

# HIV TESTING HANDBOOK

A GUIDE TO YOUR RIGHTS



BRITISH COLUMBIA CIVIL LIBERTIES ASSOCIATION  
BCCLA.ORG

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# 1. IMPORTANT NOTICE AND QUALIFICATION

This handbook has been prepared and published for educational and discussion purposes only. It is not legal advice and it is not intended that this handbook should in any way replace legal advice from a qualified lawyer. Individuals with specific legal problems should seek advice from a qualified lawyer.

## INTRODUCTION

This handbook covers some of the topics that you need to know to understand your rights in regards to HIV testing in a new environment where the push is for “routine testing.”

It covers topics like informed consent, “non-nominal” (no name) testing, how to safeguard your medical privacy and limit who can view your medical information, and information about the criminal law and non-disclosure of HIV status to sexual partners.

This handbook is designed for both patients and service providers and sets out what you need to know about your rights and making the right choice for you.

## ABOUT THE BCCLA

The B.C. Civil Liberties Association (BCCLA) is a registered charity, located in Vancouver, British Columbia. Since 1962 the BCCLA has worked to protect and promote civil liberties in British Columbia and Canada. Our programs include education, complaint assistance, legal reform and litigation. The majority of our funding comes from private grants and donations. The BCCLA does not provide legal advice and is not a legal referral service.

## 2. INTRODUCTION TO HIV TESTING

There is a lot of excitement about new treatment options for people living with HIV (the virus that causes AIDS). New HIV treatments have been “game-changers” for many people in Canada who may now live with HIV as a long-term, manageable condition instead of a fatal illness. In addition, people on these medications drastically reduce their risk of passing on HIV to sexual partners. So it is more important than ever that people have access to HIV testing and treatment.

**But increased access to testing doesn't mean automatic or forced testing. It is still critical that people have the information to make their own choices and**

**exercise their rights.** Just because HIV testing is a great idea generally doesn't mean that the timing is right for you right now. Plus, you might want to take some steps to protect your medical privacy before you have an HIV test.



This handbook covers some topics that you need to know to understand your rights in regards to HIV testing. It deals specifically with HIV testing in British Columbia, although people in other parts of Canada may find some of the information useful as well. This Handbook is intended for patients who are looking for more detailed information and as a resource for service providers.

### 3. DIFFERENT KINDS OF HIV TESTS

HIV testing is free and available from many health care providers including your family doctor, and at sexual health clinics and community health clinics.

#### **Blood Test**

The usual way to test for HIV is with a blood test. A blood sample that is drawn by a health care provider is sent to a medical laboratory and the results of the test are returned to the health care provider who informs you of the result. This process usually takes a week or two.

Some health care providers are now offering to give test results over the phone if the test result is negative (that is, no HIV was found). The problem with that system is that by process of elimination, you would know if you can't get your results over the phone that it must be a positive result (that is, HIV was found). So, even if results are offered over the phone, you might want to make the effort to return to the health care provider to get your results so that you can be supported and have your questions answered.

#### **Rapid Test**

Several health care providers in B.C. are now offering rapid tests (also known as point-of-care tests). These tests don't have to be processed by a laboratory, so you get the results right away. These are very accurate tests, but it is still possible that the result might be a "false positive".

If your rapid test is positive, you should have a regular HIV blood test done as a confirmatory test to make sure that the rapid test result was correct.

#### **Home Test Kits**

Although some HIV home testing kits are advertised on the Internet for mail order, they aren't licensed for use in Canada.

## 4. INFORMED CONSENT

There is a big push for health care providers to do “routine” testing. This is supposed to mean that people are routinely *offered* an HIV test. Unfortunately, some health care providers are misunderstanding the call for “routine testing” and are testing people without proper informed consent. For example, some hospitals and emergency rooms have introduced routine testing for all patients and there have been reports of people not knowing that they were being tested for HIV or thinking it was mandatory. Pregnant women often report being tested without their knowledge and consent. It is increasingly important for people to understand that if they are in a hospital or emergency room and told that they are going to be tested for HIV, that they have a right to say no to that “offer”.



## 4. INFORMED CONSENT

### CONSENT TO HIV TESTING NEEDS TO BE:

#### Informed

- You have the relevant information to make a choice

#### Voluntary

- You can't be forced
- However, there are a few situations in which an HIV test is a requirement, for example: an HIV test is part of an immigration medical exam

#### Specific

- You must know the test is specifically for HIV
- It is not enough to be told that the healthcare provider is doing "some tests" or "some blood work"

## 5. THE NEED FOR MORE COMMUNICATION FROM PATIENTS AND PROVIDERS

You might find that your health care provider assumes you are consenting to an HIV test unless you say that you do not want an HIV test. This is called “opt out” testing. **If you do not want an HIV test and you are in an “opt out” situation, it is not enough that you do not say “yes”; you will have to actually say “no”.**

Ideally, you would get counselling before and after your test to get the information you need and answers to all your questions. However, not everyone has access to these important services. There is a view among some health care providers that pre-test counselling is a “barrier” to testing and some health care providers say that they don’t have the time to do comprehensive counselling.

**Pre- and post-test counselling are very important HIV prevention and education opportunities, and obviously there is no informed consent without relevant information.** While some providers are relying on short “fact sheets” to provide information to patients, the information in such hand-outs is limited. They rarely mention, for example, important matters like the possibility of criminal charges for people living with HIV who are accused of not disclosing their HIV status to sexual partners.

**The information in this handbook is not a substitute for pre-test counselling.** The handbook sets out the issues that patients have told us are important and relevant to their decisions on HIV testing. Since people considering HIV testing will now often need to be more pro-active in gathering needed information, this handbook should help patients to ask questions they otherwise wouldn’t even know to ask and help service providers answer those questions and make helpful referrals.

## 6. ANONYMOUS AND NON-NOMINAL TESTING

In some places in Canada you can get an anonymous test, which means that there are no identifiers attached to your test. **There is currently an anonymous HIV testing pilot project in B.C. where your name and contact information are not collected or recorded.** You are given a numbered testing code that only you know and you must provide that code to get your result. Anonymous HIV testing is available at several clinics in the Lower Mainland. For information on where to test, go to <http://smartsexresource.com/topics/hiv-anonymous-testing>. It is expected that other clinics in B.C. will start offering anonymous HIV testing in the future.

You can also get a “non-nominal” (no-name) HIV test. For a non-nominal test, your blood sample goes to the laboratory with just initials and a birth date. Some healthcare providers don’t tell patients about non-nominal tests or try to discourage patients from getting non-nominal tests, but you have the right to test non-nominally if that is what you would like.



The privacy benefit of non-nominal and anonymous testing is limited if the test result is positive. That is because care and treatment of HIV, things like HIV viral load testing and HIV medications, are recorded in electronic systems attached to your name. If you want to safeguard your privacy beyond initial testing, you need to take pro-active steps. We discuss how to do this in the following sections.

## 7. REPORTING TO PUBLIC HEALTH

In British Columbia, HIV is a reportable disease and that means that new cases of HIV are reported to public health authorities. There are nominal (name) and non-nominal (no-name) reporting options. In nominal reporting, your name and contact information is forwarded to public health. Even if you do a test using your name you can say that you do not want a positive test result to be reported under your name. If you say you want non-nominal reporting, that is supposed to be indicated on the laboratory form and if the result is positive, only your initials and no contact information are reported to public health.

Many health care providers are not aware of the non-nominal reporting option. **If you do not want a positive test result to be reported to public health with your name, be sure to say at the time of testing that you want non-nominal reporting.**

Your right to decline to be identified to public health authorities is found in the *Health Act Communicable Disease Regulation, B.C. Reg 4/83* regarding the contents of reports to public health:

(5) A report made under section 2(2) or (3) or section 3 respecting a person who voluntarily submitted to testing for Human Immunodeficiency Virus must omit the name and address of the person if that person so chooses.



## 8. PRIVACY AND CONFIDENTIALITY

Until recently, your HIV test results could only be viewed by very few people. Only authorized people were supposed to see the results, which were held in very few places, so even if non-authorized people tried to see them, they generally could not. This has changed. Now, electronic health records are held in large databases that are available to many people. Provincial databases can be accessed by health care providers and support staff all across the province. Anyone who has access to these databases is only supposed to look at records of patients that are actually in his or her care. Most health care professionals take patient privacy rights very seriously, but privacy violations do still happen.

**The change from records held and controlled by a health care provider to centralized databases accessible through tens of thousands of portals has very serious implications for patients' privacy rights.** It also affects the relationship of trust that is the cornerstone of the relationship between patients and health care providers. In its 2011 Principles for the Protection of Patients' Personal Health Information, the Canadian Medical Health Association said that:

Patients should be informed that the treating physician cannot control access and guarantee confidentiality for an electronic health record (EHR) system.

Are patients receiving this information? So far it appears that the vast majority are not. And because people generally view sexual health information as particularly privacy sensitive, it stands to reason that people considering an HIV test may be particularly in need of information about protecting their information in these new systems.

## 8. PRIVACY AND CONFIDENTIALITY

Medical information, including HIV test results, could be recorded in several different databases. **It is possible for you to restrict who can see your information in some of these databases, but it's not automatic. You have to specifically request this and take certain steps in order to have your records restricted.**



## 9. RESTRICTING ACCESS TO YOUR HEALTH INFORMATION

### Restricting Access to Your HIV Laboratory Test Results

**You can restrict access to your laboratory test results by putting a keyword on your record.** This is called a Disclosure Directive and to get one, you need to download a form from the Ministry of Health website, or call Health Insurance B.C. (Lower Mainland 604.683.7151; elsewhere in B.C. 1.800.663.7100). You have to mail in the form along with photocopies of your identification and when the Ministry responds, there is a process for selecting your keyword. Except for emergencies, a health care provider will need to have your keyword before they can look at your records. This way you control the access to your information.

For full instructions on keyword protecting laboratory tests results and other health records, go to the website of the B.C. Freedom of Information and Privacy Association (BC FIPA): [www.healthinfoprivacybc.ca/who-can-see-or-change-a-health-record/limiting-who-else-can-see-your-health-information#ehealth](http://www.healthinfoprivacybc.ca/who-can-see-or-change-a-health-record/limiting-who-else-can-see-your-health-information#ehealth)

### Restricting Access to Your Information in Health Authority and Hospital Databases

Unfortunately, B.C.'s health data system is very complex, and there is no one easy way to restrict access to your personal health information across all systems. Some of the databases used by health authorities and hospitals allow patients to put access restrictions on their records. But processes vary.

The best approach is to contact the privacy office of the health authority in your region.

See BC FIPA's website for a handy list: [www.healthinfoprivacybc.ca/home/contact-information-for-health-authority-privacy-offices](http://www.healthinfoprivacybc.ca/home/contact-information-for-health-authority-privacy-offices).

## 9. RESTRICTING ACCESS TO YOUR HEALTH INFORMATION

### Restricting Access to Your Prescription Information

PharmaNet is the database that holds information about all British Columbians' prescription drugs. Although HIV test results are not on PharmaNet, patients interested in health privacy are often also interested in putting a keyword on their PharmaNet records. It is much easier to restrict access to your PharmaNet records than to laboratory test records. Just go to any pharmacy with your identification and ask to put a keyword on your records. Only health care providers that you give your keyword to will have access to your record.

See: [www.bcpharmacists.org/you\\_your\\_pharmacist/pharmanet\\_patient\\_record/patient\\_keyword.php](http://www.bcpharmacists.org/you_your_pharmacist/pharmanet_patient_record/patient_keyword.php).



## 10. BY THE BY, THIS IS YOUR INFORMATION



You can see and/or get copies of your health records from any health care provider. For information on how to do this:

- see the BCCLA Privacy Handbook ([bccla.org/privacy-handbook](http://bccla.org/privacy-handbook)); or
- call Dial-A-Law and select script 421 “Getting your medical records.”  
Dial-A-Law ([dialalaw.org](http://dialalaw.org)): in the Lower Mainland: 604.687.4680;  
elsewhere in B.C.: 1.800.565.5297.

## 11. CRIMINAL LAW AND NON-DISCLOSURE OF HIV STATUS

**Under the criminal law in Canada, people who know that they are HIV positive have a duty to tell their sexual partners before they engage in activity that poses a “realistic possibility” of HIV transmission.\***

In late 2012, in a case called “*Mabior*”, the Supreme Court of Canada created the new legal ‘test’ for disclosure to sexual partners. The problem with the wording of the ‘test’ is that “realistic possibility” doesn’t mean what most people think it does. In the eyes of the law, almost any risk requires disclosure to sexual partners.

We are going to know more about this law as more cases appear in the courts. But at this time, the courts are saying that for vaginal intercourse, you have to tell your partner that you have HIV UNLESS you have a low viral load (below 1500 copies) AND you use a condom. It is not clear at this time if the same condom-plus-low-viral-load combination is sufficient in the case of anal intercourse. And we don’t know at this point whether the courts are going to say that you need to disclose to a partner before oral sex without a condom.

This uncertainty in the law is creating tremendous anxiety for people living with HIV, who are trying to understand their criminal risk, and for service providers, who are trying to give accurate information. Health and other service providers are often reluctant to discuss the criminal law and non-disclosure because they feel that they are not qualified to give “legal advice”. But basic legal information is different than “legal advice” and there is a great need for legal information on this subject.

- \* For intravenous drug users, there may also be a duty to disclose to someone who is sharing needles and syringes with you, but no Canadian court has made a decision on this issue yet.

## 12. THERE'S MORE THAN ONE KIND OF RISK

There are only very narrow exceptions to the requirement to disclose your HIV status to sexual partners. And there are severe criminal consequences for failing to inform sexual partners of your HIV positive status when the law says you must.

If there is an obligation to inform a sexual partner, but you don't tell, it's the same in law as if your partner never consented to have sex with you. And sex without consent is sexual assault. The usual charge for HIV non-disclosure is aggravated sexual assault.

When we are considering an HIV test, it's important that we have at least some idea of what the law will require of us if we test HIV positive. For example, people with active addictions or people with violent and abusive sexual partners can have serious challenges in disclosing and very serious risk of being criminally charged if they don't.



You know your own situation and vulnerabilities best. It's very important to take care of your health, but you may be facing other risks as well. If disclosing your status would put your physical safety at risk, you might want to test at a later time when you are in a safer place.

To stay updated on the law about HIV disclosure to sexual partners, see the website of the Canadian HIV/AIDS Legal Network: [www.aidslaw.ca](http://www.aidslaw.ca).

### 13. NO “DUTY TO REPORT” IN RELATION TO THE CRIMINAL LAW

There is often confusion among service providers about the meaning of “duty to report.” HIV is a “reportable disease,” which means that there is a duty to report new cases to public health. This does not mean that there is a duty to report suspected cases of non-disclosure to sexual partners to the police. In fact, service providers’ duties go in exactly the opposite direction. Service providers have a duty of confidentiality to patients with only rare exceptions, such as the duty to report suspected child abuse. The public policy rationale for the high standard of confidentiality is obvious.

Service providers should be assisting and supporting patients/clients with their challenges in disclosing to partners and, in the rare and difficult scenario where it becomes clear that the person is unwilling or unable to disclose, the service provision agency may have recourse to the assistance of public health officials, not the police.



## 14. COURTS CAN ORDER THE DISCLOSURE OF SERVICE PROVIDERS' RECORDS

Frontline service providers working in sexual health know that the lives of their patients and clients are complex. People may need support, time and education to disclose their status to sexual partners. This counselling is most effective in a relationship of trust. But the problem is that no matter how much the service provider is determined to maintain confidentiality, a court can order any records held by a service provider be handed over.

As patients, we should understand that our records could be demanded ("subpoenaed") by a court. We may choose to limit how we discuss issues about our sexual partners with our service providers.

As service providers, we should create guidelines on record-keeping that balance the need for appropriate data for care/service with rules for minimizing data that could prejudice the patient/client.

The Canadian HIV/AIDS Legal Network has a helpful resource kit that addresses record-keeping: [www.aidslaw.ca/EN/community-kit/index.htm](http://www.aidslaw.ca/EN/community-kit/index.htm).

## 15. HIV TESTING AND PREGNANCY

HIV testing is part of the standard pre-natal panel of tests that is generally done for pregnant women in British Columbia. Because it is part of “standard” testing, many women have been tested without their informed consent. Even though it is standard, that doesn’t mean that health care providers should be testing without women’s informed consent. Your rights don’t change just because you are pregnant.

That said, there are very good reasons for testing during pregnancy. Most women want to be tested for HIV during pregnancy knowing that the availability of new treatment options has virtually eliminated mother-to-child HIV transmission in British Columbia.

The high prevalence of pre-natal HIV testing in B.C. makes it quite difficult to find out what the implications might be for women who decline to test. Simply put, it is hard to find examples. Some service providers note that, if the Ministry of Children and Families is involved in a pregnancy, the Ministry will pay close attention to pre-natal care. Other service providers suggest that a woman delivering in a hospital is very likely to be rapid tested (with or without consent) if the hospital has no information on HIV status.



## 16. FORCED TESTING OF SOURCE PERSONS IN ENCOUNTERS WITH POLICE, PARAMEDICS AND FIRE-FIGHTERS

British Columbia passed *The Emergency Intervention Disclosure Act* in 2012 which allows police, paramedics and fire-fighters to apply for a court order to have someone force tested for infections, including HIV, if the worker has been exposed to that person's bodily fluids in the course of his or her work. This law has been heavily criticized. For example, the Provincial Health Officer for B.C. opposed the law, stating that it would "in no way reduce the risk of infection or result in any fewer episodes of occupational disease transmission."

Post-exposure prophylaxis (PEP) (HIV medications taken after possible exposure to prevent infection) should ideally be started within 2 hours of exposure. Since PEP needs to be started almost immediately, a process for getting a court order to force test the person the body fluid came from clearly provides no protection to the worker. The violation of the human rights of the source person provides no safety benefit to the worker.

There is similar legislation in other provinces in Canada and thus far, these laws are rarely used. This is unsurprising, given that most source persons are extremely cooperative in cases of accidental exposure. These provisions are very likely to be subject to a constitutional challenge at some point.

If you are the subject of a court order for forced testing, consult a lawyer. For the name of a lawyer to consult, call the Lawyer Referral Service (in the Lower Mainland: 604.687.3221; elsewhere in British Columbia: 1.800.663.1919). If you wish, you could also contact the BCCLA (in the Lower Mainland: 604.687.2919; elsewhere in British Columbia: 1.866.731.7507). We will be interested in the case.

## 17. RESOURCES

**If you are looking for information on where to get tested, including where you can get an anonymous test...**

The Smart Sex Resource at <http://smartsexresource.com>

**If you believe your rights have been infringed...**

The B.C. Civil Liberties Association: online at [www.bccla.org](http://www.bccla.org) or call our Caseworker at 604.630.9754

**If you have a complaint about a doctor's conduct...**

Dial-A-Law – Lower Mainland: 604.687.4680; elsewhere in B.C.: 1.800.565.5297; select script 423 *Making a complaint against your doctor*

**If you have a complaint about a violation of your privacy rights...**

The Office of the Information and Privacy Commissioner of British Columbia: [www.oipcbc.ca](http://www.oipcbc.ca)

**If you are newly diagnosed HIV positive and need information and support...**

The Positive Living Society of British Columbia: [positivelivingbc.org](http://positivelivingbc.org)

**If you are looking for more information about occupational exposure situations...**

*HIV and Occupational Exposure: A Guide for First Responders and Their Families* at [http://bccla.org/our\\_work/hiv-and-occupational-exposure](http://bccla.org/our_work/hiv-and-occupational-exposure)

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