



Background

This is the first of a series of 19 info sheet on HIV testing. It provides background information on the series, refers to the resources on which the info sheets are based, and explains how the info sheets can be used.

HIV Testing and Confidentiality: Final Report

In the past years, new testing technologies, advances in HIV/AIDS treatments, and changing patterns of HIV infection have forced us to reconsider approaches to HIV testing (for more details, see info sheet 2). A comprehensive analysis of the new issues and challenges can be found in *HIV Testing and Confidentiality: Final Report*, prepared by Ralf Jürgens and released in the fall of 1998 by the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society. The report examines the following questions:

- Is **specific** informed consent to testing still necessary, or should **general** consent suffice?
- How can access to HIV testing be improved, and should the testing options include anonymous testing?
- Is pre- and post-test counseling still necessary?
- Should new forms of testing for HIV, such as rapid and/or home testing, be made available in Canada?
- Are any exception(s) warranted to the principle that testing always be voluntary? Is mandatory or compulsory testing, or testing of specific groups of the population (or under certain circumstances) ever justified?
- Are there any new exceptions to the principle that testing only be done when confidentiality of results or anonymity of testing can be guaranteed?
- Should HIV and AIDS reporting provisions be changed?
- What approach to partner notification should be adopted?

Rapid HIV Screening at the Point of Care: Legal and Ethical Questions

In the spring of 2000, another new development has forced us to reexamine approaches to HIV testing in Canada: the first rapid HIV screening test was licensed for sale in Canada on 15 March 2000, for use by health professionals at the “point of care” (for more details, see info sheet 10). A comprehensive analysis of the issues raised by the availability of rapid HIV screening can be found in *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*, prepared by Richard Elliott and Ralf Jürgens and released by the Legal Network in March 2000.

Goals of the Reports

The goals of both reports are to:

- assist people with HIV/AIDS, their advocates and counselors, health-care providers, AIDS service organizations and other service providers in understanding the new challenges in the area of testing;

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- assist legislators and policymakers in appreciating the complexity of the issues;
- contribute to a process of informed and rigorous discussion concerning the future of HIV testing in Canada, by ensuring that decisions will be based on a careful consideration of risks and benefits, informed by solid scientific research, that balances an individual's human rights and society's need to maintain public health; and
- avoid the damage to persons and public health that would be caused by poorly considered moves toward emphasizing a more coercive approach to HIV/AIDS.

The Info Sheets

Based on the two reports (*HIV Testing and Confidentiality: Final Report* and *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*), the series of 19 info sheets on HIV testing provides more concise, easy-to-read information on the issues examined in great depth in the reports. The info sheets are:

1. Background
2. The “Canadian Approach” to HIV Testing
3. Benefits from Testing
4. A Shift to a Different Approach to HIV Testing?
5. Consent to Testing
6. Access to Testing
7. Anonymous HIV Testing
8. Counseling
9. Advances in HIV Testing Technologies
10. Rapid Point-of-Care Testing
11. Home Testing
12. Mandatory Testing
13. Forced HIV Testing to Avoid Infection? Testing of Patients, Health-Care Workers, and Prisoners
14. HIV Testing and Pregnancy
15. Forced HIV Testing after Occupational Exposure or Assault
16. Immigrants and HIV Testing
17. Confidentiality
18. Partner Notification
19. Essential Resources

The Relationship between the Info Sheets and the Reports

The info sheets are based on the reports. The reports provide in-depth analysis of policy, legal, and ethical issues, with hundreds of references to other articles, reports, scientific studies, and legal cases, and contain a comprehensive bibliography. The info sheets provide more concise, easy-to-read information. They can be used for educational purposes, in advocacy efforts, as the basis for further research, or for policy decisions, by anyone working on or interested in HIV/AIDS.

For Further Copies ...

The info sheets and reports are available on the Network website at www.aidslaw.ca or through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: aids/sida@cpha.ca). Reproduction of the info sheets is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. For further information, contact the Network (tel: 514 397-6828; email: info@aidslaw.ca).

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HIV Testing

The “Canadian Approach” to HIV Testing

This info sheet summarizes what the “Canadian approach” to HIV testing has been to date, and explains why this approach has recently had to be reexamined.

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.

The consequences of HIV antibody testing differ from those of many other tests that are used in medicine today. This test can seriously harm persons being tested.... At the same time, there are many great benefits to be obtained from its use. This test, in raising many complex dilemmas and issues, is symbolic of the many problems that we are being faced with by the HIV epidemic. As such, the approaches adopted by Canadian society to use HIV antibody testing will set far-reaching precedents. Consequently, great caution is needed in deciding how we, as a society, will govern that use.

– MA Somerville & N Gilmore, 1988

Since the HIV-antibody test was first made widely available in 1985, it has been the subject of controversy. A great deal has been written on the question of its appropriate legal and ethical use. How would the test be used? How would people be counseled about the test’s significance? Would, and could, the results be kept confidential? Would voluntary testing be a prelude to compulsory screening? What would be the consequence of testing for the right to work? To go to school? To obtain insurance?

Emergence of a “Canadian Approach” to HIV Testing

In Canada, a broad consensus emerged in the late 1980s that, except in a few well-defined circumstances, people should be tested only with their informed, voluntary and specific consent, with counseling before and following testing, and when confidentiality of results or anonymity of testing can be guaranteed.

Controversial Issues and Problems

However, opinion around several other issues has remained divided. In particular, there continues to be a lack of consensus regarding whether – and, if yes, how – positive test results should be reported to public health authorities; and about the role that partner notification efforts should play in comprehensive HIV prevention programs. This lack of consensus is reflected in wide divergences in legislation and practice between and within Canadian provinces and territories with respect to reporting, partner notification, and availability of anonymous testing.

In addition, there are issues that, although in theory consensus has been reached, in practice remain unresolved. Access to testing remains a problem, particularly for women and Aboriginal people; some people are tested without providing specific informed consent; many do not receive adequate counseling; and calls for mandatory testing of certain groups, such as sex offenders, prisoners, and immigrants, have continued.

New Developments

In recent years, new controversies have arisen, in particular because of advances in HIV testing technology, the shifting demographics of the epidemic, and the availability of new treatments.

Advances in HIV testing technology

The development and approval, in the United States, of home HIV testing kits raises the possibility that in Canada HIV testing might soon become available outside the health-care setting. The current model of HIV testing is closely directed by a health-care professional and involves (or should involve) counseling and support. Should the sale and distribution of home HIV testing kits in Canada be allowed?

Important legal and ethical issues are also raised by the development of new rapid tests that allow for provision of results within 15 minutes. In Canada, the first such test was licensed for use by health-care professionals in March 2000.

Shifting demographics of HIV infection

Early in the epidemic, the vast majority of people affected were those who had engaged in some readily identifiable high-risk activity. It was widely accepted that the most effective method of prevention was education to reduce high-risk behaviour, and not mandatory testing, notification of public health authorities, and partner notification. Today, in Canada the epidemic is still disproportionately affecting injection drug users and men who have sex with men, but it has moved beyond those who engage in readily identifiable high-risk activity. In particular, women are increasingly becoming infected with HIV. Many of them may have contracted HIV as a result of sexual relations with men who had not disclosed that they had engaged in high-risk behaviour. These women may have had no reason to believe that they were at risk of HIV infection, and as a result may not have taken precautions. This raises the question of whether more aggressive public health measures may be warranted. It has been argued that more aggressive testing and reporting policies, particularly in relation to people who may not otherwise be aware that they are at any risk of HIV infection, may be appropriate.

New treatments

Recent scientific discoveries and the availability of new antiretroviral drugs have changed the approach to the treatment of HIV infection. In particular, the introduction of highly active antiretroviral therapy (HAART) in industrialized countries has led to a considerable change in therapeutic possibilities for HIV disease. While many uncertainties surround the new therapies, they are driving the demand for earlier and more widespread opportunities for diagnosis. In particular, improvements in therapy have raised the question of whether in some cases a more aggressive, and even mandatory, testing and treatment program might effectively prevent the further spread of HIV infection.

Reexamination of the Issues

In 1998-2000, these developments prompted a reexamination of the issues raised by HIV testing and confidentiality in Canada. The main question addressed was whether the new developments warrant a departure from the Canadian approach to HIV testing. Is specific informed consent to testing still necessary? Should options for HIV testing include anonymous testing facilities and should new forms of testing for HIV, such as rapid point-of-care testing and/or home testing, be made available? Is pre- and post-test counseling still necessary? Is mandatory testing of specific groups (or under certain circumstances) now justified? Are there any new exceptions to the principle that testing only be done when confidentiality of results or anonymity of testing can be guaranteed? Should an approach emphasizing partner notification be adopted? Should HIV become nominally reportable in all provinces and territories? These questions are analyzed in more detail in info sheets 3-18.

Additional Reading

Human immunodeficiency virus antibody testing in Canada. Recommendations of the National Advisory Committee on AIDS. *Canada Diseases Weekly Report* 1989; 15(8): 37-43. The best expression of the “general principle governing HIV antibody testing in Canada.”

The information in this series of info sheets is based on two reports prepared by the Canadian HIV/AIDS Legal Network: *HIV Testing and Confidentiality: Final Report and Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Copies of the reports and info sheets are available on the Network website at www.aidslaw.ca or through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: aids/sida@cpha.ca). Reproduction of the info sheets is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. For further information, contact the Network (tel: 514 397-6828; email: info@aidslaw.ca). **Ce feuillet d'information est également disponible en français.**

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HIV Testing

Benefits from Testing

An assumption underlies much of the changing approach to HIV testing – that testing today involves huge benefits and few harms and that it can therefore be undertaken routinely, without specific consent, counseling, and assurance of confidentiality of the results. This info sheet examines the benefits of HIV testing for both individuals and the community. Info sheet 4 examines whether these benefits warrant a departure from the current approach to HIV testing..

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.

The Early Days – 1985-1988

When the HIV test was first introduced in 1985, it was of very limited utility for the purposes of medical treatment of the individual or for the prevention of the spread of infection to the community.

Benefits for individuals

People at risk had little reason to seek out an HIV test and considerable reason to fear that the test results might be used to discriminate against them. Shortly after the test was first introduced, it came to be used to discriminate against people with HIV in a variety of settings, and people testing positive risked losing friends, employment, insurance, housing, and educational or travel opportunities. In addition, the availability of clinically effective antiretroviral treatment was years away. HIV testing was actively discouraged in the communities at risk.

Benefits for the community

Most people agreed that, apart from its use to screen donors of blood and other body products, HIV testing was not a particularly useful measure to reduce the rate of infection. It was widely accepted that education to reduce high-risk behaviour was the most effective measure to prevent the further spread of HIV, and that this education was in no way related to, or dependent upon, HIV testing.

The Middle Years

The attitude discouraging the use of the HIV test changed around 1989, when treatments first became available for some of the opportunistic diseases associated with HIV infection, particularly PCP prophylaxis. There now existed clear benefits from testing.

Benefits for individuals

It became clear that the HIV test could be used as a diagnostic tool that could lead to beneficial medical interventions for people with HIV. As a result, many more people began to seek out HIV testing and related treatments. However, treatments were not particularly successful at slowing the progression of HIV infection, and many continued to prefer not to find out their HIV status because they believed that this knowledge would have little impact on their behavioural decisions, might lead to greatly increased anxiety, and/or might lead to discrimination and stigmatization.

Benefits for the community

Benefits for the community remained questionable. There was no particular evidence that available treatments could reduce the infectivity of people with HIV. Moreover, the early evidence indicated that the treatments were not significantly effective at reducing the risk of perinatal transmission. As a result, there was

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little reason to believe that testing and treatment could further efforts to prevent the spread of HIV infection. Instead, prevention efforts remained focused on education and, in particular, the reduction of high-risk behaviour. Testing and treatment were regarded as matters relevant to the health care of people with HIV, not to the prevention of the spread of HIV infection. The World Health Organization, in its 1992 *Statement from the Consultation on Testing and Counselling for HIV Infection*, concluded:

The evidence that voluntary HIV testing may play a role in the prevention of transmission is not conclusive, except for discordant couples.... Testing in itself is not a preventive measure.

Today

In recent years – and particularly since the XI International Conference on AIDS in Vancouver in July 1996 – a great deal has happened to make the early diagnosis of HIV infection more important.

Benefits for individuals

Scientific discoveries and the availability of new antiretroviral drugs have changed the approach to treatment of HIV infection. Early diagnosis of HIV infection now allows individuals to make important treatment decisions.

Benefits for the community

In addition to the increased benefits for individuals, early diagnosis, if followed by treatment, has come to be considered as beneficial to the community and as contributing to the prevention of the further spread of HIV.

The issue of whether knowing one's HIV test results changes behaviour remains disputed. However, new research has shown that HIV counseling and testing *can* and *does* motivate behaviour change in *some individuals*. What is also clear, however, is that it does not always lead to behaviour change, nor is it equally successful in influencing behaviour across a wide range of settings and populations.

Apart from motivating behaviour change in some individuals, knowledge of a person's HIV infection can assist HIV prevention in other ways. Mother-to-infant HIV transmission can be reduced if seropositive women learn their HIV status and initiate preventive measures.

In addition, persons receiving a regimen of reverse transcriptase inhibitors and protease inhibitors have been found to have lower levels of circulating virus, suggesting that treatment not only benefits the patient but may also reduce the risk of transmission. Finally, there is hope that the new treatments, if administered very shortly after exposure to HIV, can reduce the risk of seroconversion.

Conclusion

Since the HIV-antibody test was first introduced in 1985, benefits from testing for the community and for the person being tested have increased substantially. In particular, “sound medical practice calls for HIV testing for those who want it so they may gain the knowledge that can lead to needed treatment.” In 2000, there can be no doubt that voluntary HIV testing accompanied by counseling has a vital role to play within a comprehensive range of measures for HIV/AIDS prevention and support, and should be encouraged. It is therefore essential to ensure that HIV testing is readily accessible to all Canadians and that barriers to testing, whether real or perceived, be removed.

However, the question of whether the new developments warrant a major departure from the “general principle governing HIV antibody testing in Canada” and the utilization of more coercive public health approaches remains extremely controversial. This question is examined in info sheet 4.

Additional Reading

Wolitzki RJ et al. The effects of HIV counseling and testing on risk-related practices and help-seeking behavior. *AIDS Education and Prevention* 1997(Suppl B): 52-67. Reviews 35 studies published since 1991 to reassess the scientific data regarding the ability of HIV counseling and testing to motivate changes in risk-related practices and to promote help-seeking behaviour.

The information in this series of info sheets is based on two reports prepared by the Canadian HIV/AIDS Legal Network: *HIV Testing and Confidentiality: Final Report and Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Copies of the reports and info sheets are available on the Network website at www.aidslaw.ca or through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: aids/sida@cpha.ca). Reproduction of the info sheets is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. For further information, contact the Network (tel: 514 397-6828; email: info@aidslaw.ca). **Ce feuillet d'information est également disponible en français.**

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HIV Testing

A Shift to a Different Approach to HIV Testing?

Info sheet 3 examined benefits of HIV testing for both individuals and the community. This info sheet examines whether, in light of the increased benefits of testing, a departure from the “general principle governing HIV antibody testing in Canada” (see info sheet 2) and the utilization of more coercive public health approaches is warranted.

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.

Background

In the first decade of the epidemic, the prevalence of stigmatization of and discrimination against people with HIV/AIDS, particularly gay men, was one of the factors that led public health authorities to adopt a voluntary approach to the measures taken to prevent the transmission of HIV. This approach, which some have called “AIDS exceptionalism,” departed from such measures as mandatory testing, reporting of HIV-positive individuals, and contact tracing in favour of voluntary behaviour change, testing only with informed consent, protection of confidentiality, and voluntary partner notification. It was necessary because, without the assurance that they would not be subject to coercion or to the consequences of disclosure, gay men would have been harder to reach by education and prevention programs, and gay organizations would have been unwilling to cooperate with public health officials in reaching them.

“AIDS Exceptionalism”

The term “AIDS exceptionalism” is, however, an unfortunate misnomer. The public health response to all infectious diseases has not been uniform, and there is no natural or authentic approach to public health crises – each epidemic produces unique public health policies. It is therefore wrong to portray the voluntarist strategy of dealing with HIV/AIDS as an extraordinary rupture with prior practice.

The Call for Coercive Measures

Those persuaded that “conventional” public health measures would be more successful in preventing transmission and providing treatment have called the appropriateness of the voluntary approach into question, particularly now that antiretroviral therapies have been shown to reduce the transmission of HIV from mother to child, to lower the level of virus in the blood of people with HIV to undetectable levels, and to extend the lives of people with HIV. They typically suggest that there is a conflict between the privacy rights of individuals who have or may have HIV and public health needs, and that individual rights must take a back seat if the battle against the spread of HIV is to be effective.

Voluntary Approach Remains Valid

However, the voluntary approach to public health measures maintains its validity.

Discrimination continues

HIV infection still carries such stigmatization and potential for discrimination that people with HIV/AIDS or affected by HIV/AIDS continue to require the protections afforded by HIV “exceptionalism.” Discrimination remains pervasive in Canada, as

documented in a recent study (*HIV/AIDS and Discrimination: A Discussion Paper*). To make matters worse, there is little or no redress for those discriminated against: there are grave concerns about the limitations of human rights legislation and procedures as a means to protect people with HIV/AIDS.

HIV affects even more marginalized populations

HIV still primarily affects marginalized populations fearful of government institutions. Indeed, it could be said that in Canada it is now affecting populations that are even more marginalized and vulnerable than gay men were in the 1980s: injection drug users, Aboriginal people, young gay men, and prisoners. A shift toward more coercive measures could hinder rather than assist efforts to curb the spread of HIV in these populations.

New treatments no panacea

There is still no cure for AIDS. There are many unsolved questions with regard to treatments, and access to them is often a problem, particularly for the people in the marginalized populations in which HIV infection is spreading most rapidly. In addition, a critical public health distinction between AIDS and other diseases remains: while, for example, therapies for tuberculosis and syphilis render the patient non-infectious, anti-HIV drugs do not eliminate the risk of HIV transmission, but only, in some cases, reduce that risk.

Behaviour modification must be encouraged

In 2000, as in the 1980s and early 1990s, educational strategies to encourage behaviour modification must remain the centerpiece of HIV-prevention efforts. “The sexual and drug-related behaviours that place individuals at heightened risk of HIV infection are unchanged from the 1980s and retain their central features: they remain extremely private, closely intertwined with personal identity, difficult to change, and often poorly understood.”

No conflict between public health and human rights

Finally, there is no conflict between public health and individual rights. Instead, available evidence strongly suggests that rather than impeding the protection of public health, the promotion and protection of the human rights of those infected and affected is an essential component in preventing transmission of HIV.

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

The status quo with regard to HIV testing and confidentiality in Canada is insufficient. Changes to policies and practices are necessary. In particular, HIV testing (and anti-HIV treatments) must be more readily accessible to all Canadians and more must be done to ensure that barriers to testing (and to accessing treatments), whether real or perceived, are removed.

However, decisions about the directions that policy and programs should take must not be based only on the availability of new treatments and the availability of new testing technologies. These decisions must also take into account that stigma and discrimination continue to be prevalent, that HIV and AIDS still primarily target marginalized populations, that there still is no cure for AIDS, that modification of intimate behaviours continues to be essential, and that there is usually no conflict between public health and individual rights.

Additional Reading

de Bruyn T. *HIV/AIDS and Discrimination: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998. Also available at <www.aidslaw.ca>. Shows how pervasive discrimination against people with HIV/AIDS remains.

Kirby M. Human rights and the HIV paradox. *Lancet* 1996; 348: 1217-1218. Reprinted in *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 50-52. Shows how the imperatives of individual rights and public health are mutually compatible.

Burr C. The AIDS exception: privacy vs. public health. *Atlantic Monthly* June 1997, at 57-67. A manifesto arguing – unconvincingly – that we need a new public health approach to HIV/AIDS.

The information in this series of info sheets is based on two reports prepared by the Canadian HIV/AIDS Legal Network: *HIV Testing and Confidentiality: Final Report and Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Copies of the reports and info sheets are available on the Network website at www.aidslaw.ca or through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: aids/sida@cpha.ca). Reproduction of the info sheets is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. For further information, contact the Network (tel: 514 397-6828; email: info@aidslaw.ca). **Ce feuillet d'information est également disponible en français.**

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HIV Testing

Consent to Testing

This info sheet makes recommendations directed at ensuring that physicians fulfill their legal and ethical obligations and undertake testing only with the voluntary, specific, and informed consent of the person being tested. The info sheet does not address the question of whether mandatory testing of specific groups of the population (or in specific circumstances) is ever justified as an exception to the rule. That question is addressed in info sheets 13-16.

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.

The General Consensus

There is widespread agreement in Canada and in most other jurisdictions that HIV testing should generally only be undertaken with the voluntary, informed, and specific consent of the person being tested. According to the Canadian Medical Association (CMA) *Counselling Guidelines for HIV Testing* (see info sheet 8),

- 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.

Professional guidelines for physicians adopted by other regulatory bodies, such as the College of Physicians and Surgeons of Ontario, are consistent with the CMA Guidelines:

HIV testing must be specifically agreed to by the patient.... [T]esting for HIV seropositivity is a serious matter for patients.... While it is understandable that some physicians might be tempted to ignore consent requirements concerning HIV testing, it is important to remember that conducting procedures which require consent in the absence of such permission is contrary to the Canadian Medical Association Code of Ethics and may constitute professional misconduct.

Informed Consent for Medical Interventions

In insisting on informed consent to HIV testing, the CMA Guidelines parallel general principles enunciated in Canadian law regarding consent to medical interventions. The Supreme Court of Canada and provincial appellate courts have repeatedly affirmed the doctrine of informed consent, ruling that care providers will be liable in tort (for negligence or battery) if they carry out a medical intervention without such consent.

Informed Consent for HIV Testing

While it is clear that medical *treatment* requires informed consent, *testing* is not quite the same as treatment. The law in this area is less clear, although the starting premise remains that testing without consent requires some specific legal authority, either statutory or judicial. And there is strong authority from both the Supreme Court of Canada and provincial appellate courts suggesting that forced HIV testing by the

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state or pursuant to state authority (eg, statute) is *prima facie* illegal:

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 SCR 417 at 431-432)

[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 SCR 30 at 46)

[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 CCC (3d) 502 at 513)

Given the relevant court decisions, and the seriousness of the consequences of HIV testing for persons tested, a physician who conducts an HIV test on a patient without obtaining informed consent would be vulnerable to both a civil action for damages, as well as disciplinary proceedings before his or her licensing body for professional misconduct and failing to meet adequate standards of practice.

Testing without Consent

Physicians have a profound responsibility to educate themselves about the meaning, appropriate use, and potential adverse consequences, of the HIV-antibody test before ordering a single test. The impact of test results on the patient, and the impact on the patient's life, if these results become known to others, are potentially devastating. This is still the case.... It is therefore wrong and misguided to view HIV testing as "routine" and as no longer requiring the safeguards of confidentiality, counseling, and consent.

– Roy, 1991

Nevertheless, research studies and anecdotal evidence show that HIV testing without obtaining *specific* informed consent is widespread. Physicians and hospitals have performed HIV tests without obtaining such consent, relying instead on the implied consent to treatment and blood tests that hospital patients typically provide. There is concern that the availability of rapid HIV screening will lead to even more frequent instances of testing without specific informed consent.

Recommendation

Professional codes of conduct, ethical consciousness, and Canadian law require consent to HIV testing. In order to reinforce that testing can only be undertaken with the specific informed consent of the person being tested, colleges of health-care professionals, and health-care professionals' associations, should adopt (or update) regulations and/or policies that:

- unequivocally state that performing HIV testing without informed consent, or pressuring or coercing patients into testing, is unethical, could give rise to civil or criminal liability, and could carry disciplinary sanctions;
- specifically state that rapid HIV testing technology does not remove the requirement for informed consent to testing in every circumstance; 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

Stoltz L, Shap L. *HIV Testing and Pregnancy: Medical and Legal Parameters of the Policy Debate*. Ottawa: Health Canada, 1999. Also available at <www.aidslaw.ca>. Contains a thorough discussion of the legal doctrine of informed consent (at 25-30).

Elliott R, Jürgens R. *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Montréal: Canadian HIV/AIDS Legal Network, 2000. Also available at <www.aidslaw.ca>. See the section on testing without informed consent at 49ff.

The information in this series of info sheets is based on two reports prepared by the Canadian HIV/AIDS Legal Network: *HIV Testing and Confidentiality: Final Report* and *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Copies of the reports and info sheets are available on the Network website at www.aidslaw.ca or through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: aids/sida@cpha.ca). Reproduction of the info sheets is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. For further information, contact the Network (tel: 514 397-6828; email: info@aidslaw.ca). **Ce feuillet d'information est également disponible en français.**

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Access to Testing

For most Canadians, access to different forms of HIV testing is fairly easy, but problems continue: women still sometimes find it difficult to access testing, and Aboriginal people face greater barriers to accessible testing than most other Canadians. This info sheet suggests ways to overcome these problems. It does not deal with access to anonymous testing, or with the issues raised by rapid testing. These are addressed in info sheets 7 and 10 respectively.

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.

Why Is Easy Access to Testing Essential?

As discussed in info sheet 3, voluntary HIV testing accompanied by counseling has a vital role to play within a comprehensive range of measures for HIV/AIDS prevention and support. It is therefore essential to ensure that HIV testing is readily accessible to all Canadians and that barriers to testing, whether real or perceived, be removed. This is particularly true in light of the fact that many Canadians are living with HIV without knowing it, missing the possibility of benefiting from new treatments: in 1996 Health Canada estimated that 11,000 to 17,000 persons were unaware of their infection.

Recommendation

All Canadians should be aware of and have access to a variety of voluntary, high-quality, bias-free testing options. All options should be made available and accessible in a variety of sites, including rural and Aboriginal communities, and appropriate and scientific methods of evaluation should be used to ascertain the efficacy and usefulness of the different types of testing.

What Are the Problems?

Access to testing for women

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

- There still is a perception that only men who have sex with men, drug users, and sex workers are at risk for HIV. This has prevented women from seeking testing. It has also led physicians not to offer testing to women whom they do not perceive to be at risk for HIV.
- Some women have even been refused 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 they are given access to a test. Women find these inquiries stigmatizing and difficult to challenge, given differences in power and (frequently) gender between the woman and her health-care provider.
- Testing and counseling for women has been closely associated with prenatal care. There appears to be less concern for the welfare of women than for that of their children or potential children. Women who are not pregnant or of childbearing age have found it difficult to access HIV testing.
- Women often live in situations of abuse and economic dependence and are fearful of the potential repercussions of testing. Women who test HIV-positive may experience negative consequences that most men who test positive do not have to deal with

– one study showed that 52 percent of women who tested positive feared that their partners would leave them, and 12 percent expected to be assaulted – many were indeed subjected to violent acts by their partner.

Recommendations

1. Increased education that focuses specifically on women needs to be undertaken. Women need to be made aware that they may be at risk of HIV.
2. Education and training directed at increasing doctors' awareness of the potential vulnerability of women to HIV should be undertaken. Many women will not be reached by public education. For these women, a doctor's office may be the only place where they have the opportunity to receive appropriate information about HIV and testing options.
3. The broader problems of abuse and economic dependence of women need to be addressed to create a climate in which women will be less fearful of the potential consequences of testing.
4. Efforts to increase access to testing for women need to focus on all women and not primarily on pregnant women.

Access to testing for Aboriginal people

Aboriginal people can receive HIV testing off reserve 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 Canadian cities. On reserve, Aboriginal people can generally be tested for HIV at the community health centre by a health nurse.

However, for a number of reasons, Aboriginal people face greater barriers to accessing HIV testing than other Canadians:

- In some parts of the country, an Aboriginal person may have to travel long distances to get tested. The period between taking a test and getting the result is generally much longer in rural and reserve communities. Further, many communities are visited by a health nurse only sporadically. In these circumstances, the chances that a person will get tested or,

having been tested, will return to the health centre to get the result, are reduced.

- Because reserves are small communities, people may be reluctant to use the local health centre due to concerns about confidentiality.
- Mainstream facilities in cities often do not take into account cultural differences between Aboriginal and non-Aboriginal people, making these facilities less accessible to Aboriginal people.

Recommendations

1. Federal, provincial, territorial, and Aboriginal government health providers, and Aboriginal AIDS organizations and others in the Aboriginal community should work together to develop accessible options for HIV testing.
2. HIV/AIDS education for Aboriginal communities must be emphasized in order to help reduce stigmatization related to HIV testing.
3. Mobile HIV testing units should be examined for their potential to help overcome some of the barriers to accessing testing.

Additional Reading

Matiation S. *HIV Testing and Confidentiality: Issues for the Aboriginal Community. A Discussion Paper* (2nd edition). Montréal: Canadian HIV/AIDS Legal Network & Canadian Aboriginal AIDS Network, 2000. Provides a thorough discussion of HIV testing issues specific to Aboriginal people, and recommendations. Also available at <www.aidslaw.ca>.

Jackson LA 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 Canadian study on women's experience of HIV testing.

North RL, Rothenberg KH. Partner notification and the threat of domestic violence against women with HIV infection. *New England Journal of Medicine* 1993; 329: 1194-1196. The study showing that women testing HIV-positive may experience negative consequences, such as violent acts by their partner.

The information in this series of info sheets is based on two reports prepared by the Canadian HIV/AIDS Legal Network: *HIV Testing and Confidentiality: Final Report and Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Copies of the reports and info sheets are available on the Network website at www.aidslaw.ca or through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: aids/sida@cpha.ca). Reproduction of the info sheets is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. For further information, contact the Network (tel: 514 397-6828; email: info@aidslaw.ca). **Ce feuillet d'information est également disponible en français.**

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Anonymous HIV Testing

This info sheet provides a definition of anonymous HIV testing, shows where such testing is available in Canada, and discusses the benefits of making it available, as well as concerns raised. It concludes that the benefits of making anonymous HIV testing available outweigh the concerns, and recommends that all provinces and territories should make it available as part of a variety of voluntary, high-quality, bias-free testing options.

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.

There is consensus in Canada that people should have access to a variety of voluntary testing options, and that access to quality testing must be improved, in particular for women and Aboriginal people (see info sheet 6). But there is no consensus on whether access to HIV testing should include access to *anonymous* testing.

Definition

Anonymous testing is testing in which the results can be linked to the person being tested by a code known only to the patient. Neither the physician ordering the test nor anyone else knows the identity of the patient.

Current Status

Anonymous testing is expressly provided in six provinces (Newfoundland, Nova Scotia, Québec, Ontario, Saskatchewan, and New Brunswick). In four provinces and territories, while technically not allowed, it can sometimes be obtained in practice (Northwest Territories, Yukon, Manitoba, and Alberta). In Prince Edward Island, only nominal and non-nominal testing is available. Finally, British Columbia does not offer anonymous testing, but promotes a system of flexible, non-nominal reporting. Nearly all testing undertaken at public health clinics (and some testing done by physicians) is non-nominal. People are asked to use their initials and date of birth as codes, but they are allowed to give a false name and date of birth.

Benefits of Anonymous Testing

The benefits of making anonymous testing available have been discussed in great detail in the literature. In particular, there is evidence that:

- *The availability of anonymous testing encourages people to be tested.* For example, a study of people seeking testing at the Hassle Free Clinic in Toronto revealed that 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 particularly people at greatest risk to be tested.* Studies have shown that people at greatest risk of HIV infection are more likely to undergo testing for HIV if the testing is anonymous.
- *Anonymous testing sites often offer “best practice” pre- and post-test counseling.* Personnel at anonymous testing sites have developed invaluable expertise in providing counseling, and some people prefer anonymous testing services because of the quality of the counseling available. An evaluation of Ontario’s anonymous testing clinics showed that people who test repeatedly at these clinics are more successful at remaining HIV-negative than those tested elsewhere.

Concerns

Despite these benefits, the debate over anonymous testing continues. Those who oppose anonymous testing argue that it

- prevents the collection of important epidemiological data about the incidence and prevalence of HIV and its pattern of transmission;
- compromises partner notification because it does not permit the identification of the HIV-positive individual, and thus prevents health-care or public health workers from reaching unsuspecting partners who may be at risk; and
- is expensive.

In addition, they point out that some of the people tested in anonymous testing facilities never return to pick up their results. Consequently, some seropositive persons do not learn of their HIV status.

These concerns, however, should not be overstated:

- Relevant data for epidemiological purposes – including demographic information about the age, sex, and geographic location of an infected person, as well as information about the likely route of transmission – can be obtained through anonymous testing. Even many of the states in the United States that have adopted nominal reporting of HIV have maintained the option of anonymous testing, implicitly recognizing that the benefits from maintaining this option may outweigh the potential negative impact on the collection of epidemiological data.
- It is true that partner notification is entirely voluntary when an individual tests anonymously. However, partner notification can be carried out by HIV-positive persons themselves or by their physicians. Generally, the Canadian approach has been to emphasize that many HIV-positive individuals voluntarily notify sexual or needle-sharing contacts who may not be aware that they have been at risk, and to point out that, while partner notification can make a positive contribution to a successful HIV/AIDS public health and prevention program, it should respect the human rights and dignity of the index person and partners, and be voluntary, non-coercive, and non-prejudicial.

- Anonymous testing programs need not be expensive. For example, in Ontario the cost of an anonymous test is less than half the cost associated with providing the test through a physician in private practice.
- 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 – in Ontario, fewer than five percent did not return; in New Brunswick, only three percent.

Impact of New Developments

It has been suggested that the availability of new treatments makes anonymous testing superfluous because people testing positive will likely seek medical care as soon as they find out their HIV status, and will forfeit their anonymity as soon as they enter a doctor's office. However, stigmatization of and discrimination against people with HIV remain pervasive in Canada. Therefore, people may still want to be tested anonymously and, if they test positive, decide for themselves whether and when to seek treatment.

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 variety of voluntary, high-quality, bias-free testing options (or, at a minimum, provide access to flexible, non-nominal testing, such as in British Columbia); and
- widely advertise the availability of anonymous testing, reduce waiting periods at such facilities, and undertake ongoing evaluation.

Additional Reading

Bureau of HIV/AIDS STD and TB Update Series, Laboratory Centre for Disease Control. *Anonymous HIV Testing in Canada*. Ottawa: Health Canada HIV/AIDS Epi Update, May 1999.

The information in this series of info sheets is based on two reports prepared by the Canadian HIV/AIDS Legal Network: *HIV Testing and Confidentiality: Final Report and Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Copies of the reports and info sheets are available on the Network website at www.aidslaw.ca or through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: aids/sida@cpha.ca). Reproduction of the info sheets is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. For further information, contact the Network (tel: 514 397-6828; email: info@aidslaw.ca). **Ce feuillet d'information est également disponible en français.**

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Counseling

Inadequate counseling is not only unethical and poor practice, it is also contrary to the legal doctrine that medical interventions require a patient's informed consent. Nevertheless, many of those getting tested for HIV receive inadequate or no counseling. This info sheet explains why pre-test and post-test counseling remain important, and provides recommendations designed to improve the availability and quality of counseling.

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.

Background

There is widespread agreement that quality pre- and post-test counseling are essential components of HIV testing. Indeed, inadequate counseling is not only unethical and poor practice, it is contrary to the legal doctrine that medical interventions require a patient's informed consent.

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

The Guidelines provide detailed information regarding the essential components of counseling.

Components of pre-test counseling

These include: assessing the patient's risk of HIV infection; assessing the window period; providing information regarding HIV infection, risk activities, and ways to avoid or reduce risk; identifying testing options available in the region and the differences between them; discussing record-keeping with respect to the test results and access to those records by other health-care professionals; discussing the advantages and disadvantages of testing so the patient has an opportunity to weigh these in the context of their particular circumstances; and, should the patient choose to proceed with the HIV test, determining the timing of testing and the post-test visit.

Components of post-test counseling

These 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.

Current Situation

Both anecdotal evidence and research studies reveal serious inadequacies in current counseling practices. A recent qualitative study in Ontario reported numerous negative experiences of the testing/counseling process. Research has also specifically identified poor testing/counseling experiences of women (a Toronto study of 40 HIV-positive women's experiences related to HIV testing revealed that 43 percent received no counseling at all, and only seven percent received both pre- and post-test counseling), pregnant women, and Aboriginal communities. In addition, a qualitative evaluation of the CMA Guidelines showed that over one-third of the primary-care physicians participating reported not having a copy of the Guidelines. While 80

percent of the physicians who had tested patients for HIV reported they provided counseling, 17 percent indicated they had provided counseling only for those who tested positive.

Counseling No Longer Necessary?

As shown in info sheets 3 and 6, with the advent of new treatments, access to HIV testing is more important than ever. Some people have suggested that requiring pre- and post-test counseling for all who seek testing may in fact discourage some people from being tested by “over-dramatizing” the testing situation and creating a “crisis” atmosphere around the decision to be tested.

However, the consequences of HIV testing for those who test positive remain serious – personally, socially, and legally. In their personal lives, individuals 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 upon 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 – in 2000 – can result in the loss of personal relationships, employment, and medical care, and otherwise dramatically impact upon their quality of life.

The legal consequences are equally far-reaching. Public health legislation in all Canadian provinces and territories requires that cases of AIDS be reported to public health officials; HIV positivity is reportable in many provinces and territories (see info sheet 17). This same legislation establishes, for each province and territory, a framework that governs the conduct of persons with designated infectious or communicable diseases (such as HIV disease and AIDS), insofar as that conduct may present a risk of transmission to other persons.

In the criminal context, the effect of the Supreme Court of Canada’s decision in *R v Cuerrier* is to require those individuals who know they are HIV-positive to disclose their HIV status to sexual partners before engaging in conduct that poses “a significant risk of serious bodily harm.”

For all these reasons, it would be a serious mistake to “trivialize” HIV testing and to push people to be tested without providing them with pre-test counseling. 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 providing counseling and meeting the other basic elements of informed consent would be vulnerable to both a civil action for damages, as well as disciplinary proceedings before their licensing body for professional misconduct and failure to meet adequate standards of practice.

Post-test counseling also remains important. More than ever, counseling for persons testing positive needs to stress that they can remain healthy and productive for a long time; emphasize the importance of 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 counseling maximize the benefits from testing for the persons being tested and for society, while reducing potential harms. Therefore, testing should be undertaken only with quality pre- and post-test counseling.

1. The CMA and other counseling guidelines should be updated and made widely available.
2. Colleges and universities providing professional education to health-care professionals should include, as mandatory components of their curricula, training in counseling principles and techniques, and on HIV/AIDS (including psychosocial issues related to HIV/AIDS).
3. Professional associations, regulatory bodies, and/or provincial health ministries need to provide training and education to health-care professionals in HIV counseling and testing.

Additional Reading

Canadian Medical Association. *Counselling Guidelines for HIV Testing*. Ottawa: The Association, 1995. Authoritative guidelines that clarify the standard of care expected of physicians when conducting HIV testing.

The information in this series of info sheets is based on two reports prepared by the Canadian HIV/AIDS Legal Network: *HIV Testing and Confidentiality: Final Report and Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Copies of the reports and info sheets are available on the Network website at www.aidslaw.ca or through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: aids/sida@cpha.ca). Reproduction of the info sheets is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. For further information, contact the Network (tel: 514 397-6828; email: info@aidslaw.ca). **Ce feuillet d'information est également disponible en français.**

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Advances in HIV Testing Technologies

This info sheet describes the standard HIV testing procedure, as well as two newer forms of HIV testing – rapid point-of-care testing and home testing. Info sheets 10 and 11 will discuss rapid point-of-care testing and home testing in more detail.

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.

Recent advances in HIV testing technology are increasing the options for HIV testing. Several years ago, the only type of HIV-antibody test available was a blood test done through a doctor's office or an HIV testing clinic. Today there are different types of tests available, and some can even be done at home. In addition, rapid tests have become available that can provide test results within 15 minutes.

Standard HIV Testing

Currently in Canada, the *standard procedure* for HIV testing involves a trained health-care worker drawing a blood sample from the person getting tested in a clinical setting, usually a physician's office or a testing clinic. The blood is then tested in a clinical laboratory to detect the presence of HIV-specific antibodies, using an enzyme immunoassay (EIA, or "ELISA" test) as a screening test. A negative result is reported if the EIA is non-reactive. Any blood sample that tests positive, however, undergoes a second, confirmatory test. Only *confirmed* test results are given to the health-care provider who ordered the test.

Although the actual testing does not require much time, typically one to two weeks pass before results are available. This is because blood samples are generally "batched" (ie, tested in groups) to decrease testing costs, and because time is needed to complete confirmatory testing. Every person getting tested, whether the test is positive or negative, must return to the testing site for a second visit to learn their results.

Rapid Testing

Rapid HIV test kits were first licensed for use in authorized HIV testing laboratories in Canada in April 1998. In March 2000, the first kit – developed by BioChem Immunosystems and Saliva Diagnostic Systems ("SDS") and called *Fast Check HIV-1/2* – was licensed for sale in Canada *to be used by health-care professionals*. (This is sometimes referred to as "point-of-care" testing, meaning testing done in the setting where health care is provided.) The kit is designed for single use to screen one specimen of whole blood for antibodies to HIV using an EIA.

How does the rapid test work?

A kit contains the following components:

- a package insert indicating the proper and permitted use of the kit, directions, performance characteristics, and other information;
- a lancet for obtaining a blood sample from a finger prick;
- a pipette to collect the blood sample;
- a plastic cassette or cartridge in an airtight container, with a well for the specimen and often a

separate opening where the coloured “test” and “control” strips are seen; and

- buffer solution.

A drop of blood is collected by pricking the patient’s finger, and is placed in the well of the cassette using the blood pipette. The blood is allowed to sit in the package insert for several minutes. Then a specific amount of buffer is added to the blood, and the mixture is allowed to incubate for several minutes. When HIV antibodies are present in the patient’s blood in sufficient concentrations, a colour reaction occurs along a test strip. Some tests include a separate “control” line that should appear as well, to indicate the test was performed properly.

How well do they perform?

Rapid HIV test kits have been studied at several sites in Canada in order to validate their effectiveness and performance in point-of-care testing. The kit licensed in March has the same sensitivity, specificity, and performance characteristics as the *screening* methods used in approved laboratories. This ensures a reliable negative test, which permits health-care professionals to complete the HIV testing and counseling in a single visit for those whose test result is negative.

However, as is true of all screening tests, a reactive rapid HIV test result must be confirmed at an approved HIV testing laboratory. This means that a full blood sample must be taken from a vein and sent to a laboratory, and the patient must return to the testing site for a second visit. In future, when more rapid tests are licensed for point-of-care use in Canada, it *may* become possible to use specific combinations of two or more rapid tests for screening and confirming HIV infection.

Point-of-Care versus Home Testing

Point-of-care testing can be defined as testing in the presence of a health professional, as opposed to a testing procedure that is carried out wholly or partially without the involvement of a health professional. Currently in Canada all HIV testing is point-of-care testing at a health facility of some sort.

The term *home testing* often creates confusion, as it is used to refer to two different forms of testing: home sample collection or home-access testing; and true home testing, sometimes referred to as home self-testing or home validated testing.

“Home sample collection” (or “home access”) testing

This form of testing requires a person to purchase an over-the-counter HIV test kit and collect the sample themselves. The sample is mailed to a laboratory and, several days later, the person can receive the test results by telephone. The testing itself – and the interpretation of the test results – is carried out by trained laboratory professionals.

“True” home tests

They are also called home self-tests or home validated tests. They are essentially rapid tests that can be carried out entirely at home without the involvement of an outside party. Home pregnancy testing is an example of true home testing. In this situation, a consumer purchases an over-the-counter kit, receives instructions by pamphlet, collects the sample, conducts the test at home, and obtains the result within a few minutes. Interpretation of results and instructions for follow-up are provided by written materials in the kit.

HIV home sample collection testing kits have been approved and sold in the United States since mid-1996, but no home test has as yet been approved in Canada.

Additional Reading

Elliott R, Jürgens R. *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Montréal: Canadian HIV/AIDS Legal Network, 2000. The most up-to-date summary of advances in HIV testing technology, at 4-12. Available at <www.aidslaw.ca>.

Kassler WJ. Advances in HIV technology and their potential impact on prevention. *AIDS Education and Prevention* 1997; 9(Suppl B): 27-40. Another good, but less recent, summary of advances in HIV testing technology.

The information in this series of info sheets is based on two reports prepared by the Canadian HIV/AIDS Legal Network: *HIV Testing and Confidentiality: Final Report* and *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Copies of the reports and info sheets are available on the Network website at www.aidslaw.ca or through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: aids/sida@cpha.ca). Reproduction of the info sheets is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. For further information, contact the Network (tel: 514 397-6828; email: info@aidslaw.ca). **Ce feuillet d’information est également disponible en français.**

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Rapid Point-of-Care Testing

This info sheet examines the potential benefits of rapid point-of-care testing, as well as questions and concerns that have been raised about the use of rapid tests. It concludes that rapid test kits should only become available in those settings and under those conditions in which their benefits will be most likely realized and the potential misuses prevented.

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.

Background

In March 2000, Health Canada licensed the first rapid HIV test kit *for use by health-care professionals*. The test performs as well as the *screening* methods used in approved laboratories. However, as with other screening tests, it will yield a significant proportion of false-positive results, and all positive results must be confirmed at an approved HIV testing laboratory (see info sheet 9).

Who is legally permitted to administer rapid HIV tests? As mentioned above, the kit 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/territorial legislation defining “health services” and those who are entitled to provide them may end up defining the parameters of who is legally permitted to administer the tests. These provisions vary from jurisdiction to jurisdiction, and may include health-care professionals who currently do not provide HIV testing.

Potential Benefits

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

- clients’ satisfaction can be improved because they can receive their results sooner;
- rapid screening kits are easier and safer to administer;
- more people would receive their test results; and
- access to HIV screening could be improved.

In addition, it has been argued that rapid screening could make it possible, for women whose HIV status is unknown at the time of labour, to undergo screening during labour and, for those screening positive, to initiate preventive measures to reduce the risk of mother-to-child transmission. Rapid screening could also provide more information for decisions about post-exposure prophylaxis (PEP).

However, little is known about how significant some of these benefits would be in the Canadian context. In addition, some potential benefits would be realized only in certain limited circumstances:

- There would be a benefit to faster delivery of results *for those who tested negative*. But those who tested positive 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 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 between testing sites, and are generally lower than in the US.

- The potential benefits of providing rapid HIV screening in remote settings should not be overestimated. 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 a person with a preliminary positive result during that period.
- The issue of whether it would be ethically appropriate or legally sound to use rapid HIV screening during labour is contentious.
- Rapid HIV screening offers some potential benefit with respect to making decisions about PEP, but it does not change the requirement that testing for HIV must always be done with consent.

Concerns

There are numerous concerns about using rapid HIV screening. They range from concerns about the implications of disclosure of positive screening results when a significant number of false-positive results will occur; to concerns that people undergoing rapid HIV screening will not receive adequate counseling; to concerns that women in labour may be screened without their informed consent; to concerns that in a variety of other situations there will be a push for testing without consent.

What Must Be Done?

Many of these concerns are related to *who* could potentially administer rapid HIV screening tests. There would be little concern if the test was administered by a test provider in a testing clinic, particularly if the provider had received training in how to administer the tests and in how to provide counseling; and if the clinic was able to provide support to a person who screened positive, and a confirmed test result within a short period of time. But there would be concern if the test was administered by a physician who had little experience with HIV testing and no training about rapid screening kits; and even greater concern if testing was done by health-care professionals who currently do not administer HIV testing.

Therefore, regulating the use of rapid HIV screening tests will be important. Otherwise, there is a real threat that technology will drive what type of testing will be available in Canada and how testing will be done, rather than a careful consideration of risks and benefits, informed by scientific research.

Recommendations

Governments must exercise their regulatory authority to ensure that rapid test kits are only available in those settings and under those conditions in which their benefits will be most likely realized and the potential misuses prevented. In particular:

1. Where these devices are introduced, their use should be phased in by providing rapid testing as an option in specific sites only, followed by evaluation of the experience.
2. Governments should establish, in consultation with community-based organizations, health-care professionals, and current testing providers, which “health-care professionals” will be permitted to administer a rapid HIV test.
3. Governments should use their regulatory powers, and health-care professionals’ regulatory bodies should similarly use their powers, to issue regulations, guidelines, or policies to restrict the use of rapid HIV screening tests to point-of-care settings that ensure that a person receiving a positive screening test will have accelerated access to a confirmed result, and to support while waiting for the confirmed result; and that those providing testing have received training in how to provide quality pre- and post-test counseling.
4. Federal and provincial authorities must ensure that the restrictions placed on the use of rapid test kits are actually enforced, by responding decisively and swiftly to breaches of these conditions.

Additional Reading

Elliott R, Jürgens R. *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Montréal: Canadian HIV/AIDS Legal Network, 2000. Everything you need to know about rapid HIV screening, and more. Available at <www.aidslaw.ca>.

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Home Testing

This info sheet examines the potential benefits of home testing, as well as concerns that have been raised about the use of home tests.

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.

Background

The term “HIV home testing” refers to two forms of testing: *home sample collection testing* (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); and *true home testing*, which can be carried out 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. *True home tests* have not been approved for sale, but many are advertised over the Internet, and at least one company is seeking approval to market its home saliva test to consumers.

In contrast, Health Canada has not received any applications for a licence to sell *home sample collection* or *true home tests*.

Claimed Benefits

Expansion of testing: Advocates of home testing have stated that there is an urgent need for a new mode of testing, pointing out that many people with HIV are unaware of their infection. 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 Canadians. For some, especially those living in remote areas or in provinces or territories where anonymous testing is not offered (see info sheet 7), *home sample collection tests* might represent the only opportunity to be tested anonymously.

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. This may increase the willingness of people to be tested.

Positive impact on public health: Proponents have argued that the main benefits would be earlier treatment, based on the assumption that more people would be tested earlier and choose treatment; and decreased sexual transmission, based on the assumption that more people would be tested sooner, and not engage in unsafe behaviours.

Decreased costs: Availability of home testing may reduce demand for, and costs associated with, testing at publicly funded testing sites.

Questions and Concerns

Support for *home sample collection testing* has grown over the past years, but support for *true home tests* remains more divided. A number of questions and concerns remain, some of which are relevant only in the context of true home tests, some in the context of both types of tests.

Lack of counseling

There are serious concerns about the possible negative consequences of the absence of pre-test counseling for both home sample collection tests and true home tests; the absence of post-test counseling for true home tests; and the fact that post-test counseling for home sample collection tests is provided over the phone.

Impact on public health

Would availability of home testing really have a beneficial impact on public health? Nobody would deny the potential benefits of HIV testing for the individual, but its public health impact remains contentious (see info sheet 3). The evidence for the impact of HIV testing in bringing about behaviour change is mixed, and doubts have been expressed about the effectiveness of testing without pre- and post-test counseling in modifying behaviour. In addition, some oppose the introduction of home testing on the basis that it would hamper efforts to control HIV through partner notification and other public health measures.

Accuracy

Many of the home sample collection tests are accurate and fairly easy to use. However, true home tests are only as good as current screening tests, which lead to a significant number of false-positive results. Imagine a person receiving a positive screening result at home, without any counseling 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 accuracy of tests are usually obtained under optimal conditions by trained technicians and may not reflect a real-life situation – untrained lay persons can easily misinterpret test results or use the test incorrectly.

Potential for abuse

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 test others without their consent. True home tests

could be used directly at border controls – by future employers, by parents, and by 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 via the Internet, the name and address must be provided so that the test can be mailed; databases created by companies that distribute the tests could be misused; 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

As of the spring of 2000, Health Canada had not received any applications for a licence to sell *home sample collection* or *true home tests* in Canada. Such testing will therefore not become available in Canada in the immediate future. However, a rapid HIV screening test was licensed for sale in Canada before governments had exercised their regulatory authority to ensure that it would only be used under circumstances in which its benefits will be most likely realized and the potential misuses prevented. There are lessons to be learned from that experience, including the need for better research about the benefits and harms of a new testing technology, and the need for serious debate on the legal and ethical questions raised by the potential licensing in Canada of home tests, particularly *true home tests*.

Additional Reading

Schopper D, Vercauteren G. Testing for HIV at home. What are the issues? *AIDS* 1996; 10: 1455-1465. The best discussion of the issues raised by home testing.

The information in this series of info sheets is based on two reports prepared by the Canadian HIV/AIDS Legal Network: *HIV Testing and Confidentiality: Final Report and Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Copies of the reports and info sheets are available on the Network website at www.aidslaw.ca or through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: aids/sida@cpha.ca). Reproduction of the info sheets is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. For further information, contact the Network (tel: 514 397-6828; email: info@aidslaw.ca). **Ce feuillet d'information est également disponible en français.**

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Mandatory Testing

This info sheet explains why there have been calls for mandatory testing of so-called “high-risk groups” and of specific populations, such as prisoners, immigrants, and health-care workers. It then shows why mandatory testing programs are not in the interest of public health, and presents some general principles that should govern consideration of any proposals for mandatory testing. Info sheets 13 to 16 more closely examine the issues around mandatory testing in two specific situations – before and after a potential exposure to HIV – and in two populations: pregnant women, and immigrants.

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.



Background

Despite the consensus that HIV testing should generally be undertaken only with the informed consent of the person being tested (info sheet 5), there have been repeated calls for mandatory testing of the entire population or of certain groups.

Initially, in the face of a rapidly growing HIV/AIDS epidemic, calls for mandatory testing were easy to understand. People naturally searched for concrete solutions, and the notion of mandatory testing – coupled perhaps with forced segregation of people with HIV – had obvious superficial appeal. Calls for mandatory testing became a fairly common political response to HIV/AIDS, partly because they create the appearance of taking a strong stand against the threats of AIDS.

Early in the epidemic, some even recommended mandatory testing of all members of the so-called “high-risk groups,” in particular gay men, injection drug users, and hemophiliacs. However, such proposals were rejected because it was recognized that:

- it is high-risk activity, not identification with a group that has a high seroprevalence rate, that causes transmission of the virus;
- a mandatory testing program would face obvious problems in identifying members of the targeted groups; and
- mandatory testing of these groups would have increased discrimination toward them, and given everybody else a false and potentially dangerous sense of security.

In contrast, calls for more-targeted mandatory testing programs have continued. In Canada, they have most frequently been made concerning pregnant women, newborns, prisoners, persons accused or convicted of sexual assault, sex-trade workers, health-care workers and patients, and immigrants. One or more of the following factors seem to underlie these proposals for testing: a perceived high risk of being HIV-positive; a perceived high risk of infecting others with HIV; culpability due to involvement in criminal activity, so that being required to undergo the test can be considered a just component of punishment; and the use that can be made of test results.

The Case against Mandatory Testing

Most calls for mandatory testing could succeed only by playing upon public ignorance about the disease.

– Field, 1990

Generally, as the World Health Organization (WHO) has stated, “mandatory testing and other testing without informed consent has no place in an AIDS prevention and control programme.... There are no benefits either to the individual or for public health

MANDATORY TESTING

arising from testing without informed consent that cannot be achieved by less intrusive means, such as voluntary testing and counselling.” The WHO continued by saying that “public health experience demonstrates that programmes that do not respect the rights and dignity of individuals are not effective” and that it is therefore “essential ... to promote the voluntary cooperation of individuals rather than impose coercive measures upon them.”

Testing programs that do not require and secure an individual’s informed consent can be damaging to efforts to prevent HIV transmission – and are therefore not in the interest of public health – for the following reasons:

- Because of the stigmatization of and discrimination directed at people with HIV, individuals who believe they might be infected tend to go “underground” to escape mandatory testing. As a result, people at highest risk for HIV infection may not hear or heed educational messages about prevention.
- Testing without informed consent damages the credibility of health services and may discourage people needing services from obtaining them.
- In any testing program, there will be people who falsely test negative, so mandatory testing can never identify all people with HIV.
- Mandatory testing can create a false sense of security, especially among people who are outside its scope and who use it as an excuse for not following more effective measures for protecting themselves and others from infection.
- Mandatory testing programs are expensive, and divert resources from effective prevention measures.

For these reasons, although there have been calls for the widespread mandatory testing of certain groups, all major Canadian reports dealing with the issue of testing have rejected such calls.

General Principles

There are several general principles that should guide consideration of any calls for mandatory testing:

- The purpose of testing must be ethically acceptable. Protecting public health and preventing transmission of HIV are acceptable purposes, while denying needed services and expressing disapproval of certain groups are not.

- The proposed use of test results must contribute to the goals of a prevention program.
- The testing must be the least restrictive or intrusive means for attaining these goals.
- The benefit to public health must warrant the extent of intrusion into personal liberties. This principle does not suggest that public health should be sacrificed in order to protect civil liberties, but only that an uncertain or minimal public health benefit should not be used to justify gross invasion of personal rights.

Additional Reading

World Health Organization. *Statement from the Consultation on Testing and Counselling for HIV Infection*. Geneva: WHO Global Programme on AIDS, 1992. Clearly sets out why mandatory testing is generally not in the interest of public health.

Human immunodeficiency virus antibody testing in Canada. Recommendations of the National Advisory Committee on AIDS. *Canada Diseases Weekly Report* 1989; 15(8): 37-43. Sets out that compulsory HIV testing is only justified “if its benefits outweigh its potential harms and is the least restrictive, least invasive, likely to be effective, reasonably available approach.”

Field MA. Testing for AIDS: uses and abuses. *American Journal of Law and Medicine* 1990; 16: 33-106. An early, but still relevant and very comprehensive analysis of uses and abuses of HIV testing.

The information in this series of info sheets is based on two reports prepared by the Canadian HIV/AIDS Legal Network: *HIV Testing and Confidentiality: Final Report and Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Copies of the reports and info sheets are available on the Network website at www.aidslaw.ca or through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: aids/sida@cpha.ca). Reproduction of the info sheets is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. For further information, contact the Network (tel: 514 397-6828; email: info@aidslaw.ca). **Ce feuillet d'information est également disponible en français.**

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13

HIV
Testing

Forced HIV Testing to Avoid Infection?

Testing of Patients, Health-Care Workers, and Prisoners

Some have argued that they need to know the HIV status of others to avoid or minimize the risk of exposure to HIV. For example, some health-care workers have said that they should be able to test patients for HIV before providing medical attention; some patients have said that health-care workers should be tested in the interest of avoiding the risk of infection to patients; some prison staff have argued that all prisoners should be tested so that staff could better protect themselves against infection; and so on. This info sheet examines whether compulsory testing in such situations is justified.

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.

Testing of Patients

Some health-care workers have suggested that all patients (or at least those perceived as being at “high risk” for HIV) be tested prior to 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 violates the autonomy and privacy of the patient.
- It is unnecessary because universal precautions can (and must) be taken, and knowledge of an HIV test result will make little, if any, difference. It has never been demonstrated that knowledge of a patient’s HIV status will make it possible for health-care workers to reduce the risk of transmission. In fact, in most of the cases of reported transmission, the patient’s HIV status was already known to the health-care worker in question. Provided that universal precautions are already in effect, it is not clear what additional precautions could be taken to reduce the risk of transmission once a patient has been identified as HIV-positive. Some might argue that additional precautions would be taken if a patient is known to be HIV-positive (such as use of a double layer of latex gloves for procedures involving exposure of health professionals’ hands to a significant volume of blood). However, if such a concern exists, erring on the side of additional precautions achieves the goal of protecting both the health-care worker and the patient’s autonomy and privacy.
- It is ineffective and possibly counterproductive. A negative HIV test result for a patient in the “window period” between infection and seroconversion may lull the provider into a false sense of security. It also ignores the possible presence of other, more communicable bloodborne pathogens. Less careful adherence to universal precautions could end up putting the health professional at higher risk of infection, as well as putting the patient at risk of infection from the health-care worker.
- HIV testing of patients will often 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. There is also Canadian case law to the effect that the refusal to provide medical treatment to a person with HIV amounts to prohibited discrimination.
- Finally, testing without consent can result in poor medical practice. The fear of discrimination encourages patients to conceal their HIV-positive status (which is possible if testing is not routinely done on

all patients) and/or their risk activities (if only those deemed to be at risk of infection are tested). This undermines full disclosure of information to health-care professionals that is potentially relevant to decisions about optimal treatment.

Testing of Health-Care Workers

Testing of some or all health-care workers has been proposed to reduce any risk that HIV-positive health-care workers may present to patients. Some health-care workers, particularly dentists and surgeons, frequently perform highly invasive procedures. Occasionally they may sustain a skin puncture whereby some of their blood might enter a patient's body. Therefore, such procedures may in some very limited circumstances result in the transmission of HIV from an infected health-care worker to a patient. However, since the beginning of the epidemic, there have been only two known cases of health-care workers infecting a patient with HIV. Nevertheless, these cases have provoked considerable public anxiety, even though the estimates of the risk of HIV transmission are "vanishingly small": 1/40,000 to 1/400,000 from HIV-positive surgeons and 1/200,000 to 1/2,000,000 from HIV-positive dentists.

Would forced testing of health-care workers be justified? Most health-care providers do not perform invasive procedures – they do not pose any risk of HIV infection, and testing them would clearly not be justified.

What about those who do perform invasive procedures? Those who argue against forced testing emphasize that the risk of transmission is extremely low, even in the case of invasive procedures. In contrast, proponents of testing argue that although the risk of transmission is low, public health should urge that certain precautions be taken; and that the consequences of HIV infection are uniformly serious, if not fatal, justifying coercive and costly measures to prevent transmission.

However, an effective public health response need not necessarily involve mandatory testing and exclusion. 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. In contrast, forced testing and blanket exclusion would not be justified.

Testing of Prisoners

There have been claims that prisoners should be forced to be tested for HIV. Those advocating forced testing have said that such testing (and disclosure and/or segregation) would protect staff and fellow inmates from contracting HIV in prisons. However, for the same reasons that HIV testing of patients is not justified, HIV testing of inmates is also not justified. In particular, there is no public health or security justification for mandatory or compulsory HIV testing of all prisoners.

Additional Reading

Jürgens R. *HIV Testing and Confidentiality: Final Report*. Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1998. Available at <www.aidslaw.ca>. See pages 155-163 for more details on HIV testing of prisoners; and pages 187-196 for testing of health-care workers.

The information in this series of info sheets is based on two reports prepared by the Canadian HIV/AIDS Legal Network: *HIV Testing and Confidentiality: Final Report* and *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Copies of the reports and info sheets are available on the Network website at www.aidslaw.ca or through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: aids/sida@cpha.ca). Reproduction of the info sheets is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. For further information, contact the Network (tel: 514 397-6828; email: info@aidslaw.ca). **Ce feuillet d'information est également disponible en français.**

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HIV Testing and Pregnancy

HIV testing of pregnant women makes it possible, for women who test positive, to initiate preventive measures that can substantially reduce the risk of transmitting the infection to their newborns. As a result, there has been pressure to test pregnant women without their informed consent. This info sheet discusses such proposals. It concludes that all women considering pregnancy or already pregnant be routinely offered voluntary HIV testing, with quality pre- and post-test counseling, but that they should not be tested without their specific, informed consent.

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.

Background

Before 1994, knowledge about HIV and pregnancy was scarce. Evidence suggested that about one-third of babies born to HIV-positive women would be HIV-positive themselves. There was fear that pregnancy might accelerate the development of AIDS in women who were HIV-positive but had no symptoms. Most often, HIV testing was offered only to pregnant women considered to be at risk for HIV, or provided at the request of the patient herself.

In 1994, research in the US showed that giving AZT to HIV-positive pregnant women and to their infants after birth could reduce the rate of HIV transmission from mother to child from 25.5 to 8.3 percent. Since then, studies have shown that the risk of transmission can be reduced even further if other preventive measures (such as caesarean delivery) are taken. This has caused debate about how best to offer HIV testing to pregnant women, so that women testing HIV-positive can be offered anti-HIV therapy and/or other measures to reduce the risk of transmission to their children.

Who Should Be Offered Testing?

All pregnant women should be offered HIV counseling and testing as early in pregnancy as possible. 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.

Voluntary versus Compulsory Testing

Only a policy of compulsory testing could ensure that *all* pregnant women seeking prenatal care are tested for HIV. However, there are many reasons why such a policy should not be adopted. First, a law mandating HIV testing for pregnant women would probably be unconstitutional, because it violates women's equality and their "security of the person." Second, compulsory testing is not necessary – where voluntary testing programs have been well designed and implemented, they have been effective. Third, voluntary testing maintains a woman's relationship of confidence in her physician, a relationship that is necessary for open discussion of the risks and benefits of antiretroviral treatment and/or other preventive measures. Fourth, compulsory HIV testing could heighten the existing mistrust of the public health system in communities disproportionately affected by HIV, driving some women away from care. Finally, in contrast to a policy of compulsory testing, a policy of voluntary testing is respectful of the autonomy of the woman, treating her as a person in her own right, rather than as a means to an end (imposing testing on her to potentially benefit her child).

Is Informed Consent Required?

The current standard of professional care in Canada requires that HIV testing be carried out only after the person to be tested has given informed consent

following pre-test counseling (info sheet 5). Should this requirement be abrogated for pregnant women?

No. Canadian courts do not consider informed consent a luxury, to be abandoned because it is perceived as too burdensome by physicians. There is no valid reason to eliminate the requirement for pregnant women. Indeed, obtaining a pregnant woman's consent and counseling her is particularly important. The sooner she is informed about the advantages and disadvantages of testing and available treatments, the more likely she is to make decisions that will ultimately benefit herself and her child. 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.

Should Testing Be Characterized As “Routine”?

Characterizing HIV testing as “routine” does not relieve physicians of their obligation to make sure that women give voluntary, specific and informed consent. However, it appears that many physicians mistakenly believe that they need not secure the informed consent of pregnant women to the tests listed on the standard laboratory requisition form used in prenatal care, because they are so-called “routine” tests. A problem with characterizing the test as “routine” is therefore the increased chance that women will be tested for HIV without their informed consent. Such a policy or practice would be open to legal challenge. The term “routine” to describe the HIV testing of pregnant women in Canada should be avoided.

Rapid HIV Screening

What of those women who, by the time of labour, have not accessed prenatal care, or have accessed such care but not been tested for HIV? Some have suggested they could undergo rapid HIV screening during labour, and be offered treatment to prevent transmission of the virus. But there is controversy over whether it is ethically appropriate or legally sound to use rapid HIV testing for women in labour.

Recommendations

1. 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 routinely offered voluntary HIV testing, with quality pre- and post-test counseling. Doing an HIV test should not be characterized as “routine” for pregnant women in policies, forms, or the education of health care professionals; rather, *offering* counseling and testing should be routine. Pregnant women should only receive HIV testing with their specific, informed consent.
2. Provinces and territories should phase in the use of rapid HIV screening tests for women in labour whose HIV status is unknown through pilot studies and evaluation, before any decision is made about recommended practice.

Additional Reading

Stoltz L, Shap L. *HIV Testing and Pregnancy: Medical and Legal Parameters of the Policy Debate*. Ottawa: Health Canada, 1999. Available at <www.aidslaw.ca>. A comprehensive analysis of the issues raised by pregnancy and HIV testing.

Elliott R, Jürgens R. *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Montréal: Canadian HIV/AIDS Legal Network, 2000. Available at <www.aidslaw.ca>. At 29-32 and 52-59, discusses whether and, if yes, how rapid HIV screening should be offered to pregnant women during labour. See also the ethical analysis in Appendix A.

The information in this series of info sheets is based on two reports prepared by the Canadian HIV/AIDS Legal Network: *HIV Testing and Confidentiality: Final Report and Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Copies of the reports and info sheets are available on the Network website at www.aidslaw.ca or through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: aids/sida@cpha.ca). Reproduction of the info sheets is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. For further information, contact the Network (tel: 514 397-6828; email: info@aidslaw.ca). **Ce feuillet d'information est également disponible en français.**

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Forced HIV Testing after Occupational Exposure or Assault?

Potential exposure to HIV almost always elicits intense fear and distress. It is often claimed that the person who was potentially exposed has a need to know the HIV status of the person who is the source of the exposure. This info sheet examines whether compulsory testing of the person at the source of a potential exposure, and disclosure of the test result to the person exposed, would be justified.

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.

Objectives of Testing

Health protection

Does a person need to know the source person's HIV status in order to make decisions about post-exposure prophylaxis (PEP)?

PEP is a course of anti-HIV medication taken (usually for about a month) following exposure in an attempt to prevent HIV infection in case the source person is infected. There is still a lack of *direct* evidence that PEP works, but giving PEP to health-care workers exposed to HIV has been *associated* with an 80 percent reduction in the likelihood of infection. PEP is unlikely to be effective if taken more than 72 hours after exposure and should be started within a few hours of exposure. This means that, following the standard testing procedure, test results cannot be obtained quickly enough to provide any useful information for deciding whether to *initiate* PEP. In contrast, rapid HIV screening could provide a test result within 15 minutes. However, it would not be able to provide *certainty*. If the result is negative, the person tested could still be infected but be in the "window period" (the period between infection and production of the antibodies to HIV that are detected by the test). If the result is positive, it could be a false positive (see info sheet 10).

Testing the source person might also provide information relevant to decisions to *continue* PEP. If the exposed person cannot tolerate the side effects of the drugs used in PEP, they might be willing to stop taking the drugs if the source person tests HIV-negative – even if a negative test cannot provide certainty that the source person is not infected.

Providing reassurance

Testing only provides uncertain information of limited usefulness. In some cases the test result would be negative even though the source person is infected and infectious – the person who may have been exposed would be falsely reassured. And if a rapid HIV screening test was used, it would produce a relatively high proportion of false-positive results.

Legal Considerations

Thus, there are some limited benefits to be gained from knowing a source person's HIV status. If the source person provides consent to HIV testing, there is no difficult legal or ethical issue to be resolved. However, what if the source person refuses testing? Should the exposed person be entitled to compel the source person to be tested without consent?

Occupational exposure

There have been occasional calls for compulsory testing, most recently in a private member's bill, Bill C-244 (*Blood Samples Act*). The bill would permit compulsory blood testing of persons for HIV or hepatitis B/C where peace officers, firefighters, or other

FORCED HIV TESTING AFTER OCCUPATIONAL EXPOSURE OR ASSAULT?

emergency services or health-care workers may have been occupationally exposed to possible infection.

While possible benefits of compulsory HIV testing in these cases are limited, the harms to the rights of those to be forcibly tested are significant. In particular, state authorization of forced HIV testing breaches the right to security of the person guaranteed by the Charter and is not in accord with the “principles of fundamental justice.” Forced HIV testing also violates the Charter right to be secure against “unreasonable search or seizure.” Other solutions to the risks faced by emergency services personnel would offer greater protection against possible exposure to communicable diseases, and at the same time respect the rights of Canadians to privacy and bodily integrity. 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 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? There is no legislation specifically authorizing compulsory HIV testing of offenders in Canada, and existing criminal legislation also provides no authority for testing. In *R v Beaulieu* (Court of Québec, 1992), the court refused to order HIV testing of a person *accused* of sexual assault.

Proposals to introduce compulsory HIV testing have been rejected. 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; is an unrealistic approach to addressing a sexual assault survivor’s needs; perpetuates the misperception that information about an assailant’s HIV status is critical to the survivor’s health; does not facilitate a survivor’s psychological recovery; and sets a dangerous precedent for extending mandatory testing to others.

Ethical Considerations

The law notwithstanding, could a moral argument for testing a source person without consent be made? If a source person intentionally and voluntarily caused harm

to another person, it could be said that the source person has a moral duty to mitigate the harm that person suffers. However, the exact nature of this duty is unclear. It might be seen as a matter of retributive justice – the wrongful conduct of the source person has set the moral scales out of balance, and that balance must be restored. It is hard to see, however, how a non-consensual test could morally rectify an assault. Alternatively, the duty might be seen as a matter of corrective justice – providing compensation for harms suffered. But the goal of testing would be to reduce future harm, not to try to make up for harm already suffered. Therefore, neither type of justice would morally justify testing a source person without consent.

Recommendations

1. Federal and provincial governments should not enact legislation authorizing compulsory HIV testing, including for those accused or convicted of sexual assault or of persons at the source of an occupational exposure.
2. 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.
3. Health Canada, the Department of Justice, Status of Women, and their provincial counterparts, as well as employers, must ensure that best-practice counseling, short- and long-term care, treatment, and other services are accessible to sexual assault survivors and those who have been occupationally exposed to possible infection with HIV (or other communicable diseases).

Additional Reading

Jürgens R. *HIV Testing and Confidentiality: Final Report*. Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1998. Available at <www.aidslaw.ca>. See pages 164-179 for more details on testing of persons accused or convicted of sexual assault.

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Immigrants and HIV Testing

This info sheet describes the current policy in Canada with respect to HIV testing of short-term visitors, immigrants, and refugees. It then discusses whether HIV testing should become mandatory for potential immigrants. It concludes that Canada should not introduce mandatory HIV testing of immigrants, and that people with HIV or other similar conditions should not automatically be excluded from immigrating. Rather, a system must be developed that allows people with HIV to immigrate, in certain clearly defined circumstances.

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.

Background

Canada's travel policy

Canada's *Immigration Act* does not mention HIV/AIDS or any other disease or illness specifically. Section 19(1)(a) of the Act says that visitors to Canada must meet two criteria before being allowed to enter Canada: they must not represent a danger to public health and safety; and their admission must not place excessive demand on Canada's health and social service systems.

Prior to 1991, the government considered that people with HIV represented a danger to public health, and should not be allowed to visit Canada. In April 1991, a new policy was announced, stating that a person with HIV did not constitute a threat to public health during short-term travel to Canada, and would be treated like any other visitor. This policy is still in place. It means that HIV-positive people entering Canada for less than six months should not be denied entry or encounter trouble at the border because of their HIV status.

Canada's immigration policy

Persons who wish to immigrate to Canada must meet the same criteria as visitors: they must not represent a danger to public health and safety, and must not place excessive demand on Canada's health and social service systems.

As of spring 2000, it is the policy of the Canadian government that people with HIV/AIDS do not represent a danger to public health and safety, but would place excessive demand on Canada's health and social service systems. Immigration applicants who are found to be HIV-positive are assessed as "medically inadmissible" and will not normally be allowed to immigrate. However, some asymptomatic HIV-positive immigrants may not be detected because an HIV test is not routinely required during the medical examination that applicants for immigration have to undergo. The examining physician *may require* an immigration candidate to take an HIV test. Some physicians test all applicants for immigration, while other physicians don't.

However, HIV testing may soon become routinely required during the medical examination.

Refugees

In contrast to immigrants, persons who are found to be refugees do not have to meet any medical criteria. There has been at least one case where a person with HIV has been allowed into Canada as a refugee: the Immigration and Refugee Board granted refugee status to a Polish man persecuted because of his sexual orientation and HIV-positive status, [1994] DSSR No 92 (QL).

Mandatory Testing of Immigrants

The opportunity to immigrate to Canada is a privilege and not a right, and it is a legitimate criterion for immigration that a prospective immigrant be reasonably

expected to contribute to Canadian society. HIV-positive persons will impose costs on Canada's health-care systems. Nevertheless, Canada should not make HIV testing of immigrants mandatory:

- To institute such testing would appeal to the deepest prejudices of people opposed to anyone they perceive as unlike themselves, of whom immigrants are a prime example.
- Testing could significantly harm people identified as being HIV-positive who live in countries with coercive laws or practices.
- Immigrants would be the first and probably only group of people for whom mandatory HIV testing would be imposed. This would heavily stigmatize all prospective immigrants and immigrants already living in Canada.

HIV-Positive Immigrants

There is no public health rationale for restricting liberty of movement or choice of residence on the grounds of HIV status.... Where States prohibit people living with HIV/AIDS from longer-term residency due to concerns about economic costs, States should not single out HIV/AIDS ... for such treatment and should establish that such costs would indeed be incurred in the case of the individual alien seeking residency. In considering entry applications, humanitarian concerns, such as family reunification and the need for asylum, should outweigh economic considerations.

– United Nations, 1998

Even more important than the question of whether to mandate HIV testing of all prospective immigrants is the question of what to do if prospective immigrants are known to be HIV-positive. Currently, all HIV-positive immigrants who self-disclose their HIV status or are tested on the discretion of the examining physician are excluded from immigration, with very limited exceptions: in some cases, they may receive a Minister's Permit that gives them a legal right to be present in Canada, but otherwise provides fewer rights than regular immigration status.

Canada needs a system that does not automatically exclude people with HIV/AIDS, but takes the circumstances of each case into account. Because of new treatments, people with HIV lead longer and potentially

very productive lives during which they can contribute a great deal to Canadian society. At the same time, the costs of the new treatments are high. Assessing the potential costs and potential benefits of allowing a particular person with HIV to immigrate to Canada will not be easy, but must be attempted. In a considerable number of cases, the benefits will outweigh the costs, and people with HIV should be allowed to immigrate to Canada on that basis. In addition, in some cases – even when in purely monetary terms the costs would outweigh the benefits – people with HIV should be allowed to immigrate to Canada on compassionate grounds.

HIV and AIDS must not be treated differently from other diseases or situations with potentially high costs for Canadian taxpayers. Any rules must be applied equally and fairly to all potential immigrants.

Finally, as a society, we need to make a fundamental decision about how far we want to go in excluding potential immigrants. Should we hold persons of over 50 years of age medically inadmissible because they are unlikely to contribute significantly to Canadian society in monetary terms, but are likely to need costly health care relatively soon after immigrating to Canada? Should we screen for genetic disorders? It is submitted here that we should not. Immigrants as a group have made, and continue to make, significant contributions to Canadian society.

Recommendations

1. Canada should not introduce mandatory HIV testing of prospective immigrants.
2. People with HIV/AIDS or other similar conditions should not automatically be excluded from immigrating. A system should be developed that takes the individual circumstances of each case into account, weighs the costs against the benefits of allowing a particular person to immigrate, and takes humanitarian concerns into account.

Additional Reading

Jürgens R. *HIV Testing and Confidentiality: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998. Available at <www.aidslaw.ca>. At pages 196-207, discusses HIV testing of immigrants.

The information in this series of info sheets is based on two reports prepared by the Canadian HIV/AIDS Legal Network: *HIV Testing and Confidentiality: Final Report* and *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Copies of the reports and info sheets are available on the Network website at www.aidslaw.ca or through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: aids/sida@cpha.ca). Reproduction of the info sheets is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. For further information, contact the Network (tel: 514 397-6828; email: info@aidslaw.ca). **Ce feuillet d'information est également disponible en français.**

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Confidentiality

People with HIV/AIDS have many concerns about the confidentiality of personal information, including (but not limited to) HIV test results and other health information. In Canada, a patchwork of laws and policies regulate the protection of and breach of confidentiality by various actors in a variety of situations. This info sheet cannot deal with all the issues and concerns. It explains why protecting confidentiality of medical information is generally important in medicine, and is particularly important in the context of HIV/AIDS; and discusses the duty of confidentiality that health-care professionals owe their patients, as well as exceptions to that duty.

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.

Why Confidentiality Is Important

Confidentiality is *generally* important in medicine. There are two main reasons for this:

- The ethical reason is that respecting confidentiality is a way of respecting the dignity of the patient. The patient's most personal physical and psychological secrets are kept confidential in order to decrease a sense of shame and vulnerability.
- The pragmatic reason is that, if physicians and other professionals are to elicit information from patients and clients, they must be able to guarantee that what is revealed will be confidential. In the absence of such a pledge, there can be no assurance of candour, and in the absence of candour, the capacity to engage in effective clinical work would be impaired. Thus, confidentiality is also an essential prerequisite for the accessibility of the health-care system, an important aspect of the right to health. Effective health care requires that patients feel free to come forward to seek medical advice or necessary treatment, and do not feel inhibited from entrusting physicians with information of a personal nature.

Confidentiality is *particularly* important with respect to HIV because of the stigma and discrimination experienced by people with HIV or AIDS:

From its inception, AIDS, and later HIV infection, evoked grave concerns about privacy, giving rise to early accounts of a "third epidemic" of blame, stigma, prejudice, and discrimination.

In 2000, discrimination remains pervasive in Canada, and there is little or no redress for those discriminated against (info sheet 4).

Infection with HIV continues to be associated with profoundly intimate actions, including sexual activity and drug use, the revelation of which may expose people to stigmatization, discrimination, and even rejection by family, friends, and community... HIV and AIDS disproportionately affect populations that already experience discrimination in our society... Given the enduring nature of some of these prejudices, and the fundamentally intimate nature of the information, it is not surprising that many individuals do not want information on their HIV status to be disclosed.

Therefore, the importance of confidentiality in fighting HIV/AIDS remains as strong as it ever was. The trust and cooperation of people at risk of infection or in need of medical treatment for HIV-related conditions still depends on the guarantee of confidentiality. In the context of fear and discrimination that continues to surround the HIV/AIDS epidemic, the perceptions of individuals affected by HIV matter as much as the

reality of confidentiality protections. People must trust that the health-care system will protect their interests. Loss of that trust could lead people to avoid contact with the system, with serious ramifications both for those individuals' health and for the public health in general.

The Duty of Confidentiality

The common law has long recognized that health-care professionals owe a duty of confidentiality to their patients, subject to some exceptions. In some provinces, the duty of confidentiality is also imposed by statute. Furthermore, it is professional misconduct for a health professional to disclose information about a patient to another person without the patient's consent, except "as required or allowed by law."

Exceptions

However, professional bodies, legislatures, and courts have recognized that, in some circumstances, confidentiality must give way in order to protect other interests – including the protection of third parties.

For example, the Canadian Medical Association (CMA) advises physicians that disclosure to a spouse or current sexual partner may not be unethical and may indeed 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: the partner is at risk of infection with HIV and has no other reasonable means of knowing of the risk; the patient has refused to inform their sexual partner; the patient has refused an offer of assistance by the physician to do so on the patient's behalf; and the physician has informed the patient of the physician's intention to disclose the information to the partner. According to the CMA Counselling Guidelines, before breaching confidentiality, the physician should intervene to motivate the patient to either disclose or stop unsafe behaviours, through counseling and discussion of possible barriers to risk reduction. However, if such interventions ultimately fail, the physician is advised by the CMA to report the situation to public health authorities (see also info sheet 18 on partner notification).

Obligations to breach confidentiality may also be imposed by statute. Two jurisdictions (Yukon and Prince Edward Island) have legislation that requires or permits physicians to disclose confidential information without a patient's consent if doing so is necessary to protect a

third party. In all other jurisdictions, the physician must be guided by existing legislation regarding medical confidentiality and by any common law regarding confidentiality (and permitted or obligatory breaches of confidentiality).

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 with candour about their behaviour?... Will the public health suffer as a consequence?

We face an extraordinary irony: the ethics of the clinical relationship, which usually favour strict confidentiality, appear to dictate a breach of confidentiality, while the ethics of public health, which are usually less concerned with confidentiality, may dictate a stricter adherence to it. In the end,

although in highly exceptional cases there may be justifications for overriding confidentiality, the requirement of medical confidentiality is a very strong, though not absolute, obligation. Patients, their contacts, doctors and their staff, and the common good are most likely to be best served if that tradition continues to be honoured.

Additional Reading

Jürgens R. *HIV Testing and Confidentiality: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998. Available at <www.aidslaw.ca>. At pages 209-224, discusses the issue of medical confidentiality in the HIV testing context more broadly, and contains a number of recommendations.

Elliott R. *After Cuerrier: Canadian Criminal Law and the Non-Disclosure of HIV-Positive Status*. Montréal: Canadian HIV/AIDS Legal Network, 1999. Available at <www.aidslaw.ca>. At pages 57-63, discusses circumstances in which disclosure of information about a person's HIV status may be compelled by law.

The information in this series of info sheets is based on two reports prepared by the Canadian HIV/AIDS Legal Network: *HIV Testing and Confidentiality: Final Report and Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Copies of the reports and info sheets are available on the Network website at www.aidslaw.ca or through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: aids/sida@cpha.ca). Reproduction of the info sheets is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. For further information, contact the Network (tel: 514 397-6828; email: info@aidslaw.ca). **Ce feuillet d'information est également disponible en français.**

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Partner Notification

This info sheet provides a definition of partner notification and explains the different approaches to partner notification. While partner notification programs were initially controversial, today 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 be achieved. This info sheet also reviews guidelines on partner notification released in 1997, and makes a series of recommendations.

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.

Definition

Partner notification (once called “contact tracing” and now sometimes called “partner counseling”) is the spectrum of public health activities in which sexual and injection equipment-sharing partners of an individual with HIV (“index person” in public health terminology) are notified, counseled about their exposure, and offered services.

Approaches

There are two 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 health-care providers or other health workers, who then confidentially notify the partners directly.

Background

In the first years of the epidemic, partner notification was the subject of considerable debate. Proponents argued that partner notification programs had been successful in controlling certain STDs in the past, had a good track record in maintaining confidentiality, and that a relatively high percentage of HIV-positive people appeared to be unaware of having been exposed to infection.

Opponents argued that partner notification programs had little proven value for their relatively high cost; that the long asymptomatic incubation period made location of partners difficult; that casual contacts could often not be traced; and that programs may lead to discrimination and dissuade individuals most at risk for HIV from seeking testing. They also noted that informing a partner may expose an HIV-positive person to abuse, injury, and even death from an abusive spouse.

It was broadly recognized that among communities or populations at “high risk”— such as gay men and injection drug users – partner notification programs served no particular goal:

As all these persons were at a high risk, the only effective measure was to encourage everyone to practice risk-reducing behaviour, regardless of their HIV status, and regardless of whether they may have had contact in the past with a person with HIV.

Today, however, it is almost universally recognized that partner notification programs can make a positive contribution to a successful HIV/AIDS public health and prevention program, particularly with regard to persons who may be unaware that they are at any increased risk of HIV infection, and as a result are not informed or aware of any need to practise risk-reducing behaviour. Partner notification programs can encourage these persons to seek HIV testing and, if necessary, HIV-related

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treatments. In addition, knowledge about the effectiveness of partner notification has increased. A review of the literature has shown that

- in many, if not most, instances HIV-positive individuals voluntarily cooperate with public health professionals in confidentially identifying at least some of their sex partners;
- if located, sex partners are generally receptive to 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 systems, especially when there are numerous partners to be notified;
- sex partners often are unaware, misunderstand, discount, or deny their HIV risks; and
- sex and needle-sharing partners of HIV-positive persons have high rates of HIV infection.

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

The 1997 Guidelines

The *Guidelines for Practice for Partner Notification in HIV/AIDS*, released in 1997 by the Federal/Provincial/Territorial Advisory Committee on AIDS, answer that question. According to them, 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.

Only in certain limited circumstances should partner notification be considered when consent to notification cannot be obtained: if an HIV-positive person has been

thoroughly counseled; counseling has failed to result in the appropriate behavioural changes; the person refuses to inform or to consent to the notification of their partners; a real risk of HIV transmission to the partners exists; the partners have little or no reason to suspect they are at risk; and the HIV-positive person is given reasonable advance notice. Partner notification can then be undertaken by the person's physician or, if the physician requests it or the patient prefers it, by public health authorities. However, it is important for health providers to act rationally, bearing in mind that wilful transmission or deliberate negligence is rarely the cause of a person's refusal to notify a partner. In many cases – particularly for women – social inequalities and fear of violence are the main reason for a fear to notify a partner and, generally, the public health benefits of maintaining confidentiality and patient autonomy may outweigh frequent involuntary disclosure (info sheet 17).

Recommendations

1. Partner notification programs should be implemented in every jurisdiction in Canada, and should be consistent with the principles set out in the 1997 *Guidelines for Practice for Partner Notification in HIV/AIDS*.
2. Whether existing partner notification programs are reviewed or new programs created, the involved communities must participate from the outset in the discussions and the decision-making process. Once a program is decided upon through consultation and consensus, the program and its elements should be made public.
3. Each person who requests HIV testing and counseling must be made aware of the partner notification program in their jurisdiction and its implications, before testing proceeds.

Additional Reading

West GR, Stark KA. Partner notification for HIV prevention: a critical reexamination. *AIDS Education and Prevention* 1997; 9(Suppl B): 68-78. A review of literature on partner notification.

Federal/Provincial/Territorial Advisory Committee on AIDS. *Guidelines for Practice for Partner Notification in HIV/AIDS*. Ottawa: Health Canada, 1997. Provides a framework that provinces and territories should use to shape their partner notification programs.

The information in this series of info sheets is based on two reports prepared by the Canadian HIV/AIDS Legal Network: *HIV Testing and Confidentiality: Final Report and Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Copies of the reports and info sheets are available on the Network website at www.aidslaw.ca or through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: aids/sida@cpha.ca). Reproduction of the info sheets is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. For further information, contact the Network (tel: 514 397-6828; email: info@aidslaw.ca). **Ce feuillet d'information est également disponible en français.**

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Essential Resources

There is a vast amount of literature on HIV testing, counseling, partner notification, and the use of HIV test results. This info sheet provides information about a number of selected, essential resources – articles, books, reports, and newsletters that provide crucial information and/or recommendations on these issues, particularly the legal and ethical issues raised.

This is one of a series of 19 info sheets on HIV testing.
For the titles of all info sheets, see info sheet 1.



American Civil Liberties Union. *HIV Partner Notification: Why Coercion Won't Work*. An ACLU Report. New York, NY: ACLU, March 1998. Emphasizes that the public health benefit gained from partner notification “must be measured by considering how money spent for partner notification might otherwise have been spent.”

Bayer R. Public health policy and the AIDS epidemic. An end to HIV exceptionalism? *New England Journal of Medicine* 1991; 324(21): 1500-1504. Traces the history of the public health response to HIV/AIDS, and coins the term “HIV exceptionalism.”

Bayer R, Toomey K. HIV prevention and the two faces of partner notification. *American Journal of Public Health* 1992; 82: 1158-1164. Traces the history of two distinct approaches to partner notification – the public health tradition of “contact tracing” and the health professional’s so-called “duty to warn” – and how the ethical considerations and legal parameters of each have affected the other. Focused on the US experience, but the issues are of general applicability.

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Canadian Public Health Association. *HIV & AIDS: A Public Health Perspective*. Ottawa: The Association, 1993. The result of a long consultation process. Provides a “framework for public health policy and practice for the future.”

Casswell D. Disclosure by a physician of AIDS-related patient information: an ethical and legal dilemma. *Canadian Bar Review* 1989; 68: 225. Reviews Canadian common law and statutes relevant to the physician’s legal position regarding breaching confidentiality and the question of a “duty to warn.” Argues that, “in the absence of legislation authorizing or requiring such disclosure, policy considerations compel the conclusion that such disclosure is illegal.”

Centers for Disease Control. Sensitivity, specificity, and predictive value. Available at <www.cdc.gov/nchstp/hiv_aids/pubs/rt/sensitivity.htm>. A simple explanation of these terms.

de Bruyn T. *HIV/AIDS and Discrimination: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998. Also available at <www.aidslaw.ca>. Shows how pervasive discrimination against people with HIV/AIDS remains.

ESSENTIAL RESOURCES

Elliott R. *After Cuerrier: Canadian Criminal Law and the Non-Disclosure of HIV-Positive Status*. Montréal: Canadian HIV/AIDS Legal Network, 1999. Available at <www.aidslaw.ca>. Analyzes, among many other things, whether the Supreme Court of Canada decision in *R v Cuerrier* changes existing legal obligations in the field of public health practice, including counseling, reporting, and partner notification.

Elliott R, Jürgens R. *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Montréal: Canadian HIV/AIDS Legal Network, 1999. Available at <www.aidslaw.ca>. Provides a comprehensive analysis of legal and ethical questions raised by rapid HIV screening, and includes an ethical commentary.

Federal/Provincial/Territorial Advisory Committee on AIDS. *Guidelines for Practice for Partner Notification in HIV/AIDS*. Ottawa: Health Canada, 1997. Provides a framework that provinces and territories should use to shape their partner notification programs.

Federal/Provincial/Territorial Working Group on Confidentiality in Relation to HIV Seropositivity. *Report*. Ottawa: The Working Group, 1988. "Attempts to outline the basic guiding principles which would enable sound public health measures while ensuring that the rights of the individual are protected."

Field MA. Testing for AIDS: uses and abuses. *American Journal of Law and Medicine* 1990; 16: 33-106. An early, but still relevant and very comprehensive analysis of uses and abuses of HIV testing.

Flanagan W. Equality rights for people with AIDS: mandatory reporting of HIV infection and contact tracing. *McGill Law Journal* 1989; 34: 531-602. Assesses the constitutionality of reporting of HIV and mandatory partner notification.

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Hertz-Picciotto I, Goltz J, Noble J. HIV test-seeking before and after the restriction of anonymous testing in North Carolina. *American Journal of Public Health* 1996; 86(10): 1446-1450. A study concluding that efforts to abolish anonymous testing could deter people from seeking testing. See also Kassler et al, *infra*.

Higgins D et al. Evidence for the effects of HIV antibody counseling and testing on risk behaviors. *Journal of the American Medical Association* 1991; 266: 2419-2429. Examines 50 studies published or presented at professional meetings prior to July 1990 to ascertain the

behavioural effects of HIV counseling and testing among men who have sex with men, injection drug users, pregnant women, and heterosexual populations. Across populations, the evidence regarding the ability of HIV counseling and testing to motivate risk reduction was limited or inconclusive in many instances. See also Wolitzki, *infra*.

Hoffmaster B, Schrecker T. An ethical analysis of HIV testing of pregnant women and their newborns. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(4): 5-11. Available at <www.aidslaw.ca>. Concludes: Mandatory testing programs are simpler and cheaper and, moreover, are directed at those who are most deserving – completely vulnerable, completely innocent newborns. That course could be pragmatically and politically tempting. Taking that course would, however, flout the respect for autonomy that a civilized society owes all its members; ignore the special consideration that a caring society owes its most vulnerable members; and violate the equal concern and respect that a just society owes its least fortunate members.

Interdepartmental Committee on Human Rights and AIDS. Report of the Working Group on Sexual Assault and HIV Antibody Testing: Human Rights Issues Relating to HIV Antibody Testing of Persons Accused or Convicted of Sexual Assault. Ottawa: The Committee, 19 April 1994. Makes recommendations regarding HIV testing and other interventions in the context of sexual assault.

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Jackson LA 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 Canadian study on women's experience of HIV testing.

Joint United Nations Programme on HIV/AIDS. *UNAIDS Policy on HIV Testing and Counselling*. Geneva: UNAIDS, August 1997. A concise statement of UNAIDS' policy.

Joint United Nations Programme on HIV/AIDS. *Counselling and HIV/AIDS: UNAIDS Best Practice Collection: Technical Update*. Geneva: UNAIDS, November 1997. Defines what best-practice counseling is.

Jürgens R. *HIV Testing and Confidentiality: Final Report*. Montréal: Canadian HIV/AIDS Legal Network, 1999. Available at <www.aidslaw.ca>. A comprehensive 300-page reevaluation of legal and policy issues raised by HIV testing and confidentiality.

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Kassler WJ. Advances in HIV technology and their potential impact on prevention. *AIDS Education and Prevention* 1997; 9(Suppl B): 27-40. A good summary of advances in HIV testing technology, but less recent than Elliott & Jürgens, supra.

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Magnusson RS. A decade of HIV testing in Australia. Part 1: A review of current legal requirements. *University of New South Wales Law Journal* 1995; 18(2): 341-363; and Part 2: A review of some current debates. *University of New South Wales Law Journal* 1995; 18(2): 364-408. A comprehensive overview of Australian policy and law.

Matiation S. *HIV Testing and Confidentiality: Issues for the Aboriginal Community. A Discussion Paper* (2nd edition). Montréal: Canadian HIV/AIDS Legal Network & Canadian Aboriginal AIDS Network, 2000. Provides a thorough discussion of HIV testing issues specific to Aboriginal people, and recommendations. Available at <www.aidslaw.ca>.

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. Reports numerous negative experiences of the counseling/testing experience. For a summary, see *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(4): 25-28; available at <www.aidslaw.ca>.

National Advisory Committee on AIDS. Human Immunodeficiency Virus Antibody Testing in Canada. Recommendations of the National Advisory Committee on AIDS. *Canada Diseases Weekly Report* 1989; 15(8): 37-43. Sets out that compulsory HIV testing is only justified "if its benefits outweigh its potential harms and is the least restrictive, least invasive, likely to be effective, reasonably available approach."

Neron C. *HIV and Sexual Violence Against Women. A Guide for Counsellors Working with Women Who Are Survivors of Sexual Violence*. Ottawa: Health Canada, 1998. Also addresses HIV testing in the context of sexual assault.

North RL, Rothenberg KH. Partner notification and the threat of domestic violence against women with HIV infection. *New England Journal of Medicine* 1993; 329: 1194-1196. The study shows that women testing HIV-positive may experience negative consequences, such as violent acts by their partner. See also Rothenberg & Paskey, infra.

Ontario Law Reform Commission. *Report on Testing for AIDS*. Toronto: The Commission, 1992. Makes recommendations on how HIV testing should be undertaken in Ontario.

Rothenberg KH, Paskey S. The risk of domestic violence and women with HIV infection: implications for partner notification, public policy, and the law. *American Journal of Public Health* 1995; 85: 1569-1576. Argues that partner notification strategies must take into account the safety and autonomy of patients who face a risk of abuse. See also North & Rothenberg, supra.

Royal Society of Canada. *AIDS: A Perspective for Canadians – Summary Report and Recommendations*. Ottawa: The Society, 1988. A comprehensive report on the medical, social, ethical, legal, research, and economic aspects of HIV/AIDS in Canada. Many sections are outdated, but the legal and ethical aspects are not. See also the *Background Papers*.

Schopper D, Vercauteren G. Testing for HIV at home. What are the issues? *AIDS* 1996; 10: 1455-1465. The best discussion of issues raised by home testing.

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Somerville MA, Gilmore N. Human Immunodeficiency Virus Antibody Testing in Canada. A Report Submitted to and Approved by the National Advisory Committee on AIDS. Montréal: McGill Centre for Medicine, Ethics and Law, 1988. Based on the legal and ethical analysis in this report, the National Advisory Committee (see supra) established the "general principle governing HIV antibody testing in Canada."

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West GR, Stark KA. Partner notification for HIV prevention: a critical reexamination. *AIDS Education and Prevention* 1997; 9(Suppl B): 68-78. A review of literature on partner notification.

Wolitzki RJ et al. The effects of HIV counseling and testing on risk-related practices and help-seeking behavior. *AIDS Education and Prevention* 1997; 9(Suppl B): 52-67. Reviews 35 studies published since the study by Higgins et al (see supra) to reassess the scientific data regarding the ability of HIV counseling and testing to motivate changes in risk-related practices and to promote help-seeking behaviour.

World Health Organization. *Statement from the Consultation on Testing and Counselling for HIV Infection*. Geneva: WHO Global Programme on AIDS, 1992. Provides concise guidance on HIV testing and counseling.

World Health Organization/UNAIDS. Questions and Answers on Reporting, Partner Notification and Disclosure of HIV Serostatus and/or AIDS: Public Health and Human Rights Implications. Geneva: WHO/UNAIDS, June 1999. Available at <www.who.int/asd/knowledge/rptngdiscl.html>.

Selected Newsletters and Journals

Canadian HIV/Policy & Law Newsletter

Regularly carries articles on HIV testing, new testing technologies, etc. For info, contact the Canadian HIV/AIDS Legal Network (tel: 514-397-6828 ext 227; email: info@aidslaw.ca). Also available at <www.aidslaw.ca>.

AIDS Education and Prevention

This journal often contains articles on HIV testing and counseling.

AIDS & Public Policy Journal

Has published some important articles on policy issues raised by HIV testing.

Selected Websites

<http://www.aidslaw.ca>

The website of the Canadian HIV/AIDS Legal Network. Contains a section on HIV testing & confidentiality, and numerous articles on the subject published in the *Canadian HIV/AIDS Policy & Law Newsletter*.

<http://HIVInSite.com>

Has a huge section on HIV testing. Go to “topics” in the main menu bar, and select “testing & surveillance” under “prevention strategies.” Check out also “travel and immigration” under “topics,” and you will find, among other things, a link to a list of countries that require HIV testing from visitors and/or immigrants, compiled by the US State Department.

<http://thebody.com>

Not as good as HIVInSite, but it does have a large section on HIV testing (with a subsection on mandatory testing, reporting, and notification) under “AIDS Basics and Prevention.”

<http://cdc.gov>

The site of the [US] Centers for Disease Control and Prevention, including a section on HIV testing at <http://www.cdc.gov/nchstp/hiv_aids/testing.htm>.

For More Resources ...

consult also *Legal and Ethical Issues Raised by HIV/AIDS: Literature Review and Annotated Bibliography*. Montréal: Canadian HIV/AIDS Legal Network, 2nd edition, 1998. Contains a section on public health with many additional resources. The web version, available at <<http://www.aidslaw.ca>>, is bilingual (English and French).

The information in this series of info sheets is based on two reports prepared by the Canadian HIV/AIDS Legal Network: *HIV Testing and Confidentiality: Final Report and Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Copies of the reports and info sheets are available on the Network website at www.aidslaw.ca or through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: aids/sida@cpha.ca). Reproduction of the info sheets is encouraged, but copies may not be sold, and the Canadian HIV/AIDS Legal Network must be cited as the source of this information. For further information, contact the Network (tel: 514 397-6828; email: info@aidslaw.ca). **Ce feuillet d'information est également disponible en français.**

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