

KNOW YOUR RIGHTS

INDIGENOUS
COMMUNITIES:
HIV, PRIVACY, AND
CONFIDENTIALITY



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LAND ACKNOWLEDGEMENT:

The HIV Legal Network and CAAN Communities, Alliances & Networks are located across this land now called Canada on treaty lands, stolen lands, and unceded territories of many different Indigenous groups and communities who have respected and cared for this land since time immemorial. Together, we work to address the ongoing injustices and resulting health inequities faced by Indigenous Peoples, which contribute to the disproportionate impact of the HIV epidemic on Indigenous communities. We are committed to learning to work in solidarity and to dismantling and decolonizing practices and institutions to respect Indigenous Peoples and Indigenous ways of knowing and being.

Ki'l na asutmn mu wen kinua'tuan ta'n telpukwin wjit HIV. Ki'lewey HIV telpukuwik na Mimkwatasik, ki'l kjiitu'n pasik. Kaqi'sk, ktu tlmj pilue'k wenik ala'tu'n HIV asma ki'l. Asma na ki'l mu ktu' kinua'tuawj wen mita mu kejitu'n ta'n tl-kinua'tuan skwiji'nu'k kiswa wjit aluamujik newte'jk teliksatiiket wen, aluamulk ta'n wenin, mo'qi aluwamujik wenik two-spirited-ewultijik skwijinu'k, aqq/kiswa aluwamut aqq mo'qi aluwamujik skwijinu'k HIV-ewultijik.

Mu talnuta'nuk tliman kikmaq kiswa kitapk ketlewey ala'tu'n HIV, na'sik jiptuk kisata'sitsk tla'teken tle'tmn apoqnmasuti wja'tun. Mu nuta'nuk tliman pilue'k skwijinu'k, nkutey asutk ki'k kiswa ta'n tetk weskewa'sin, aqq etek awisu kinua'tuan alsusit ta'n etl-lukwen. Mu elt nuta'nuk kinua'tuan malpale'witm, nuji menapito'teket, kiswa pilue'k nuji mpitaqatite'wk wjit nekmowey. Pasik etekl telitpiaql (e.g. Keskmna'q wipetiwog wen ta'n kisi pesekuan), ki'l na ta'n telte'tmn ktu'kinua'tuan tel'pnen kiswa mu.

Mita HIV telpukwik na ki'lewey kinua'taqn, etekl rules-l ta'n ankweyask mimkwasin ki'l HIV-ewin ta'n health care settings, lukwaqniktuk, kiswa laplusunk eyk. Ala'tu'n elt na ki'l mu ewlo'tasin. Teluek ma pilueyulsinow (emeko'tasin) mita alatun HIV.

Nenmn ta'n kisitla'tekemk aqq tel nuta'q ta'n tujiw eknua'teken HIV-ewin, wli anko'tasin aqq mu kinua'tasin na mo'qi mlkiknewa'lsin wjit ki'l. Ula telwekl ika'tasikl Kinua'teken wjit kaqi'sk pipanikesimk net wjit HIV. Mu kinua'tasin, aqq mimkwatasin te'sk piluey koqoey teliaq, nkutey health care, lukwaqniktuk, aqq university-l aqq college-l-Etekl ta'n pukwelkik l'nu'k skwijinu'k ala'tu'tij HIV ta'n sespete'tmi'tis ta'n tli wimkwasiw. Wjit kinua'taqn tel wimkwatasin eyk laplusnk, ankapte'n Know YourRights-Indigenous Communities and HIV/HCV net federal prisons. Net guide let Ekinua'tekek kisi e'wmn ta'n tujiw o'pla'luk kiswa "o'pla'tasin." Ula kisi e'wten na Wije'wk Canadian legal system, pasik etekl kisi tela'tekemk nikana'tu'tij aqq elukwek L'nue'kati'l.



Gidinenimigoo ji-aabajitooyan giimoojichigewin apii ezhi-ayaaman HIV ezhiwebiziyen. Eyaaman HIV giimoojichigaade, ezhi-gikenjigaazoyan debendaman. Gegaa apane, giishpin wiindamaageyan eyaaman HIV booshke giin igo. Gidaa-inaakonige ji-wiindamaagesiwan wenji-debwetanziwan waa-izhi-wiindamaageyan gemaa gaye wenji-zegiziyen izhi-mazhiwewin, zhiingenindiwin, aandaadiziwin, zhiingenimindwaa weniizho-jijaakowaad bemaadizijig, gemaa gaye agajiwin miinawaa ezhi-zhiingenimindwaa eyaamowaad HIV.

Gaawiin gidizhi'igoosii ji-wiindamawadwaa gidinawemaaganag gemaa gaye giwijiwaaganag eyaaman HIV geget, giga-inaakonigemidog ji-wiindamawadwaa giishpin debwetaman ji-naadamawiwaad. Gaawiin booch gidaa-wiindamawaasiig bekaanizijig, dibishkoo epakwe'amawid gemaa gaye iw waakaa'igan endaayan, miinawaa bangii naaningodinong gidaa-wiindamawaa gidoogimaam. Gaye gaawiin booch gidaa-wiindamawaasii gimashkikiwininiim, giwiibidaakewininiim, gemaa gaye bakaan awiya meno-ayaakejig ezhiwebiziyen, wiin dash giga-inaakonigemidog giishpin booch waa-ayaaman maamawi-nanaandawi'iwewin. Wiin dash naaningodinong ezhihigeyan (e.g. jibwaa-mazhiweyan waa-izhi-odaapinaman inapinewin), booshke giin enaakonigeyan giishpin waa-wiindamawad awiya ezhiwebiziyen.

Nindawaaj HIV ezhi-ayaaman gekenjigaazoyan debendaman, atewan inaakonigewinan ji-ganawenimigoyan eyaaman HIV imaa wenji-mino-ayaakeng, wenji-anokiing, wenji-gikinoo'amaagozing, gemaa gaye gibaakwa'odiwigamigong. Gaye eyaaman inaakonigewin ji-giskinigooyan zhiingenimigooyan. Mii maanda edaming gaawiin bakaan ge-izhi-doodaagooyan (maji-doodamowin) wenji-bimaadiziyen eyaaman HIV.

Gekendaman gidinenimigoowinan miinawaa ge-izhichigeyan apii HIV dazhindaman, giimoojichigeyan, miinawaa izhi-giimoojichigeyan gichi-apiitendaagwad ji-izhi-naadamaadizoyan. Maanda izhi-naadamaagewin ji-ateg nakwetamowinan gagwedweng ko onji HIV waa-dazhindaming, giimoojichigewin, miinawaa izhi-giimoojichigewin anooj ezhiwebakin, dibishkoo wenji-mino-ayaakeng, wenji-anokiing, miinawaa wenji-gikinoo'amaagozing – ningoji wenji-baata'iinowaad eyaangig HIV ogii-dazhindaanaawaan naanaagadawendamowaad ogiimoojichigewiniwaa. Giishpin waa-nandagikendaman giimoojichigewin gibaakwa'odiwigamigong, waabandan Gikendan Gidinenimigoowinan – Anishinaabe Oodenawan miinawaa HIV/HCV gichi-gibaakwa'odiwigamigong. Maanda izhi-naadamaagewin wenji-dibaadodaming waa-izhichigeng apii gigiimoojichigewin mawine'aming gemaa gaye "boonendaming." Onow waa-izhichigeng wenji-ategin Canadian ezhi-inaakonigeng, wiin dash gaye wenaabanjigaadegin ezhi-dazhiikaming miinawaa ezhi-dibendaming Anishinaabe oodenaang.

You have the right to privacy when it comes to your HIV status. Your HIV status is private, personal information. Most of the time, whether you tell others that you have HIV is up to you. You may choose not to disclose because you are not sure how to tell people or because of homophobia, racism, transphobia, discrimination against Two-Spirit people, and/or stigma and discrimination against people living with HIV.

You have no obligation to tell your family or friends that you are HIV positive, but you might decide to do so if you think their support could help. You do not need to tell other people, such as your landlord or the shelter where you are living, and there are very few times that you would have to tell your boss. You also do not have to tell your doctor, dentist, or other health-care workers about your status, but you might decide to as it may be necessary to get the best care possible. Except in some circumstances (e.g. before sex that poses a realistic possibility of transmission), it is your decision whether to disclose your status to someone.

Because HIV status is personal information, there are rules that protect the confidentiality of your HIV status in health care settings, at work, in post-secondary schools, or in prison settings. You also have the right to be free from discrimination. This means you cannot be treated differently (in a negative way) because you are living with HIV.

Knowing your rights and responsibilities when it comes to HIV disclosure, privacy, and confidentiality is an important way to empower yourself. This guide provides answers to commonly asked questions on HIV disclosure, privacy, and confidentiality in different settings, such as health care, workplaces, and universities and colleges — places where many Indigenous people living with HIV have expressed concerns about their privacy. For information about privacy in prison settings, see *Know Your Rights — Indigenous Communities and HIV/HCV in federal prisons*. This guide also describes options when your privacy is violated or “breached.” These options are based on the Canadian legal system, but there are also options led by and grounded in Indigenous communities.

WHAT DOES “HIV DISCLOSURE” MEAN?

HIV disclosure means telling someone you are living with HIV.

For Indigenous people living on a reserve or in small, tightly knit communities, concerns about privacy and confidentiality are heightened because an Indigenous person living with HIV will often 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 maintain their privacy about their HIV status. Many Indigenous people have experienced violations or “breaches” of privacy by health care providers and others. Privacy may be violated through rumours and discussion between family, friends, and others or through actions that seem harmless, such as sending bills for HIV-related health services to a person’s band council or sending a letter to someone with an AIDS service organization’s logo on the envelope.

When a person’s HIV status is revealed without their permission, this harms them and the harmful effects can also be felt by their entire community. Others in the community may be more hesitant to get tested for HIV or get HIV treatment, care, and support because they are also concerned about their privacy being violated. This makes the protection of privacy for Indigenous people a matter of community importance.

DISCLAIMER: This is public legal information, current to February 2023. It is not legal advice. Please consult a lawyer for specific legal advice.

HEALTH CARE SETTINGS

Your HIV status is considered **your** “personal health information.” Most provinces and territories in Canada have laws that require health professionals and others to keep your personal health information private (confidential). These laws set rules around when health care workers can collect, use, or reveal your HIV status.

Health care providers can only disclose your HIV status to others in limited circumstances and must protect this information from being shared.

1. DO I NEED TO TELL A HEALTH CARE PROVIDER THAT I'M LIVING WITH HIV?

No. Legally, you are not required to tell your doctor, nurse, dentist, surgeon, or paramedic that you are living with HIV.

This means **you get to decide** whether to disclose your HIV status to your health care provider.

Indigenous people have experienced severe racism, discrimination, and other abuse when seeking health care, which has undermined trust between patients and health care providers. It may be difficult for you to share your HIV status with your health care provider. That said, telling your doctor about your HIV positive status is often necessary to get the best care possible, including ensuring you get the best treatment or receive proper referrals. You do not need to do this alone, and you have the right to have someone with you when you see your doctor. There are also laws that prohibit discrimination in health care settings. This means health care providers are not allowed to refuse to provide care or treat you negatively because you are HIV positive.

Note that things might be different if you are pregnant as the law may require you to take measures not to transmit HIV to your child during pregnancy, birth, and infant feeding. Your care providers who care for you during your pregnancy, childbirth, and after can help look after your health and wellbeing and decrease the possibility of transmitting HIV to your child.

2. CAN I BE SUED FOR LYING ON A MEDICAL FORM ABOUT MY HIV STATUS?

Health care providers can ask you questions that are relevant to your care. 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. Sometimes these forms ask you to check a box to indicate you are living with HIV. However, you are not required to provide such information if you don't want to. If you don't feel safe disclosing your HIV status, you have the right to refuse to respond to these questions. In most situations (see discussion around pregnancy above), not telling or lying to a health care provider about your HIV status **cannot be used against you legally**.

3. IF I TELL A HEALTH CARE PROVIDER MY HIV STATUS, WILL THIS INFORMATION BE RECORDED?

Health care providers must keep records of a patient's consultations/appointments, medical condition(s), and treatment. Therefore, you might not be able to prevent a doctor from including your HIV status 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 ask your doctor not to share it or to restrict access to the information in their system. The practice of recording your health information differs from one province/territory to another, so you should ask your health care provider how you can prevent this sharing or limit the extent to which your health information is shared.

4. 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 only ask you questions that are relevant to the purpose of providing care for you. 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 HIV status, you can ask how the question is relevant to your care. If the health care provider pressures you for this information, and it is too difficult to have this discussion or feel that you cannot trust your health care provider, you may consider switching health care providers, if that is possible.

5. CAN ONE HEALTH CARE PROVIDER TELL ANOTHER HEALTH CARE PROVIDER MY HIV STATUS WITHOUT MY PERMISSION?

Yes, in certain circumstances. Generally, health care providers do not require your "express" consent (meaning permission that you give verbally or in writing) to share your health information to other health care providers if it is for the purpose of providing care for you. This practice is called sharing information within the "circle of care." In many provinces, your consent will be considered "implied," meaning that you won't be asked to provide permission because it will be assumed that you are okay with this.

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 can tell other health care professionals treating you that you are living with HIV.
- 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 see it for the purpose of providing care. (Health care facilities should have policies in place to protect privacy. You can call or write to any health care facility and ask how your privacy is protected and who can see your information.)

Note that information shared within the "circle of care" should be limited to what is *necessary for the particular purpose* of providing health care.

For specific information on privacy and health records, see HIV Legal Network *Know Your Rights* series at www.hivlegalnetwork.ca/site/kyr/.

6. ARE THERE LIMITS TO MY RIGHT TO PRIVACY IN HEALTH CARE SETTINGS?

The right to privacy and confidentiality is not absolute. In every province and territory, there might be circumstances where the law requires your personal information to be disclosed without your consent.

The laws are different from one province/territory to another, but here are some examples of situations where disclosure of personal health information may occur without your consent:

- Disclosure is required to provide you with appropriate medical care, but it is impossible to get your consent in a timely manner (e.g. emergency situations).
- Disclosure is required to prevent an imminent and significant risk of harm or to protect public health.
- Disclosure is made to someone who is acting on your behalf (e.g. a person legally responsible for making health-care decisions on your behalf).
- Disclosure is required for the purpose of mandatory reports (e.g. certain types of reporting of HIV test results to public health authorities — see Question 8 below).
- Disclosure is required to comply with a warrant or other court order.

Finding out that your health information can be shared without your consent or control can be stressful. But it is helpful to know when this can happen, and your AIDS service organization may be able to provide support. You can also find a list of organizations below to contact for more information.

7. WHAT CAN I DO IF A HEALTH CARE PROVIDER OR FACILITY VIOLATES MY PRIVACY?

Options for when you experience a privacy violation:

- Talk to your provider or the health care facility directly to let them know how you have been affected
- File a complaint to your province or territory's privacy commissioner
- File a complaint to the relevant college regulating a health care provider
- File a lawsuit in court for a violation or "breach" of privacy

If you believe that your privacy has been violated (or "breached") by a health care provider or facility, write down what happened. It will help you to remember details if you decide to take action in response to the breach of confidentiality. 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

If your privacy has been violated, you have several options:

Speak to them directly: 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 with whom you can share your concerns.

Privacy complaint: Another option is to file a complaint with your provincial or territorial privacy commissioner (or ombudsperson). Commissioners usually have the power to investigate and make official decisions about complaints. The privacy commissioner's office may try to resolve a complaint by negotiating or mediating with you and the other person involved. The commissioner may also investigate a complaint and issue a report with recommendations, but they may not be able to provide you with an outcome that feels satisfactory to you. Be aware that there may be a deadline to file a complaint. The process to file a complaint differs depending on where you live. Visit this link to learn more about the process in your province or territory: www.priv.gc.ca/en/about-the-opc/what-we-do/provincial-and-territorial-collaboration/provincial-and-territorial-privacy-laws-and-oversight/.



RECENT PRIVACY COMPLAINT FROM NEWFOUNDLAND AND LABRADOR

[EASTERN HEALTH (RE), 2022 (NL IPC), PH-2022-001]

In 2020, a person living with HIV in Newfoundland went to a blood collection clinic. When this person was checking in at the registration desk, the worker behind the desk loudly asked their co-worker for a registration code. The code included “HIV,” which the clerk loudly repeated. The person living with HIV was concerned that other patients and staff in the room could have heard this interaction and learn about their HIV status.

Afterwards, the person complained to clinic’s management, but was not satisfied with the response. The person then launched a complaint with the provincial Information and Privacy Commissioner. The Commissioner recognized that HIV is extremely sensitive personal health information and that the worker’s actions violated the person’s privacy. The outcome of the complaint was that the Commissioner recommended that the blood clinic remind staff to be mindful of not speaking too loudly.



Submit a complaint to the regulatory college: You could also file a complaint with the provincial or territorial organization that controls the health care professional that breached your privacy. Different health care professionals are regulated by different organizations (often called “colleges”), such as the College of Physicians and Surgeons or the College of Nurses. So, if a nurse violates your privacy, you would make a complaint to the nursing college in your province/territory. Colleges can launch investigations into complaints made against their members and take disciplinary action when appropriate, like suspending their licence or requiring them to take more training. Note that some workers in health care settings (like receptionists or intake workers) are not controlled by a college, meaning this approach would not work.

A RECENT EXAMPLE OF A COMPLAINT TO A PROFESSIONAL COLLEGE

[FORD V PD, 2022(ON HPARB), 21-CRV-0282]

In a 2022 case from Ontario, a person living with HIV filed a complaint with the Ontario College of Pharmacists, after a pharmacy worker accidentally outed his HIV status to his brother. The pharmacy worker called the person’s home phone, and his brother picked up the call. The brother asked for the name of the medication, and the worker told him, without confirming they were speaking to the right person. The brother then looked up the medication name on the internet and saw that it was for HIV.

The College found that this was a privacy breach and ordered the pharmacist in charge to undergo re-training on privacy.

Sue for breach of privacy: Depending on where you live, you could also sue for breach of privacy in court. Four provinces (British Columbia, Manitoba, Saskatchewan, and Newfoundland and Labrador) have privacy laws that allow you to sue someone who has violated your privacy. Except in Manitoba, these laws require proof that the person *intentionally* violated your privacy by disclosing your HIV positive status to others and had no legal excuse for doing so. You do not need to prove that it caused you harm in order to 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*.

If you live in Alberta, Nova Scotia, Ontario, or Saskatchewan, you could also sue someone for “public disclosure of private facts” if they publicly reveal your HIV status. Most of the cases in this area so far have dealt with “revenge porn” situations, but it is possible that the law would apply to violations of personal health information (e.g. your HIV positive status has been revealed through social media). In Ontario, you can also sue someone who intentionally invades your privacy, e.g. if someone accesses your health record without justification, for “intrusion upon seclusion.” You do not need to prove that you suffered harm in order to succeed with a lawsuit on these grounds but the person’s actions must be serious enough to seem highly offensive and harmful.

The main advantage of going to court is that you may receive a money payout if you win your case (although the amount may be small). A disadvantage of only going to court is that a money payout is the only thing they can order whereas a privacy commissioner or regulatory college can order other things like staff training or changes to institutional policies. Lawsuits can also be expensive, complicated, emotionally draining, and time-consuming, and they may not provide you with the solution you are looking for. You may also face cultural, financial, language, or other barriers. Note also that there are also deadlines regarding when you can file a lawsuit (called “limitation periods”), which may differ depending on your province/territory.

Privacy laws in Canada are very complicated and change frequently. The best thing to do if you want to file a complaint or lawsuit is to contact a lawyer.

Taking action can be overwhelming and isolating. Your local AIDS service organization may be able to support you if you experience a breach of privacy. 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. You may be able to find help among the list of resources below.

HIV-RELATED AND OTHER SOCIAL AND COMMUNITY SERVICES

8. WHEN I GET TESTED FOR HIV, WILL MY NAME BE RECORDED?

When you test positive for HIV, the test result is reported to the public health authority responsible for the area where you got tested. The type of information that gets reported to public health is different depending on the location. In a “nominal” test, your name and contact information is reported, but there may be an option of getting an anonymous HIV test, which is a test without your name being reported to public health.

If you get an anonymous HIV test, the test result and non-identifying information (like your age or gender) is supposed to be reported to the public health authority, but not your name. However, if you test HIV positive, when you begin accessing medical care for HIV, there is a good chance that your name will be reported to public health even if you tested anonymously at first. In Ontario, the law allows you to access medical care without being reported to the public health authority, but many people, including health care providers, are not aware of this option. If you live in Ontario and want further information about this, call the HIV & AIDS Legal Clinic Ontario (HALCO) to speak to a lawyer before you agree to any further blood tests using your name. HALCO’s information is below.

Recently, some people have also been able to get HIV self-testing kits that allow them to test themselves on their own or with the help of others such as community organizations. If your self-test comes back positive, you will usually have to get a “confirmatory” test before you can get medical care for HIV. At that point, you have a choice between getting a nominal or anonymous test, as above, to confirm your HIV status.

Whether you get tested anonymously or provide your name, the testing provider is likely to ask you questions about your sex activity such as how many partners you have or have had, what kind of sex you have, whether you always use condoms, etc. to determine the need for testing. Your feeling of safety is important and you **do not need to give this information to get a test for HIV**. You should not be refused an HIV test if you do not feel comfortable getting into detail but still want to get tested.



9. WILL MY PARTNER(S) LEARN THAT I AM HIV POSITIVE IF MY HIV TEST COMES BACK POSITIVE?

HIV “partner notification,” or “contact tracing,” is the practice of finding and informing someone that a person they have had sex or used drugs with has been diagnosed with HIV.

If you test positive for HIV, someone from public health may ask you for information about your sex or drug-using partners, including their names. They may ask you or your doctor to contact them to tell them that they may have been exposed to HIV, and to advise them to get medical care. Or they may contact your partners directly. While public health staff should not share your name with those contacts, in some situations they may figure out that you have HIV.

While it may feel like an unfair invasion of your privacy, some provinces and territories have laws that *require* that partner notification be carried out, while others *allow* it to be carried out. Where there is no specific law requiring contact tracing, health officials conduct contact tracing based on available Canadian guidelines.¹ It is unlikely that legal action would be taken if you don't know or can't remember those contacts.

10. IS MY PRIVACY PROTECTED WHEN I ACCESS COMMUNITY AND SOCIAL SERVICES?

Community services, including AIDS service organizations, Indigenous services, harm reduction services, and shelters provide important support to people living with HIV. Service providers, whether they are staff or volunteers of an organization or a regulated professional (e.g. nurse or social worker) have an obligation to respect the confidentiality of their client, including information about their HIV status or any information provided during counselling (e.g. information around sexual practices, disclosure to partners, etc.).

It means your personal health information (including HIV status) can only be shared with your permission or consent, unless required by law (e.g. through a subpoena or a search warrant) or permitted by law (e.g. to prevent harm to others).

Organizations often have policies regarding record keeping and confidentiality. You have the right to ask about these policies and how your information will be used and/or shared within the organization and others.

11. DO I NEED TO SHARE MY HIV STATUS WITH A “CHILD PROTECTION” WORKER WHO IS INVOLVED WITH MY FAMILY?

No. Usually, you are not legally obligated to tell a child protection worker your HIV status.

The “child welfare” or family policing system has a long and violent history towards Indigenous peoples. In some circumstances, 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. 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. But telling your worker may not feel safe, and you could consider getting support from a lawyer, social worker, or trusted advocate when asked to answer questions from child protection workers. Sharing your Indigenous identity with your lawyer allows them to take steps to provide culturally safe options. Seeking support from community, Elders, knowledge keepers, trusted family members, and friends can also be helpful.

If your HIV status is known by a child protection worker, the worker is required to keep that information private and they are not allowed to treat you negatively because you are living with HIV. They cannot separate someone from their child because of their HIV status.

For more information on disclosure, privacy and parenting, see the HIV Legal Network *Know Your Rights* series at www.hivlegalnetwork.ca/site/kyr/.

¹ CATIE, The HIV testing process, Fact Sheet, Updated in 2021 and available at www.catie.ca/sites/default/files/2022-02/hivtestingprocess-EN-20210713.pdf

WORKPLACES

12. DO I HAVE TO TELL MY EMPLOYER THAT I AM LIVING WITH HIV?

Usually, you do not have to tell your employer or anyone you work with that you are living with HIV. Whether or not you disclose your HIV status at work, and to whom, is entirely up to you. It would be discriminatory for your employer to force you to share this information as a condition of your employment.

But be aware that if you work in a health care setting, practice standards *may* require you to take certain steps to protect others such as consulting an expert in infectious disease or disclosing your status to the regulatory body of your profession. These requirements are set out by the organizations that regulate your profession, like the College of Dentists or College of Physicians and Surgeons. If you work in health care or are considering a career in health care, it might be a good idea to contact the relevant regulatory body to find out the specific rules that would apply to you.



13. WHEN I APPLY FOR A JOB, CAN AN EMPLOYER ASK ME IF I AM LIVING WITH HIV OR MAKE ME TAKE AN HIV TEST?

No. Generally, employers cannot legally ask for your HIV status as a condition of hiring you, including on a job application or during an interview. This is because it would be discriminatory for your employer to force you to share this information as a condition of your employment. As discussed above, there are very few legal exceptions to this rule (e.g. health care workers).

A potential employer *can* ask you questions to figure out whether you can perform the duties of the job. Sometimes, employers can require a medical exam *after* making an offer of employment to determine if you are able to perform specific duties (e.g. if you are physically able to lift heavy objects) or if you require accommodation for a disability (meaning an employer is required to remove hurdles so you are able to do the main duties of the job). An HIV test should not be included in such medical tests because a positive test result is not relevant to whether or not you can perform specific job duties.

Despite that, some municipalities require people applying for a body rub license to take a medical exam that includes an HIV test, and to test negative for HIV in order to obtain a license. Even though this is discriminatory and violates human rights laws, these practices still exist.

If you are applying for jobs and are concerned about applications or interviewers that might ask about your health status or specific medical conditions, including HIV, brainstorm ideas ahead of time about how you would handle these questions. How you choose to answer these questions is a personal decision.

Some things to think about when deciding how to answer these questions could include:

- Do you want to wait until a later stage in the hiring process to decide whether to disclose some health information (e.g. after you learn more about the specifics of the work or after they offer you the job)?
- Does this employer provide health insurance? If so, you may want to see a copy of the enrolment form, as some insurance plans do not require any information about individual employees' medical records, and others may ask for your personal health information.
- Do you expect to need health-specific accommodations when you are on the job?
- How public are you about your HIV status?
- Do you want to provide partial information to test how they may respond?

If you decide to tell a potential employer that you have HIV or refuse to answer questions about your HIV status and you are not hired because of this, this would likely be considered discrimination based on disability.

14. DO I NEED TO TELL MY CO-WORKERS THAT I AM LIVING WITH HIV?

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

15. IF I REQUEST ACCOMMODATION AT WORK OR NEED TIME OFF, DO I NEED TO TELL MY EMPLOYER IT IS BECAUSE I AM LIVING WITH HIV?

No. If you require accommodation at work, you do not need to tell your employer it is because you are living with HIV. But you will probably need to provide medical documents explaining the specific limitations or requirements that you have in order to be able to perform the main 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 an insurance 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 main duties of your job. 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 keep your job.

16. DOES MY EMPLOYER HAVE TO KEEP MY HIV STATUS PRIVATE?

Yes. If you decide to tell your employer or a co-worker who is *acting on behalf of your employer* (such as a human resources manager) that you have HIV, they are required to keep this information to themselves. Legally, your employer (or the person acting on their behalf) cannot share information about your HIV status or other medical information to third parties (such as other employees, clients, other companies, friends, etc.) without your permission.

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 go to court. For more information about this option, refer to Question 7.

Finally, be aware that if you tell a co-worker (who is not acting on behalf of your employer) your HIV status, that co-worker does not have the same legal requirement of confidentiality as your boss. Even so, there may be situations where they can be taken to court for publicly sharing your HIV status when you've told them to keep the information private. As with breaches of privacy in other areas, you may have the option to go to court.

BEARS



POST-SECONDARY INSTITUTIONS

17. IF I AM A STUDENT, DO I HAVE TO TELL THE INSTITUTION WHERE I STUDY THAT I AM LIVING WITH HIV?

No. Usually, there is no legal obligation to tell a post-secondary institution (such as trade school, job training program, college, or university) that you are living with HIV. If your band office is administering the funds for your post-secondary studies, you are not legally required 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.

It would be discrimination for a school to request this information as a condition to accept you or for you to continue in a program of study.

If you are studying in a health care program, there may be some exceptions to this general rule. Contact the relevant regulatory bodies of the profession you are studying for, in order to find out the specific rules that would apply to you.

18. 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 fairness for students living with disabilities, post-secondary institutions are required to provide accommodation to students who need it because of a disability, which HIV is considered. This 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 carry out — then the institution does not need to provide it.

The institution should develop accommodations for you that respond to your needs, and they should check in with you to see if the accommodations are helping, or if they need to be changed. Academic accommodation does not change the main requirements or expectations of your program. You will still need to pass tests or exams, turn in assignments, and demonstrate that you have mastered the required skills. Accommodations are about trying to “level the playing field” with other students so you are able to perform at a similar level to students without a disability. For example, a student with a health condition that results in tiredness might be given extra time to complete tests or assignments.

To request 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. To get accommodation, you do not need to tell the school about your specific medical condition(s), such as HIV. However, if you do not provide enough medical information, the school may not be required to accommodate your needs.

19. DO I NEED TO TELL MY CLASSMATES THAT I AM LIVING WITH HIV?

No. HIV cannot be transmitted through casual contact, like hugging, talking, or kissing. You get to decide if you want to share that information with other students or not.



20. IF I TELL SOMEONE AT SCHOOL THAT I AM LIVING WITH 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 secret. 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 requirements 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 school. In other words, if you tell a friend that you are living with HIV, the friend does not have the same legal responsibility to keep this information a secret, but there may be situations where you can take them to court for publicly sharing your HIV status when you've told them to keep the information private.

Even where someone has a legal obligation to keep your HIV status confidential, sometimes there may be violations of your privacy. 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 Question 7.

OTHER SITUATIONS

21. DO I NEED TO SHARE MY HIV STATUS WITH A LANDLORD OR THE SHELTER WHERE I AM LIVING?

No. HIV cannot be transmitted through casual contact. You get to decide if you want to share that information with your landlord or the people managing the shelter where you are living. They are also not permitted to discriminate against you if they know your HIV status. Human rights laws across the country prohibit landlords from discriminating against you because you have HIV (or even if you are just thought to have HIV).

22. DO I NEED TO SHARE MY HIV STATUS WITH FRIENDS, FAMILY, OR SEXUAL PARTNERS?

You do not need to disclose that you have HIV to your family (parents, children) or to friends. In non-sexual interactions or situations, it is up to you to decide who you want to disclose your HIV positive status to.

However, it is important for you to know that sex is an exception in Canada. Not telling a *sexual* partner that you are HIV positive before sex may expose you to criminal prosecution. Current criminal law in Canada requires disclosure before sex that poses what the courts have called “a realistic possibility of transmission.” If you do not disclose your HIV positive status in these circumstances, 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 telling your sexual partners that you are HIV positive.

This legal obligation to disclose your HIV status applies equally to any sexual partner — 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.

Disclosure requirements under the criminal law

Generally, you do not need to tell your sexual partner your HIV status if:

- You have a low viral load (less than 1,500 copies of HIV/mL of blood) and use a condom, *or*
- You have an undetectable viral load (less than 200 copies of HIV/mL of blood).

The requirements to disclose in other situations depend on what province or territory you live in. For more information on HIV disclosure to sexual partners, see [HIV and the Criminal Law in Canada](#).

23. WHAT CAN I DO IF A FRIEND, PARTNER, OR EX-PARTNER REVEALS MY HIV STATUS TO OTHER PEOPLE?

Once your privacy has been violated, 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 HIV status — about the importance of keeping that information private may help prevent future violations. Your 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 options and available outcomes are limited and will depend on where you live and work. For more information on going to court, see Question 7.

Remember: you do not need to deal with your questions and concerns about privacy alone. You can access support and care. In addition to AIDS service organizations, below are some resources you can consult or contact if you have further questions.

ADDITIONAL RESOURCES

HALCO, CAAN, and HIV Legal Network, [HIV and the Criminal Law in Canada](#), 2023.

HIV Legal Network, *Know Your Rights — Indigenous Communities and HIV/HCV in federal prisons*, 2023.

CAAN Communities, Alliances and Networks at www.caan.ca

HIV Legal Network at www.hivlegalnetwork.ca.

If you are in Ontario, you can contact the HIV & AIDS Legal Clinic Ontario at www.halco.org or 416-370-7790 or 1-888-705-8889 (toll-free).

If you are in Quebec, you can contact Coalition des organismes communautaires québécois de lutte contre le sida (COCQ-SIDA) at <https://cocqsida.com/outils/contact.html> or 514-844-2477 (poste 0) or 514-844-2498.

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For more information:
hivlegalnetwork.ca/IndigenousCommunities

