



INDIGENOUS COMMUNITIES HIV, Privacy and Confidentiality



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Questions and Answers

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People living with HIV face stigma and discrimination in many places, from their school to their workplace to health care settings. Sometimes, being HIV-positive makes you a social outcast. That's why protecting their privacy is an important concern for people living with HIV. For Indigenous people living on a reserve or in small, tightly knit communities, concerns about privacy and confidentiality are heightened because in many situations an Indigenous person living with HIV will know a health care worker personally. Their employer, colleague, teacher or classmate may also be a family member or friend. In smaller communities, it is very difficult for people living with HIV to keep their health condition to themselves.

Most provinces and territories in Canada have specific laws to protect health information, which require health professionals and others to keep your personal health information private. These laws set particular rules and conditions around the collection, use and disclosure of personal health information, including your HIV status. In other words, your personal health information can be disclosed without your permission only under limited circumstances.

Even though there are laws in place to protect your personal health information, your privacy can be violated. Many Indigenous people have experienced breaches or violations of privacy by health care providers and others. Privacy may be breached through rumours and discussion between family, friends and others or through practices that seem harmless, such as sending bills for HIV-related health services to a patient's band council, or sending a letter to someone at work with an AIDS service organization's logo on the envelope.

When the privacy of an Indigenous person living with HIV has been compromised, the harmful effects can be felt by an entire community. If your HIV-positive status has been disclosed without your permission, others in the community may be more reluctant to get tested for HIV or get HIV treatment, care and support. This makes the protection of privacy for Indigenous people all the more important.

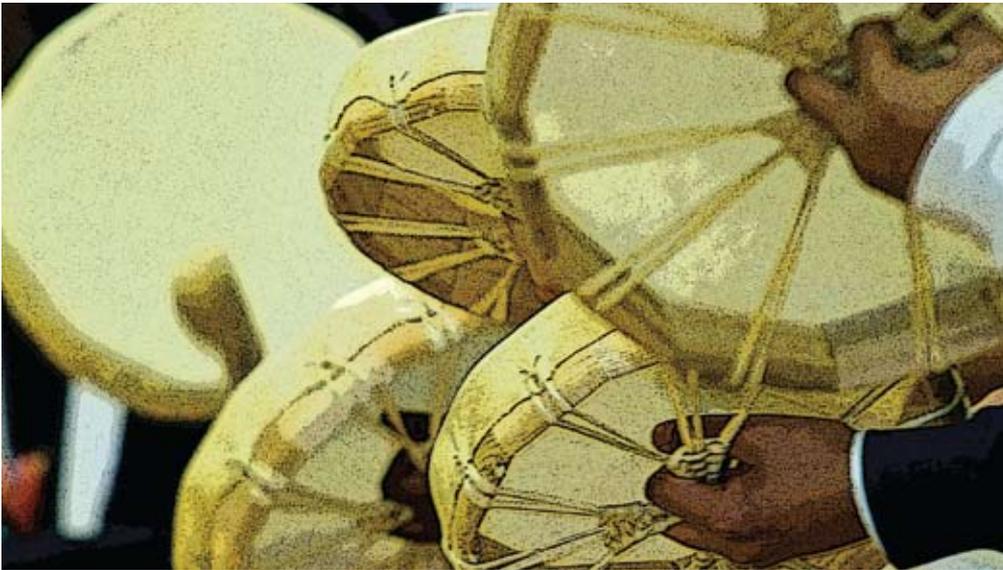
Knowing your rights and responsibilities when it comes to HIV disclosure, privacy and confidentiality is an important way to protect your privacy. This guide provides answers to common questions on disclosure, privacy and confidentiality in the health care settings, workplaces, post-secondary institutions and other settings — places where many Indigenous people living with HIV have expressed concerns about their privacy.

Health care settings

Do I need to tell a health care provider that I'm HIV-positive?

Legally, you are not required to tell your doctor, nurse, dentist, surgeon, paramedic or any other health care professional that you are HIV-positive. This means you decide whether to disclose your HIV status to your health care provider or not. Your personal health information, including your HIV status, is private, personal information. Health care providers — whether or not they know their patients' HIV status — should use universal precautions to prevent exposure to blood-borne infections at all times.

However, not having a *legal* obligation to disclose doesn't mean you should withhold your status from your health care provider. Telling your doctor about your HIV-positive status, even if the doctor is not your primary care physician, is often necessary to get the best care possible.



Can I be sued for lying on a medical form about my HIV-positive status?

Health care providers can ask you questions that are relevant to providing care for you. This is why you may be asked to complete a form and provide information about your health when meeting with a doctor or a dentist for the

first time. However, you have no obligation to provide such information if you don't want to. If you don't feel comfortable disclosing your HIV status, you have the right to refuse to respond to your doctor's questions. Lying to a health care provider about your HIV-positive status cannot be used against you.

If I tell a health care provider my HIV status, will this information be recorded?

Health care providers have professional obligations with regard to documentation. They must keep records of a patient's consultations, medical condition and treatment. Therefore, you might not be able to prevent a doctor from including your health information in your medical record. However, if you do not want

the information to be shared with others, including other health care providers, you may be able to request that your doctor not share your information with others or help you restrict access to the information in their system.

Can a health care provider ask me questions about my HIV status if the information is not relevant to caring for me?

Generally, health care providers should ask you questions that are only relevant to the purpose for which the information is required. This means they should not ask for your HIV status if they do not need the information to examine or treat you.

If you do not know why a health care provider is asking for your status, you can ask

how the question is relevant to your care. You could bring a friend with you for support. If you find it too difficult to have this discussion or you feel you cannot trust your health care provider, you may want to find an alternative health care provider, if possible.



Can one health care provider tell another health care provider my HIV status without my permission?

Generally, health care providers do not require your permission or your “express” consent (that is, either said out loud or in writing) to disclose your health information to other health care providers for the purpose of providing or assisting in providing care. This practice is called sharing information within the “circle of care.” In many provinces, your consent will be considered implied; in other words, you won’t be asked to provide consent.

Unless you tell your health care professional differently,

- a family doctor who refers you to a specialist can share your health information with that specialist.
- a hospital can share information about your health with your family doctor.
- if you disclose your status to an emergency room doctor, that doctor is allowed to tell other health care professionals treating you that you are HIV-positive.
- if you disclose your HIV status to hospital staff as part of the admitting procedure, your status can be shared for the purposes of your visit to the hospital. The information will be included in your patient file, and staff members involved in your care will be able to access it for the purpose of providing care. (Health care facilities should have policies in place to safeguard privacy. You can call or write to any health care facility and ask how your privacy is protected and who has access to your information.)



Note that information shared within the “circle of care” should be limited to what is *necessary for the particular purpose of disclosure*, i.e., providing or assisting in providing health care. Finally, you should know that you may be able to prevent one health care provider from disclosing your HIV status to another, including within a health care facility like a hospital, if you explicitly say you do not want the information disclosed.

What can I do if a health care provider or facility breaches my privacy?

If you believe that your privacy has been breached by a health care provider or facility, you have several options.

First, you may want to discuss the matter directly with that health care provider or facility. Health care facilities such as hospitals usually have people on staff responsible for privacy issues.

Another option is to file a complaint with a privacy commissioner (or ombudsperson). Commissioners usually have the power to investigate and make rulings about complaints. The privacy commissioner's office may attempt to resolve a complaint through negotiation or mediation. The commissioner may also investigate a complaint and issue a report with recommendations. Be aware that there may be a deadline to file a complaint. There may be a specific procedure in place for complaints related to electronic health records (or centralized databases).

For more information about filing a complaint with a privacy commissioner, see Canadian HIV/AIDS Legal Network, *Know Your Rights: Privacy and health records*, 2014.

Depending on where you live, you could also sue for breach of privacy. Four provinces (British Columbia, Manitoba, Saskatchewan, and Newfoundland and Labrador) have privacy laws (Privacy Acts) that allows you to sue someone who has violated your privacy. These laws require proof that the person *intentionally* violated your privacy (except in Manitoba) and had no





legal excuse for doing so. You do not need to prove that the privacy violation caused you harm in order to win the case. You may be awarded a monetary award if you win the case.

In Quebec, you may be able to sue claiming your privacy was violated and get money based on the *Civil Code of Quebec* and the *Quebec Charter of Human Rights and Freedoms*. In Ontario, you may be able to sue claiming your privacy was violated and get money based on a legal wrong called “intrusion upon seclusion.” As with the above-mentioned Privacy Act claims in other provinces, you do not need to prove that you suffered harm in order to succeed with a lawsuit in Ontario.

If you live in another province or territory, it may be more difficult to bring a case to court and obtain a monetary award. In many provinces, the law in this area is still uncertain and evolving. The main advantage of going to court is that you may receive a monetary award if your case is successful (although the amount may be small). But lawsuits can be expensive, complex and lengthy, and may not ultimately provide you with a solution. You may also face cultural, financial, language or other barriers. Note also that there are limitation periods which vary between provinces/territories, restricting the amount of time available for launching a lawsuit after the breach occurs.

You should be aware that remedies for violating privacy are limited and a complaint or lawsuit may not provide you with the outcome you are looking for. The process will vary from one jurisdiction to another. The application of privacy laws in Canada is very complicated, and you may need expert advice. For more information about your options, please contact a lawyer.

What can I do if I experience discrimination?

Under human rights law, you are protected from HIV-related discrimination and harassment (which is considered a form of discrimination) in health care settings. If you believe a health care provider has discriminated against you (e.g., your doctor refused to treat you because you are HIV-positive), write down what happened. If possible, your notes should include

- the date of the incident(s)
- a description of the incident(s)
- the names and contact information of any witness(es)
- what was said or done to you and how you responded
- copies of all relevant correspondence and documents

Sometimes, talking with the person who is responsible for the discrimination may resolve the problem. You might also try to discuss the matter with the person's supervisor, if necessary.

If you want to file a complaint, you can do so with the organization that regulates the profession of that particular health care professional. Such organizations are usually called "colleges" (e.g., College of Physicians and Surgeons of Ontario). They can take disciplinary action on their members.

Another option is to file a human rights complaint with a human rights commission or tribunal. In most cases, health care services are regulated by the province or territory. Therefore, if you wish to file a complaint against a health care provider or facility (e.g., a provincial hospital), you should contact the appropriate provincial/territorial human rights commission or tribunal. The procedures and services available in each province/territory vary, so contact the appropriate commission for detailed information. In British Columbia, Ontario and Nunavut, complaints are filed directly with the provincial/territorial Human Rights Tribunal rather than with the commission. If you experience discrimination at a federally regulated institution, you should contact the Canadian Human Rights Commission.

Human rights commissions and tribunals offer information and services to people who believe they have suffered discrimination, including information about other options for conflict resolution (such as mediation). Many complaints are settled through mediation. If mediation efforts are unsuccessful, the commission will decide whether to refer the case to a human rights tribunal for a hearing. If the commission decides not to refer the case to a tribunal, it will be the end of the complaint.

Filing a human rights complaint is free of charge. You do not need a lawyer to represent you, although you may choose to have one. If you hire a lawyer, you will have to pay for the service unless you are able to get free services through a legal aid service such as a legal clinic. The human rights commission you contact can suggest appropriate resources that may be available.

Note that there is usually a “limitation period,” which means you must file your complaint within a certain period of time after the discrimination takes place. Often this period is one year, but you should check with the relevant commission or tribunal.

Filing a formal complaint can be overwhelming and isolating. Your local AIDS service organization may be able to support you if you experience discrimination. It may also be helpful to have a friend or outreach worker support you during the process. Remember that many different people and organizations can provide you with information and support, but only a lawyer can give you legal advice. If you require legal advice about your specific situation, you should contact a lawyer.



Workplaces

Do I have to tell my employer that I have HIV?

Usually, you do not have to tell your employer or anyone you work with that you have HIV. Whether or not you disclose your HIV status at work, and to whom, is entirely up to you. Your personal health information, including your HIV status, is private, personal information.

Most jobs pose no real risk of transmitting HIV to anyone else. So, you have no legal obligation to tell anyone your status and it would be unlawful discrimination for your employer to request this information as a condition of hiring you. But be aware that if you work in a health care setting, there may be some exceptions to this general rule. For more information, see Canadian HIV/AIDS Legal Network, *Know Your Rights: Disclosure at work*, 2013.



When I apply for a job, can an employer ask me if I have HIV or make me take an HIV test?

No. Employers cannot legally ask for your HIV status as a condition of employment, including on a job application or during an interview. Canada's human rights laws prohibit discrimination based on disability, and HIV and AIDS are considered disabilities under the law.

This means that employers cannot ask for your HIV status, just as they cannot ask about your sexual orientation, marital status, religion or other similar membership categories.

A prospective employer can ask questions in order to assess your ability to perform the duties of the job. Sometimes, employers can require a medical exam after making an offer of employment in order to determine if you are able to perform specific tasks (e.g., if you are physically able to lift heavy objects) or if you may require accommodation for a disability (meaning an employer is required to remove barriers so you are able to do the essential duties of the job). An HIV test should not be included in such medical tests because an employer would not be able to know from a positive test result if you are able to perform specific job duties or not.

However, even though it's against the law, some job applications do ask about specific medical conditions, including HIV, and some interviewers do ask questions regarding your health status and specific conditions. How you choose to answer these questions is a personal decision. You may skip the question on a form, lie or say something general about your health or that you have a disability but without specifying that you have HIV. Think ahead of time about how you will handle such questions if they come up, because not only may your response affect your chances of getting the job, but also there may be consequences later on if the employer finds out that you were not honest.

If you decide to reveal that you have HIV and you are not hired because of this, this scenario probably would be considered unlawful discrimination based on disability.

Do I need to tell my co-workers that I have HIV?

No. HIV cannot be transmitted through casual contact. You decide if you want to share that information with your co-workers or not.

If I request accommodation at work or need time off, do I need to tell my employer it is because I have HIV?

No. If you require accommodation at work, you do not need to provide a specific diagnosis to your employer. But you will probably need to provide medical documents explaining the specific limitations or requirements that you have to be able to do the essential duties of your job.

If you are requesting a medical leave from your job because you are no longer able to perform the work, you may be able to apply for sick leave benefits or short-term or long-term disability benefits through a group plan sponsored by your union or employer. To apply for disability benefits, you will need to submit more detailed medical information demonstrating that you are unable to fulfill the essential duties of your occupation. While you are not required to disclose your HIV status to your employer, your doctor will have to tell the insurance company your status if it is relevant to your ability to maintain employment.

Does my employer have to keep my HIV status private?

Yes. If you decide to tell your employer or a co-worker *acting on behalf of your employer* (such as a human resources manager) that you have HIV, they are obliged to keep this information private. Legally, your employer

cannot share information about your HIV status or other medical information to third parties (e.g., other employees, clients, other companies, friends, etc.) without your permission.

Though provincial, territorial and federal privacy laws limit the collection, use and disclosure of health information and protect the confidentiality of an

individual's health information, in practice, legal options are limited if your privacy is violated. If you believe that your privacy was violated by your employer, contact a lawyer, legal clinic or your privacy commissioner for advice. Be aware that there may be a deadline to file a complaint. As with breaches of privacy in other areas, you may have the option to sue. For more information about this option, refer to the question "What can I do if a health care provider or facility breaches my privacy?" above.

Finally, be aware that if you tell a co-worker your HIV status (other than someone who acts in an official capacity as a representative of your employer), then that co-worker does not have the same legal duty of confidentiality and is not obliged to keep this information private.



How am I protected against discrimination and harassment at work?

Under human rights laws and certain other laws that apply to the workplace, you are protected at work from HIV-related discrimination and harassment (which is considered a form of discrimination).

The *Canadian Charter of Rights and Freedoms*, which is part of the Constitution, protects you from discrimination by the government, at whatever level, throughout the country. This includes the government's treatment of you as an employee if you work for the government.

In addition, human rights codes require equal treatment without discrimination in the workplace. These codes apply to both government employers and private sector employers (e.g., private individuals, corporations, associations). Each province and territory has its own human rights code, and there is also a federal human rights act that applies at the federal level.

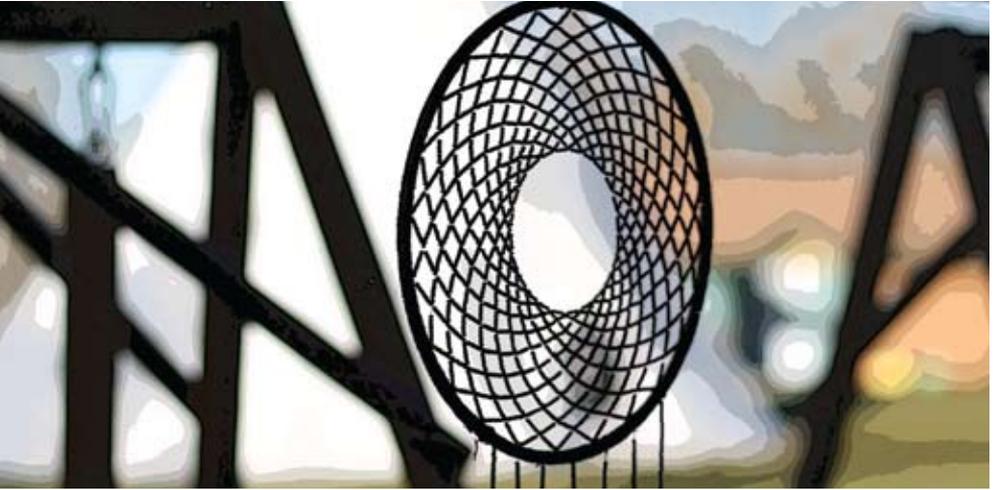


All human rights codes in Canada prohibit discrimination against you because you have HIV or AIDS (or even if you are just perceived to have HIV or AIDS). Employers are not allowed to discriminate against employees based on membership categories such as race, sex, disability, sexual orientation, religion and so on listed in the relevant human rights code. The duty not to discriminate also means that employers are legally required to provide reasonable accommodation to employees with disabilities.

You are also entitled to equal protection and benefits, without discrimination, under any other applicable laws protecting your rights in the workplace. For example, employment standards laws outline basic standards that apply to all workers (e.g., hours of work, public holidays, minimum wages and vacation entitlements, pregnancy and parental leave, etc.). Occupational health and safety laws are aimed at ensuring minimum standards for workplace safety. In some jurisdictions, these laws include specific protections against workplace harassment or violence. Each province and territory, as well as the federal government, has its separate laws with these sorts of workplace protections. You cannot be denied these protections because of your HIV status, as this would be discrimination and against the human rights code. For more information about filing a human rights complaint, refer to the question “What can I do if I experience discrimination?” in the “Health care settings” section above.

If you are a member of a union, another source of protection is your union's collective agreement with the employer, which incorporates the human rights code that applies to that employer. This means that discrimination can also be challenged by your union through a grievance under the collective agreement.

Which laws apply to your situation depends on where you live and whom you work for. Contact a lawyer, legal clinic or your union representative for advice.



Post-secondary institutions

If I am a student, do I have to tell the institution where I study that I have HIV?

No. Usually, there is no legal obligation to tell a post-secondary institution (i.e., trade school, job training program, college or university) that you have HIV. If your band office is administering the funds for your post-secondary studies, you have no legal obligation to disclose your HIV status to your band office. You decide if you disclose your HIV status at school, and to whom. Your personal health information, including your HIV status, is private, personal information.

HIV is not transmitted through casual contact, so there is usually no reason for an educational institutional to ask for your HIV status. It would be unlawful discrimination for a school to request this information as a condition to accept you or for you to continue in a program of study.

BUT if you are studying in a health care program, there may be some exceptions to this general rule. For more information, see Canadian HIV/AIDS Legal Network, *Know Your Rights: Disclosure and post-secondary education*, 2013.

Find out if the post-secondary institution you plan to attend has a policy on HIV and AIDS, and if so, consult this policy for more information.

Can I ask for help to meet deadlines and educational goals because of illness or limitations related to my HIV status?

Yes. In order to ensure equality for students living with disabilities, post-secondary institutions are obliged to provide accommodation to students who need it because of a disability. This obligation applies to both publicly and privately funded schools. If the accommodation requested would cause “undue hardship” to

the institution — meaning it would be too difficult or expensive to implement — then the institution is not required to provide it. But the institution must be able to prove this would be the case.

The accommodation should be based on a student’s individual needs, provided in a timely manner, and monitored and evaluated so it can be changed over time if necessary. Academic accommodation might mean adjusting teaching and evaluation procedures to meet the particular needs of a student with a disability and allow these students to do their best on a level playing field with other students. For example, a student with a health condition that results in unusual fatigue might be given extra time to complete tests or assignments.

To be eligible for accommodation, you need to tell the school that you have a disability and provide appropriate documentation (e.g., a letter from your doctor) explaining the accommodation you need in order to meet the requirements of the program. To get accommodation, you do not need to disclose your specific medical condition(s), such as HIV. However, if you do not provide adequate medical information, the institution may not be required to accommodate your needs.

Academic accommodation does not change the essential program requirements or expectations within your educational program. You will still need to pass tests or exams, turn in assignments and demonstrate that you have mastered the required skills.

Do I need to tell my classmates that I have HIV?

No. HIV cannot be transmitted through casual contact. You decide if you want to share that information with other students or not.

If I tell someone at school that I have HIV, does that person have to keep the information private?

It depends.

If you disclose your HIV status to a teacher, dean, mentor, counsellor, residence staff, administrative staff, or someone working in an official capacity at a post-secondary institution or at the band office that is administering funds for your post-secondary studies, then yes, that person must keep this information confidential. Legally, an institution cannot disclose information about a student's HIV status (or other medical information) to others (not even to your parents, teachers, other students, or potential employers) without the student's permission, except in rare circumstances. If your HIV status is recorded in your file at the school's health services or counselling services, it is considered private or confidential information and should not be shared with other departments of the institution.

However, these legal obligations to keep your HIV status private **do not apply** to a classmate, peer or any other person at the school who is not acting in an official capacity for the institution.

In practice, however, it is often difficult to control the flow of information at school, and legal options are limited if your privacy is breached. Provincial and territorial privacy laws protect the confidentiality of an individual's personal information, including their health information in official school records. If you believe that your educational institution violated your privacy, contact a lawyer, legal clinic or your provincial/territorial privacy commissioner for advice.

As with breaches of privacy in other areas, you may also have the option to sue. For more information about this option, refer to the question "What can I do if a health care provider or facility breaches my privacy?" above.

What should I do if I experience discrimination at school?

If you believe you are being discriminated against or harassed at school, you should try to keep a record of what is happening. If possible, your notes should include

- the date of the incident(s)
- a description of the incident(s)
- the names and contact information of any witness(es)
- what was said or done to you and how you responded
- copies of all relevant e-mails, text messages, posts on social media (e.g., Facebook, Twitter), letters and documents.

Sometimes, confronting the person who is responsible for the discrimination may resolve the problem. You may also bring the matter to the attention of a supervisor, professor/instructor or dean, as the school is obligated to take steps to make sure students don't face discrimination there. Your local AIDS service organization may be able to help you consider different options and support you if you decide to take such actions.

How am I protected against discrimination and harassment at school?

Under human rights law, you are protected from HIV-related discrimination and harassment (which is considered a form of discrimination) at school. Human rights codes apply to both governments and the private sector. This means educational institutions are covered. In

the federal jurisdiction, and in each province and territory, there is a human rights act that applies to educational institutions. In most jurisdictions, the applicable human rights commission offers information and services to people who believe they have suffered discrimination. Many complaints are settled through mediation. If mediation efforts are unsuccessful, the commission will decide whether to refer the case to a human rights tribunal for a hearing. If the commission decides not to refer the case to a tribunal, it will be the end of the complaint.

For more information about filing a human rights complaint, refer to the question "What can I do if I experience discrimination?" in the "Health care settings" section above.



Remember that many different people and organizations can provide you with information and support, but *only* a lawyer can give you legal advice, specific to your individual situation. Your lawyer may contact your college, university or school on your behalf and attempt to stop the discrimination.



Other situations

Do I need to tell my HIV status to a child protection worker who is involved with my family?

No. People living with HIV continue to face discrimination and stigma for being parents not only from their family and community, but also from child protection workers. Usually, you are not legally obligated to tell a child protection worker your HIV status.

However, it may be helpful to tell the worker that you are living with a chronic illness or episodic disability, in order for the worker to provide appropriate supports and referrals. And in certain circumstances, HIV-related issues may be relevant considerations. For example, if you are undergoing treatment or accessing support services, or if poor health or periods of disability were affecting your ability to meet your child's needs — this information would be relevant to a child protection worker who is assessing your family situation or providing support and counselling to your family.

If your HIV-positive status is known by a child protection worker, the worker is required to keep that information private.

For more information, see Canadian HIV/AIDS Legal Network, *Know Your Rights: Disclosure, privacy and parenting*, 2014.

Do I need to tell my HIV status to friends, family or partners?

You do not need to disclose that you have HIV to your family or to friends, unless you engage in sexual activity with your friends. HIV cannot be transmitted through casual contact. You decide if you want to share your HIV status with family or friends.

However, people living with HIV in Canada are obligated under the criminal law to tell their sexual partners they are HIV-positive before having sex that poses what the courts call “a realistic possibility of transmission.” So if you engage in sexual activity that, according to the law, carries a realistic possibility of transmitting HIV, and you do not disclose your HIV-positive status first, you could be charged with a serious crime — usually aggravated sexual assault. If you are found guilty, you could go to jail. It does not matter whether HIV is transmitted or not. You can be charged simply for not disclosing to your sexual partners that you are HIV-positive.

This legal obligation to disclose your HIV status applies equally to everyone — whether your sexual partner is your spouse, whether you are in a long-term or short-term relationship, whether the sex was in exchange for money, or whether it was a one-time thing. For more information on HIV disclosure to sexual partners, see Canadian HIV/AIDS Legal Network, *Indigenous Communities and HIV Disclosure to Sexual Partners: Questions and Answers*, 2016.

What can I do if a friend, partner or ex-partner reveals my HIV status to other people?

Once your privacy has been breached, it is difficult to undo the damage. However, sometimes speaking with the person who is responsible for violating your privacy — as well as those who now know your personal information — about the importance of keeping that information private will help

prevent future breaches of privacy. Your local AIDS service organization may be able to support you if you decide to take such action.

If you would like to seek a legal option for the breach of privacy, be aware that the laws protecting the privacy of your personal health information are an assortment of rules that vary from one province/territory to another, and most privacy laws do not protect the flow of information between individuals. When your privacy has been violated, the legal options and available remedies are limited and will depend on where you live and work. The primary legal option is to go to court.

For more information on going to court, see the question “What can I do if a health care provider or facility breaches my privacy?” above.

Additional resources

Canadian Aboriginal AIDS Network, *Creating Environments that Respect the Privacy and Confidentiality of Aboriginal People Living with HIV/AIDS: A Resource for Aboriginal HIV/AIDS Service Organizations and other Organizations that Provide Services for Aboriginal People living with HIV/AIDS*, 2010.

Canadian HIV/AIDS Legal Network, *Know Your Rights* series, 2014.

Canadian HIV/AIDS Legal Network, *Indigenous Communities and HIV Disclosure to Sexual Partners: Questions and Answers*, April 2016.

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