

# Know Your Rights



## Privacy and health records



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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 care. Your records contain health information they have collected and stored. This information is diverse and can include information about your physical or mental health, as well as that of your family health history; copies of your test results, prescriptions, doctors' notes, or X-rays; information related to payments or eligibility for insurance coverage; etc.

With the development of new technologies, your information is now more often stored electronically by your physician or health-care facilities. Information may also be included 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, but it can include laboratory test results, prescribed medications, hospital visits, surgeries, allergies, etc.

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

Health-care professionals and facilities (and other health information custodians) have a legal and ethical obligation to maintain confidentiality and take measures to safeguard your health information. This is true whether your information is included in their paper or electronic medical records. Maintaining confidentiality is fundamental to the relationship of trust between doctor and patient. Health professionals also have the obligation 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). Moreover, when your information is included in a centralized database (EHR), your physician can no longer guarantee the confidentiality of that information. Finally it can be very 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. (For information about legislation protecting personal health information in Canada, see "Disclosure as a patient" in this series.)

### 3. Is there anything I can do if I don't want certain information in my health record 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). Health-care professionals are often entitled to assume that you have consented to the sharing of your personal health information with *other health-care professionals* involved in your care. This is how they are able to share your information within the “circle of care” without asking you for your *express* consent. (For more information, see “**Disclosure as a patient**” in this series.) In some provinces/territories, this is true unless you have told your doctor you do not want your information (e.g., your HIV-positive status) to be shared with another health-care professional.

In Ontario, for example, the term “lock box” is used in situations where you have expressly told a health-care professional not to share your information with others, even if they are involved in your care. If you make this request with respect to your HIV-positive status, then your doctor is not supposed to include that information in records going to other health professionals.

Depending on the applicable provincial/territorial legislation, your doctor might still be able — or even 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. 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 is likely to vary from one institution to another.

Finally, in some limited circumstances, the law might authorize or require the disclosure of your health information *without* your consent, in order to prevent harm, 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-positive status would not prevent the sharing of that information.

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

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

Legislation varies 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 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 below).
- Disclosure is necessary in order to verify your eligibility to receive health care and related services.
- Disclosure is necessary for the administration, planning or evaluation of a health-care program.
- 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 for the purposes of research (specific conditions usually exist for disclosure in this context).

### 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 disclose your health information to someone who is *not* a health professional involved in your care. However, things may be different with respect to members of your family or people with whom you have a close relationship.

Legislation varies from one province/territory to another, but the law usually authorizes health professionals to disclose (at least) information related to your physical presence in the facility and your general condition to family members or other close contacts, unless you say you do not want them to be told. In practice, this means a hospital will be able 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 jurisdictions, like Ontario and Manitoba, the law also allows certain general information to be released beyond friends and family. If you are concerned about this happening, tell your facility that you do not want your information to be disclosed.

Finally, in every jurisdiction, a health professional can disclose your personal health information if necessary to prevent an imminent risk of serious harm. Therefore, a physician could have the right, in some circumstances, to disclose your HIV-positive status to your spouse or partner, if the physician believes your partner is at clear and imminent risk of serious harm (e.g., if you engage in risky sexual activity without disclosing your HIV-positive status).

## 6. Can I access my health records?

Your personal health information belongs to you. Health legislation recognizes 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. You might need to make a request in writing or complete a particular form. Contact your health professional, or the relevant health-care facility, to find out about the procedures involved.

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

- It would likely reveal confidential information about another individual;

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

If a health professional refuses access to information, they must explain why and indicate that you have the right to file a complaint against the decision with the relevant *privacy commissioner* (a.k.a., *ombudsman* or *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, 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 with regard to the correction of your medical record, you can file a complaint with the relevant privacy commissioner.

## 8. Who is informed of my HIV status when I take an HIV test?

When you take an HIV test, the results are known to the person who provided you with the test and informed you of the results, as well as the laboratory that analyzed your blood. Depending on the type of test, your name may not necessarily be identified. If you take an HIV test through your family doctor, they will also likely know about your results.

HIV and AIDS are reportable illnesses in all Canadian provinces and territories. That is, when an individual tests positive for HIV, the result is also reported to the *provincial or territorial public health authorities*. The type of information that gets reported to public health, and perhaps stored in a database, depends on the law and practice in a province or territory. In Ontario, for instance, if you take a *nominal* test, the testing laboratory will report your HIV-positive status, your name, date of birth, gender, and contact information to public health. If you decide to take an *anonymous HIV test*, only your test result and non-identifying information will be reported to public health and no one except you will

know that you took an HIV test. (However, once you seek medical care for HIV, your name will be reported to public health). Unfortunately, anonymous testing is not available across the country. In jurisdictions 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. To learn about the options available to you, contact your local AIDS-service organization or public health department.

Finally, it's important to know that public health authorities are responsible for protecting public health and preventing the transmission of infections including HIV. If a person tests positive for HIV, public health will promote the notification of your sexual and drug-use partners. This is known as contact-tracing, partner counselling, or partner notification. The powers and procedures of public health authorities vary from one province/territory to another.

## 9. 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-positive status will be included in records created by health professionals and facilities that have collected that information (e.g., your doctor, or your dentist, if you chose to disclose to them). Today, health professionals usually store information electronically.

In addition to health records held by health-care providers and facilities, information about your HIV status (e.g., laboratory results or HIV-related prescriptions) might also 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 are being developed across Canada to consolidate

patients' health information. While such records might be seen as improving care by allowing health professionals involved in your care to easily and instantly access your health information, they also pose serious challenges in terms of privacy protection. They complicate an individual's ability to control what health information can be accessed and by whom, making it difficult to meaningfully consent to that access and receive the guarantee that only authorized health-care professionals (i.e., those directly involved in the person's care) will see the relevant information. Existing EHRs and other centralized database include the Ontario Laboratories Information System, Alberta Netcare, PharmaNet in B.C., and the Quebec Health Record.

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

You may not have the right to refuse having your information included in centralized databases or EHRs. However, you may be able to restrict access to or mask your information in some cases. For example, you can restrict access to your information in PharmaNet, B.C.'s database for prescription drug-use, by asking a pharmacist to include a keyword in your record so that only health-care professionals who know that keyword will be able to gain access. In Alberta, you may be able 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.

For more information about protecting information related to your HIV-positive status, contact the B.C. Civil Liberties Association, or the HIV & AIDS Legal Clinic Ontario (HALCO). Provincial privacy commissioners should also be able to provide you with information about the protection of health information in electronic records and databases. Finally, many health-care facilities have policies in place to protect privacy, and staff members responsible for 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.

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

If you believe that your privacy has been breached by a health professional, you have several options.

- First, you may want to discuss the matter directly with the health professional or facility in question. Health facilities, such as hospitals, usually have staff members responsible for privacy issues.
- You can also file a complaint with a privacy commissioner. Commissioners (or ombudsman) usually have the power to investigate and make rulings about complaints. Be aware that there may be a deadline to file a complaint. If you live in Prince Edward Island, Nunavut, Northwest Territories or the Yukon, and you want to make a claim against a physician in private practice or another private health provider (rather than a public body like a public hospital, for example),

you will need to contact the office of the *Privacy Commissioner of Canada*. In any other case, you should contact the privacy commissioner (or ombudsman) for your province/territory.

- For complaints related to EHRs (or centralized databases), there might be a specific procedure in place. For instance, in Quebec, complaints about the Quebec Health Record can be addressed to an agent in charge of the central co-ordination database.

Note that provincial laws which specifically protect health information make it an offence to either knowingly or willingly collect, use or create health information contrary to the legislation. Other offences and associated penalties might be found under each law, or in other privacy legislation. For more information, you should consult the applicable legislation, if any, in your province/territory.

## 12. Can I sue a health professional or health facility for breaching my privacy?

It depends on where you live. Four provinces (B.C., Manitoba, Saskatchewan, and Newfoundland and Labrador) have specific legislation (a Privacy Act) that allows you to sue a person who has violated your privacy. These statutes require proof that the person acted willfully in violating your privacy (except in Manitoba), and had no legal excuse for doing so. You will not need to prove that you suffered harm as a result of the privacy violation in order to succeed. You may be awarded monetary damages if you win the case.

In Quebec, you may be able to bring a suit alleging violation of your privacy, and obtain damages, based on the *Quebec Civil Code* and the *Quebec Charter of Human Rights and Freedoms*. If you

live in another province or territory, it will be more difficult to bring a case to court and obtain damages. 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). However, lawsuits can be expensive, complex and lengthy, and may not ultimately provide you with a solution. Moreover, they may expose you to further publicity. Note that there are also limitation periods which vary between provinces/territories, restricting the amount of time available for launching a lawsuit after the breach occurs. Finally, if you decided to sue, you should be represented by a lawyer. A lawyer can also provide more information about your options.

### For further information

- British Columbia Civil Liberties Association, *Privacy Handbook*. Includes information about Electronic Health Records (EHRs) and their development in Canada. On-line: <http://bccla.org/privacy-handbook/>
- Provincial/territorial government websites provide information, Q&A documents and brochures about laws that protect health information. See, for example, *Saskatchewan Health Information Protection Act* ([www.health.gov.sk.ca/hipa](http://www.health.gov.sk.ca/hipa)), or *Ontario Health Information Protection Act* ([www.health.gov.on.ca](http://www.health.gov.on.ca) > Legislation).

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