]

If you want uptake on HIV testing, you have to reduce stigma and discrimination. [Online Survey Respondent]

The research highlights continued myths and misunderstandings around HIV/AIDS, its modes of transmission and the benefits of HIV testing on the part of women and the general population. There is therefore a need for awareness and education tools and campaigns about HIV/AIDS in Canada, including information about risk factors, the benefits of early diagnosis, stigma and discrimination, and other issues that directly affect access to HIV testing. A national HIV testing day, akin to the one that takes place in the United States every June 27th, may also yield some interesting results with regard to raising awareness about HIV testing, reducing the stigma associated to testing, and encouraging more people to seek testing.¹⁶

• **Training and Sensitizing Health-Care Providers**

A doctor has the moral and ethical obligation to offer the test, but a woman can refuse. In general, women don't know that they can say no. Hence the fact that there is no counseling being done, you see? [Key Informant Interview]

In no way does this report aim to question the motives of health-care providers or to undermine some of the excellent services being provided in communities throughout the country. However, in some cases, health-care providers may lack the time, training or capacity to effectively respond to women's needs and concerns as they relate to HIV testing. Consequently, the development and provision of training to health-care providers on issues pertaining to women's HIV risks and the gendered dimensions of HIV testing could be particularly useful. Training could take various forms, including the distribution and development of written resources and accompanying workshops, to be offered directly to health-care providers and through professional organizations and resources. On a smaller scale, the development of short and concise documents could also provide a useful tool for health-care providers to offer testing services that are more responsive to women's needs.¹⁷

¹⁶ Additional information about National HIV Testing day can be found on the website of the U.S. Department of Health and Social Services at www.hhs.gov/aidsawarenessdays/days/testing/

¹⁷ A number of related tools already exist, including the Canadian Medical Association's (2005) "Counseling Guidelines for HIV Testing," the Ontario Ministry of Health and Long Term Care's (2008) "Guidelines for HIV Counseling and Testing," and the Saskatchewan Ministry of Health's (2010) "HIV Point of Care Test Kits: Information for Health Care Providers."

- **Enhancing the Capacity of Service Providers**

I always term my group a 'sexual health group,' because if they put it over the PA, 'It's an HIV/HEP C group,' nobody's going to come, because there's so much stigma around it. Even if you just want information, people are going to look at you sideways when you come out of the room because they're automatically going to think that you're outing yourself. So I've learned over the years that strategically, if you want to reach women, if you want them to come, you have to put it in a different way. So I always tell women it's a sexual health group and when they come I say that irregardless of your status, this is about information, prevention and education. [Key Informant Interview]

Community-based organizations, clinics, AIDS service organizations, health-care and other service providers have developed numerous interventions and strategies to help enhance women's access to HIV testing in their communities. The development of resources and opportunities to facilitate the exchange of knowledge and skills between service providers and with other stakeholders could help enhance women's access to HIV testing in Canada.

- **Making Anonymous and Rapid Testing Universally Accessible in Canada**

The 2-week turnaround time for an HIV test result in Whitehorse prevents people from testing in Whitehorse especially if they have to drive in from the rural communities. Rapid HIV testing would solve a lot of issues/barriers for us. [Online Survey Respondent]

Alternate testing sites can be a good idea –it is critical that these initiatives safeguard confidentiality and personal safety. Sometimes testing at special events is influenced by peer or family pressure. One must assure that the process is safe for all. [Online Survey Respondent]

While they offer clear benefits, anonymous and rapid testing services are not universally accessible in Canada. Making anonymous and rapid testing available in the provinces and territories where they are currently absent, and increasing the number of anonymous and rapid testing sites overall could also play a key role in broadening access to HIV testing in Canada. In smaller communities, where individuals are likely to know their health care providers personally, the availability of anonymous testing may not make a large difference. In such cases, support should be provided for individuals to access anonymous testing outside of their community, or through alternative programs like mobile testing clinics. Alternatively, provisions could be made to ensure better confidentiality, including combining HIV testing with other health services, thus allowing users to feel more comfortable since they could potentially be accessing a range of health services, not an HIV test specifically.

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