Canadian HIV/AIDS Legal Network
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HIV Testing

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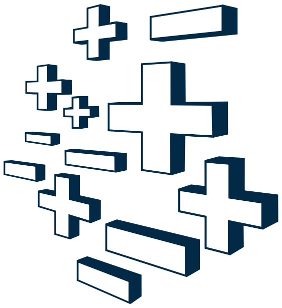
This is one in a series of 12 info sheets on HIV testing in Canada.



Evolution of HIV testing policy and technology in Canada

Since the HIV antibody test was first made widely available in Canada in 1985, HIV testing has been a policy challenge for health authorities. What are the ethically appropriate uses of HIV testing, and how should testing be regulated? How should people be counselled about the significance of the test? Should the results of HIV tests be kept confidential? What uses should be allowed by law of a person's test results? Are there circumstances in which testing should not be voluntary? How can the law help people realize the benefits of HIV testing? And how can the law protect people against the possible negative consequences of testing HIV-positive, such as discrimination?

Testing before and after advances in HIV treatment

Before there was effective treatment for HIV or opportunistic infections, HIV testing was a hard sell. Without treatment options, even people who might consider themselves at risk of having HIV had little reason to seek HIV testing, and considerable reason to fear discrimination if they were to test positive. Instances of discrimination in areas such as insurance, housing, education, employment and travel opportunities reinforced this fear. Sensible policy-makers recognized that education and awareness-raising were the most effective prevention tools available, and these tools were not dependent on HIV testing. By the end of the 1980s, treatment or prophylaxis became available for some opportunistic diseases associated with HIV, notably *P. carinii* pneumonia. Knowing one's HIV status was more beneficial, though the limited impact of available treatments and well-founded fear of discrimination were still impediments to seeking HIV testing.

It was recognized, therefore, that HIV testing should be promoted and conducted in ways that took into account the reality of widespread stigma and discrimination against people with HIV and against particular groups such as gay men, sex workers, and people who use drugs. It was understood that respecting and protecting people's rights would be central to implementing HIV testing successfully as part of the overall effort to prevent the spread of HIV and treat those living with the virus. As a result, a broad consensus emerged among public health authorities, leaders in the gay community responding to the emerging epidemic, health care professionals and policy-makers that:

- People should be tested only with their informed, voluntary and specific *consent*.
- *Counselling* should be provided both before and after HIV testing.
- HIV testing should occur only when *confidentiality* of results can be guaranteed (and in some places, testing could even be done anonymously).

Policies in Canadian jurisdictions and guidelines from federal authorities thus generally reflected what came to be called "the three Cs" of HIV testing — consent, counselling and confidentiality.

In 1996, the International AIDS Conference in Vancouver highlighted scientific breakthroughs in the effectiveness of treatment for HIV-related disease. In addition, by early 1998 it was known that even a short and affordable course of antiretroviral medicines could greatly reduce the risk that HIV would be transmitted during pregnancy or childbirth from mother to fetus or newborn. Numerous other clinical benefits for people living with HIV of knowing their HIV status early in the course of their disease have been well documented. Early diagnosis allows individuals to make important treatment decisions. These advancements in prevention of and medical care for HIV/AIDS gave a new urgency to ensuring access to HIV testing.

HIV testing technology

With changes in HIV treatment came changes in the technology of HIV testing. The standard procedure for HIV testing in Canada involves a trained health professional drawing blood from the person to be tested, usually in a physician's office or a testing clinic. The blood is then tested in a medical laboratory to detect the presence of antibodies to HIV, using a type of test known as an enzyme-linked immunosorbent assay (or "ELISA") as a screening test.

HIV-negative result

The ELISA test is very sensitive. If the ELISA test does not detect any HIV antibodies in the blood sample — i.e., the test is "non-reactive" — the person is diagnosed as HIV-negative and this result is reported to the health care provider who ordered the test. However, it is still important to understand that it takes time for a person's immune system to produce antibodies to HIV; this does not happen immediately upon infection. Because the ELISA test detects antibodies to the virus, this means there is a "window period" between the point at which the person is infected and the point at which the test will show infection. A person may test negative for HIV antibodies during this period even though he or she is infected. The window period can vary from a few weeks to a few months after infection. If the person is getting tested soon after a possible exposure to the virus (and might therefore be in the window period), the test should be repeated in a few weeks or months.

HIV-positive result

If the ELISA test is "reactive," this means the test has detected antibodies in the blood sample. But because this test is designed to be very sensitive, the trade-off is that the test is not so specific to detecting antibodies to HIV in particular. In other words, the ELISA test casts a wide net to avoid missing HIV antibodies, but may end up detecting something other than HIV in the blood sample. In that case, the reactive result would be a "false positive." Therefore, any blood sample that tests positive using an ELISA test undergoes a second, confirmatory test using a different test that operates differently (most commonly a test known as the "Western blot" assay), which identifies antibodies to specific components of the virus. Only if this result is also reactive is the person diagnosed as HIV-positive.

Only confirmed test results are given to the health-care provider who ordered the test for the patient. It is generally too expensive to test each blood sample one at a time, so laboratories perform tests on samples in batches. Because of this, and depending on how busy laboratories are, it can take one to two weeks before the final result is available. (It may take longer if the patient lives in a more remote location and the blood sample needs to be transported to a lab elsewhere for testing.) Thus, people who are tested, whether the test is positive or negative, generally have to return to the testing site a second time to obtain their results.

Rapid HIV tests

More recently, rapid HIV tests have been developed. These tests can be done quickly, without a lab. Some work on a small sample of blood from a finger prick, some test a urine sample, and others require a saliva sample. The rapid test is still a screening test — any initially positive result must still be confirmed with another test (such as a Western blot test done on a full blood sample). Rapid tests have been licensed in Canada for use only by health professionals in health care settings ("point of care" testing), raising the question of whether testing should be available elsewhere and in other ways. Rapid tests have obvious benefits, particularly in remote or underserved areas, where the difficulty of returning for a second visit to obtain test results may be an important barrier to access to HIV testing. Rapid tests also raise a number of challenging policy questions, such as whether and how to keep them in the hands of health professionals only and how to ensure that counselling, confidentiality and informed consent remain part of HIV testing. (See info sheet 9 in this series for more information on rapid tests.)

Changes in policy directions

More than 25 years into the HIV/AIDS epidemic, some experts now suggest that discrimination based on HIV status is not as severe as it was in the early years of the epidemic. So, they say, testing procedures and policies might safely be modified to reduce emphasis on "the three Cs" and the human rights protections they represent. For example, some provinces and territories in Canada have adopted policies on HIV testing of pregnant women that place the onus on the woman to refuse or "opt out" of an HIV test that will otherwise be done. This is a different approach from allowing an individual to initiate HIV testing voluntarily with a clear statement of consent to the test. While there may well be some benefits from health care providers more actively encouraging HIV testing with patients, how this is done raises important ethical and human rights concerns. (See info sheet 2 in this series for more discussion of these policy changes.)

Additional reading

Csete J. & R. Elliott. "Scaling up HIV testing: human rights and hidden costs." *HIV/AIDS Policy & Law Review* 2006; 11(1): 1, 5ff, on-line: www.aidslaw.ca/testing. This article summarizes the human rights case for strong adherence to the "three Cs," in response to calls for scaling up HIV testing without necessarily ensuring that pre-test counselling and informed consent are part of the process.

Jürgens R. *HIV Testing and Confidentiality: Final Report*. Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998, on-line: www.aidslaw.ca/testing. A comprehensive legal and ethical analysis of Canada's HIV testing experience through 1998; much of the discussion remains pertinent in 2007.

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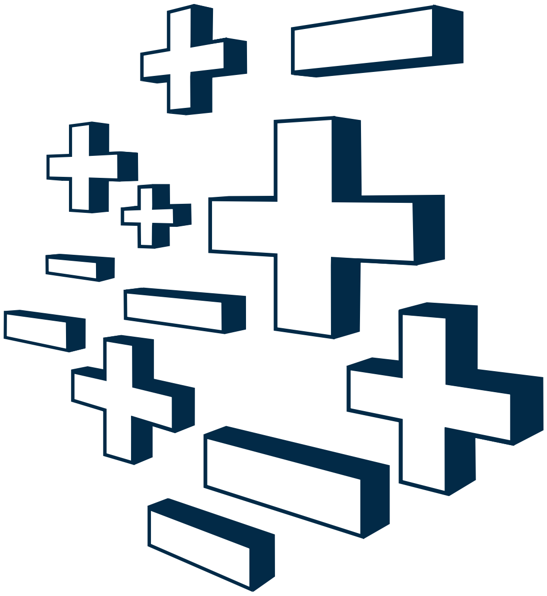

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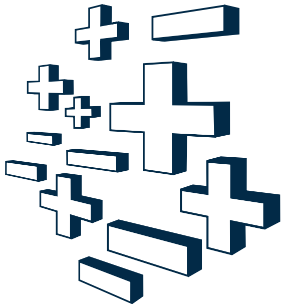

Shifting HIV testing policies

Background

Early in the epidemic, stigma and discrimination against people living with HIV/AIDS, particularly gay men, were among the factors that led public health authorities to adopt a voluntary approach to HIV prevention measures. This approach, sometimes referred to as "AIDS exceptionalism," departed from such traditional public health strategies as compulsory testing and contact tracing, in favour of voluntary behaviour change, testing only with informed consent, protection of confidentiality (or even anonymity in some cases), and voluntary partner notification. This shift was necessary because, without the assurance that they would not be subject to coercion or to the negative consequences of disclosure, gay men and other vulnerable groups seen as being at higher risk of HIV infection might have been unwilling to cooperate with public health officials, making it harder to reach them through HIV education and prevention programs.

"AIDS exceptionalism"

The term "AIDS exceptionalism" is unfortunate and misleading. Public health responses to infectious diseases have never been uniform. There is no default approach to public health crises — different epidemics often require different public health policies. It is therefore wrong to portray a voluntary approach to HIV testing as an extraordinary rupture with prior practice. Furthermore, the HIV epidemic has presented challenges that could improve the way in which other health problems are approached, particularly ones that are surrounded by stigma and affect particularly marginalized groups.

Calls for abridging the "three Cs" of HIV testing

Those persuaded that conventional public health measures would be more successful in preventing and treating HIV have called the voluntary approach into question. They suggest that there is a conflict between public health goals — getting treatment, and therefore testing, to as many people as possible — and the rights of individuals who have or may have HIV, and that individual rights must take a back seat if the response to HIV is to be effective. For example, a widely cited 2002 article by Kevin De Cock, then with the U.S. Centers for Disease Control and as of 2006 the director of the HIV/AIDS Department in the World Health Organization, criticized human rights protections surrounding HIV testing as hampering the scaled-up response needed to the emergency of HIV/AIDS in Africa.

A number of influential leaders, including De Cock, have called for more reliance on testing initiated by health care providers rather than by the person to be tested. New terms have been introduced into the policy discussion, including "routine testing" (i.e., everyone in a given setting is tested without necessarily relying on individual consent) or "opt-out" testing (i.e., the default option in a given situation is to test everyone unless a person clearly and specifically refuses the test). Some experts promote what they call "routine offer" of an HIV test with the possibility of opting out. The use of the word "offer," though, suggests a choice that may not be real if the offer is so "routine" that it doesn't come with the chance to learn more about HIV, and if patients are pressured such that they cannot refuse the "offer." All of these approaches differ from the voluntary counselling and testing model — in which testing is initiated by the person to be tested — that has, until recently, been the dominant approach in Canada and elsewhere.

In 2002, the Canadian Medical Association (CMA) adopted a short resolution recommending that health authorities and physicians in Canada adopt "a routine prenatal HIV screening test with an 'opt out' policy." Some provinces and territories in Canada — including Alberta, Nova Scotia, Newfoundland and Labrador, the Northwest Territories and Nunavut — had already adopted opt-out policies for HIV testing of pregnant women. Others, such as New Brunswick and Manitoba, have done so since the CMA recommendation. In some of these provinces and territories, it is not clear how women experience the "offer" of testing or even whether there is a clear offer, a clear opportunity for a woman to be informed about HIV sufficiently, and a process for exercising informed consent. More research is needed on how these policies are playing out in Canada. (See info sheet 8 in this series on HIV testing during pregnancy.)

Voluntary approach remains valid

The policy shift toward healthcare providers making HIV testing of patients more routine raises serious ethical and human rights questions. There is little doubt of the need to improve access to good-quality HIV testing services in Canada, particularly for certain groups that face additional barriers. For example, all pregnant women should be offered HIV testing services with pre-test counselling, information that enables truly informed consent to take place, and confidentiality of test results. Health care providers should be given adequate training to provide HIV testing services and encouraged to offer HIV testing regularly to patients.

However, it is not warranted or justified to adopt a default approach of routinely testing every woman receiving prenatal care, or every patient using some health service, unless the person expressly opts out of testing — particularly if such testing is done without providing pre-test counselling or an opportunity for truly informed consent. There are numerous reasons why "the three Cs" of HIV testing and their inherently voluntary "opt-in" approach remain crucial to protect human rights.

Discrimination continues

HIV infection still carries the stigma and potential for discrimination such that people living with or affected by HIV/AIDS continue to require special protections in HIV testing. Discrimination remains pervasive in Canada, as documented in recent Health Canada-funded surveys of the Canadian population on attitudes toward HIV/AIDS.

For example, a 2006 study found that about half the population would be uncomfortable using a drinking glass that had once been used by someone living with HIV; over 40 percent of Canadians thought that people living with HIV/AIDS should not be hairstylists; and about one quarter would not be comfortable shopping at a small grocery store where the owner is living with HIV/AIDS. These disturbing findings come from a population of highly educated people who consider themselves well informed about HIV/AIDS.

While Canada has broad legal protections against discrimination, including discrimination based on HIV status or AIDS diagnosis, human rights tribunals are limited in their capacity to provide redress in cases of discrimination. For many people living with HIV/AIDS, trying to enforce legal protections against discrimination is too costly, and even finding legal advice or assistance remains a challenge.

HIV/AIDS affects marginalized people

HIV/AIDS affects marginalized people who may have a well-founded fear of government institutions and who may be even more marginalized and vulnerable than gay men were in the 1980s — namely, people who use drugs, Aboriginal people, prisoners and former prisoners, women, and people from countries where HIV/AIDS is endemic. In addition to being disproportionately affected by HIV/AIDS, Aboriginal communities often face additional barriers to health services. Discrimination, language barriers, cultural norms, concerns about confidentiality and the fear of stigma present additional hurdles to health services for some migrants.

Canadian law still offers little, and in some cases no, protection against certain kinds of discrimination experienced by some of those most vulnerable to HIV. There is very limited protection against discrimination against people living in poverty. While addiction to drugs may be considered a disability in some circumstances, with limited protection against discrimination on this basis, people who use illegal drugs, whether drug-dependent or not, face widespread stigma and discrimination with little recourse. There is limited recognition of prisoners' equality rights (including the right to equivalent health services). The stigma and discrimination faced by sex workers is pervasive, and there is no clear prohibition on this or remedy for it; in fact, the continued criminalization of sex workers under Canadian law perpetuates this stigma and undermines sex workers' health, safety and other human rights.

A shift towards more coercive measures could hinder, rather than assist, efforts to curb the spread of HIV by contributing to fear, stigma and discrimination. These would undermine the confidence in the health system needed to provide successful long-term treatment of HIV.

Testing that includes the "three Cs" may be more effective in the long run

It is not surprising that opt-out HIV testing may result in higher numbers of people being tested. But that is not the only outcome important to an effective response to HIV/AIDS. If people are tested without being prepared for the test with information and counselling, they may be more likely to suffer adverse psychological outcomes such as depression and suicidal tendencies if they are found to be HIV-positive. They may be less likely to be able to protect themselves from violence and other abuse if others discover their status, because they are not adequately prepared. Pre-test and post-test counselling can also help to inspire confidence in the health system, which is needed to ensure good long-term care for HIV-related disease. Moreover, high rates of testing uptake are possible without adopting opt-out measures, as has been shown in Ontario where in 2004 the proportion of pregnant women accepting HIV tests voluntarily reached 90 percent.

No conflict between public health and human rights principles

For these reasons, there is no necessary conflict between public health and individual rights. Evidence strongly suggests that rather than impeding the protection of public health, the promotion and protection of the human rights — including through increasing access to testing and encouraging testing — are essential components in preventing HIV transmission.

Conclusion

> *There may be a time when HIV is so unremarkable a part of our social landscape, and care for it so routinely available to those who need it, that no one will reasonably fear being identified as a person with HIV. But we are nowhere close to that time yet.*
>
> — American Civil Liberties Union, 1997

A decade after this observation, its assertion remains valid, for Canada and most countries. Everyone has the right to know his or her HIV status, and to receive treatment if he or she has HIV. But the availability of treatment for HIV/AIDS and of tools to reduce mother-to-child transmission should not override the continuing need for the human rights protections provided by the "three Cs." In Canada as elsewhere, HIV testing with pre- and post-test counselling, informed consent and confidentiality of test results is the highest attainable standard of care, and health authorities have an obligation to provide it.

Additional reading

Canadian HIV/AIDS Legal Network. *A plan of action for Canada to reduce HIV/AIDS-related stigma and discrimination* (2004), on-line: www.aidslaw.ca/discrimination. An extensive analysis of dimensions of HIV-related stigma and discrimination in Canada and detailed plan for addressing the many facets of the problem.

Canadian HIV/AIDS Legal Network, CHANGE & Gay Men's Health Crisis. *Outcomes of the symposium on HIV testing and human rights (Montréal, October 2005)* (2006), on-line: www.aidslaw.ca/testing. This report of a symposium that brought together people living with HIV/AIDS, UN officials, front-line health service providers, and human rights experts examines the human rights challenges associated with scaling up HIV testing.

Csete J. & R. Elliott. "Scaling up HIV testing: human rights and hidden costs". *HIV/AIDS Policy & Law Review* 2006; 11(1): 1, 5ff, on-line: www.aidslaw.ca/testing. This article summarizes the human rights case for strong adherence to the "three Cs," in response to calls for scaling up HIV testing without necessarily ensuring that pre-test counselling and informed consent are part of the process.

De Cock K.M. et al. "Shadow on the continent: public health and HIV/AIDS in Africa in the 21st century". *Lancet* 2002; 360: 67–72. The authors suggest that human rights protections may impede an urgent response to Africa's AIDS emergency, including in the area of HIV testing.

Ekos Research Associates, Inc. *HIV/AIDS attitudinal tracking survey 2006 — final report*. Ottawa: Health Canada, March 2006, on-line: www.phac-aspc.gc.ca. This survey commissioned by the Public Health Agency of Canada assesses many facets of the Canadian population's attitudes toward HIV/AIDS.

Elliott R. "Protection against discrimination based on HIV/AIDS status in Canada: the legal framework". *HIV/AIDS Policy and Law Review* 2005; 10(1): 20–31, on-line: www.aidslaw.ca/review. This article reviews the ways in which Canadian law affords protection against HIV/AIDS-related discrimination, providing an inventory of relevant policies and decisions in federal, provincial and territorial jurisdictions.

Heywood M. "Human rights and HIV/AIDS in the context of 3 by 5: time for new directions?" *Canadian HIV/AIDS Policy & Law Review* 2004; 9(2):1, 7ff, on-line: www.aidslaw.ca/review. An analysis of the human rights challenges raised by the imperative of HIV treatment scale-up, including testing-related factors.

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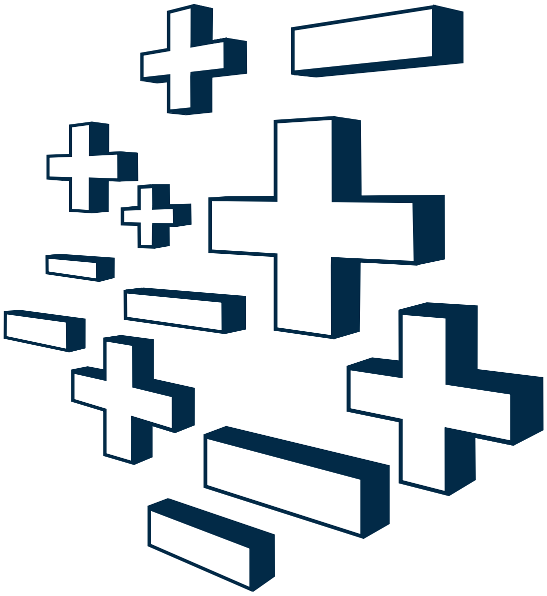

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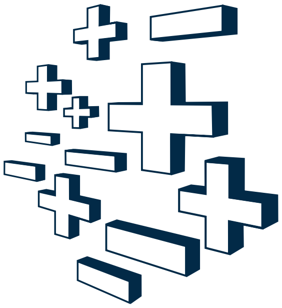

Consent to HIV testing

Consensus on consent?

Until recently there was widespread agreement in Canada and in most countries that HIV testing should generally only be undertaken with the voluntary, informed, and specific consent of the person being tested. According to the *Counselling Guidelines for HIV Testing* published by the Canadian Medical Association (CMA) in 1995,

- informed consent cannot be implied or presumed;
- obtaining informed consent "involves educating, disclosing advantages and disadvantages of testing for HIV, listening, answering questions and seeking permission to proceed through each step of counselling and testing"; and
- to obtain informed consent for testing to HIV, a patient must be deemed competent, must understand the purposes, risks, harms and benefits of being tested, as well as those of not being tested, and his/her consent must be voluntary.

However, some authorities have begun to propose approaches to HIV testing that downplay the central importance of informed consent, or that risk doing so in practice. The CMA's policy in 2000 was that "[b]ecause of the potential psychologic, social and economic consequences attached to a positive HIV test result, informed consent must, with rare exceptions, be obtained from a patient before testing." Yet in 2002, the CMA adopted a short resolution recommending that health authorities and physicians in Canada adopt an approach to HIV testing of pregnant women that involves "a routine prenatal HIV screening test with an 'opt out' policy." This resolution says nothing explicitly about informed consent, but the resolution was said to be inspired by an article in the *Canadian Medical Association Journal*, in which the authors proposed that "testing would be done unless the woman specifically objected to it" and called this "an 'opt-out' strategy for prenatal HIV testing with patient notification and counselling," without reference to informed consent. In contrast, the 2001 recommendations of the Canadian Paediatric Society, reaffirmed in 2006, note explicitly that informed consent should be part of prenatal HIV testing. (See info sheet 8 in this series for more on HIV testing during pregnancy.)

Outside Canada, there have been similar worrisome shifts in policy on the question of ensuring that consent to HIV testing is specific and informed, and even some recommendations that could, in practice, call into question the voluntary aspect of testing. New HIV testing guidelines proposed by the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) in 2006 maintain that informed consent is required, but recommend against a requirement for obtaining written consent. They also suggest that pre-test counselling is not necessary to ensure informed consent, and can be replaced with "simplified pre-test information." The revised HIV testing guidelines issued by the U.S. Centers for Disease Control and Prevention in 2006 go even further, recommending that pre-test counselling and "separate written consent" for HIV testing are unnecessary if consent to an HIV test is "incorporated into general consent for medical care."

Informed consent: a legal requirement

These recently proposed approaches — that recommend less attention to pre-test counselling and testing on the basis of presumed consent — risk violating the fundamental principle of informed consent, which seeks to respect and protect patients' autonomy. This is not only an ethical requirement, but also a legal one: Canadian courts, including the Supreme Court of Canada, have held on numerous occasions that care providers can be sued if they carry out a medical intervention without the informed consent of the patient. The general rule is that a health care provider must disclose all the information that a reasonable person in the particular patient's circumstances would want to know before choosing to accept or reject the procedure.

Also, except in the case of an emergency, testing without consent requires some specific legal authorization — and the Supreme Court of Canada has ruled that the state cannot test someone for HIV without consent, or authorize testing without consent, unless there is some compelling justification for overriding constitutionally protected rights.

> [T]he forcible taking of parts of a person, in the absence of legislation authorizing such acts, is an infringement of the right to security of the person and constitutes an unreasonable seizure [prohibited by the Charter].
> — *R. v. Legere* (1988), 43 C.C.C. (3d) 502 at 513 (N.B. Court of Appeal)
>
> The use of a person's body without his consent to obtain information about him, invades an area of personal privacy essential to the maintenance of his human dignity . . . [T]he protection of the Charter extends to prevent a police officer, an agent of the state, from taking a substance as intimately personal as a person's blood from a person [such as a physician] who holds it subject to a duty to respect the dignity and privacy of that person.
> — *R. v. Dyment*, [1988] 2 S.C.R. 417 at 431–432 (Supreme Court of Canada)
>
> [The Charter protects] "the right of the individual to determine for himself when, how, and to what extent he will release personal information about himself."
> — *R. v. Duarte*, [1990] 1 S.C.R. 30 at 46 (Supreme Court of Canada)

Given the seriousness of the consequences of HIV testing, and the legal requirement for informed consent for medical procedures, a physician who conducts an HIV test without obtaining informed consent could be subject to a civil lawsuit or professional discipline.

Testing without consent

In spite of professional guidelines and court decisions, research studies and anecdotal evidence show that HIV testing without obtaining specific informed consent is a concern in Canada. In particular, in provinces and territories that have adopted "opt-out" HIV testing of pregnant women, some evaluations have suggested that consent may be less informed and specific than in "opt-in" systems. (See info sheet 8 in this series for more discussion about HIV testing in pregnancy.) In addition, there is concern that the availability of rapid HIV screening tests could lead to even more frequent instances of testing without specific informed consent. (See info sheet 9 in this series for more information on rapid HIV testing.)

Recommendations

Professional codes of conduct, ethical practice, and Canadian law require informed consent to HIV testing. Colleges of health care professionals and health care professionals' associations should adopt (or update) regulations and/or policies that:

- state clearly that performing HIV testing without informed consent, or pressuring or coercing patients into testing, is unethical and could give rise to legal liability and disciplinary sanctions;
- state specifically that rapid HIV testing technology or the need to scale up testing to improve treatment does not remove the requirement for informed consent to testing;
- recognize that general consent to medical care does not automatically imply consent to HIV testing; and
- require a patient's informed consent to HIV testing to be recorded in writing.

They should communicate these regulations and/or policies to their members.

Additional reading

Bitnum, A. et al. “Failure to prevent perinatal HIV infection”. *Canadian Medical Association Journal* 2002; 166(7): 904–905. Article that influenced the CMA’s 2002 resolution on HIV testing.

Canadian Medical Association. *CMA Policy – Acquired Immunodeficiency Syndrome (Update 2000)*, Policy Document PD01-02, on-line via www.cma.ca (in “CMA Policy Base”). Policy statement affirming the importance of pre- and post-test counselling and the importance of obtaining informed consent to HIV testing.

Canadian Medical Association (Expert Working Group on HIV Testing: Counselling Guidelines). *Counselling Guidelines for HIV Testing*. Ottawa: CMA, 1995. This is the third edition of the CMA’s guidelines.

Canadian Paediatric Society. *Testing for human immunodeficiency virus type 1 (HIV-1) infection in pregnancy*, CPS Statement ID 2001-04. Ottawa: CPS, 2001, on-line: http://www.cps.ca. Also published in Paediatrics & Child Health 2001; 6(9): 685–689. HIV testing policy statement, reaffirmed in 2006, which stresses the importance of informed consent for HIV testing in the antenatal care setting.

Elliott, R. & R. Jürgens. *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Canadian HIV/AIDS Legal Network, 2000, on-line: www.aidslaw.ca/testing. Extensive discussion of issues that should be addressed to best realize the potential benefits of rapid HIV tests, while minimizing possible harms. See the section on testing without informed consent (pp. 49ff).

Stoltz, L. & L. Shap. *HIV Testing and Pregnancy: Medical and Legal Parameters of the Policy Debate*. Ottawa: Health Canada, 1999, on-line: www.aidslaw.ca/testing. Contains a thorough discussion of the legal doctrine of informed consent (pp. 25–30).

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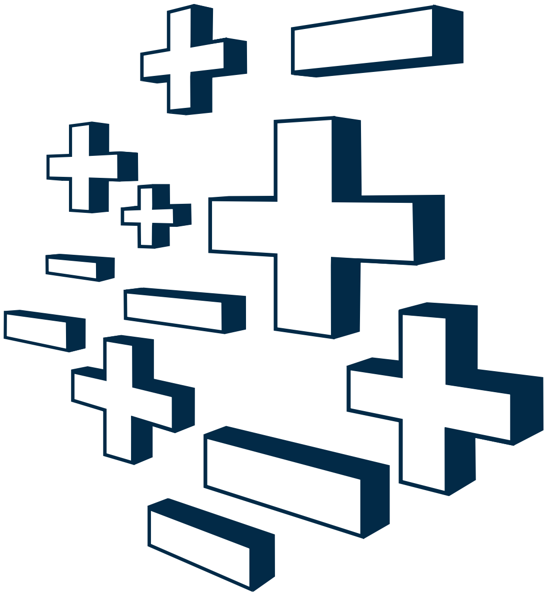

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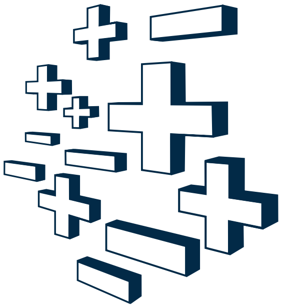

Counselling

Importance of counselling in HIV testing

For most of the history of the HIV/AIDS epidemic, there has been widespread agreement that high-quality pre- and post-test counselling is an essential part of HIV testing. Pre-test counselling is widely regarded as the best way to provide the level of information needed to ensure informed consent, which is required as part of sound, ethical practice and by Canadian law (see info sheet 3 in this series).

As stated in the *Counselling Guidelines for HIV Testing* published by the Canadian Medical Association (CMA) in 1995:

> [s]erological testing for HIV without counselling has a psychological, medical and social impact on patients. Therefore . . . testing must be preceded and followed by appropriate counselling by trained or experienced professionals.

These CMA guidelines provided detailed information regarding the essential components of counselling.

Pre-test counselling should include:

- assessing the patient's risk of HIV infection and the window period;
- providing information regarding HIV infection, risk activities, and ways to avoid or reduce risk;
- identifying available testing options and the differences between them;
- discussing the advantages and disadvantages of testing so the patient can consider these in the context of his or her particular circumstances; and
- determining the timing of testing and the post-test visit.

Post-test counselling should include:

- communicating the test result;
- assessing the patient's understanding of the result;
- assessing the need for follow-up and care; and
- discussing the importance of risk-reducing behaviour regardless of the test result.

Policy shift

Since the late 1990s, some experts in Canada and internationally have questioned the value of pre-test counselling. A 2001 evaluation of the Alberta "opt-out" antenatal program indicates that pre-test counselling has generally been replaced by giving women some written material on HIV — and even then some women did not see the materials. The evaluation's authors recommend better access to written materials but do not recommend pre-test counselling. However, giving women brochures is not the same as counselling in which they have the chance to ask questions in a confidential setting of a well-informed professional. The CMA's one-sentence 2002 resolution in favour of "opt-out" testing of pregnant women does not mention counselling — although its policy as of 2000 was that "physicians should provide counselling to patients before and after HIV antibody testing." (See info sheet 8 in this series for discussion of HIV testing in pregnancy.)

Going well beyond the case of pregnant women, the 2007 HIV testing guidelines issued by the World Health Organization and the Joint United Nations Programme on HIV/AIDS (UNAIDS) recommend that every patient receiving services in a health care facility be tested for HIV unless the patient refuses the test — even as they recommend that pre-test counselling be replaced by "simplified pre-test information" that would include the benefits and potential adverse outcomes of testing and an opportunity to ask questions. The combination of these two recommendations will likely increase the number of people getting tested (the stated objective), but these guidelines treat as secondary the goal of ensuring that people voluntarily give specific, informed consent to testing

Even before the publication of guidelines de-emphasizing pre-test counselling, both research studies and anecdotal evidence revealed serious inadequacies in counselling practices in Canada over the years — raising the concern that moving to even more "routine" approaches to HIV testing will worsen the problem. A 1994 evaluation found that over one third of the participating primary-care physicians reported not having a copy of the then-current CMA guidelines on HIV testing. While 80 percent of the physicians who had tested patients for HIV reported they provided counselling, 17 percent indicated they had provided counselling only for those who tested positive. A 1998 qualitative study in Ontario reported numerous experiences of inadequacies of the testing and counselling process.

Research has also specifically identified poor testing/counselling experiences of women: for example, a 1997 study of the experiences of 40 HIV-positive women in the Toronto area revealed that 43 percent had received no counselling at all, and only 7 percent had received both pre- and post-test counselling. Studies on HIV testing among pregnant women suggest ongoing cause for concern about the extent to which, in practice, women are getting adequate information and discussion with physicians to give truly voluntary, specific and informed consent to prenatal HIV testing. (See info sheet 8 in this series on HIV testing in pregnancy.)

Concerns have also been identified about the experiences of Aboriginal people with HIV testing and counselling services. At a 2006 national consultation on HIV testing, some health professionals expressed concern that inadequate compensation for physicians for counselling time may lead to poor-quality HIV counselling, a concern that has been raised repeatedly over the years.

Necessity of counselling before and after an HIV test

The consequences of HIV testing for those who test positive remain serious — personally, socially and legally. Counselling is important to help mitigate the most negative consequences of disclosing HIV status. In their personal lives, people who test HIV-positive must confront the fact of their infection and the meaning of that diagnosis for their present and future health. Socially, they must confront a range of difficult issues: the potential impact of their diagnosis on those close to them; to whom and when they should disclose their HIV status; and the well-founded fear of stigma and discrimination associated with disclosure that still can result in the loss of personal relationships, employment, and medical care, and otherwise dramatically affect their quality of life.

The legal consequences are equally far-reaching. Public health legislation in all Canadian provinces and territories requires that each diagnosed case of HIV infection be reported to public health officials (see info sheet 5 in this series). This legislation establishes, for each province and territory, a framework that governs the conduct of persons with designated infectious or communicable diseases (such as HIV and AIDS), insofar as that conduct may present a risk of transmission to others. In the criminal context, a person who knows that he or she is HIV-positive may face criminal prosecution, and possibly years in jail, for not disclosing his or her HIV status to sexual partners before engaging in conduct that poses "a significant risk of serious bodily harm."

Internationally, the benefits of counselling linked to HIV testing have been demonstrated in several countries. A widely cited 2000 study in Kenya, Tanzania and Trinidad-Tobago showed that people who received well-supported and individualized counselling with HIV testing were more likely to reduce HIV risk behaviours than those who received health information without the chance to talk with a counsellor. Counselling for couples was especially helpful in leading to safer sex. The authors of a 2004 review of outcomes for women in developing countries of disclosure of their HIV status suggest that at least some of the many HIV-positive women who face violence, abandonment and other abuse may be helped by counselling that could assess their risks and help them anticipate and mitigate the worst reactions.

In view of all these factors, it would be a serious mistake to trivialize or normalize HIV testing and to push people to be tested without providing adequate pre-test and post-test counselling. People should be encouraged to be tested, but they must be provided with the support that will help them to maximize the benefits from testing while reducing potential harms. Given the seriousness of the consequences of HIV testing for persons tested, a physician who conducts an HIV test on a patient without meeting the basic elements of informed consent, including pre-test counselling to the extent needed by the individual patient, could be held legally liable. Post-test counselling also remains crucial. Counselling for HIV-positive persons needs to stress that they can remain healthy and productive; link them to medical follow-up; encourage self-education on care and treatment; discuss new developments in the management of HIV infection; discuss risk-reduction strategies; and, if necessary, arrange for partner notification.

Recommendations

- Pre- and post-test counselling maximize the benefits of HIV testing for the persons being tested and for society, while reducing potential harms. Therefore, testing should be undertaken only with good-quality pre-test and post-test counselling.

- The CMA, provincial and territorial authorities, and associations of health professionals should emphasize in their guidelines the importance of counselling in providing HIV testing. They should publicize these guidelines widely to physicians and other health professionals, and they should ensure that training and education are available to all relevant health professionals on HIV counselling and testing.

- Colleges and universities educating health care professionals should include, as mandatory components of their curricula, training in counselling principles and techniques, and on HIV/AIDS (including related psychosocial issues).

Additional reading

Canadian HIV/AIDS Legal Network. *Prevention and Protection: Enhancing Both HIV Testing and Human Rights in Canada* (2007), on-line: www.aidslaw.ca/testing. Report reviewing the available literature and informed by discussions at 2006 national workshop on HIV testing issues in Canada, with a focus on HIV testing in pregnancy and questions raised by rapid tests.

Canadian Medical Association. *CMA Policy – Acquired Immunodeficiency Syndrome (Update 2000)*, Policy Document PD01-02, on-line via www.cma.ca (in "CMA Policy Base"). Policy statement affirming the importance of pre- and post-test counselling and the importance of obtaining informed consent to HIV testing.

Canadian Medical Association (Expert Working Group on HIV Testing: Counselling Guidelines). *Counselling Guidelines for HIV Testing.* Ottawa: CMA, 1995. This is the third edition of the CMA's guidelines.

Howard Research and Instructional Systems, Inc. *Alberta routine prenatal HIV screening program: Final evaluation report*. Alberta Medical Association and Alberta Health and Wellness, 2001.

Jackson L.A. et al. "HIV-positive Women Living in the Metropolitan Toronto Area: Their Experiences and Perceptions Related to HIV Testing". *Canadian Journal of Public Health* 1997; 88(1): 18–22.

Matiation, S. *HIV Testing and Confidentiality: Issues for the Aboriginal Community*, 2nd ed. Canadian HIV/AIDS Legal Network & Canadian Aboriginal AIDS Network, 1999, on-line: www.aidslaw.ca/aboriginal. Overview of issues related to HIV testing and confidentiality of particular concern to Aboriginal people and communities.

Medley, A. et al., "Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: Implications for prevention of mother-to-child transmission programmes", *Bulletin of the World Health Organization* 2004; 82(4): 299–307. This review of 17 studies from Africa and Asia suggests that pre-test counselling may help identify women who face particular risk of adverse outcomes of disclosure of their HIV-positive status.

Myers, T. et al. *The HIV Test Experience Study: An Analysis of Test Providers' and Test Recipients' Descriptions and Critical Appraisals of the HIV Antibody Test Experience*. Toronto: University of Toronto, 1998. Summary of study results reported in: Myers, T. & D. Haubrich. "The HIV Test Experience Study". *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(4): 25–28, on-line: www.aidslaw.ca/review.

Rowan, M.S. et al. "Qualitative evaluation of the Canadian Medical Association's Counselling Guidelines for HIV Serologic Testing". *Canadian Medical Association Journal* 1996; 154(5): 665–671. Reports findings of evaluation by structured focus groups among physicians in six cities to assess the relevance, clarity and practicality of the CMA guidelines, including physicians' experiences and practices of HIV testing of patients.

Voluntary HIV-1 Counselling and Testing Efficacy Study Group. "Efficacy of voluntary HIV-1 counselling and testing in individuals and couples in Kenya, Tanzania and Trinidad: a randomised trial". *Lancet* 2000; 356(9224): 103–112. Report of one of the few controlled trials on the value of counselling in HIV testing with respect to such outcomes as safer sexual practices.

Copies of these info sheets are available on the website of the Canadian HIV/AIDS Legal Network at www.aidslaw.ca/testing or from the Canadian HIV/AIDS Information Centre (aidssida@cpha.ca). Reproduction is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of the information. For further information, contact the Legal Network at info@aidslaw.ca. *Ce feuillet d'information est également disponible en français.*

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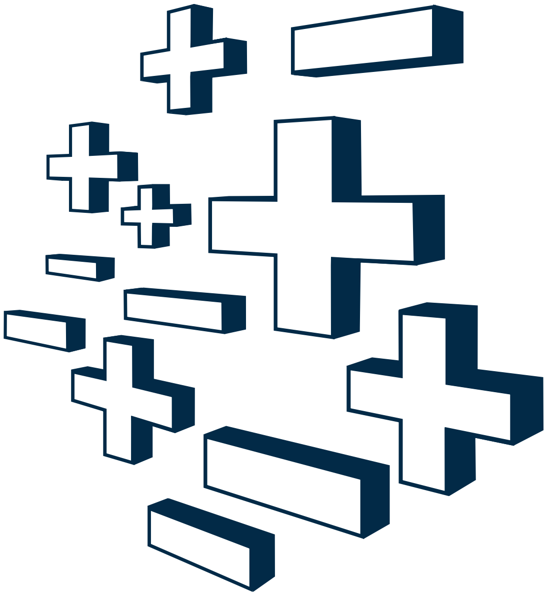

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HIV Testing

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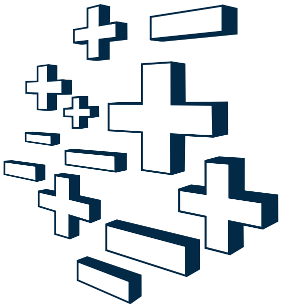

Anonymous HIV testing

Definitions

Anonymous testing is HIV testing in which the test results are recorded and reported without revealing the name of the person tested. In other words, unlike *nominal testing*, anonymous testing does not result in test results being recorded and reported to public health authorities by the person's name. Instead, a unique identification code is assigned to the sample being tested, and only the person tested knows the code.

Non-nominal testing is similar to anonymous testing in that a unique code, rather than the person's name, is attached to the sample. However, while the person's name is not reported to public health authorities, the health care provider who orders the HIV test knows this code and can match the test result to the patient by name. (In some cases, "flexible" non-nominal testing is possible: the unique code is made up of the person's initials and date of birth, but the person tested can give a false name and date of birth so that a test result cannot be traced back to him or her.)

Importance of anonymous HIV testing

Many benefits of ensuring access to anonymous testing have been documented over the years. There is evidence that:

- *The availability of anonymous testing encourages people to be tested.* For example, in a 1990 study at the Hassle Free Clinic in Toronto, 30 percent of the people tested at the clinic said that they would not have chosen to be tested if anonymous testing had not been available.
- *The availability of anonymous testing encourages people at greatest risk to be tested.* Studies have shown that people at greatest risk of HIV infection, including those marginalized by society such as people who use illegal drugs and former prisoners, are more likely to undergo testing for HIV if the testing is anonymous and the counselling and test results are dependably confidential.
- *Anonymous testing sites often offer "best practice" pre- and post-test counselling.* Personnel at anonymous testing sites often have outstanding expertise in providing confidential counselling, and some people prefer anonymous testing services because of the quality of the counselling available.

Availability of HIV testing in Canada

Since May 2003, HIV infection has been a "notifiable" disease in every jurisdiction in Canada — in other words, every diagnosed case of HIV infection must be reported to the relevant public health authorities, usually by physicians or the laboratories that conduct the tests. Only some jurisdictions currently provide for fully anonymous testing, although all jurisdictions provide at least the option of non-nominal testing. The Public Health Agency of Canada update on HIV/AIDS of August 2006 provided the summary shown in Table 1 *(overleaf)* of provincial and territorial policies on HIV testing and reporting.

Debates over anonymous testing

Despite the benefits of anonymous testing, the debate over it continues. Critics of anonymous testing claim that it is expensive, that it may prevent the collection of epidemiological data about HIV transmission patterns, and that it leaves notification to sexual partners that they may be at risk entirely in the hands of the individual who has been tested, rather than enabling public health

Table 1: HIV testing and reporting by province/territory

Province/territory	Type of HIV testing available	Who is responsible for reporting HIV cases	Type of testing reported to authorities
British Columbia	N, NN	L, P	N, NN
Yukon	N, NN	P	N
Northwest Territories	N, NN	L, P, RN	N
Nunavut	N, NN	L, P, RN	N
Alberta	N, NN, A	L, P	NN
Saskatchewan	N, NN, A	L, P	NN
Manitoba	NN	L, P	NN
Ontario	N, NN, A	L, P	N, NN
Quebec	N, NN, A	L, P	NN
New Brunswick	N, NN, A	L, P, RN	NN
Nova Scotia	N, NN, A	L, P	N, NN
Prince Edward Island	N, NN	L, P, RN	N, NN
Newfoundland and Labrador	N, NN, A	L, P	N

N — nominal/name-based
A — anonymous
P — physician
NN — non-nominal/non-identifying
L — laboratory
RN — nurse

authorities to notify partners. (See info sheet 7 in this series for more on partner notification.) In addition, critics point out that people who have tested anonymously and who do not return for their results cannot be contacted to urge them to do so.

However, these concerns should not be overstated, for the following reasons:

- *Anonymous testing programs need not be expensive.* For example, in Ontario in the mid-1990s it was estimated that the cost of an anonymous test is less than half the cost associated with providing the test through a physician in private practice.

- *Relevant data for epidemiological purposes can be obtained through anonymous testing.* This includes information such as age, sex, and geographic location of an HIV-positive person, as well as the likely route of transmission. Many jurisdictions that have adopted nominal reporting of HIV have also maintained the option of anonymous testing, recognizing that the benefits of preserving this option may outweigh the potential impact on epidemiological data collection.

- It is true that partner notification is entirely voluntary with anonymous testing. However, *partner notification can be carried out by HIV-positive persons themselves or by the physicians from whom they subsequently seek care.* Many HIV-positive individuals voluntarily notify sexual or needle-sharing contacts who may not be aware that they are at risk. Partner notification should ideally respect the human rights and dignity of both the person tested and his or her partners, and be voluntary, non-coercive, and non-prejudicial.

- The experience of existing anonymous testing programs in Canada suggests that *the vast majority of people who test anonymously do return to learn their test results.* For example, in 2000, 92 percent of clients of the Hassle Free Clinic, a noted anonymous testing site in Toronto, returned for their test results.

Recommendation

The benefits of making anonymous testing available outweigh the concerns. In order to encourage as many people as possible to learn their HIV status, provinces and territories should:

- make anonymous testing available as part of a range of voluntary, high-quality, discrimination-free testing options (or, at a minimum, provide access to flexible, non-nominal testing);
- widely advertise the availability of anonymous testing, reduce waiting periods at such facilities, and undertake ongoing evaluation; and
- reinforce processes and training to minimize breaches of confidentiality in all medical procedures.

Additional reading

Jürgens, R. *HIV Testing and Confidentiality: Final Report*. Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998, on-line: www.aidslaw.ca/testing. Discusses the issue of medical confidentiality in the HIV testing context (pp. 209–224) and anonymous testing in Canada (pp. 63–71), and contains a number of recommendations.

Public Health Agency of Canada. "HIV Testing and Infection Reporting in Canada", in *HIV/AIDS Epi Update* (August 2006), pp 13–18, on-line: www.phac-aspc.gc.ca/aids-sida/publication/index.html#er. Update of policies on reporting of HIV test results by province and territory.

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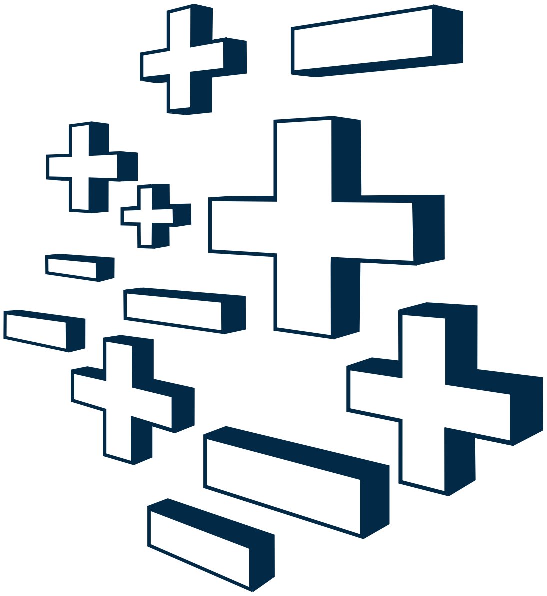

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HIV Testing

6

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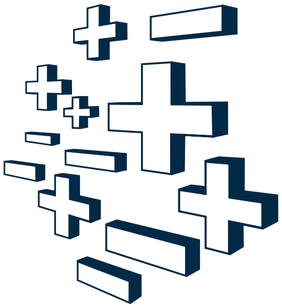

Confidentiality

Confidentiality refers to the keeping of medical records, including HIV test results or even the fact of seeking an HIV test, in ways that protect people's privacy. This includes storing test information in files that are protected from unauthorized viewing. Confidentiality also extends to the counselling that should accompany HIV testing. Confidentiality is an ethical and legal duty that flows from the individual's human right to privacy. Obligations of confidentiality may sometimes need to be balanced against other important considerations.

Confidentiality in ethical and effective medical practice

Duties of confidentiality are generally important in medicine for two main reasons:

- Respecting confidentiality is ethically required out of respect for the dignity of the patient. The patient's most personal physical and psychological secrets are kept confidential in order to minimize a sense of vulnerability or shame.

- There is also a pragmatic reason to protect confidentiality. Physicians and other professionals must be able to assure patients that what they reveal will remain confidential. Without such a guarantee, patients may be less than fully candid, and inadequate information from the patient can impair effective clinical care by the health care provider. Effective health care requires that patients feel free to come forward to seek medical advice or treatment, and do not feel inhibited from entrusting physicians with personal information.

Privacy and confidentiality are particularly important with respect to HIV because of the stigma and discrimination experienced by people with HIV or AIDS. Discrimination against people living with HIV, or perceived to have HIV, remains a reality in Canada. The success of HIV treatment depends on long-term contact with the health-care system. People must trust that the system will protect their privacy. Loss of that trust could lead people to avoid the health system, with serious consequences for the health of those individuals and for public health more broadly.

The legal duty of confidentiality and its limits

In Canada, courts have long recognized that health care professionals owe a legal duty of confidentiality to their patients, subject to some exceptions. In some provinces, the duty of confidentiality is also imposed by statute. In addition, under binding codes of practice, it is professional misconduct for a regulated health professional to disclose information about a patient to another person without the patient's consent, except as permitted or required by law.

However, professional bodies, legislatures, and courts have recognized that, in some circumstances, patient confidentiality must give way in order to protect other interests, including the protection of others. For example, legislation in some provinces says that a person who has been involuntarily exposed to the bodily fluids of another — for example, through a workplace accident — may get an order forcing the "source person" to be tested for HIV if he or she does not consent to testing, and for the test results to be disclosed to the exposed person. (See info sheet 11 in this series for more on forced HIV testing.)

Aside from those unusual circumstances, however, confidentiality must also be balanced against the benefits of notifying a person's past sexual or drug equipment-sharing partners ("partner notification") that they may have been exposed to possible infection. In some cases, the difficult question of breaching confidentiality to protect someone who may be at risk of infection may also arise (often referred to as a "duty to warn"). The rest of this info sheet looks at these two issues.

Partner notification

Partner notification — once called "contact tracing" and sometimes called "partner counselling" — is the set of activities by which persons who have had sex or shared drug equipment with an individual with HIV (the "index person") are notified and counselled about their exposure to HIV and offered services. There are three approaches to partner notification:

- *Patient referral:* HIV-positive persons are encouraged to notify partners of their possible exposure to HIV, without the direct involvement of health care providers.
- *Provider referral:* HIV-positive persons give partners' names to a health professional (e.g., a public health nurse or physician), who then notifies the partners directly.
- *Conditional referral:* A combination of these two approaches. HIV-positive persons choose to notify partners themselves, but agree with the health professional that if some partners cannot be located, or if some of the partners do not contact public health authorities for follow-up, the health professional will contact the partners directly.

Background

The value of partner notification — with appropriate protection of anonymity — is widely recognized today. The Public Health Agency of Canada estimates that more than one quarter of people living with HIV in Canada are unaware of their HIV status. Partner notification can be one of the most effective ways to reach these persons, encouraging them to seek HIV testing and, if necessary, HIV-related care, treatment and support.

The importance of partner notification seems to be well understood by index persons in many settings. Research in North America has shown that:

- with appropriate counselling and support, index persons most often voluntarily co-operate with public health professionals in confidentially identifying at least some of their sexual or drug-using partners;
- if located, sexual partners are generally receptive to and even grateful for confidential notification of their potential exposure to HIV by the patient or the health department, and will usually seek HIV testing;
- patient referral is probably less effective than provider-referral approaches, especially when there are numerous partners to be notified; and
- sexual partners often are unaware of, misunderstand, discount, or deny their HIV risks.

The question is not whether sex partners or needle-sharing partners should be informed that they may have been exposed to HIV, but how this notification should happen.

Canadian guidelines on partner notification

According to the *Guidelines for Practice for Partner Notification in HIV/AIDS*, released in 1997 by the Federal/Provincial/Territorial Advisory Committee on AIDS, partner notification should, among other things:

- respect the human rights and dignity of the index person and the partners;
- be voluntary, non-coercive, and non-prejudicial;
- maintain strict confidentiality of all information concerning both the index person and the partners, including written records, locating information for partners and, when the health worker does the notification, the identity of the index person;
- ensure that during the notification process, when partners are told of the possibility of HIV exposure, no additional information is given that may identify the index person; and
- attempt to ensure that index persons and their partners have adequate social support systems.

In some cases, a sexual or drug-sharing partner of someone who has been diagnosed as HIV-positive may currently be at risk of HIV infection, so notifying that person can take on extra urgency. In some such circumstances, if the index person's consent to notifying a current partner cannot be obtained, the guidelines on partner notification indicate that it may be justified for the health professional to undertake partner notification without this consent. However, efforts should first be made to assist the index person in notifying the partner, and the index person should be given reasonable advance notice.

It is important for health providers to bear in mind that wilful exposure is rarely the cause of a person's refusal to notify a partner. Disclosure of HIV-positive status can be particularly difficult for various reasons, not least the stigma and shame that still too often surround a diagnosis of HIV infection. In some cases — particularly for women — fear of violence may be the reason for not notifying a partner. Some jurisdictions include screening for domestic violence as part of the partner notification process. Counselling and other support may be needed if violence is a concern, and these considerations need to be addressed as part of making partner notification possible and protecting the health and safety of not only the person notified but also the index person. Economic dependence and fear of abandonment or loss of family may also make disclosure difficult. Generally, involuntary partner notification should be done only after other efforts to support an index person with notification; the public health benefits of maintaining confidentiality and patient autonomy may outweigh regularly engaging in involuntary disclosure.

Protecting persons at risk of harm: "duty to warn"

In some cases, partner notification, including with assistance from a health professional, is not successful or is not practical. The question then arises whether a health professional may breach confidentiality to disclose a patient's HIV status to another person who may be at risk of harm. This is sometimes referred to as a "duty to warn," although any legal obligation is probably more accurately understood as the duty to take reasonable steps to prevent harm. Depending on the circumstances, this might require a direct warning to the person thought to be at risk, but it may also be possible to take other steps that make the person aware of the risk without directly breaching obligations of confidentiality owed to the patient.

In some jurisdictions, breaching patient confidentiality for this reason is explicitly permitted by statute under certain conditions. For example, at least six provinces or territories (Alberta, Manitoba, Saskatchewan, Ontario, Prince Edward Island and the Yukon) have legislation that requires or permits physicians to disclose confidential information without a patient's consent if there are reasonable grounds to believe that this will avoid or minimize a danger to another person. Where such statutes do not exist, health professionals must be guided by any other relevant legislation that governs medical confidentiality, court decisions regarding confidentiality and its limits, and professional codes or guidelines.

There have not been any Canadian court cases specifically on the issue of whether, in certain circumstances, a health professional must or may breach confidentiality to disclose a patient's HIV-positive status to someone else without consent. However, given a decision of the Supreme Court of Canada in the case of *Smith v. Jones*, [1999] 1 S.C.R. 455, that raised similar questions in a somewhat different context (not related to HIV), it is likely that courts would conclude that a health professional may breach confidentiality where: (1) there is a clear risk of harm to an identifiable group or group of persons; (2) the risk is of serious bodily harm or death; and (3) the danger is imminent. No Canadian court has yet ruled that a health professional must breach confidentiality in these or similar circumstances.

Policies and guidelines adopted by health professionals' regulatory bodies generally take a similar approach. The Canadian Medical Association (CMA) advises physicians that disclosing a patient's HIV-positive status to a spouse or current sexual partner "may be indicated when physicians are confronted with a patient who is unwilling to inform the person at risk." Such disclosure may be justified when all the following conditions are met: (1) the partner is at risk of infection with HIV and has no other reasonable means of knowing of the risk; (2) the patient has refused to inform the sexual partner; (3) the patient has refused the physician's offer to help by notifying the partner on the patient's behalf; and (4) the physician has informed the patient of the physician's intention to disclose the information to the partner.

Conclusion

Breaches of confidentiality raise difficult questions. What will occur if it becomes generally known that clinicians breach confidentiality to protect third parties? Will patients cease to speak candidly about their behaviour, including activities that risk transmitting HIV, and to seek assistance in changing that behaviour or notifying partners who might be at risk? Will public health suffer as a consequence?

The requirement of medical confidentiality is a very strong obligation, although in highly exceptional cases there may be justifications for overriding it. Patients, their contacts, doctors and their staff, and the common good are most likely to be best served if that obligation continues to be honoured.

Recommendations

- Partner notification programs should be implemented in ways consistent with the principles set out in the 1997 *Guidelines for Practice for Partner Notification in HIV/AIDS*, which should be distributed widely. In addition, domestic violence counselling and screening should be included in partner notification programs, with appropriate support to index persons as indicated.

- Each person who requests HIV testing and counselling must be made aware before testing of the partner notification program in his or her jurisdiction. This includes making people aware, before and after HIV testing, of the assistance available to them for notifying past partners in ways that preserve the anonymity of the person being tested as much as possible in the circumstances. It also includes making persons getting tested aware of the limits on confidentiality if they put current or future partners at significant risk of infection without disclosing to them.

Additional reading

Canadian HIV/AIDS Legal Network. *Privacy Protection and the Disclosure of Health Information: Legal Issues for People Living with HIV/AIDS in Canada* (2004). Report reviewing legal aspects of privacy and confidentiality of medical information for people living with HIV in Canada (see especially pp. 38–40 on disclosure to prevent harm to others). See also: *HIV/AIDS and the Privacy of Health Information* (2004), a series of info sheets summarizing key elements of the report. Both on-line at www.aidslaw.ca/privacy.

Canadian Medical Association. *CMA Policy — Acquired Immunodeficiency Syndrome (Update 2000)*, Policy Document PD01-02, on-line via www.cma.ca (in "CMA Policy Base"). Policy statement affirming the importance of pre- and post-test counselling and the importance of obtaining informed consent to HIV testing.

Christie, T. & P. Kendall. "The science of partner notification: A review of the available evidence". *British Columbia Medical Journal* 2003; 45(3): 124–127, on-line via www.bcma.org. Succinct and useful summary of research on partner notification in Canada.

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Copies of these info sheets are available on the website of the Canadian HIV/AIDS Legal Network at www.aidslaw.ca/testing or from the Canadian HIV/AIDS Information Centre (aidssida@cpha.ca). Reproduction is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of the information. For further information, contact the Legal Network at info@aidslaw.ca. *Ce feuillet d'information est également disponible en français.*

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HIV Testing

This is one in a series of 12 info sheets on HIV testing in Canada.

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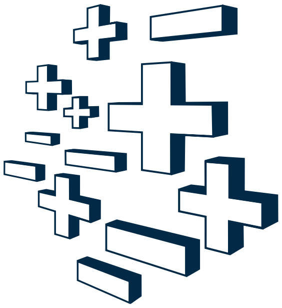

Access to HIV testing

Voluntary HIV testing with counselling is vital to HIV/AIDS prevention, treatment, care and support. Therefore, HIV testing needs to be readily accessible to all Canadians; barriers to testing, whether real or perceived, need to be removed. This is particularly important given estimates by the Public Health Agency of Canada that, as of 2006, one quarter of people living with HIV in the country are unaware of their status and are, therefore, missing the possibility of benefiting from care, treatment and support. This means it is important to ensure access to a range of HIV testing services, including ones that address possible concerns about anonymity and confidentiality, given the stigma and discrimination that still too often surround HIV/AIDS and remain a significant barrier to seeking tested. (See info sheet 5 in this series regarding anonymous and non-nominal HIV testing).

For certain groups, there are particular barriers to HIV testing that need to be addressed to ensure equitable access to this important health service.

Women

Women face a number of barriers in access to HIV testing:

- There still is a perception that only men who have sex with men, people who use drugs, and sex workers are at risk for HIV, which has prevented some women from seeking testing. It has also led physicians not to offer HIV testing to women whom they do not perceive to be at risk. For a significant number of women, a doctor's office may be the only place where they have the opportunity to receive appropriate information about HIV and testing options.
- Some women have been refused HIV testing by their physician on the assumption that they are not at risk, or have been required to answer questions about drug use and sexual activity before the physician agrees to order an HIV test. Women may find these inquiries stigmatizing and difficult to challenge, given differences in power and (sometimes) sex between the woman and her health care provider.
- Testing and counselling for women have been closely associated with prenatal care. There often appears to be less concern for the welfare of women than for the welfare of their fetuses. Women who are not pregnant or of child-bearing age have sometimes found it difficult to get an HIV test.
- Women living in situations of abuse or economic dependence may understandably fear the potential repercussions of HIV testing. Studies in Canada and elsewhere have shown that some women have a well-founded fear of being abandoned or assaulted if they are discovered to be HIV-positive.
- Fear of losing custody of children may also impede some women, particularly sex workers or women who use illegal drugs, from seeking HIV testing and related health services.

Aboriginal people

Aboriginal people can seek HIV testing from the same sources as the general population. In addition, a small number of testing clinics or programs specifically designed for Aboriginal people are available in some cities. On-reserve Aboriginal people can generally be tested for HIV at the community health centre by a health nurse. However, specific barriers to HIV testing services are faced disproportionately by Aboriginal people in Canada:

- In some parts of the country, people may have to travel long distances to be tested. In these circumstances, the chances are reduced that a person will get tested or, having been tested, will return to the health centre to get the result.

- Some remote communities are visited by a health nurse only sporadically. The period between taking a test and getting the result is generally much longer in rural communities than elsewhere, and access to counselling and support services, especially in a timely fashion, may be limited.
- Some Aboriginal communities may not provide adequate HIV testing services.
- On reserves that are small, closely knit communities, people may be reluctant to use the local health centre due to concerns about confidentiality.
- Racism can make some facilities less accessible to Aboriginal people, as can lack of sensitivity to Aboriginal culture in the design of services.

Other groups

Other persons in Canada may face particular challenges to seeking or gaining access to HIV testing:

- Some *people from countries where HIV is endemic* may fear seeking an HIV test because of real or perceived insecurity of their immigration status. Finding HIV counselling that is culturally appropriate and available in their mother tongue may also be difficult. In some cases, people in these communities, particularly women, may fear rejection or even violence if it is known that they are HIV-positive. This may also have implications for immigration status if the person is being sponsored by a partner or other family member.
- *People who use illegal drugs* may often hesitate to use health services for fear that their drug use will be discovered and that they will be prosecuted; some may also fear loss of custody of their children if they are known to use drugs. Special efforts are needed to enable people who use drugs to seek HIV testing safely and without fear.
- Because of outdated laws criminalizing elements of sex work, and the possibility of criminal charges for not disclosing HIV status to sexual partners, *sex workers* may fear arrest or prosecution if they seek an HIV test.
- Discrimination based on sexual orientation or gender identity, or fear of such discrimination, can keep some lesbian, gay, bisexual or transgender people from seeking health services. The lingering perception of HIV as a "gay disease," and homophobia, can be a barrier more broadly to men seeking HIV testing.
- Recent studies of HIV/AIDS knowledge reveal that *youth* in Canada may not have accurate information about HIV transmission and HIV testing services. Young people may also not perceive themselves to be at risk, or may avoid HIV testing services unless they feel they can get supportive, non-judgmental information and help. Youth may have particular concerns about disclosure of confidential information to parents, including sexual or drug-using activity. Street-involved youth may have particular concerns about interventions by child protection authorities.
- Given the difficulty of preserving confidentiality when seeking health services in prisons, *prisoners* may have particular concerns about stigma, discrimination and violence that keep them from seeking HIV testing, even if their past or current activities put them at risk of HIV infection. Yet prisoners are often at higher risk of HIV, because they have little or no access to HIV prevention tools even though high-risk activities occur in prison (e.g., unsafe tattooing practices, sharing of equipment to inject illegal drugs).

Recommendations

- Sustained public education campaigns about HIV, its transmission and prevention, and available HIV testing services, as well as campaigns countering stigma and discrimination based on or related to HIV, must be funded by all levels of government as an urgent public health need, including varied efforts aimed at reaching particular segments of the population (e.g., youth). All people in Canada should be aware of, and have access to, a range of voluntary, high-quality options for HIV testing, free from stigma and discrimination, including access to anonymous testing (or, at a minimum, access to flexible, non-nominal testing).
- Awareness-raising efforts are needed to ensure that women know their risk of HIV infection. Materials and messages tailored to the situations of Aboriginal women and women from countries where HIV is endemic are needed.
- Efforts to increase women's awareness of HIV testing, and their access to testing services, need to focus on all women, not just pregnant women.
- Doctors need to be aware of women's potential vulnerability to HIV. They should routinely offer HIV testing to their female patients (and not just those who are pregnant or considering pregnancy). Doctors should order an HIV test at their patient's request, without discouraging the patient based on their own perceptions of the patient's risk.
- Health care providers, including HIV testing providers, need to be aware of women's concerns about abuse and economic dependence that may affect their willingness or ability to get tested for HIV, and to address these concerns and needs as best they can in order to assist women in making decisions about HIV testing.

- Federal, provincial, territorial, and Aboriginal governments, and Aboriginal AIDS and health service organizations and providers need to work together to ensure accessible options for HIV testing for Aboriginal people.
- Culturally and linguistically appropriate HIV/AIDS education, and discrimination-free HIV testing services, must be better supported for Aboriginal people and people from countries where HIV is endemic to help reduce stigmatization and other barriers to HIV testing.
- Street outreach services are needed to connect street-involved people, including youth, to HIV testing and other health services is needed.
- Mobile HIV testing units with good confidentiality protocols, use of rapid tests with appropriate safeguards and prompt confirmatory tests, and other innovations should be investigated for their potential to help increase access to testing for various populations that have limited access to standard HIV testing services.

Additional reading

African and Caribbean Council on HIV/AIDS in Ontario. *HIV/AIDS Stigma, Denial, Fear and Discrimination: Experiences and Responses of People from African and Caribbean Communities in Toronto*. Toronto ACCHO, 2006, on-line: www.accho.ca. Qualitative study exploring experiences of HIV-positive people and members of these communities at large, and examining how these factors affect responses to HIV, including testing, treatment and support.

Alliance for South Asian AIDS Prevention. *Discrimination & HIV/AIDS in South Asian Communities: Legal, Ethical & Human Rights Challenges – An Ethnocultural Perspective*. Toronto: ASAAP, 1999, on-line: www.asaap.ca. Overview of factors affecting response to HIV in this community, including access to health services (see especially pp. 59–62).

Csete, J. *Vectors, vessels and victims': HIV/AIDS and women's human rights in Canada*. Toronto: Canadian HIV/AIDS Legal Network, 2005, on-line: www.aidslaw.ca/women. Highlights ways in which subordination of women and other human rights abuses may impede access to HIV services for women, including testing and counselling (see especially pp. 19–21, 38–41).

Jackson, L.A. et al. "HIV-positive women living in the Metropolitan Toronto area: their experiences and perceptions related to HIV testing". *Canadian Journal of Public Health* 1997; 88(1): 18–22. An important study on women's experience of HIV testing.

Leonard, L. *Testing times: Ontario's prenatal HIV testing programme: application, acceptability and advancement*. Toronto: Ontario AIDS Bureau, 2001. Includes testimony from women of HIV testing experiences and barriers to testing access.

Matiation, S. *HIV Testing and Confidentiality: Issues for the Aboriginal Community — A Discussion Paper*, 2nd ed. Canadian HIV/AIDS Legal Network & Canadian Aboriginal AIDS Network, 2000, on-line: www.aidslaw.ca/aboriginal. Provides a thorough discussion of HIV testing issues specific to Aboriginal people and recommendations.

Myers, T. et al. *An HIV research needs assessment of MSM in ethno-cultural communities: Perspectives of volunteers and service providers: technical report.* Toronto: HIV Social Behavioural and Epidemiological Studies Unit, University of Toronto, 2001.

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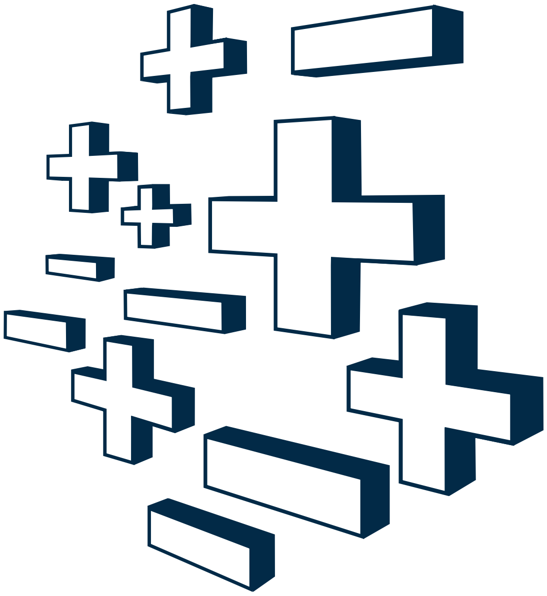

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HIV Testing

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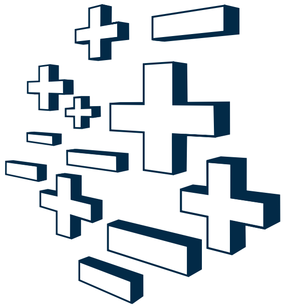

HIV testing and pregnancy

Background

Before 1994, knowledge about HIV and pregnancy was limited. Evidence suggested that about one third of babies born to HIV-positive women would be HIV-positive themselves. Nonetheless, in Canada HIV testing was offered most often only to pregnant women considered to be at obvious risk for HIV. In 1994, research in the United States showed that giving the antiretroviral drug AZT to HIV-positive pregnant women and to their infants after birth could reduce the rate of mother-to-child HIV transmission by about two thirds. In 1998, research in Thailand showed that even a short course of AZT, which would be affordable in almost every country, would significantly reduce transmission risk. Studies have also shown that the risk of transmission can be reduced even further if other preventive measures (e.g., Caesarean delivery) are taken. These findings invigorated debate about how best to ensure that pregnant women have the opportunity to be tested for HIV.

Who should be offered testing?

All pregnant women should be offered HIV counselling and testing as early in pregnancy as possible, as should women who are considering pregnancy. Several studies have shown that offering HIV testing only to women considered to be at risk of infection fails to identify many HIV-positive women.

Should HIV testing be "routine" for pregnant women?

Only a policy of compulsory testing of pregnant women could ensure that all pregnant women seeking prenatal care are tested for HIV. However, such a practice would an ethically indefensible denial of women's autonomy, and would violate women's basic human rights to equality and to security of the person (i.e., the right to control what happens to one's body); it would almost certainly be ruled unconstitutional in Canada. Even in countries highly affected by HIV, virtually no one openly advocates for compulsory testing of pregnant women.

In recent years, however, some experts have argued for policies that they say would make HIV testing for pregnant woman a routine or default option. Most often these policies take the form of informing women they will be tested for HIV unless they "opt out" of the test. In Canada, opt-out HIV testing for pregnant women has been adopted by Alberta, New Brunswick, Nova Scotia, the Northwest Territories, Nunavut, Manitoba, and Newfoundland and Labrador.

A number of human rights concerns are raised by opt-out testing policies:

- *Is the offer really a free-choice offer?* In opt-out systems, it is not clear whether women always experience the offer of testing as something that truly allows them to choose to be tested or not. In some Canadian research among pregnant women in three provinces, a disturbing number of women reported that they did not experience the offer to test as voluntary, and some thought they were required to get tested. The "offer" may not feel like a matter of choice if it comes with no clear explanation of the woman's right to refuse the test or without enough information to make an informed choice, or if women are not accustomed to questioning doctors or other health professionals.

- *Is there really informed consent?* Some studies, conducted in both opt-in and opt-out jurisdictions, have revealed a significant number of pregnant women did not feel they received adequate information about HIV testing, the risks of mother-to-child transmission or options for reducing the chance of transmission. In some cases, women did not recall having been offered an HIV test at all or thought that it may have been presented as part of a long list of tests. Even where voluntary opt-in testing is the norm, informed consent processes may be flawed, but some evidence suggests that under opt-out HIV testing policies, health professionals may put less emphasis on obtaining informed and specific consent.

In Canada, the current standard of professional care requires that HIV testing be carried out only after the person to be tested has given specific, informed consent following pre-test counselling. (See info sheets 3 and 4 in this series for more information on consent and counselling.) Canadian courts do not consider informed consent a luxury, to be abandoned because it is perceived as too burdensome by health professionals or because of the desire to increase HIV testing uptake. Obtaining a patient's consent, and providing counselling that is adequate to her needs, are particularly important to enable her to make decisions. In addition, requiring that testing be done only with her specific and informed consent will enhance the trust necessary for establishing a collaborative relationship with the physician.

- *What are the real benefits and costs of opt-out policies?* It is not surprising that opt-out policies, under which HIV testing is done unless a woman explicitly refuses, may lead fairly rapidly to higher rates of HIV testing among pregnant women. But the measure of good-quality HIV testing practices cannot be based only on the number of women tested. If opt-out policies undermine pre-test counselling, the calculation of their cost must include adverse consequences of testing women who are not prepared to be tested and not well informed about what to expect if they are HIV-positive. Depression, irrational fears, suicidal tendencies and other psychological problems may result. Women may face abandonment and violence with no preparation for dealing with these tumultuous events. HIV testing policies and practices should contribute to minimizing these outcomes. The experience of Ontario, where 90 percent of pregnant women agreed to an HIV test in 2004 without an opt-out policy, also indicates that very high testing rates are possible without compromising on counselling and informed consent.

- *Does routine, opt-out testing reduce stigma?* Those who favour more routine approaches to HIV testing often claim that these approaches normalize HIV and thus reduce stigma. But there is no evidence from jurisdictions in Canada with opt-out policies, or in countries such as Botswana with similar policies, that these policies reduce HIV-related stigma. Stigma and discrimination related to HIV are still widespread in Canada (see info sheet 2 in this series), and it will take much more than making testing more routine to combat them. In the meantime, it is ethically dubious to expose people to this stigma and discrimination without ensuring that they make specific, informed and voluntary choices about HIV testing.

Rapid HIV testing during labour

For women who arrive at a hospital in labour but who have somehow not had prenatal care or been offered an HIV test, is there an appropriate HIV testing option? Some experts suggest these women could undergo rapid HIV screening during labour. (See info sheet 9 in this series for more on rapid HIV testing.) Women who screen HIV-positive would be offered treatment to prevent transmission of the virus. (A rapid screening result could also provide essential information for interventions such vaccination of the infant against tuberculosis, which should not be done if the infant may be HIV-positive.) Many experts believe rapid testing is an important tool for women in this situation. Others have cautioned that it may be difficult in practice to ensure adequate counselling and un-coerced informed consent when a woman is in labour. This practice requires well-trained and sensitive health professionals who will try to the degree possible to empower the woman to make her own, informed choice in difficult circumstances. This includes ensuring that women are given information in a language they understand.

Recommendations

- Provincial and territorial governments, in conjunction with health care professionals' associations and regulatory bodies, should improve efforts to ensure that all women have access to HIV testing services, and that all pregnant women be offered voluntary HIV testing, with good-quality pre- and post-test counselling. Pregnant women should only receive HIV testing with their specific, informed consent.

- Provincial and territorial health authorities should not designate HIV testing of pregnant women as "routine," which risks encouraging the view that testing for HIV can be done without obtaining specific, informed consent. Rather, there should be clear directives to health care workers that all pregnant women should routinely be offered HIV testing, and even that such testing should be recommended to them. There must be equally clear directives that health care providers should explain that women are not obliged to be tested, that test results are kept confidential (except where disclosure may be required by law), and that their testing decision will not affect their care or their legal rights.

- In jurisdictions that have adopted policies encouraging routine, opt-out testing of pregnant women (notwithstanding the recommendations against such an approach), public education campaigns encouraging HIV testing must ensure that women are aware that HIV testing is a routine part of pre-natal care and that they have a right to refuse the test. Public education campaigns should be rerun periodically to ensure that this information is widely known (including to those women who are new to the jurisdiction, young women who are becoming sexually active, etc.).

- Laboratory forms required for physicians to request an HIV test should note that HIV tests require informed consent, following pre-test counselling suitable for the individual woman to make an informed decision. The forms should not include HIV among default tests that may proceed in the absence of informed consent by the patient.
- Research is urgently needed on pregnant women’s real experience of HIV testing under both opt-out and other policies. The degree to which opt-out practices allow for pre-test counselling and informed consent should be investigated. Research is needed on whether women understand that testing requires their consent, whether they have a clear opportunity to be informed about HIV testing before they consent, and whether the consent sought from them is specific to HIV testing or just for a long list of tests.
- Provinces and territories should evaluate carefully the experience of the use of rapid screening tests for women in labour whose HIV status is unknown. These evaluations should include meaningful participation of women who have experienced the offer of rapid testing during labour. Policy development in this area should take account of women’s real experiences.
- All provinces and territories should establish protocols for the HIV counselling and testing process that include assessing risks to women’s safety in unthreatening, non-invasive and confidential ways. Every test provider should have a clear and well-established system of referral to appropriate services in the case of violence and abuse, and clear assurances of confidentiality of HIV test results for women who fear repercussions from law enforcement or child welfare authorities.

Additional reading

Canadian HIV/AIDS Legal Network. *Prevention and Protection: Enhancing Both HIV Testing and Human Rights in Canada*. Toronto: Legal Network, 2007, on-line: www.aidslaw.ca/testing. Report reviewing the available literature and informed by discussions at 2006 national workshop on HIV testing issues in Canada, with a focus on HIV testing in pregnancy and questions raised by rapid tests.

Csete, J. & R. Elliott. “Scaling up HIV testing: human rights and hidden costs”. *HIV/AIDS Policy & Law Review* 2006; 11(1): 1, 5ff, on-line www.aidslaw.ca/testing. Summarizes the human rights case for strong adherence to the “three Cs,” responding to calls for scaling up HIV testing without necessarily ensuring that pre-test counselling and informed consent are part of the process.

Elliott, R. & R. Jürgens. *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Montreal: Canadian HIV/AIDS Legal Network, 2000, on-line: www.aidslaw.ca/testing. Discusses whether and how rapid HIV screening should be offered to pregnant women during labour (at pp. 29–32, 52–59). See also the ethical analysis in Appendix A.

Howard Research and Instructional Systems, Inc. *Alberta routine prenatal HIV screening program: Final evaluation report*. Alberta Medical Association and Alberta Health and Wellness, 2001.

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Leonard, L. *Testing times: Ontario’s prenatal HIV testing programme: application, acceptability and advancement*. Toronto: Ontario AIDS Bureau, Ministry of Health and Long-Term Care, 2001. Includes testimony from women in Ontario of how they experienced HIV testing and perceived barriers to testing access.

Leonard, L. et al., “HIV counselling and testing among pregnant women in Canada: Best practices,” in: C. Amaratunga and J. Gahagan, eds., *Striking to the Heart of the Matter: Selected Readings on Gender and HIV* (Halifax: Atlantic Centre of Excellence on Women’s Health, 2002), pp. 65–74.

Leonard, L. & L. Shap. “A different kind of risk? – Pregnant women’s experience of HIV testing in pregnancy”. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 5(1): 18–21.

Stoltz, L. & L. Shap. *HIV Testing and Pregnancy: Medical and Legal Parameters of the Policy Debate*. Ottawa: Health Canada, 1999, on-line: www.aidslaw.ca/testing. A comprehensive analysis of the issues raised by pregnancy and HIV testing.

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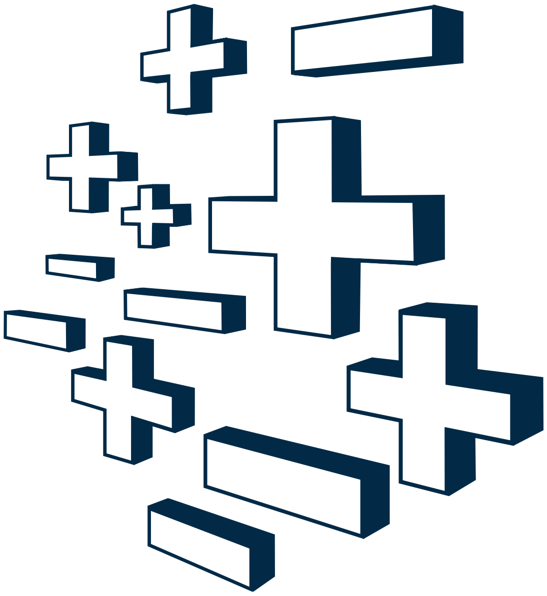

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HIV Testing

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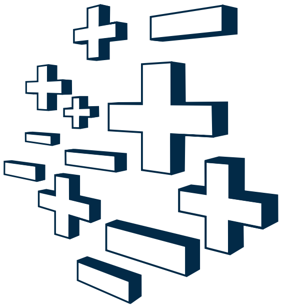

Rapid HIV testing

Background

In March 2000, Health Canada licensed the first rapid HIV test kit for use by health care professionals. Subsequently, it was withdrawn from the market in 2002 because of concerns about its accuracy that were discovered through its use at a number of testing sites. In November 2005, Health Canada approved a different rapid HIV test — the INSTI™ HIV-1/HIV-2 Rapid Antibody Test manufactured in British Columbia by bioLytical™ Laboratories — for use in health facilities or doctors' offices (i.e., at the "point of care"). Using a drop of blood, this screening test can give results in about one minute. The test was determined to be about as accurate as laboratory screening tests used in Canada. Like those tests, it will yield some false positives (i.e., a result suggesting HIV infection when the person in fact is not infected). Therefore, all positive results from the rapid test must be confirmed at an approved HIV testing laboratory. (See info sheet 1 in this series.)

As of early 2007, no rapid test kit has been licensed for sale in Canada for home use. The rapid test has been licensed for use by health-care professionals, defined in federal law as persons "entitled under the laws of a province to provide health services in the province." This means that provincial and territorial legislation defining both "health services" and those who are entitled to provide them governs who is legally permitted to administer rapid tests. In some places, those authorized to use rapid tests may include health care professionals who never provided conventional HIV testing.

Potential benefits

The following potential advantages of using rapid HIV screening at the point of care have been put forward:

- *Clients receive their results sooner.* A 2002 evaluation of the first approved rapid test indicated that over 90 percent of people seeking anonymous testing at the Hassle Free Clinic in Toronto preferred rapid tests when given the choice.

- *Rapid screening kits are easy to administer.* The test approved for sale in Canada requires just a drop of blood from a finger prick. Other rapid tests can be performed on a sample of urine or oral fluid.

- *More people receive their test results.* In the Hassle Free Clinic evaluation, rapid testing significantly increased the percentage of clients who received their final test results, compared to conventional tests for which it was necessary for them to return to the clinic for their test result.

- Access to HIV screening could be improved, particularly in places where there are few HIV testing providers. This could be of particular benefit to people in remote communities.

In addition, it has been argued that rapid screening could enable pregnant women whose HIV status is unknown at the time of labour to be tested. In the case where the woman screens positive, steps could be taken to reduce the risk of transmitting HIV to the infant. (See info sheet 8 in this series for more information on HIV testing and pregnancy.) Rapid screening could also provide more information for decisions about post-exposure prophylaxis (PEP). (See info sheet 10 in this series for more information on this point.)

Some of the potential benefits may be realized in limited ways or circumstances:

- The argument that rapid point-of-care screening will significantly increase the number of people who receive their test results cannot be generalized. Rates of non-return vary across the country and among testing sites.

- For people who test HIV-negative using a rapid test, the benefit would be getting results more quickly. But those who get a preliminary positive test result would have to await the result of a confirmatory test, enduring distress that could be greater than what they would have experienced with the mere uncertainty that accompanies standard testing. The 2002 evaluation conducted at Hassle Free Clinic indicated that with rapid tests, the availability of a counsellor during the waiting period for the confirmatory test was both necessary and highly appreciated by clients.

- In remote settings, it could take a long time to get a confirmed result for a positive screening test, and remote communities might not have the resources to support and counsel a person with a preliminary positive result during that period.

Concerns

As implied by some of the points above, some concerns have been raised about the use of rapid screening tests:

- Counsellors need to be trained about how to disclose preliminary positive results and explain that confirmatory tests are required.
- Rapid testing should not mean cutting back on pre- or post-test counselling or informed consent.
- Care is especially needed to develop good practices for ensuring voluntary, informed consent to rapid HIV testing by women in labour whose HIV status is unknown.
- If physicians or health professionals who lack experience providing HIV testing are authorized to use rapid tests, it will be important to ensure that they are well trained in how to administer the test, best practices in HIV counselling, and how to ensure that appropriate support and counselling are provided to those who get a preliminary positive result on a rapid test while they await confirmation.

With respect to all of these concerns, evidence-based regulation of the use of rapid HIV screening tests will be important. Otherwise, HIV testing will be driven by technology rather than by a careful and principled consideration of risks and benefits, informed by scientific research.

Recommendations

Rapid test kits should be available only in those settings and under those conditions in which their benefits will be most likely realized and the potential misuses prevented. In particular:

- In consultation with provincial and territorial health officials, AIDS service organizations, people living with and affected by HIV/AIDS, and other experts, the Public Health Agency of Canada should develop guidelines for the use of rapid HIV tests that address: best practices in pre- and post-test counselling and informed consent linked to general use of rapid tests; the use of rapid testing with women in labour; appropriate settings for using rapid tests; systems for quality control of rapid HIV tests; and appropriate uses of rapid tests to increase access to HIV testing for marginalized or remote communities.
- Governments should establish (in consultation with community-based organizations, health care professionals and their regulatory bodies, and current testing providers) which health professionals will be permitted to administer a rapid HIV test and ensure that appropriate training is available to these persons.
- Governments and professional associations should issue regulations, guidelines and policies to restrict the use of rapid HIV screening tests to point-of-care settings where a person receiving a positive screening test will have accelerated access to a confirmed result and will receive support and counselling while waiting for the confirmed result. Policies should ensure that those providing testing have received training in how to provide high-quality pre- and post-test counselling.
- Colleges and universities providing professional education to health professionals should include a mandatory component training on best practices in the use of rapid point-of-care HIV tests, including pre- and post-test counselling. Providers of continuing medical education should include refresher training on this subject as part of their other HIV training.

Additional reading

Canadian HIV/AIDS Legal Network. *Prevention and Protection: Enhancing Both HIV Testing and Human Rights in Canada*. Toronto: Legal Network, 2007), on-line: www.aidslaw.ca/testing. Report reviewing the available literature and informed by discussions at 2006 national workshop on HIV testing issues in Canada, including a discussion of rapid HIV testing.

Elliott, R. & R. Jürgens. *Rapid HIV screening at the point of care: Legal and ethical questions*. Montreal: Canadian HIV/AIDS Legal Network, 2000, on-line: www.aidslaw.ca/testing. Comprehensive legal and ethical analysis of issues raised by use of rapid HIV tests, with recommendations of how to maximize benefits and minimize potential harms in the use of rapid tests.

Guenter, D. et al. *The effects of a rapid point-of-care HIV testing program, Hassle Free Clinic, Toronto*, Community-Linked Evaluation AIDS Resource (CLEAR) Working Paper C03-3. Hamilton, ON: McMaster University, 2003, on-line: www.fhs.mcmaster.ca/slru. Valuable documentation and lessons learned on use of rapid tests in one of Canada's most experienced anonymous testing clinics.

Copies of these info sheets are available on the website of the Canadian HIV/AIDS Legal Network at www.aidslaw.ca/testing or from the Canadian HIV/AIDS Information Centre (aidssida@cpha.ca). Reproduction is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of the information. For further information, contact the Legal Network at info@aidslaw.ca. *Ce feuillet d'information est également disponible en français.*

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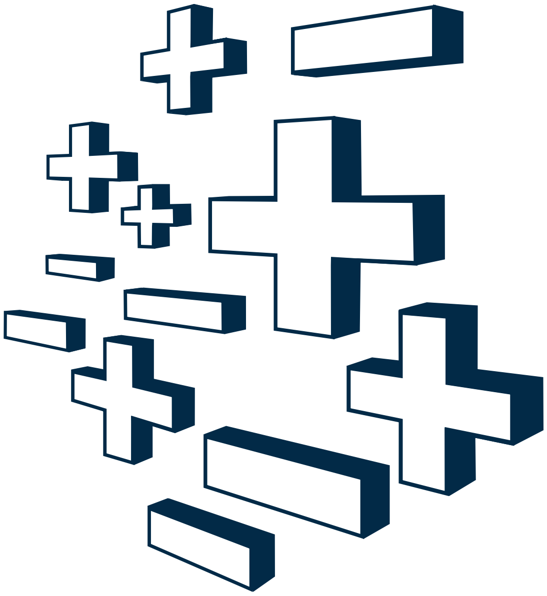

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HIV Testing

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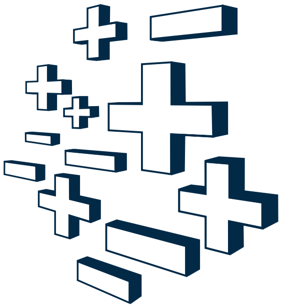

Home HIV testing

Background

There is currently no HIV test in Canada authorized for use at home. In some other countries, there are two forms of home-based HIV testing:

- *home sample collection testing*, where a person purchases an HIV test kit, collects a sample at home, mails it to a testing facility, and gets the result over the phone;
- *complete home testing*, where the test is done and results are obtained entirely at home without the involvement of an outside party, like a home pregnancy test.

In the United States, two home sample collection tests were approved for sale in 1996. One of them was withdrawn from the market in 1997; the other continues to be available. Complete at-home tests have not been approved for sale, but many unapproved test kits, of uncertain quality, are advertised on-line, and at least one company is seeking approval from the U.S. Food and Drug Administration (FDA) to sell directly to consumers its HIV test that uses saliva. The FDA held hearings on the subject in 2005. This issue may eventually be faced by government policy-makers in Canada.

Potential benefits of home testing

Expansion of testing: Advocates of home testing assert that there is an urgent need for a new mode of testing, pointing out that many people with HIV are unaware of their status. The convenience of home testing may encourage more people to be tested.

Increased access to anonymous testing: Currently, anonymous testing is not accessible to all people in Canada. (See info sheet 5 in this series.) For some, especially those living in remote areas or in provinces or territories where anonymous testing is not offered, home sample collection tests might represent the only opportunity to be tested anonymously. (The test approved for home use in the U.S. has procedures that protect anonymity, at least in theory.)

Less invasive than conventional tests: Home tests typically require only a few drops of blood from a pinprick or a swab of saliva — no blood needs to be drawn from a vein. This may increase the willingness of people to be tested.

Positive impact on public health: Proponents have argued that home testing would lead more people to get tested earlier, and therefore to get treatment earlier. They also argue that home testing could lead to decreased sexual transmission, based on the assumption that more people would be tested sooner and would change their behaviour if they test positive.

Questions and concerns

Support for home sample collection testing has grown over the past years, but complete home tests are more controversial. A number of questions and concerns have been raised, some of which are relevant only to complete home tests, some to both types of tests.

Lack of counselling

There are serious concerns about the possible negative consequences of the absence of pre-test counselling for both home sample collection tests and complete home tests. In the case of home sample collection tests, post-test counselling is provided over the phone. In the case of complete home tests, there is no post-test counselling to accompany learning the test results. Doubts have been expressed about the effectiveness of testing without pre- and post-test counselling in modifying behaviour.

Partner notification and public health statistics

One of the issues raised by the U.S. FDA has been the impossibility of keeping statistics on or providing follow-up services for HIV-positive people identified through home tests or their sexual or drug-using partners. A similar concern is raised with respect to anonymous HIV testing more generally, though most anonymous tests done through a clinic or other testing site can still yield basic data for health authorities on the age, sex and geographic location of the person found to be HIV-positive. In the U.S., the results of home testing are generally not known to federal or state authorities.

Accuracy

Many of the home sample collection tests are accurate and fairly easy to use. The U.S. FDA warns that a number of the home tests advertised on-line are unapproved and are likely not very accurate. Imagine a person receiving a positive screening result at home, without any counselling and without fully understanding the need for further testing to confirm whether or not the initial positive result is correct. An additional concern is that data on the accuracy of home tests are usually obtained under optimal conditions by trained technicians and may not reflect a real-life situation; untrained lay persons might misinterpret test results or use the test incorrectly.

Potential for abuse of the right to consent

There are very serious concerns about the ease with which home tests can be forced by one person on another. When HIV testing is done by health-care professionals, subject to legal and ethical obligations to get a patient's informed consent, the risk of testing without consent is lower. But the fact that test results can be obtained easily and rapidly, either in the home or by phone, makes them attractive for people who might want to impose involuntary HIV testing in some circumstances. For example, complete home tests could be used directly at border controls, or by employers, parents, or sexual partners without the consent of the person tested.

Confidentiality

A variety of concerns exist: if a person buys a test kit in a store, everyone in the store will know that the person is taking an HIV test; when the test is ordered by phone or on-line, a name and address must be provided so that the test can be mailed; databases created by companies that distribute the tests could be compromised; in a home sample collection kit, a person has a test ID card that is used to identify the specimen by number, and anyone who has the number can obtain the test result.

Conclusions

Although HIV tests for home use are currently not approved in Canada, the availability of a rapid screening test effectively puts the issue of home testing on the agenda. As with prescription-only medications, it is possible that rapid test kits will make their way into the hands of people outside health facilities, with the potential for misuse and negative consequences for those being tested in these circumstances.

Health Canada approval is required before any HIV test kit, including a rapid test, can be sold legally in Canada, and conditions may be attached to the licence — as has been done to date, by licensing rapid tests only for use by health professionals in laboratories or at the "point of care." In addition, the federal *Medical Devices Regulations* require that a manufacturer of a rapid test approved for sale maintain distribution records sufficient to permit a complete and rapid withdrawal of a device from the market should this prove necessary.

In theory, these rules provide some protection from unauthorized sales, but no system is foolproof. Canada's first experience with a rapid test that turned out not to be as accurate in regular, clinical use as it was in pre-approval trials also illustrates the continuing need for better research about the benefits and harms of new testing technologies.

In addition, there is clearly a need for serious debate on the legal and ethical questions raised by the potential licensing in Canada of home tests, particularly complete home tests.

Additional reading

Canadian HIV/AIDS Legal Network. *Prevention and Protection: Enhancing Both HIV Testing and Human Rights in Canada*. Toronto: Legal Network, 2007), on-line: www.aidslaw.ca/testing. Report reviewing the available literature and informed by discussions at 2006 national workshop on HIV testing issues in Canada, including a discussion of rapid HIV testing.

Jürgens, R. *HIV Testing and Confidentiality: Final Report*. Montreal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998, on-line: www.aidslaw.ca/testing. A comprehensive legal and ethical analysis of Canada's HIV testing experience through 1998; much of the discussion remains pertinent in 2007. Includes discussion of home testing (see pp. 89–111).

Schopper, D. & G. Vercauteren. "Testing for HIV at home: What are the issues?" *AIDS* 1996; 10: 1455–1465. A good if slightly dated discussion of the issues raised by home testing.

United States Food and Drug Administration, Blood Products Advisory Committee. *Hearings on rapid HIV tests for home use*. Gaithersburg, MD (USA): November 3, 2005, on-line: www.fda.gov. Both the transcript of these hearings and the written submissions raise many legal, ethical and regulatory issues related to use of rapid HIV tests in the home.

Copies of these info sheets are available on the website of the Canadian HIV/AIDS Legal Network at www.aidslaw.ca/testing or from the Canadian HIV/AIDS Information Centre (aidssida@cpha.ca). Reproduction is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of the information. For further information, contact the Legal Network at info@aidslaw.ca. *Ce feuillet d'information est également disponible en français.*

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HIV Testing

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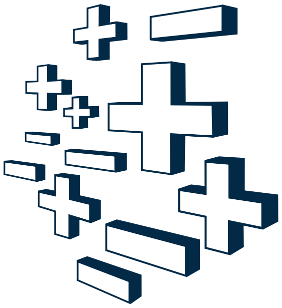

Mandatory and compulsory testing for HIV

HIV testing without consent is almost never justified. However, some people argue that there are circumstances in which the protection of the public's health justifies either:

- requiring HIV testing as a condition of obtaining a certain status, service or benefit, such as employment or health services *(mandatory testing)*; or
- compelling or forcing a person or group of people to be tested, such that the person cannot choose to refuse testing and cannot legally avoid it *(compulsory testing)*.

In this view, people who should be obliged to be tested for HIV may include people seeking surgery or other medical procedures, health care workers, prisoners, persons accused or convicted of sexual assault, and persons whose bodily fluids come into contact with emergency workers. These circumstances are considered in this info sheet.

Mandatory testing of person seeking medical procedures

Some health experts have suggested mandating HIV testing of all patients, or at least those perceived as being at "high risk" for HIV, prior to undergoing certain medical procedures. They say that this is justified by the interest of health care workers in avoiding risk of infection.

There are, however, many reasons why testing patients without their consent is not justified:

- It would violate the autonomy and privacy of the patient.
- It is unnecessary because of the "universal precautions" that should be taken in health facilities in Canada — all blood and body fluids from all patients should be considered as posing a potential risk of bloodborne diseases, and simple control measures reducing transmission risk should always be taken. With universal precautions in place, mandatory HIV testing would be redundant.
- It would be ineffective and possibly counterproductive. A negative test result for a patient in the "window period" between infection and seroconversion may lull health care workers into a false sense of security. Less careful adherence to universal precautions could end up putting health professionals at higher risk of infection, as well as putting the patient at risk of infection from the health care worker.
- HIV testing of patients may be a prelude to illegal discrimination in the provision of medical services by health care professionals who refuse to treat patients who test positive.

Unfortunately, discriminatory refusal of treatment by health care professionals persists in Canada, although refusing to treat a patient in need of medical attention — certainly when there is no significant risk to the provider — breaches the professional obligation of health care workers. Refusal to provide medical treatment to a person living with HIV also amounts to discrimination that is prohibited by law in Canada.

Mandatory testing of health-care workers

In January 2004, it was revealed that a surgeon at a Montréal hospital was HIV-positive and had operated on over 2600 patients. When this news broke, the hospital was deluged by questions from former patients and their families. In the end, the hospital tested blood from 2175 of these patients and found no cases of HIV infection. The incident provoked calls in some quarters for mandatory testing of health care workers as a condition of employment. In response to this incident, the Quebec Medical Association adopted a policy requiring doctors, as a professional obligation, to regularly seek HIV testing and to disclose their HIV-positive status to their employers (who are then expected to keep this information confidential), and to seek advice as to whether modifications to their practice is necessary. This is similar to policies adopted elsewhere.

The Canadian HIV/AIDS Legal Network and the Coalition d'organismes communautaires québécois de lutte contre le sida (COCQ-sida) reminded health authorities at the time that legislation mandating testing of health care workers was not justified, particularly in light of the virtually zero risk of transmission from health professional to patient, and would violate the human rights of these workers. Most health care workers do not perform invasive procedures; they do not pose any risk of HIV infection, and testing them would clearly not be justified. Some health care workers, notably dentists and surgeons, perform highly invasive procedures, and if their skin is pierced, patients might be exposed to their blood. In very limited circumstances, such procedures might result in the transmission of HIV to a patient. However, the risk is exceptionally low: the risk of HIV transmission from HIV-positive surgeons is estimated at 1/40 000 to 1/400 000 and from HIV-positive dentists at 1/200 000 to 1/2 000 000. Since the beginning of the epidemic, there have been only two known cases in Canada of health care workers infecting a patient with HIV.

An effective public health response need not necessarily involve mandatory testing and exclusion of these persons from medical or dental practice. Health care professionals who perform invasive procedures should monitor their HIV status regularly. In addition, if they test positive, they should seek advice about whether they need to limit their professional practice in order to protect their patients, and should be able to seek this advice confidentially or anonymously. Practice restrictions may be justified for "high-risk," exposure-prone, invasive procedures. At the same time, it is important to ensure that HIV-positive health care workers are protected from unjustified discrimination and that information about their HIV status is not unduly disclosed.

Compulsory testing of prisoners

In late 2006, the Union of Canadian Correctional Officers (UCCO) proposed to the federal Minister of Public Safety that the *Corrections and Conditional Release Act* should be amended to authorize the compulsory testing of inmates in federal prisons for HIV and other infectious diseases. The UCCO's proposal would permit compulsory testing even when no correctional officer has been exposed to bodily fluids of the prisoner. (See the section below on the question of forced testing following an occupational exposure.) The UCCO and others who promote this position say that such testing (and disclosure and/or segregation of those who test positive) would protect staff and fellow inmates from contracting HIV in prisons.

However, for the same reasons that mandatory HIV testing of patients is not justified, compulsory HIV testing of prisoners is also not justified. In particular, there is no public health or security justification for compulsory HIV testing of all prisoners, and the human rights of prisoners would be violated by such a policy. Among other things, the Legal Network argued in its submission to the Minister on the UCCO proposal that the forced testing proposed by the UCCO would infringe the Charter rights of prisoners, including the right to privacy and to protection from unreasonable search and seizure. This infringement resulting from invasive forced testing, including possibly the application of physical force to conduct testing without consent, is not warranted by the risks faced by prison workers and is not proportional to the very limited benefit that might accrue. The Legal Network also noted that the UCCO proposal does not allow for testing of prison staff if prisoners are exposed to the bodily fluids of staff, which violates the important principle of consistency in the law.

Compulsory testing following occupational exposure or assault

Emergency medical workers, firefighters and police officers may face exposure to bodily fluids of people with unknown HIV status in the course of their work. People who are assaulted sexually may also be exposed to HIV. In these cases, as with health workers' exposure, it may be possible to minimize the risk of HIV transmission through *post-exposure prophylaxis* (PEP). PEP involves taking antiretroviral drugs for 28 days and is most effective if it is begun within 72 hours of exposure. PEP is not needed if it is known that the "source person" — i.e., the person to whose bodily fluids someone has been exposed — is HIV-negative.

With rapid tests and procedures that would allow for a quick confirmatory test, it may be possible, in some circumstances, to determine the HIV status of the source person before one would need to start PEP. (See info sheet 9 in this series for more on rapid HIV testing.) If the test were negative, the source person might still be infected but in the "window period" — the period between infection and production of the antibodies to HIV that are detected by the test. The chance of this is greater if the person has recently engaged in high-risk activity (e.g., sharing needles when injecting drugs). If the result of an initial screening test (including a rapid test) is positive, there is always the risk of a "false positive"; this can be ruled out if quick access to confirmatory test results is available. (See info sheet 1 in this series for basic information on HIV testing technology.)

Testing the source person might provide useful information for making decisions about whether to discontinue PEP. If the exposed person cannot tolerate the side effects of the drugs used in PEP, he or she might be willing to stop taking the drugs if the source person tests HIV-negative, even with the uncertainty related to the window period. But does this justify compelling the source person to be tested, and what does the law say?

Compulsory testing and the law

If the source person consents to an HIV test — as appears to happen in most cases — there is no difficult legal or ethical issue to be resolved. But what if the source person refuses testing? Should the exposed person be entitled to force the source person to be tested without consent?

Occupational exposure

There have been occasional calls for compulsory testing at the federal level, including in a private member's bill in 2001 that would have amended the *Criminal Code* to permit compulsory blood testing of persons for HIV, hepatitis B, and hepatitis C where peace officers, firefighters, or other emergency services or health care workers may have been occupationally exposed to possible infection. The bill was eventually withdrawn after hearings by a House of Commons committee, and referred to the Uniform Law Conference of Canada and to federal, provincial and territorial ministers of justice for their consideration.

However, legislation authorizing forced HIV testing has now been enacted in a number of provinces: Ontario (2001, amended in 2006); Alberta (May 2004), Nova Scotia (October 2004); and Saskatchewan (October 2005). Similar legislation was introduced in the Manitoba legislature in November 2006, but had not proceeded further as of March 2007.

Several of the later statutes are modelled on the *Uniform Mandatory Testing and Disclosure Act* that was released in 2004 by the Uniform Law Conference of Canada as a model for provincial and territorial laws related to the state's authority to force HIV testing in certain circumstances. With respect to emergency workers, the Uniform Act outlines a procedure by which an exposed person can petition the relevant provincial superior court for an order to compel HIV testing of the source person. According to this procedure, the court can issue such an order if satisfied that certain conditions are fulfilled:

- that the contact occurred in the course of providing emergency services or a crime committed by the source person;
- that infection could have resulted from the contact;
- that testing the exposed person would not be enough to determine HIV status;
- that taking a blood sample would not endanger the source person; and
- that there is no other way to get this information besides compulsory testing.

While possible benefits of compulsory HIV testing of the kind proposed in these laws are quite limited, the harms to the rights of those to be forcibly tested are significant. In a way that is analogous to the prison case described above, state authorization of forced HIV testing may breach the rights to privacy and to protection from unreasonable search and seizure guaranteed by the Charter. Other solutions to the risks faced by emergency workers would offer greater protection against possible exposure to communicable diseases, and at the same time respect human rights. Proactive efforts to educate police, firefighters, and health care workers about how HIV and hepatitis are transmitted (and how they are not transmitted), and encouraging the use of universal precautions, are preferable responses.

Sexual (or other) assault

Testing the accused person will not be possible for most survivors of sexual assault; only a small percentage of assailants are arrested and convicted in a timely manner. Aside from the fact that testing is usually impractical, what does the law say?

The *Criminal Code* does not authorize HIV testing of accused persons. Some of the provincial laws on forced testing mentioned above do permit a person who has been exposed to bodily fluids through a crime to seek an order for compulsory testing.

Since the beginning of the AIDS epidemic, there have been three reported decisions of Canadian courts regarding the issue of compulsory HIV testing, all of which dealt with situations in which testing was sought against a person accused or convicted of sexual assault. In two of these cases, the source person did not oppose the request, and testing was ordered. In the one case where it was opposed, the court refused to order HIV testing of a man accused of having sexually assaulted a woman, noting that forced testing raises serious Charter concerns (*R. v. Beaulieu*, Quebec Court — Criminal Chamber, 1992). Aside from this one case, no reported judgments of Canadian courts have yet considered in detail the constitutionality of the state's ordering forced HIV testing.

In 1994, the federal Interdepartmental Committee on Human Rights and AIDS concluded that compulsory testing of persons accused of sexual assault is "misguided" because:

- it does not provide reliable information about the risks of contracting HIV;
- it is an unrealistic approach to addressing a sexual assault survivor's needs;
- it perpetuates the misperception that information about an assailant's HIV status is critical to the survivor's health;
- it does not facilitate a survivor's psychological recovery; and
- it sets a dangerous precedent for extending mandatory testing to others.

Recommendations

- Federal and provincial governments should not enact legislation authorizing compulsory HIV testing (e.g., of persons who are the source of an occupational exposure, or accused or convicted of assault, or of prisoners), nor should the law mandate HIV testing of groups such as patients or health care workers.
- In order to encourage voluntary disclosure by persons who are the source of a potential exposure, federal and provincial governments should ensure that their legislation protects the confidentiality of those who disclose their HIV-positive status.
- Health Canada, Justice Canada, Status of Women Canada, and their provincial counterparts, as well as employers, must ensure that sexual assault survivors and those who have been occupationally exposed to possible infection with HIV (or other communicable diseases) have access to best-practice counselling, short- and long-term care and treatment (including post-exposure prophylaxis if indicated), and other services.
- All health care workers should be trained on universal precautions, and implementation of universal precautions should be evaluated regularly by health authorities. Government health authorities, and employers, must ensure that workers have the equipment they need to implement universal precautions. Provinces and territories that have not already done so should enact legislation mandating certain aspects of workplace safety aimed at preventing occupational exposures to HIV and other bloodborne diseases, such as requiring the use of safety-engineered needles in health facilities.

Additional reading

Canadian HIV/AIDS Legal Network. *Legislation to authorize forced testing for HIV in the event of occupational exposure: An unjustified violation of human rights – A submission to the Government of Manitoba*. August 2005, on-line: www.aidslaw.ca/testing.

Canadian HIV/AIDS Legal Network. *Legislation to authorize forced testing of federal prisoners for HIV: An unjustified violation of human rights – A submission to the Minister of Public Safety and Emergency Preparedness Canada*. November 2006, on-line: www.aidslaw.ca/testing.

de Bruyn, T. *Testing of Persons Believed to be the Source of an Occupational Exposure to HBV, HCV, or HIV: A Backgrounder.* Montréal: Canadian HIV/AIDS Legal Network, 2001, on-line: www.aidslaw.ca/testing. Provides information with reference to policies, procedures, and scientific literature on this issue. See also the companion series of info sheets, "Occupational Exposure to HBV, HCV, or HIV" (2001), on-line: www.aidslaw.ca/testing.

Jürgens, R. HIV Testing and *Confidentiality: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998, on-line: www.aidslaw.ca/testing. Early, extensive report on HIV testing issues; see pp. 155–163 on HIV testing of prisoners; pp. 187–196 on testing of health care workers; pp. 164–179 on testing of persons accused or convicted of sexual assault (including discussion of the analysis and conclusions in 1994 of the Interdepartmental Committee on Human Rights and AIDS).

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HIV Testing

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1. Evolution of HIV testing policy and technology in Canada
2. Shifting HIV testing policies
3. Consent to HIV testing
4. Counselling
5. Anonymous HIV testing
6. Confidentiality
7. Access to HIV testing
8. HIV testing and pregnancy
9. Rapid HIV testing
10. Home HIV testing
11. Mandatory and compulsory testing for HIV
12. Immigration and HIV testing

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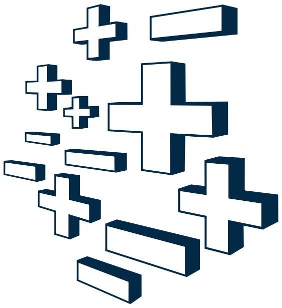


Immigration and HIV testing

Background

In recent years, there have been several important changes in Canadian policy regarding HIV testing for foreign nationals who wish to enter or stay in Canada, temporarily or permanently. Most recently, changes were made regarding the information required of visa applicants, in preparation for the XVI International AIDS Conference (AIDS 2006) in Toronto. This sheet summarizes the situation as of March 2007.

Two categories of foreign nationals seek to enter or remain in Canada.

- Foreign nationals may seek to enter Canada as *temporary residents*, a category that includes visitors (e.g., tourists, people visiting family, people attending meetings or conferences), temporary workers (including seasonal workers), and students.
- Foreign nationals seeking to immigrate to Canada on a long-term basis may apply for *permanent residence*, a category that includes skilled workers, business class applicants (e.g., investors and entrepreneurs), and family class applicants (i.e., spouses, common law partners, dependent children and some other relatives). Refugees and other "persons in need of protection" also become permanent residents if their claims are accepted.

Are persons living with HIV/AIDS allowed to enter Canada?

Unlike the policy of some countries, Canadian law does not contain a blanket exclusion of people living with HIV/AIDS.

The *Immigration and Refugee Protection Act* does not specifically mention HIV/AIDS. The Act says that a person can be deemed "medically inadmissible" to Canada — meaning the person can be denied a visa (or refused entry at the border) or permission to stay in the country — if he or she

- is likely to be a danger to public health or public safety, or
- might reasonably be expected to cause "excessive demand" on publicly funded health or social services.

Since 1991, it has been the stated policy of the Canadian government that people living with HIV/AIDS do not represent a danger to public health or safety by virtue of their HIV status.

Therefore, Canada generally excludes people with HIV only if they are expected to place an "excessive demand" on publicly funded health or social services. "Excessive demand" is defined as more than the cost of such services for the average Canadian (calculated at $4078 per year in 2004), or demand that would lengthen waiting lists for services so as to affect the morbidity or mortality of Canadians.

Temporary residence

People who want to enter Canada temporarily on a short-term basis (i.e., less than six months), such as tourists and other visitors, usually are not eligible for coverage under the public health insurance plans of provincial and territorial governments. Therefore, it would be very rare that a person living with HIV is denied entry to Canada for a short-term stay.

Some people may want to be in Canada temporarily, but for longer than six months, such as a student on a longer-term study permit or a foreign worker on a longer-term work permit.

Students coming to Canada temporarily on a study permit (of whatever length) are generally are not eligible for coverage under public health insurance plans, and must show, as part of the application for a study permit, that they have their own health care insurance arranged (e.g., through the student health plan of the Canadian institution at which they plan to study). So, students are rarely refused entry to Canada on the basis of anticipated excessive demand on publicly financed health or social services.

Foreign workers living in Canada on a temporary work permit generally do become eligible (after a certain waiting period) for coverage under the public health insurance of their province or territory of residence. Therefore, the worker might be denied entry to Canada, on the basis of anticipated excessive demand, if he or she is HIV-positive.

Permanent residence

A person applying for permanent residence may be deemed medically inadmissible if the person might reasonably be expected to cause excessive demand on health or social services. However, the law exempts refugees and "persons in need of protection" from this requirement, as well as persons who are eligible "family class" applicants who are being sponsored to immigrate by someone who is already a Canadian citizen or permanent resident. Therefore, HIV-positive applicants for permanent residence who fall into these two sub-categories will not be barred from immigrating to Canada because of their HIV status. However, other applicants for permanent residence (e.g., the independent applicant seeking permission to immigrate permanently as a skilled worker) may be denied if HIV-positive.

Does a person need to disclose his/her HIV status or take an HIV test to enter or remain in Canada?

Generally, people entering Canada for periods of less than six months are not required to disclose their HIV status or to be tested for HIV. People seeking permanent residence, on the other hand, are required to undergo a medical examination that includes an HIV test.

The requirements for short-term stays were changed in May 2005. At that time, a broad question about communicable or chronic diseases on the visa application form was replaced by narrower questions meant to address the two legal requirements of protecting public health and preventing excessive demands on health services, without unnecessarily and unjustifiably intruding into visa applicants' privacy. The two questions now asked on the visa application form are as follows:

- Within the past two years, have you or a family member had tuberculosis of the lung or been in close contact with a person with tuberculosis of the lung?
- Do you or an accompanying family member have any physical or mental disorder for which that person will require social and/or health services, other than medication, during the stay?

It is not necessary to disclose one's HIV status in answering these questions. Nor is it necessary to disclose the use of antiretroviral drugs or other medications. In rare circumstances, a medical examination might be required of someone seeking to enter Canada for a short-term stay (i.e., less than 6 months) if he or she is very ill. The visa officer has the discretion to order such an examination. However, simply being HIV-positive should not be a basis for requiring a medical examination for a visa for a short stay of less than six months. (In addition, as of August 2004, HIV testing is also not required for seasonal agricultural workers who are expecting to stay in Canada for less than nine months.)

As noted above, every applicant for permanent residence must have an immigration medical exam. As of January 2002, this medical exam automatically includes an HIV test for every applicant who is 15 years or older. It may also be required for younger children who have an HIV-positive parent or who have received blood or blood products.

Other than an application for permanent residence, there are two other circumstances in which a medical examination, including an HIV test, is required.

- A medical exam is required when someone who wishes to come to Canada for more than six consecutive months has, in the year before applying for entry, lived for a period of six or more consecutive months in a "designated country" where certain communicable diseases are more prevalent than in Canada. (This includes students and temporary workers coming to Canada for more than six months from a designated country.)
- A medical exam is also required whenever someone seeks to come to Canada to work in an occupation where protection of public health is essential, regardless of the intended period of stay in Canada.

Where and how is HIV testing done? For people applying from abroad, a medical examination is performed by a local medical practitioner designated by Citizenship and Immigration Canada. For people applying from within Canada, a designated medical practitioner performs the exam in Canada. The HIV test is supposed to be accompanied by pre- and post-test counselling, in conformity with accepted Canadian professional standards for HIV testing and counselling. In practice, this does not always happen consistently.

Additional reading

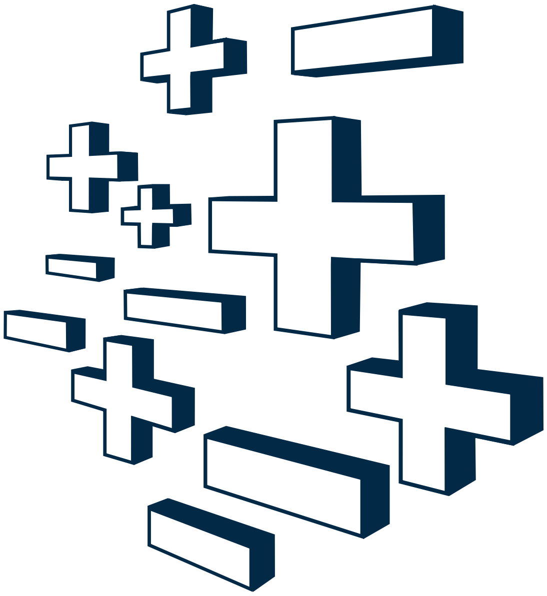
Canadian HIV/AIDS Legal Network. *Canada's immigration policy as it affects people living with HIV/AIDS: Questions & Answers*. Updated March 2007, on-line: www.aidslaw.ca/immigration. This Q&A contains somewhat more detail on the points noted above.

HIV & AIDS Legal Clinic (Ontario). *The HIV & the Law Advocates' Manual*. Toronto: HALCO, 2004, on-line: www.halco.org. Chapter 2 provides a comprehensive analysis of the immigration process and immigration issues for persons living with HIV/AIDS.

Citizenship and Immigration Canada, www.cic.gc.ca. The website provides guidance for people who want to visit Canada, to study or work temporarily in Canada, or to apply for permanent residence. It provides access to all application forms for visas and permits, as well as most of CIC's policy manuals and guidelines, and the full text of the *Immigration and Refugee Protection Act* and accompanying regulations. A list of countries whose nationals must apply for a visa to enter Canada is also available.

Copies of these info sheets are available on the website of the Canadian HIV/AIDS Legal Network at www.aidslaw.ca/testing or from the Canadian HIV/AIDS Information Centre (aidssida@cpha.ca). Reproduction is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of the information. For further information, contact the Legal Network at info@aidslaw.ca. *Ce feuillet d'information est également disponible en français.*

Funding for this publication was provided by the Public Health Agency of Canada. The opinions expressed in this publication are those of the authors/researchers and do not necessarily reflect the official views of the Public Health Agency of Canada.



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