

# Privacy and disclosure: questions and answers on HIV-related privacy and disclosure issues for women's service providers

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Increasing numbers of women in Canada are living with HIV, yet the virus remains highly stigmatized and poorly understood among the general public. For women facing challenges related to violence, substance use, housing, poverty or a plethora of other issues, questions regarding HIV-related legal issues may add an additional level of anxiety and risk. It is not always obvious where one can find accurate and accessible information. The first line of contact for many women is the staff at service agencies or programs they use.

This document addresses some common HIV-related legal questions of agencies that provide services to women in Canada. The information will help service providers inform and refer the women with whom they work to appropriate legal information and support when necessary. It will also present them with guidance about their responsibilities with respect to HIV-related information.

This Q&A was developed for representatives of agencies serving women living in poverty, newcomer women, women who use drugs, survivors of sexual or domestic violence, women without stable housing and women in conflict with the law, and of other agencies providing counselling, support or services to marginalized women. It is based on a workshop conducted for service providers in Toronto.

## **Background: challenges related to HIV disclosure**

Women represent an increasing proportion of people living with HIV in Canada. A disproportionate number of the women living with HIV in Canada are Aboriginal, from countries where HIV is endemic (primarily in Africa and the Caribbean), who use injection drugs and who are in prison.<sup>1</sup> Heterosexual contact and injection drug use are the two main risk factors for HIV infection in women.

Women may be tested for HIV in a variety of settings and for different reasons. Some women may seek out HIV testing following a possible exposure, for example. Pregnant women are offered an HIV test as part of their pre-natal care, and all foreign nationals applying for permanent residence in Canada, as well as certain applicants for temporary residence, are required to have an HIV test as part of their immigration medical exam, so many women find out they are HIV-positive during these processes. An HIV diagnosis is invariably a source of great distress and many women experience feelings of shock, denial, loss, sadness, fear, isolation, anger, shame and anxiety.

HIV disclosure is an ongoing process for women living with HIV and has considerable impacts not just on the individual woman, but on her family and community as well. Effective disclosure can have numerous positive benefits, including reducing HIV transmission, increasing access to support and improving mental and physical health.

However, because HIV remains particularly stigmatized and personal health information is generally considered private, many women are reluctant to disclose their HIV status to others. A woman may decide to disclose her HIV status for a number of reasons, including to gain access to needed services, to prevent transmission to a sexual partner or child, because she is in need of support to manage living with HIV, because of a legal obligation to do so (see below) or because of signs of disease progression. Yet, after revealing a positive HIV diagnosis, some women may experience psychological and bodily harm from their partners and others, and discrimination at work, in health care settings and other contexts. Many women legitimately fear accusations of infidelity, abandonment, violence, stigma and discrimination, or withdrawal of immigration support if they reveal their HIV-positive status. Moreover, once another person knows a woman's HIV-positive status, he or she may reveal it to other people, denying the woman control of this private personal information.

Given the complexities and intimately personal nature of disclosure, women living with HIV may need counselling and support to decide when, to whom and how to disclose their HIV status as well as to prepare for potential outcomes of disclosure. Service providers need to be sensitive to the complexity of disclosure and understand that women living with HIV do not need to be open about their HIV status. HIV disclosure should be voluntary and part of a broader HIV prevention, treatment and support strategy. Service providers should respect and protect women's privacy and provide appropriate support and referrals to assist with HIV-related challenges.

**Question: What HIV testing options are available for women in Canada?**

**Answer:** HIV tests are available in a variety of settings, including physicians' offices and hospitals, sexual health clinics, midwifery practices and some community organizations. Anonymous HIV tests are available at 50 sites in Ontario (i.e., the identity of a person who tests HIV-positive is not reported to public health authorities). Rapid HIV testing is available at 60 sites in Ontario (i.e., a point-of-care test where results are available immediately).

To find the HIV testing options near you, contact the Ontario AIDS Hotline (Toronto: 416-392-2437 or toll-free: 1-800-668-2437).

**Q: What does respecting a woman's confidentiality with respect to her HIV status mean in practice for a service provider?**

**A:** Confidentiality refers to the obligation of service providers to protect the privacy of their clients. Medical records, including HIV test results or even the fact of seeking an HIV test, must be kept in ways that protect people's privacy. This includes storing test information in files that

are protected from unauthorized viewing. Confidentiality also extends to the counselling that should accompany HIV testing and any discussions with the client while they are accessing services.

Depending on the type of service and the nature of the relationship with the client, different precautions may be required to protect the woman's confidentiality. In practice, beyond formal systems to maintain files, agencies should consider more substantively what protecting the privacy of their clients requires. For example, protecting a client's confidentiality may require that a service provider not communicate, even casually, with the client if they meet outside of the office. By revealing that the woman knows a service provider, for example, it may imply that she has a certain condition or has accessed a certain program, such as an HIV- or violence related support group. Especially for women in abusive or dependent relationships and women in tight-knit communities, confidentiality is extremely important and even minor violations of confidentiality can have severe ramifications.

**Q: Can a service provider ask a client if she has any infectious diseases, such as HIV?**

**A:** As a general principle, *collect only information that is relevant to the service you are providing and use it only for the purpose it was collected.* HIV cannot be transmitted through casual contact and therefore HIV status is not a relevant factor in the provision of most services. If it is not relevant information, service providers should not request that information from their clients.

Moreover, if a service provider comes to know of a woman's HIV status (e.g., because of the medications that she is taking or because she has volunteered that information), that information must be treated as confidential.

**Q: When are women living with HIV required to disclose their HIV-positive status?**

**A:** Under Canadian criminal law, people living with HIV are required to disclose their HIV-positive status before engaging in an activity that poses a "significant risk of serious bodily harm". The courts have interpreted this to mean that people living with HIV must tell their sexual partners of their HIV-positive status before having sex that poses a "significant risk" of HIV transmission. While this standard is vague and courts make case-by-case determinations, most often it has been interpreted as meaning that people living with HIV must disclose to their sexual partners before having unprotected vaginal or anal sex.<sup>2</sup> If a person living with HIV does not disclose in these circumstances, he or she could face serious criminal charges.

Outside of the sexual context, people living with HIV are seldom legally required to disclose their HIV-positive status. Although many choose to disclose in various circumstances, a woman living with HIV is not legally required to disclose her HIV-positive status to her employer, neighbours, children, teachers or service providers, in most circumstances.

**Q: If we come to know that a woman living with HIV may be putting someone else at risk of HIV infection (e.g., through unprotected sex with someone who is unaware of her HIV-positive status), can we breach the woman’s privacy to warn the person at risk?**

**A:** There is no easy answer, legally speaking. As the law stands in Canada, it is unclear whether a service provider may have a legal duty to disclose confidential information in order to prevent harm to another person.<sup>3</sup> What is clearly established in the law is that service providers have the *discretion* to disclose confidential information in order to prevent harm to another person *where an identifiable individual or group is in imminent danger of death or serious bodily harm.*

The *Personal Health Information Protection Act* (PHIPA), Ontario’s privacy legislation, applies to people who meet the definition of a “health information custodian”.<sup>4</sup> PHIPA relieves health information custodians from liability for breaching privacy in order to inform another of an HIV risk, or deciding not to breach privacy, when it is *reasonable in the circumstances* and *done in good faith*. The provisions of PHIPA reflect what has been established in the “common law” and therefore a similar framework likely applies also to service providers who are not covered by PHIPA.

It is advisable that agencies develop a policy or guidelines for staff and volunteers with respect to record-keeping and the decision-making procedure in case such a situation should ever arise.

If a service provider decides to take action in order to protect a person at risk of HIV infection, the service provider does not have to go to the police, and should be reluctant to do so, unless it is absolutely necessary given a particular, exceptional situation. (In the case of a child “in need of protection,” counsellors have a duty under child welfare law to report the situation to child protection authorities.)

A service provider who is in contact with the person at risk may be able to have a general discussion with that person about HIV, how it is transmitted and why it is important to practise safer sex (or use sterile injection equipment) and get tested for HIV, in order to raise the person’s awareness about potential exposure without breaching the client’s confidentiality. Another option may be to alert public health authorities, who can contact the person at risk without revealing the identity of the possible source of exposure.

If a service provider decides to breach confidentiality in order to protect another person, the disclosure of confidential information should be as limited as possible so as to protect the client’s confidentiality (e.g., a person may be advised to seek testing for sexually transmitted infections without being told through whom they may have been exposed). The service provider should always record the reasons for his or her decision and also inform the client of the action taken.

**Q: What should we do if the police ask us for copies of our confidential records about a client?**

**A:** You only need to provide information to the police if they present a valid search warrant. If they present a valid search warrant you are legally obliged to provide them with the specific information requested on the search warrant, but nothing more.

You can attempt to protect the confidentiality of your client's information by placing copies of the requested documents (hard-copies or electronic, as appropriate) in a sealed envelope or box. Label it: "Do not open. Confidential information. Privilege asserted." before giving it to the police. Contact your own lawyer and inform the client as soon as possible.

**Q: How can a woman living with HIV prevent her HIV-positive status from being included in her medical file (for example, if her physician is referring her to a specialist)?**

**A:** In Ontario, the *Personal Health Information Protection Act* (PHIPA) contains a number of patient privacy protections, including a so-called "lock box" provision. This provision allows a patient to prohibit her health care providers from disclosing the patient's HIV-positive status to others by saying "I do not want you to tell anyone that I am HIV-positive." For example, when referring to a specialist, the physician would not be permitted to disclose the patient's HIV status to the specialist. (Note that there are a few exceptions where the health care provider would still be able to disclose the patient's HIV-positive status.)

However, if the health care provider reasonably believes that disclosing the patient's HIV-positive status (or other information protected by a "lock box") to another health care provider is important for the provision of health care to the patient, the health care provider cannot disclose the information, but is permitted to say something like "there is information that I think is reasonably necessary for you to have in order to treat this patient, but I am not able to provide it to you directly."

**Q: What remedies do women have if their HIV-positive status has been revealed without their consent?**

**A:** If someone has breached your client's privacy and the breach is covered by legislation, she can complain to the Information and Privacy Commissioner of Ontario (if the breach is to provincial legislation like PHIPA) or to the Office of the Privacy Commissioner of Canada (if the breach is to federal legislation like the *Personal Information Protection and Electronic Documents Act*). There may be a time limit, depending on which legislation applies (e.g. PHIPA has one year time limit for complaint concerning a breach of privacy). Where no legislation applies, your client could also try to sue in court, using the "common law."<sup>5</sup>

You should contact a lawyer or legal clinic for information specific to your situation.

The websites of the Information and Privacy Commissioner of Ontario ([www.ipc.on.ca](http://www.ipc.on.ca)) and the Office of the Privacy Commissioner of Canada ([www.priv.gc.ca](http://www.priv.gc.ca)) also provide information about privacy rights and how to make a complaint.

**Q: Where can I refer a client who needs HIV-related legal advice?**

**A:** The HIV & AIDS Legal Clinic Ontario (HALCO) is a charitable not-for-profit community-based legal clinic that provides free legal assistance to people living with or affected by HIV/AIDS in Ontario. (Toronto: 416-340-7790 or toll-free in Ontario 1-888-705-8889). There are also many other lawyers and legal clinics, some that specialize in different areas of law.

**For further information**

- **On HIV testing:** [www.aidslaw.ca/testing](http://www.aidslaw.ca/testing)
  - HIV Testing (info sheets)
- **On the privacy of health information:** [www.aidslaw.ca/privacy](http://www.aidslaw.ca/privacy)
  - HIV/AIDS and the privacy of health information (info sheets)
- **On the criminal law and HIV disclosure:** [www.aidslaw.ca/criminallaw](http://www.aidslaw.ca/criminallaw)
  - Criminal law and HIV non-disclosure in Canada: Questions and Answers
  - Criminal law and HIV (info sheets)
  - HIV Disclosure and the Law: A Resource Kit for Service Providers
- **On women and HIV-related legal issues:** [www.aidslaw.ca/women](http://www.aidslaw.ca/women)
  - Women and HIV (info sheets)

This Q&A is based on a workshop provided for service providers in the Toronto area. Presentations at the workshop were delivered by Marvelous Muchenje for Women’s Health in Women’s Hands Community Health Centre, Renée Lang for the HIV & AIDS Legal Clinic Ontario (HALCO) and Alison Symington for the Canadian HIV/AIDS Legal Network. Note that the information in this Q&A is Ontario-focused because the workshop on which it is based was held in Ontario.

This publication contains general information. It does not constitute legal advice and should not be relied upon as legal advice. Copies of this Q&A are available on the website of the HIV/AIDS Legal Network at [www.aidslaw.ca/women](http://www.aidslaw.ca/women). Reproduction is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. *Ce document est également disponible en français.*

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## References

<sup>1</sup> Public Health Agency of Canada, *Population-Specific HIV/AIDS Status Report: Women*, 2012.

<sup>2</sup> Please refer to [www.aidslaw.ca/criminallaw](http://www.aidslaw.ca/criminallaw) for updates on this evolving legal standard.

<sup>3</sup> Note, however, that certain service providers may have specific duties because of their relationship with the person at risk (e.g., if a fiduciary duties exists) or obligations related to the specific regulations applicable to their profession. See *HIV and the criminal law: A resource kit for service providers* for further information.

<sup>4</sup> See s. 3 of the *Personal Health Information Protection Act*, 2004, S.O. 2004, Ch. 3, which defines a “health information custodian.” Very broadly, someone who delivers traditional health care may be a custodian depending on where she works. If you work in a hospital, the hospital is the custodian. If you have your own practice, you are the custodian. If you have a job that does not involve the delivery of traditional health care, then you are not a custodian even though you may be a member of a regulated health college or a registered social worker.

<sup>5</sup> See, for example, Ontario Court of Appeal case of *Jones v. Tsige*, 2012 ONCA 32.