

# HIV TESTING POCKETBOOK

A GUIDE TO YOUR RIGHTS



**& YOUR**



BRITISH COLUMBIA  
CIVIL LIBERTIES ASSOCIATION  
BCCLA.ORG

The B.C. Civil Liberties Association is grateful to the MAC AIDS Foundation and the Law Foundation of B.C. for providing support for this project.



© B.C. Civil Liberties Association 2012. Contents may not be commercially reproduced without permission, but any other reproduction is encouraged.



Where reproduced, attribution should be given to the BC Civil Liberties Association.

The B.C. Civil Liberties Association thanks the many people who assisted in the creation of this resource by sharing their insights as health care and other service providers, lawyers, patients and people living with HIV.

## IMPORTANT NOTICE AND QUALIFICATION

This pocket guide is for information and education purposes only. It is not legal advice and it is not intended that this pocket guide should in any way replace legal advice from a qualified lawyer.

Written by Micheal Vonn

Cover art by and illustrations by Lindsay Chetek

Cataloguing data available from Library and Archives Canada.

Electronic copies available for download at [bccla.org](http://bccla.org). To order copies of the *HIV Testing Handbook* and *Pocket Guide* contact:

B.C. Civil Liberties Association  
900 Helmcken Street, 2nd Floor  
Vancouver, BC V6Z 1B3

Tel: 604.630.9755  
[info@bccla.org](mailto:info@bccla.org)

## 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.



## INTRODUCTION TO HIV TESTING

**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 pocket guide 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 provinces can find some of the information useful. This booklet is a pocket-sized version of a longer *HIV Testing Handbook*.

## 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.

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

## DIFFERENT KINDS OF HIV TESTS

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 ask questions.

### 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.

## DIFFERENT KINDS OF HIV TESTS

### 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.



## INFORMED CONSENT

There is a big push on 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 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. **If you are in a hospital or emergency room and you are told that you are going to be tested for HIV, you have a right to say no to that “offer”.**

# 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.
- Although 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 health care provider is doing "some tests" or "some blood work"

## OPT OUT AND THE NEED TO SPEAK UP

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 all the information you need and answer all your questions. Not everyone has access to these important services. **You may have to be assertive to get the information you need. If you have questions, ask!**

## 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 no official anonymous testing in British Columbia.

But that does not mean that you have to use your name to get an HIV test.

**It is possible to get a “non-nominal” (no name) test. For a non-nominal test, your blood sample goes to the laboratory with just initials and a birth date.**



## ANONYMOUS AND NON-NOMINAL TESTING

Some health care providers don't tell patients about non-nominal tests or try to discourage patients from getting a non-nominal test. You have the right to test non-nominally if that is what you would like.

The privacy benefit of a non-nominal test is limited if the test result is positive. That is because everything that is likely to come after a positive test, like HIV viral load tests and HIV medications, are 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.

## 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.

**If you choose a non-nominal test, your name is not supposed to be reported to public health unless 1) you consent or 2) there is reason to believe that you will put others at risk.**

Even many health care providers do not know about this. 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

## REPORTING TO PUBLIC HEALTH

Human Immunodeficiency Virus must omit the name and address of the person if that person so chooses.



## 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.

## PRIVACY AND CONFIDENTIALITY

Your medical information, including your HIV test result, 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.**



## RESTRICTING ACCESS TO YOUR HIV LABORATORY TEST RESULTS

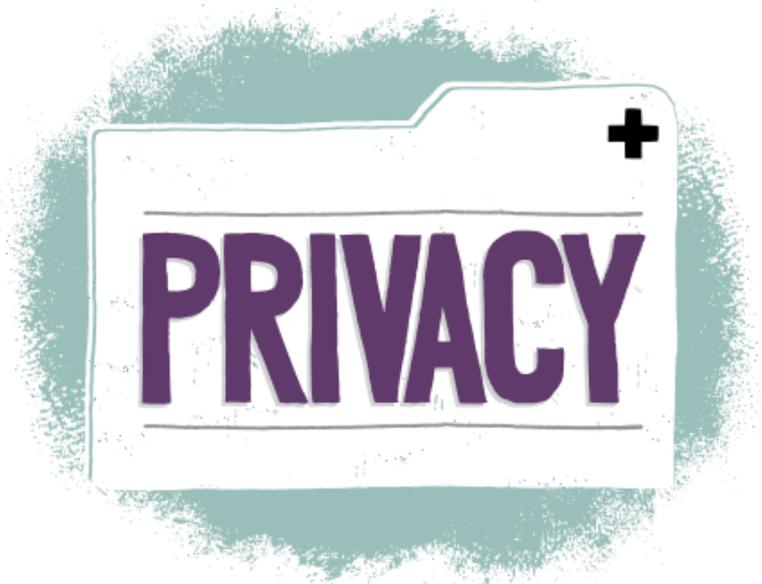
**You can restrict access to your laboratory test results by putting a keyword on your record.**

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.

## RESTRICTING ACCESS TO YOUR HIV LABORATORY TEST RESULTS

For full instructions on keyword protecting laboratory tests results and other health records, go to the comprehensive health privacy resource from the B.C. Freedom of Information and Privacy Association: [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 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)

## 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.: 1.800.663.1919.



## 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 significant risk” of HIV transmission.\* The problem with the legal test for “significant risk” is that courts have interpreted it in different ways.

- \* 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.



## CRIMINAL LAW AND NON-DISCLOSURE OF HIV STATUS

Up until just recently it was at least clear that the law required that HIV positive people had to tell their partners before having unprotected (no condom) anal or vaginal intercourse. In regards to other kinds of sex, different courts have sometimes come to different decisions on whether there is a duty to tell sexual partner that you are HIV positive if you use a condom, or if you are only having oral sex.

Plus, there is a question about whether you have to disclose your status if you are on HIV treatment that reduces the virus in your system so much (“undetectable viral load”) that there is almost zero chance of infecting your sexual partner.

## THERE'S MORE THAN ONE KIND OF RISK

The Supreme Court of Canada is expected to release a decision in the fall of 2012 that will clarify the law in this area. Changes to the legal test for when disclosure is required are expected, but it is still likely that there will continue to be possible criminal consequences for failing to inform sexual partners of your HIV positive status in certain circumstances. 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.



## THERE'S MORE THAN ONE KIND OF RISK

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)

## 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.

## RESOURCES

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

The BCCLA: online at [www.bccla.org](http://www.bccla.org) or  
call our Case Worker 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.oipc.bc.ca](http://www.oipc.bc.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)

# HIV TESTING POCKET GUIDE

## A GUIDE TO YOUR RIGHTS

This pocket guide 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 pocket guide 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.