



# KNOW YOUR RIGHTS

PRIVACY  
AND HEALTH  
RECORDS



## Know Your Rights: Privacy and health records

**You have the right to privacy when it comes to your HIV status.** Your HIV status is your personal health information. Most provinces and territories in Canada have laws that require health professionals to keep your personal health information private (confidential). These laws set rules around when healthcare workers can collect, use, or reveal your HIV status.

Healthcare providers can only disclose your HIV status in limited circumstances and must protect this information from being shared without your consent. It can be difficult to fully understand how your health information is being collected, stored, used, or disclosed, especially as you engage with many different health professionals throughout your life. You should not hesitate to ask your health professionals and/or health facilities about their policies for protecting your personal health information.

**The information contained in this publication is information about the law as of December 2023, but it is not legal advice. For legal advice, please contact a lawyer in your region.**

The HIV Legal Network works on the land now called Canada, which is located on treaty lands, stolen lands, and unceded territories of Indigenous groups and communities who have respected and cared for this land since time immemorial. We work to address the ongoing injustices and resulting health inequities faced by Indigenous Peoples that 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.

## Acknowledgements

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**Graphic Design:** Ryan White, R.G.D. (Mixtape Branding)

**Translation:** Laetitia Walbert



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## 1. What are health records?

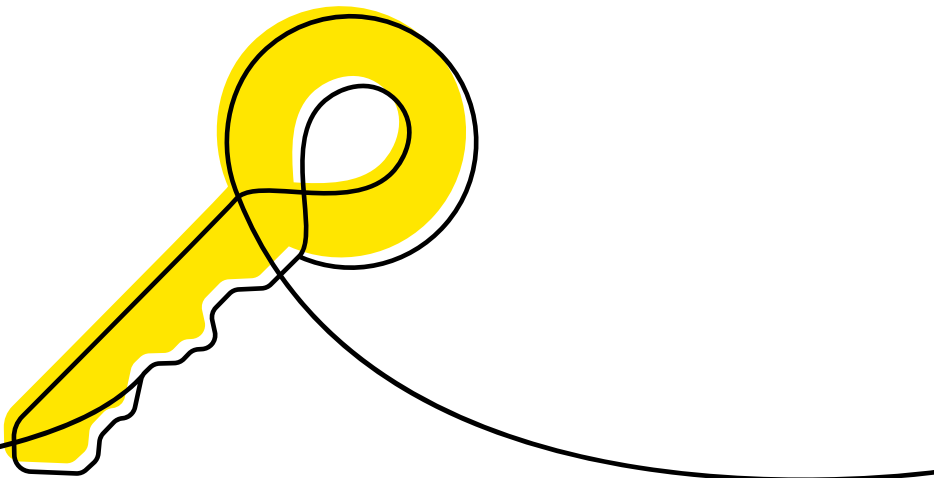
Health records are created by health professionals (e.g. doctors, nurses, dentists, psychiatrists) and facilities (e.g. clinics, hospitals) that provide you medical care. Your records contain health information that has been collected and stored in the course of providing you medical care. This information is diverse and can include information about your physical or mental health, including your HIV status, or your family health history; copies of your test results, prescriptions, doctors' notes, or X-rays; or information related to payments or eligibility for insurance coverage, among other things.

In most provinces and territories, your information is stored electronically by your physician or healthcare facilities in centralized province-wide databases (sometimes called "Electronic Health Records" or EHRs), which can be accessed by many different health professionals across a province. The information included will vary from one province/territory to another.

## 2. Is the confidentiality of my health records protected?

Healthcare professionals and facilities have a legal and ethical obligation to maintain confidentiality and take measures to safeguard your health information. This confidentiality is critical to building trust between a healthcare provider and patient. Health professionals are also obligated to keep your information accurate, current, and complete, and to protect it from theft, loss, or unauthorized use or disclosure.

However, the right to privacy and confidentiality is not absolute. In every province and territory, there might be circumstances where the law authorizes or requires your personal information to be disclosed without your consent (see below).



### 3. Is there anything I can do if I don't want certain information in my health records to be shared with another health professional?

In most cases, your health information can only be disclosed with your consent — but your consent does not always need to be express (i.e. stated verbally or in writing). Healthcare professionals are generally *allowed* to assume that you have consented to the sharing of your personal health information within your “circle of care,” which is the term used to refer to the group of healthcare professionals involved in your medical care. In other words, information can be shared within the “circle of care” without your express consent.

While this may be the general rule, you can also tell your doctor you do not want your information (e.g. your HIV status) to be shared with another healthcare professional. In those situations where you have expressly told a healthcare professional not to share specific health information with others, your doctor is not supposed to include that information in records going to other health professionals, even if they are involved in your care. (For information about limiting access to your Electronic Health Record, see Q11 below.)

Depending on the applicable provincial/territorial legislation, your doctor might still be able — or even be obliged — to tell other health professionals that there is important information for your care that has not been included in your shared records. In this way, the other professional knows that an important piece of information is missing and can discuss it directly with you.

Within a hospital setting, there may be a specific process in place to limit the sharing of your health information. If you don't want all members of your medical team to have access to certain information, you may have to fill out a specific request form to block it. This process might vary from one institution to another.

Finally, in some rare cases, the law might authorize or require the disclosure of your health information without your consent. This might need to be done for different reasons, including to prevent harm, to protect public health, or, for example, to comply with a court order (see below). In such exceptional circumstances, the fact that you told your doctor not to share your HIV status would not prevent the sharing of that information.

## 4. In what circumstances can a healthcare professional share my health information without my consent?

Although healthcare professionals have an ethical and legal obligation to maintain confidentiality and disclose your personal health information only with your consent (whether that consent is express or implied), there are some circumstances where the law authorizes or requires them to share your health information without your consent.

**Legal rules vary 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 necessary to provide you with appropriate medical care, but it is impossible to obtain your consent in a timely manner (e.g. emergency situations).
- Disclosure is necessary 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 entitled to make healthcare decisions on your behalf).
- Disclosure is required for the purpose of mandatory reports (e.g. in certain circumstances, HIV test results can be reported to public health authorities — see below).
- Disclosure is necessary to verify your eligibility to receive healthcare and related services.
- Disclosure is necessary to comply with a warrant or other court order.
- Disclosure is necessary to inform another person about the circumstances of your death, including to help a relative make a decision about their own health.
- Disclosure occurs in a context where a patient is in custody or in a psychiatric facility, to help an institution provide them with appropriate healthcare.

## 5. Can a health professional share my health information with one of my family members or friends?

Generally, health professionals need your express consent to share your health information with someone who is not a health professional involved in your care. However, this rule may be applied differently when it comes to members of your family or people with whom you have a close relationship.

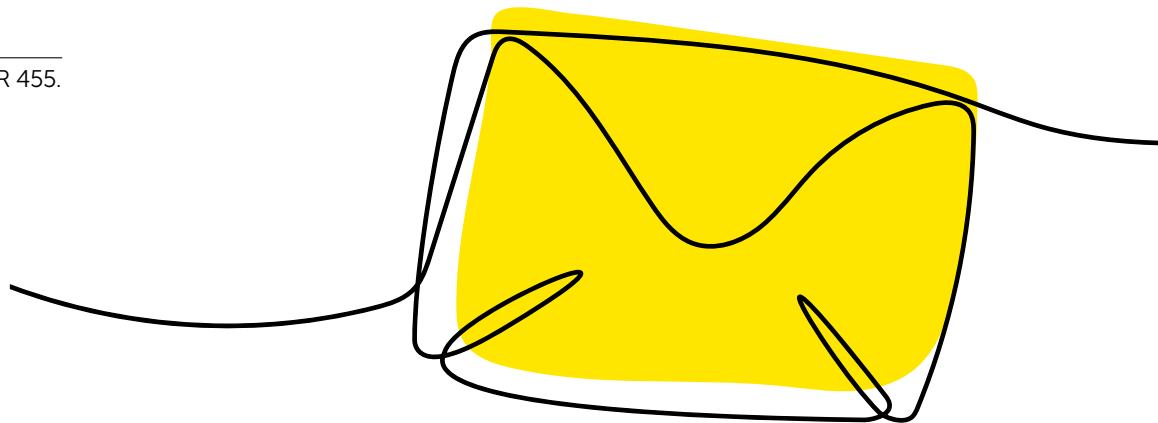
The rules vary from one province/territory to another, but the law usually authorizes health professionals to disclose at least some general information to family members or other close contacts, unless you say you do not want them to be told. In practice, the information that can be shared relates to your *physical presence* in the facility and your *general condition*. This means a hospital could be allowed to tell your mother that you are in the hospital unless you specifically tell the nurse you do not want your family to know that fact. In Quebec, health professionals cannot disclose any information regarding your health to your family members unless you have given permission to do so.

Note that in some provinces, like Ontario and Manitoba, the law also allows certain general information to be released beyond just your friends and family. If you are concerned about this happening, tell your healthcare facility that you do not want your information to be disclosed.

Finally, in every province, a health professional can disclose your personal health information to others if necessary to prevent a risk of serious harm or an “imminent risk of serious harm.”<sup>1</sup> A physician may claim they have the right, in some circumstances, to disclose your HIV status to your spouse or partner, if the physician believes your partner is at clear and imminent risk of serious harm. Keep in mind that public health authorities have confirmed that correct use of a condom prevents HIV transmission, there is no risk of transmitting HIV to a sexual partner when a person has an undetectable viral load, and there is almost zero risk of transmitting HIV when a person has a suppressed viral load (i.e. viral load measurement of less than or equal to 1000 copies per mL).

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<sup>1</sup> Smith v. Jones, [1999] 1 SCR 455.



## 6. Can I access my health records?

Your personal health information belongs to you. Health laws recognize that you have the right to request access to your medical information, and health professionals must assist you and respond to your request without delay.

There may be a fee to access the records, and you might need to make a request in writing or complete a particular form. In a growing number of provinces, you can also access your health information online through electronic health portals. Contact your health professional, or the relevant healthcare facility, to find out about the procedures involved.

**Note that, in some rare circumstances, a health professional or facility could refuse to give you access to certain information in your record, including when:**

- It would likely reveal confidential information about another individual or the identity of a third party who provided information in confidence;
- It may present a risk of harm (to you or another individual); or
- It could interfere with an ongoing investigation.

If a health professional refuses to give you access to this information, they must explain why and indicate that you have the right to file a complaint against the decision. These complaints are generally made with either a provincial or federal privacy commissioner (a.k.a. an ombudsperson or a review office). (See below for information about complaints.)

## 7. Can I make changes to my medical record?

You cannot make changes to your medical records yourself, but you can request a health professional to correct or complete your information if you think it is inaccurate or incomplete. You may have to make your request in writing.

If you are not happy with the response of a health professional regarding the correction of your medical record, you can file a complaint with the relevant privacy commissioner.

## 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. In Quebec, “nominal” details (e.g. a person’s name and contact information) related to a positive HIV test result are never shared with public health. Elsewhere, the type of information that gets reported to public health is different depending on the type of test you take. In a nominal test, your name and contact information are 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) are supposed to be reported to the public health authority, but not your name. Unfortunately, anonymous testing is not currently available everywhere in Canada. In provinces without anonymous testing, you might be able to take a non-nominal test, where your blood sample is sent to a laboratory with only your initials or a code and your name is not reported to public health, but the result is linked to your healthcare record. To learn about the testing options available to you, contact your local AIDS service organization or public health department.

However, if you test positive for HIV, there is a good chance that your name will be reported to public health when you begin accessing medical care for HIV, 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 healthcare 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. See below for HALCO’s contact information.

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 second, laboratory test to confirm your result (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 outlined 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 sexual activity, such as your number of partners, what kind of sex you have, whether you 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 sharing these details but still want to get tested.

## 9. Will my partner(s) learn that I am living with HIV 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 shared drug-use equipment 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. In Quebec, public health cannot contact your partners without your consent.

Public health staff should not share your name with those contacts, but in some situations your partners may figure out on their own 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. In any event, it is unlikely that legal action would be taken if you don’t know or can’t remember your past contacts.

## 10. Who has access to my HIV status once I test positive? Where are my results recorded?

Your test results and other information about your HIV status will be included in records created by health professionals and facilities that have collected that information (e.g. your doctor). Today, health professionals usually store information electronically.

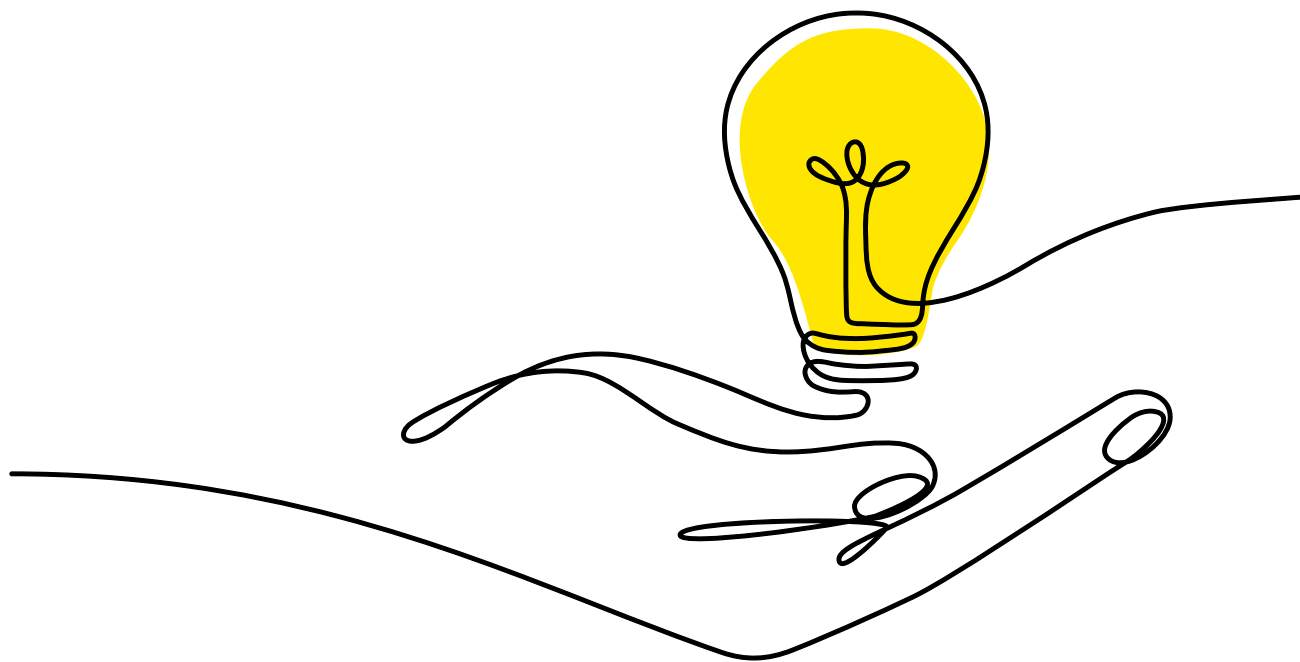
In addition to health records held by healthcare providers and facilities, in most provinces, information about your HIV status (e.g. laboratory results or HIV-related prescriptions) will be included in centralized databases and shared electronic records that can be accessed by many different health professionals within a province. Electronic Health Records (EHRs) and centralized databases allow health professionals involved in your care to easily and instantly access your health information, but they also pose serious challenges in terms of privacy protection. EHRs can complicate an individual’s ability to control what health information can be accessed and by whom. This can make it difficult to meaningfully consent to that access and receive the guarantee that only authorized healthcare professionals (i.e. those directly involved in the person’s care) will see the relevant information.

## 11. Can I limit access to my health information when it's included in centralized databases or EHRs?

It may not be possible for you to prevent your information from being *included* in centralized databases or EHRs. However, in some cases, you may be able to restrict access to or “mask” your information. In most provinces, you can request to mask certain parts of your EHR, which prevents a healthcare provider from seeing your personal health information.

In Ontario, for example, you can block healthcare providers from accessing, in whole or in part, your EHR data (including your HIV status) by asking for a “consent directive” to be added to your record. This means when a healthcare provider tries to access blocked EHR data, a notice pops up indicating that access is denied, and they will not be able to see that information. Under a limited set of conditions, however, they can access that data. This is called a “consent override” and your healthcare provider should inform you when a consent override occurs. In B.C., you can restrict access to information in your EHR through a “disclosure directive” so healthcare providers must obtain your express consent to access that information, unless an emergency occurs or other exceptions apply. In Alberta, you can ask to mask health information stored in Netcare by contacting a participating health service provider, who can help you complete the request and submit the application on your behalf.

Many healthcare facilities have policies in place to protect privacy, as well as staff members who are responsible for dealing with privacy issues. These individuals should be able to tell you how to restrict access to your health information included in shared health records and databases, if you wish to do so.



## 12. What can I do if a health professional breaches my privacy?

If you believe that your privacy has been breached by a healthcare 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 healthcare provider or facility. Healthcare 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 might 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/](http://www.priv.gc.ca/en/about-the-opc/what-we-do/provincial-and-territorial-collaboration/provincial-and-territorial-privacy-laws-and-oversight/).

**Submit a complaint to the regulatory college:** You could also file a complaint with the provincial or territorial organization that controls the healthcare professional that breached your privacy. Different healthcare 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 healthcare settings (like receptionists or intake workers) are not controlled by a college, meaning this approach would not work.

**Sue for breach of privacy:** Depending on where you live, you could also sue for breach of privacy in court. Various provinces allow you to sue for breach of privacy in

different ways based on provincial laws. Most of these laws require proof that the person intentionally violated your privacy — for example, by disclosing your HIV 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 cases of this kind 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 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. In legal terms, this is called “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 be considered highly offensive and harmful. People living in other provinces can still sue for “public disclosure of private facts” or “intrusion upon seclusion,” but courts in those provinces have not yet recognized these forms of privacy breach.

The main advantage of going to court is that you may receive a financial payout if you win your case (although the amount may be small). A disadvantage of only going to court is that a judge could be more limited in the actions that they order from a wrongdoer 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. Keep in mind that there are also deadlines regarding when you can file a lawsuit (called “limitation periods”), which may differ depending on your province/territory, and that you may be ordered to pay for some or all of your opponent’s legal fees if you lose a lawsuit (a “costs award”).

**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 or a legal clinic.**

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.







1240 Bay St. Suite 600  
Toronto, ON M5R 2A7, Canada

Phone: +1 416-595-1666

[HIVLEGALNETWORK.CA](http://HIVLEGALNETWORK.CA)

