# HIV Testing and Confidentiality: Final Report

**Prepared by Ralf Jürgens**

**ISBN 1-896735-16-9**

---

# Table of Contents

*To download and/or print:* Index of retrievable components

***To browse online:***
**Links to main sections of this Table of Contents:**

***To order hard copies:*** **contact the National AIDS Clearinghouse at** aids/sida@cpha.ca

## ADVANCES IN TESTING TECHNOLOGY

## MANDATORY OR COMPULSORY HIV TESTING

***Note to browsers:*** *For ease of loading, this chapter has been divided into two different pages. When downloading or printing, keep in mind that each of the two pages must be opened in order to access the entire chapter.*

### Part 1

### Part 2

## CONFIDENTIALITY

## REPORTING

---

# Index of retrievable components

# HIV Testing and Confidentiality: Final Report

**Prepared by Ralf Jürgens**

**ISBN 1-896735-16-9**

---

# Summary

## Why a Project on HIV Testing and Confidentiality?

In Phase 1 of the Project on Legal and Ethical Issues Raised by HIV/AIDS, jointly undertaken by the Canadian HIV/AIDS Legal Network (Network) and the Canadian AIDS Society, over sixty individuals and organizations identified testing and confidentiality issues as one of eight "top priority" legal and ethical issues raised by HIV/AIDS in Canada. Most individuals and organizations consulted expressed the view that, although many documents were produced about testing and confidentiality issues in Canada in the late 1980s and early 1990s, the issues remain unresolved or need to be reexamined.

## What Are the Issues?

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; when counselling and education before and following testing are available and offered; and when confidentiality of results or anonymity of testing can be guaranteed.

Despite the consensus around these issues, opinion on several other issues related to testing has remained divided. In particular, there continues to be a lack of consensus regarding whether and, if yes, how positive test results should have to be reported to public health authorities; and how partner notification should be undertaken to warn partners of HIV-positive people about their risk of having contracted HIV.

In addition, there are a number of issues that, although in theory consensus was reached, in practice remain unresolved. For example, as raised by many of the individuals and groups consulted during Phase I of the Joint Project, although there is agreement that HIV testing should be easily accessible for all Canadians, access to testing remains a problem, particularly for women and Aboriginal people; testing for HIV without the specific informed consent of the person being tested is taking place more and more frequently; many people, whether they test positive or negative, do not receive adequate counselling; and calls for mandatory or compulsory testing of certain groups of the population, such as sex offenders, prisoners, health-care workers, immigrants, and pregnant women, have continued.

Finally, new controversies over testing have arisen, in particular because of the availability of new and more promising treatments; the availability of new forms of HIV testing, such as rapid and home testing; and the shifting demographics of the epidemic. There has been much debate about a move toward using more coercive public health measures to fight the spread of HIV, originating in the United States, but having an increasing impact on other countries, including Canada.

## What Has the Project Done?

The Project began in June 1996. It has undertaken extensive research on legal and ethical issues raised by HIV testing and confidentiality, published numerous articles on HIV testing and confidentiality issues in the *Canadian HIV/AIDS Policy & Law Newsletter* and in *Canadian AIDS News*, given presentations at a variety of conferences, and produced a draft discussion paper that formed the basis of a national workshop on HIV testing and confidentiality, held in Toronto in March 1997. After the workshop, *HIV Testing and Confidentiality: A Discussion Paper* was published and widely distributed for comment both nationally and internationally. Comments on the *Discussion Paper* were received from both within and outside Canada and have been incorporated into the *Final Report*.

## What Does the *Report* Contain?

The *Report* contains a reexamination of the issues raised by HIV testing and confidentiality in Canada.

The main question addressed is whether new developments warrant a departure from the "general principle governing HIV antibody testing in Canada." In particular, 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 counselling still necessary?
- Should new forms of testing for HIV, such as rapid and/or home testing, be made available in Canada?
- Are any exceptions 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), 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?¸

## What Are the Goals of the Project?

The goals of the project are to

- provide a comprehensive reexamination of the issues raised by HIV testing and confidentiality in Canada;
- assist people living with HIV/AIDS, their advocates and counsellors, health-care providers, AIDS service organizations and other service providers in understanding the new challenges in the area of testing and confidentiality;

- 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 and confidentiality 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.

## What Does the *Report* Conclude?

The *Report* acknowledges that new testing technologies, in particular the availability of rapid testing and of home testing kits, new treatments, and changing patterns of HIV infection, force us to reconsider approaches to HIV testing and confidentiality. However, it urges that we not forget the lessons learned over the last fifteen years and that we keep in mind that HIV/AIDS remains different from other diseases because it continues to disproportionately affect stigmatized and marginalized populations, and because discrimination against people living with HIV/AIDS and those affected by the disease continues to be prevalent. In addition, the new treatments constitute a huge step forward, but do not represent a solution to all problems faced by people with HIV/AIDS – problems that stem from the underlying problems of poverty and discrimination that are both a result and a cause of HIV infection. Therefore, while early detection of HIV infection has indeed become a pressing priority, a trend toward making HIV testing a routine or even mandated test needs to be treated with great caution. It would be a great mistake to dismiss the importance of respecting people's rights and the risk of discrimination, and it would be imprudent to rush the implementation of coercive measures when treatments are not accessible for many of those living with HIV, their long-term benefits remain unproven, and the efficacy of coercive strategies is at best questionable.

Testing policy will continue to require constant reevaluation as treatments and technology evolve, but 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 must remain the basis of any legal and ethical approach to the threat posed by HIV.

## Follow-Up Since 1998

Since the first edition of this Report was released in October 1998, the Legal Network has widely distributed the Report and made it available on the Internet at http://www.aidslaw.ca/Maincontent/issues/testing.htm#g; produced and distributed info sheets summarizing the Report's most relevant information, targeted at a variety of interested groups; made presentations at national and international conferences about the process leading to the production of the Report and the Report's content and recommendations; undertaken additional research in several of the areas covered by this report, and published reports on *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions* in 2000 and on *HIV/AIDS and Immigration* in 2001; and continued to monitor developments in the area of HIV testing and confidentiality. Additional information on these activities can be found on the Network's website at http://www.aidslaw.ca/Maincontent/issues/testing.htm.

In 2001, the Network obtained funding to reprint the Report. At the same time, some minor changes and updates were made to it.

## For Further Information ...

contact the Canadian HIV/AIDS Legal Network at (514) 397-6828; fax: (514) 397-8570; email: info@aidslaw.ca.

## Further Copies of this *Report* ...

can be retrieved at the website of the Canadian HIV/AIDS Legal Network at http://www.aidslaw.ca/Maincontent/issues/testing.htm#g or ordered through the Canadian AIDS Clearinghouse. Tel: 1-877-999-7740; fax: (613) 725-9826; email: aids/sida@cpha.ca.

**Return to the top of this page**

**Return to Table of Contents**

# HIV Testing and Confidentiality: Final Report

**Prepared by Ralf Jürgens**

**ISBN 1-896735-16-9**

---

# INTRODUCTION

As part of their Joint Project on Legal and Ethical Issues Raised by HIV/AIDS, the Canadian HIV/AIDS Legal Network (Network) and the Canadian AIDS Society (CAS) undertook a project on HIV testing and confidentiality. The project was funded by the AIDS Care, Treatment and Support Program, Health Canada, and the HIV/AIDS Prevention and Community Action Programs, Health Canada, under the National AIDS Strategy, Phase II.

## Why a Report on HIV Testing and Confidentiality?

In 1995, during Phase I of the Joint Project, testing and confidentiality issues were identified as one of the eight "top priority" legal and ethical issues raised by HIV/AIDS. Most individuals and groups consulted expressed the view that, although many documents had been produced about testing and confidentiality issues in Canada in the late 1980s and early 1990s, the issues remained unresolved or needed to be reexamined. In particular, with respect to testing, people expressed concern about testing for HIV without informed consent of the person being tested, which is taking place more and more frequently; the lack of adequate counselling for people, whether they test positive or negative; limited access to anonymous testing and, especially for women, to testing in general; and calls for mandatory or compulsory testing of certain groups of the population, such as sex offenders, prisoners, health-care workers, immigrants, and pregnant women.

With regard to confidentiality, many people and organizations consulted felt that the importance of maintaining confidentiality was not understood, and expressed a need for guidance about situations in which people maintain that they need to know another person's HIV status. People were concerned about discrimination resulting from the disclosure of a person's HIV status. Examples of this included people being afraid to apply for benefits for fear that their HIV status would become widely known, particularly in smaller communities; or reluctance to lodge complaints with human rights commissions because "people do not want to say to the world that they are HIV-positive."

In addition, since 1995, when the consultations were undertaken, new issues and concerns have emerged. This is an area of rapid change, and many of the issues addressed in this Report have provoked a great deal of media attention, community discussion, and political debate in the last few years. For example, there has been debate about the availability of new forms of HIV testing, particularly home testing kits, which raise public policy questions unique to HIV, as well as broader issues regarding the extent to which government regulatory bodies should protect the public from technically accurate devices that may have an adverse psychological impact.1 There has also been renewed debate about using more coercive public health measures to fight the spread of HIV, centering around issues such as routine or even mandatory HIV testing of pregnant women, and nominal reporting of cases of HIV to public health authorities. Originating in the United States, this debate is having an increasing impact on other countries, including Canada.

## Activities Undertaken

The Project on HIV testing and confidentiality began in June 1996. Between 1996 and October 1998, it has, among other things:

- undertaken extensive research on legal and ethical issues raised by HIV testing and confidentiality;

- published numerous articles on HIV testing and confidentiality issues in vol 3, no 1 (October 1996) and vol 3, nos 2/3 (Spring 1997) of the *Canadian HIV/AIDS Policy & Law Newsletter*;

- given presentations on the future of HIV testing in Canada at the Canadian Bioethics Society 8th Annual Conference in Montréal on 19 October 1996; at the Sixth Annual Canadian Conference on HIV/AIDS Research in Ottawa on 24 May 1997; at the 10th Annual British Columbia HIV/AIDS Conference in Vancouver on 26 October 1997; at the tenth of a series of seminars on legal and ethical issues raised by HIV/AIDS organized by the Legal Network in Montréal on 25 November 1997; at the Federal/Provincial/ Territorial Information Sharing on HIV Prevention meeting in Calgary on 30 March 1998; and at the 12th International Conference on AIDS in Geneva, Switzerland, on 2 July 1998;

- selected two "key commentators": Prof William Flanagan, Queen’s University, Kingston; and Dr Michel Châteauvert, Montréal;

- organized a national workshop on HIV testing and confidentiality, held in Toronto from 14 to 16 March 1997. At the workshop, 30 participants from across Canada and from a variety of backgrounds (see Appendix B) presented their views and critically reviewed the first draft of the discussion paper on testing and confidentiality; and

- produced *HIV Testing and Confidentiality: A Discussion Paper*2 in March 1997. Since then, the Paper has been available for retrieval on the Network’s website and more than 1000 printed copies have been distributed in Canada and internationally to give people and organizations interested in the issues raised in the Paper an opportunity to provide input into the *Final Report*. Comments on the *Discussion Paper* have been received from a wide variety of individuals and organizations.

## The *Final Report*

The vast majority of respondents to the *Discussion Paper* and the participants at the national workshop on HIV testing and confidentiality supported the arguments put forward in the Paper, as well as its conclusions. With only a few exceptions, their comments did not warrant a significant departure from the content of the *Discussion Paper*. In the *Final Report*, much of the text of the *Discussion Paper* has therefore been retained. However, the information in the *Discussion Paper* has been updated and new material has been incorporated throughout the Report, reflecting the fact that this is an area of continuing debate. Among the many new developments that have occurred since the release of the *Discussion Paper* and have been taken into account are:

- the debate about using more coercive public health approaches to HIV, such as in an article in the *Atlantic Monthly* advocating for the end of "AIDS exceptionalism" and a return to "traditional" public health;3 among other things, this includes the move toward nominal reporting of HIV in the United States and, to a lesser extent, in other countries; renewed emphasis on partner notification efforts as a means of preventing the spread of HIV; and a move toward adopting policies of routine or even mandatory testing of pregnant women;

- the release of the final report of the Commission of Inquiry on the Blood System in

Canada,4 leading to a renewed discussion of government and public health responsibilities toward disease prevention;

- developments in the area of criminal law and HIV/AIDS and, in particular, the release of the Supreme Court of Canada decision in the case of *R* v *Cuerrier* on 3 September 1998;5

- new evidence that, in 1998, discrimination against people with HIV/AIDS remains pervasive;6 and

- new developments in the area of home and rapid testing.

While the Report addresses the issues raised by HIV testing and confidentiality in Canada, a review of the situation in other countries was undertaken, and the *Final Report* contains numerous references to international documents on HIV testing produced by the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS, as well as to approaches to HIV testing and confidentiality taken in other countries.

Many changes have also been made to the structure of the text. For example, while the *Discussion Paper* provided a detailed review of each of the recommendations on HIV testing and confidentiality made by Canadian organizations between 1986 and 1996, the *Final Report* contains a succinct summary of these recommendations. Readers interested in the full review are therefore referred to the *Discussion Paper*, which will remain available through the National AIDS Clearinghouse and on the Network's website. In addition, the chapter on confidentiality has been reorganized and the subsections on partner notification and reporting have been expanded.

Finally, while the *Discussion Paper* only reached preliminary conclusions, the *Final Report* contains recommendations directed at various Canadian provincial and federal ministries and government agencies, public health, professional organizations, and others.

## Scope and Goals

The Report considers the following questions:

- How has HIV testing been addressed to date in Canada?

- Should the Canadian approach to HIV testing be changed in light of new developments, including the availability of new treatments; the availability of new forms of HIV testing, in particular rapid testing and home testing; and the shifting demographics of the epidemic? In particular,

- is *specific* informed consent to testing still necessary, or should *general* consent suffice?

- how can access to testing be improved?

- is pre- and post-test counselling still necessary?

- should new forms of testing for HIV be made available in Canada?

- do the new developments warrant any exception(s) 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) 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?

- should an approach emphasizing partner notification be adopted, and how should partner notification be undertaken?

For each of the above issues, the Report briefly summarizes the recommendations made in some of the most important reports and policy statements published by Canadian organizations between 1986 and 1998 (History), including, but not limited to

- the 1986 report on the legal implications of HIV/AIDS of the Canadian Bar Association – Ontario (CBA–Ontario);7

- the 1988 recommendations on HIV testing in Canada of the National Advisory Committee on AIDS (NAC–AIDS),8 based on a report by Somerville and Gilmore;9

- the 1988 report on the medical, social, ethical, legal, research, and economic aspects of HIV/AIDS in Canada of the Royal Society of Canada;10

- the November 1988 report on confidentiality in relation to HIV seropositivity of the Federal/Provincial/Territorial Advisory Committee on AIDS (F/P/T Advisory Committee);11

- the 1990 report of the Parliamentary Ad Hoc Committee on AIDS;12

- the 1992 *Report on Testing for AIDS* of the Ontario Law Reform Commission

(OLRC);13

- the undated submission to the OLRC’s study on testing for AIDS of the AIDS Committee of Ottawa (ACO);14 and

- the 1993 report on the public health response to HIV/AIDS of the Canadian Public Health Association (CPHA).15

For each issue, the Report then examines Canadian policy and practice pertaining to that issue (Current Situation), assesses whether changes to policy and practice are justified (Assessment), and makes conclusions and recommendations about what should be done in response to the new developments and persisting concerns (Conclusions and Recommendations).

The goal is to contribute to a process of informed and rigorous discussion concerning the future of HIV testing and confidentiality in Canada, and to ensure that decisions about HIV testing and confidentiality 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.

## Follow-Up Since 1998

Since the first edition of this Report was released in October 1998, the Legal Network has widely distributed the Report and made it available on the Internet at http://www.aidslaw.ca/Maincontent/issues/testing.htm#g; produced and distributed info sheets summarizing the Report’s most relevant information, targeted at a variety of interested groups; made presentations at national and international conferences about the process leading to the production of the Report and the Report’s content and recommendations; undertaken additional research in several of the areas covered by this report, and published reports on *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions* in 2000 and on *HIV/AIDS and Immigration* in 2001; and continued to monitor developments in the area of HIV testing and confidentiality. Additional information on these activities can be found on the Network’s website at http://www.aidslaw.ca/Maincontent/issues/testing.htm In 2001, the Network obtained funding to reprint the Report. At the same time, some minor changes and updates were made to it.

## Limitations

### Changes over Time

This document acknowledges the changing nature of knowledge about HIV

> infection and the diseases it can produce, about HIV antibody testing, its limitations and the uncertainty this produces, and about the control of HIV transmission in Canada. Conclusions and recommendations in this document are based upon this present knowledge. Anyone reading this document should recognize that these conclusions and recommendations may not apply or may need to be modified in the future as new knowledge about this epidemic becomes available.16
>
> [N]o recommendations concerning testing policies ... can be cast in stone. While the fundamental guiding principles are unlikely to change, the specific considerations that underlie certain testing policies may need to be reevaluated as changes occur both in our understanding about AIDS and in the technology of testing techniques.17

The above statements, written many years ago, are still valid. In the same way as there is a need today to reexamine issues raised by HIV testing, because of concerns regarding current testing practices in Canada and new developments that have occurred over the last years, there will in the future be a need to reexamine the positions taken in this Report.18 The *Final Report* examines the issues against the background of our current knowledge, a task that is especially difficult because of the constantly changing environment as therapeutic interventions and diagnostic tools develop and improve and the epidemic evolves. As our knowledge continues to increase, the response of policymakers and society as a whole to HIV/AIDS in general and to HIV testing and confidentiality in particular will undergo further changes.

Already since the release of the first edition of this Report in 1998, new developments have occurred in two areas covered by the Report: rapid testing and testing of immigrants. The Legal Network has reacted to these developments by conducting further research and producing reports that complement the information and analysis in this Report. Other new developments may force us to re-analyze some of the other issues addressed in the Report. Nonetheless, it is important to note that, whatever the advances in scientific technology and whatever other new developments occur, the values that govern the development of policies concerning HIV infection – such as the principle of autonomy and respect for persons – will remain constant. The importance of this cannot be overstated. Any changes to current and future approaches to HIV testing and confidentiality (1) will have to be based on a careful consideration of the risks and benefits of a proposed new policy; (2) must be informed by solid scientific research that balances an individual's human rights and society's need to maintain public health; (3) must include meaningful consultation of those concerned by the change, in particular people with HIV/AIDS and those affected by the disease; and (4) must comply with the *Canadian Charter of Rights and Freedoms*.

## Level of Detail

The Report is not comprehensive. Many of the issues addressed in it could have been dealt with in greater detail. However, many aspects of HIV testing and confidentiality have been discussed in other papers or final reports that have been produced by the Network and/or Joint Project: those relating to Aboriginal communities in *HIV Testing and Confidentiality: Issues for the Aboriginal Community – A Discussion Paper*,19 those relating to gay men and lesbians in *Gay and Lesbian Legal Issues and HIV/AIDS: Final Report*,20 those relating to prisoners in *HIV/AIDS in Prisons: Final Report*,21 and those relating to various other populations, including injection drug users, women, youth, and sex workers, in *HIV/AIDS and Discrimination: A Discussion Paper*.22 This Report builds on and complements this work.

**Return to the top of this page**

**Return to Table of Contents**

---

## ENDNOTES

1 See, eg, BM Branson, HD Gayle. Home Testing for HIV – It's Coming. Are You Ready? *International AIDS Society Newsletter* no 4, March 1996; R Bayer et al. Testing for HIV Infection at Home. *New England Journal of Medicine* 1995; 332: 1296–1299; KA Phillips et al. Potential Use of Home Testing. Ibid at 1308–1310.

2 R Jürgens, M Palles. *HIV Testing and Confidentiality: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997.

3 C Burr. The AIDS Exception: Privacy vs. Public Health. *The Atlantic Monthly* June 1997, at 57-67.

4 *Commission of Inquiry on the Blood System in Canada: Final Report*. Volumes 1-3. Ottawa: Minister of Public Works and Government Services Canada, 1997.

5 (1998) 162 DLR (4th) S13; see also *R v Cuerrier* [1996] BCJ No 2229 (BCCA) (QL); aff'g Court File No CC941279, unreported decision of 5 January 1995, Supreme Court of British Columbia (Vancouver), Drost J. For more details about the case, see *Criminal Law Bulletin 1 (Update September 1998). The Cuerrier Case: Failing to Disclose HIV-Positive Status before Sex May Be a Criminal Assault*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, September 1998; R Elliott. *Criminal Law and HIV/AIDS: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997, Appendix B, at 9-13; Supreme Court to Hear *Cuerrier* Case. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 1, 52-54;
and infra.

6 For Canada, see T de Bruyn. *HIV/AIDS and Discrimination: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998; for the United States, see G Herek, JP Capitanio. AIDS Stigma and HIV-related Beliefs in the United States: Results from a National Telephone Survey. 12th World AIDS Conference, Geneva, 1998, abstract no 44173.

7 Canadian Bar Association–Ontario. *Report of the AIDS Committee*. Toronto: The Association, 1986.

8 Human Immunodeficiency Virus Antibody Testing in Canada. Recommendations of the National Advisory Committee on AIDS. *Canada Diseases Weekly Report* 1989; 15(8): 37-43.

9 MA Somerville, N Gilmore. 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.

10 Royal Society of Canada. *AIDS: A Perspective for Canadians –Summary Report and Recommendations*. Ottawa: The Society, 1988; Royal Society of Canada. *AIDS: A Perspective for Canadians –Background Papers*. Ottawa: The Society, 1988.

11 Federal/Provincial/Territorial Working Group on Confidentiality in Relation to HIV Seropositivity. *Report*. Ottawa: The Working Group, 1988; for a summary, see Confidentiality in Relation to HIV Seropositivity. Report of the Federal/Provincial/Territorial Advisory Committee on AIDS. *Canada Diseases Weekly Report* 1989; 15(8): 43-47.

12 Parliamentary Ad Hoc Committee on AIDS. *Confronting a Crisis: The Report of the Parliamentary Ad Hoc Committee on AIDS*. Ottawa: The Committee, 1990.

13 Ontario Law Reform Commission. *Report on Testing for AIDS*. Toronto: The Commission, 1992.

14 AIDS Committee of Ottawa. Submission to the Ontario Law Reform Commission Project on HIV/AIDS Testing. Ottawa: The Committee, no date.

15 Canadian Public Health Association. *HIV & AIDS: A Public Health Perspective*. Ottawa: The Association, 1993.

16 Somerville & Gilmore, supra, note 9 at vii.

17 MA Field. Testing for AIDS: Uses and Abuses. *American Journal of Law & Medicine* 1990; 16: 33-106 at 37.

18 R Elliott, R Jürgens. *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions.* Montréal: Canadian HIV/AIDS Legal Network, 2000 (available at http://www.aidslaw.ca/Maincontent/issues/testing.htm#g); A Klein. *HIV/AIDS and Immigration: Final Report*. Montréal: Canadian HIV/AIDS Legal Network, 2001 (available at http://www.aidslaw.ca/Maincontent/issues/immigration.htm).

19 S Matiation. *HIV Testing and Confidentiality: Issues for the Aboriginal Community: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network, 1998.

20 J Fisher et al. *Gay and Lesbian Legal Issues: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998.

21 R Jürgens. *HIV/AIDS in Prisons: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1996.

22 De Bruyn, supra, note 6.

Return to the top of this page

Return to Table of Contents

# HIV Testing and Confidentiality: Final Report

**Prepared by Ralf Jürgens**

**ISBN 1-896735-16-9**

---

# BACKGROUND

> 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, the communities to which they belong, and society as a whole. 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.23

Since the HIV-antibody test was first made widely available in 1985, it has been the subject of great controversy, and a great deal has been written on the question of its appropriate legal and ethical use. As expressed by Bayer, "[u]ncertainty about the significance of the test’s findings and about its quality and accuracy provided the technical substrate of disputes that inevitably took on a political and ethical character, since issues of privacy, communal health, social economic discrimination, coercion and liberty were always involved."24 How would the test be used outside the context of blood banking? Would groups at increased risk for HIV be encouraged to take the test? How forceful would such encouragements be? How would those who agreed to be tested be counselled about the test’s significance for themselves and others? 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? To bear children? To remain free?25 Each of these questions has forced a confrontation over the fundamental matter of the relationship between the defence of privacy and the protection of public health, and over the roles of voluntarism and coercion in the social response to the threat of HIV/AIDS.26 Some of these questions and other questions related to HIV-antibody testing and confidentiality have remained controversial or may need to be reexamined at this point in the epidemic.

# Emergence of a "Canadian Approach" to HIV Testing

In Canada, a broad consensus has emerged that, except in a few well-defined circumstances, people should be tested only with their informed, voluntary and specific consent, when counselling and education before and following testing are available and offered, and when confidentiality of results or anonymity of testing can be guaranteed. The consensus around these issues has been "supported by gay leaders, civil libertarians, bioethicists, public health officials and by professional organizations representing clinicians."28 It is best expressed in the extensive and detailed reports published by the OLRC29 and NAC-AIDS.30

# Controversial Issues

Despite the consensus around these issues, opinion around several other issues related to testing has remained divided. In particular, there continues to be a lack of consensus in Canada 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 the availability of anonymous testing.31 For example, anonymous testing has been made available in some Canadian provinces, while in other provinces public health officials have insisted on reporting the names of those testing HIV-positive to public health authorities and on partner notification through public health, and have resisted making anonymous testing available.

# Problem Areas

In addition, there are a number of issues that, although in theory consensus was reached, in practice remain unresolved. For example, although there is agreement that HIV testing should be easily accessible for all Canadians, access to testing remains a problem, particularly for women and Aboriginal people; testing for HIV without the specific informed consent of the person being tested is allegedly taking place more and more frequently; many people, whether they test positive or negative, often do not receive adequate counselling; and calls for mandatory or compulsory testing of certain groups of the population, such as sex offenders, prisoners, health-care workers, immigrants, and pregnant women, have continued.

# New Developments

Finally, ten years after NAC–AIDS adopted the "general principle governing HIV antibody testing in Canada"32 and over five years after the release of the OLRC report – the last comprehensive effort to study the issues raised by HIV-antibody testing in Canada before the release of the *Discussion Paper* in 1997 – new controversies over testing have arisen, in particular because of advances in HIV testing technology that have led to the development and approval, in some countries, of rapid testing and home testing; the shifting demographics of the epidemic; and, most important, the availability of new and more promising treatments.

## Advances in HIV Testing Technology

Recent advances in HIV testing technology are increasing the options for HIV testing.33 In particular, the development and approval, in the United States, of home HIV testing kits raises the possibility that in Canada HIV testing might soon become widely and easily 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) intensive counselling and support. Should the sale and distribution of home HIV testing kits in Canada be allowed, and how will it affect the current model of testing?

Other important issues are raised by the development of new rapid HIV-antibody tests that allow for provision of results on the same day the test is administered. A rapid test has been evaluated in public clinics in the United States, showing that "[r]apid, on-site HIV testing was feasible, preferred by clients, and resulted in significant improvement in the number of persons learning their serostatus, without increasing the costs or decreasing the effectiveness of counseling and testing."34 In March 1998, the [US] Centers for Disease Control and Prevention (CDC) changed its policy on rapid HIV tests and now recommends that their use be allowed in some instances and under certain circumstances.35 In March 2000, the first rapid HIV screening test was licensed for sale in Canada.

## Shifting Demographics of HIV Infection

Another development is the 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, such as unprotected sex between men or sharing of drug injection equipment. Among those "at risk," it was widely accepted that the most effective method of prevention was education to reduce high-risk behaviour, and not any scheme of mandatory testing, notification

of public health authorities, and partner notification. In Canada the epidemic is still disproportionately affecting men who have sex with men, and injection drug users, but it has moved beyond those who engage in readily identifiable high-risk activity. In particular, Health Canada reports that "Canadian women are increasingly becoming infected with HIV, especially those who use injection drugs and whose sexual partners are at increased risk for HIV."36 The proportion of AIDS cases among women has increased from 6.2 percent of all AIDS cases before 1990 to 6.9 percent during 1990-1995 and
10.6 percent in 1996. It is estimated that by the end of 1996, 4000 to 5000 women in Canada were living with HIV, out of an estimated total of 36,000 to 42,000 HIV-positive Canadians. Women accounted for 19 percent of all HIV-positive test reports in 1995 that included information on gender. Injection drug use was a risk factor for 20 percent of these HIV-positive women. Many of the other women 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 particular reason to believe that they were at risk of HIV infection, and as a result may not have taken any precautions. This raises the question whether more aggressive public health measures may be warranted, including mandatory reporting and partner notification. The consensus to date has largely concluded that in most cases the confidentiality of HIV test results should be maintained. However, as treatments improve, 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.37 In particular, the introduction of Highly Active Anti-Retroviral Therapy (HAART) in industrialized countries has led to a considerable change in therapeutic possibilities for HIV disease. While many uncertainties surround the new therapies,38 they are driving the demand for earlier and more widespread opportunities for diagnosis.39 At least in part because of the availability of new therapies, the predominant model of specific informed consent for all HIV testing, and confidentiality of results, is increasingly being called into question. In particular, improvements in therapy have raised the question whether in some cases a more aggressive, and even mandatory, testing and treatment program might effectively prevent the further spread of HIV infection. Finally, as Valdiserri points out, "future antiretroviral treatment may not only improve clinical status but also render the client less infectious to others," which "will provide an added public health impetus for broadening and expanding" the availability of HIV counselling and testing.40

## Reexamination of the Issues

These developments, coupled with the existing problem areas and controversial issues mentioned above, call for a reexamination of the issues raised by HIV testing and confidentiality in Canada.

The main question that needs to be addressed is whether the new developments warrant a departure from the "general principle governing HIV antibody testing in Canada."41 In particular: is specific informed consent to testing still necessary, or should general consent suffice? Should options for HIV testing include anonymous testing facilities and should new forms of testing for HIV be made available in Canada? Is pre- and post-test counselling still necessary? Is mandatory or compulsory testing or testing of specific groups of the population (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?

In order to be able to address these questions, it is necessary to analyze more closely the benefits and potential harms of testing. The Report closely scrutinizes the assumption that underlies much of the changing approach to testing – that HIV testing today involves huge benefits and few harms and that it can therefore be undertaken routinely, without specific consent, counselling, and assurance of confidentiality of the results.

## Benefits from Testing

### 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. Its most significant and universally accepted use was to screen donors of blood and other body products.

#### Benefits for Individuals

> When the HIV blood test finally became available in 1985, I wasn't interested in opening Pandora's Box. There wasn't anything you could do for HIV then anyway. It wasn't until 1989 that researchers reported that HIV-positive people – and not just patients with full-blown AIDS – might benefit from the drug AZT. Now there was a good reason to be tested.42

People at risk had little reason to seek out an HIV test and considerable reason to fear that the results of such a test 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.43 In addition, the availability of clinically effective antiretroviral treatment was years away, and the long-term prognosis of HIV infection was not clearly understood44 – initially, it was hoped that only a small minority of those infected would develop AIDS. Finally, there was an extremely high level of public fear and misunderstanding about HIV and AIDS, and there was a particularly severe stigma associated with HIV infection.45 For all these reasons, HIV testing was actively discouraged in the communities at risk.

In 1988, Somerville and Gilmore enumerated benefits and harmful consequences of HIV testing for individuals. According to them, potential benefits included:

> 1. Establishing or clarifying a diagnosis of HIV infection or disease, enabling such persons to receive appropriate health care;
>
> 2. Minimizing the danger of therapy with potentially immuno-suppressive drugs for persons who are HIV infected;
>
> 3. Reassuring seronegative persons that they are unlikely to be infected;
>
> 4. Motivating or persuading uninfected persons to avoid exposure to HIV, or HIV infected persons to avoid re-exposure to HIV and to other potentially harmful agents;
>
> 5. Enabling persons to become pregnant, or to engage safely in unprotected sexual activity, without endangering their partners who are also not infected, when testing shows these persons are not infected, even though they have engaged in activities that can transmit HIV;
>
> 6. Enabling persons to work or engage in specific activities that could be a health risk for them if they are immunodeficient, or could potentially transmit HIV to others;
>
> 7. Enabling HIV seronegative persons to travel, work, be educated, or reside in countries where this may be prohibited for HIV infected persons.46

In contrast, potential harmful consequences included:

> 1. Discovery of seropositivity can be a grave psychological stress for the person being tested;
>
> 2. Persons who are HIV antibody seropositive may be at risk of losing their friends, employment, insurance, housing and educational or travel opportunities;
>
> 3. Some persons being tested may be labelled as being seropositive when

> not infected (false positives), and some persons may be labelled as seronegative when infected with HIV (false negatives).

### 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 for reducing the rate of infection. It was widely accepted that education to reduce high-risk behaviour was the most effective measure for preventing the further spread of HIV, and that this education was in no way related to, or dependent upon, HIV testing. However, health-care providers were encouraged to routinely offer counselling and testing to all persons considered to be at "increased risk." The public health rationale was that giving people in the so-called "high-risk groups" the opportunity to know their serostatus would help them take steps to prevent the further transmission of HIV.47

## 1989-1992

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, particularly for individuals.

### Benefits for Individuals

It became clear that the HIV test could now be used as a diagnostic device that could lead to beneficial medical interventions for people with HIV. As a result, many more people at risk began to seek out HIV testing and related treatments. The context for the debate over testing underwent a first, fundamental change:

> Gay organizations began to urge homosexual and bisexual men to have their antibody status determined under confidential or anonymous conditions. Physicians [in the US] pressed for AIDS to be returned to the medical mainstream and for the HIV-antibody test to be treated like other blood tests – that is, given with the presumed consent of the patient.48

However, the available treatments were not particularly successful at slowing the progression of HIV infection, and many continued to prefer not to find out their HIV status,49 for many reasons – for example, 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 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 persons living with HIV, not to the prevention of the spread of HIV infection. As stated by Somerville and Gilmore,

> Preventing HIV transmission is the only effective strategy to control the HIV epidemic, and this requires behavioural changes. Prevention requires everyone, regardless of whether they are infected, to behave safely and to avoid engaging in risk-producing activities. This behaviour does not, of itself, require HIV antibody testing, but information obtained by HIV antibody testing may motivate, or convince, some persons to avoid behaviour that promotes HIV transmission.50

In 1991, Higgins and colleagues examined 50 studies that were published or presented at professional meetings prior to July 1990 to ascertain the behavioural effects of HIV counselling and testing among men who have sex with men, injection drug users, and pregnant women and other heterosexuals.51 Across populations, the evidence regarding the ability of HIV counselling and testing to motivate risk reduction was limited or inconclusive in many instances:

> The clearest evidence for the positive behavioral effects of HIV CT [HIV counselling and testing] came from studies of MSM [men who have sex with men] and HIV-serodiscordant couples. Studies of MSM indicated that following HIV CT, men who tested HIV seropositive were less likely to engage in high-risk sexual practices than were seronegative or untested men. Similarly, a small number of studies conducted with HIV-serodiscordant couples found consistent reductions in sexual risk practices following HIV CT. Longitudinal studies conducted with MSM and IDUs (injection drug users) that provided information regarding the effects of HIV CT also showed reductions in HIV-related risk behavior over time. These findings, however, were questioned by Higgins and colleagues as they appeared to be largely attributable to secular changes in risk-related practices and, for IDUs, the effects of drug treatment. Studies of pregnant women and other heterosexuals also provided inconsistent findings regarding the behavioral effects of HIV CT. This pattern of findings led Higgins and colleagues to conclude that the evidence regarding the effects of HIV CT was inconclusive and that additional research was needed to address the behavioral consequences of these programs.52

Similarly, the World Health Organization concluded:

> The evidence that voluntary HIV testing may play a role in the prevention of transmission is not conclusive, except for discordant couples (ie where one partner is infected and the other uninfected), in whom it has been shown to result in less risky behaviour in those settings studied. Testing in itself is not a preventive measure; it could in principle aid prevention in other settings only if it succeeds in motivating individuals to adopt or maintain safer behaviours. Individuals are more likely to be thus motivated if they believe that HIV testing is of great benefit to themselves, such as when testing is provided in the context of a comprehensive counselling programme, with care and support services available, in a favourable social environment, and when the test is client-initiated.53

## 1992–Today

> When it comes to HIV disease, knowledge is power. HIV disease commonly involves a lengthy period – as long as a decade – between infection and the development of symptoms. People who know they are HIV infected can be monitored for changes in their condition and for possible treatment, even before symptoms appear. Individuals who know they are infected with HIV can also aid prevention efforts by taking the necessary precautions to avoid spreading the disease through unprotected sex or sharing needles.54

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, particularly for individuals, but increasingly for the community.

### Benefits for Individuals

As mentioned above, recent scientific discoveries and the availability of new antiretroviral drugs have changed the approach to treatment of HIV infection. There is a growing amount of medical research showing that combinations of anti-HIV drugs improve the health of many people with HIV and reduce mortality and delay progression of disease.55 While 2255 people in Canada were diagnosed with AIDS in 1993, only 690 people were diagnosed with the disease in 1997, mainly due to the new treatments that delay the progression from HIV to AIDS in seropositive people.56

The number of hospital admissions and deaths among people with HIV/AIDS receiving drug therapy has also fallen. A study undertaken in British Columbia showed that in 1994 the death rate was as high as 100 per 1000 AIDS patients. By the end of 1996, the rate had declined to about 20 per 1000.57 Similarly, in the United States, AIDS deaths declined for the first time in 1996 (a decrease of 23 percent compared to 1995), partly due to the improved treatments.58 If initiated shortly after infection, aggressive treatment may even be able to completely eliminate any traces of HIV in the blood of those treated.

Instead of being a latent infection, as previously believed, HIV infection is now known to produce high rates of viral replication and death of CD4+ cells soon after transmission.59 The importance of early intervention is being emphasized: as long as doctors thought that HIV was not very active through the early and middle years of infection, it made sense "to conserve forces and delay treatment so they would be ready for the virus when it emerged from hibernation."60 However, it is now known that "in every day of every year, in every infected person, HIV produced not thousands, not millions, but billions of copies of itself,"61 leading to – albeit controversial62 – recommendations that aggressive treatment be started as early as possible after infection.63 The Canadian *Guidelines for antiretroviral therapy for HIV infection* recommend that

> [a]ntiretroviral therapy should be offered to all patients who are symptomatic. ... In asymptomatic patients, initiation of therapy is based on laboratory criteria, primarily the viral load and secondarily the CD4 count. A plasma viral load above 5000-
> 10 000 HIV-1 RNA copies/mL, regardless of the CD4 count, is considered an indication for treatment. A CD4 count of less than 0.3 x 109/L is an indication for treatment regardless of the plasma viral load, to prevent further damage to the immune system. For treatment decisions physicians may need to consider viral load, immune function (CD4 count) and clinical status.64

Because of these new and promising developments, 1996 has been called a year of hope for people with HIV and the year that "changed the world's outlook on AIDS."65 Within weeks of the advent of protease inhibitors,

> a majority of the patients using the therapies began to get better. Over the last year and a half, tens of thousands of people with AIDS have gotten a second chance at life. Large urban hospitals are reporting decreases in AIDS admissions, doctor's patient loads have dropped, AIDS clinics have downsized on staff and a multitude of H.I.V.-infected people are looking towards a future they were sure they didn't have.66

Many of those who have access to the new drugs and to viral load testing started feeling more optimistic, sometimes ceasing to consider AIDS as a necessarily fatal disease. After years of bad news, there was new optimism in the battle against HIV/AIDS. Some went so far as to proclaim that the "AIDS crisis
is over."67

## 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.

Prevention will continue to require everyone, regardless of whether they are living with HIV or not, to behave safely and to avoid engaging in risk-producing activities. The question whether knowing one’s HIV test results changes behaviour remains disputed. Phillips and Stryker answer it as follows:

> Sometimes. Some individuals may find that knowing their test results may help bolster their resolve to practice safer sex, wishing to preserve their status if negative, or to protect their loved ones if positive.
>
> In the aggregate, the evidence for testing’s impact on behavior is mixed.68

In 1997, Wolitski and colleagues reviewed 35 studies published since 1991 to reassess the scientific data regarding the ability of HIV counselling and testing to motivate changes in risk-related practices and to promote help-seeking behaviour. The authors concluded that, like the research reviewed by Higgins and colleagues in 1991,69 the studies included in their review generally provided mixed results regarding the behavioural effects of HIV counselling and testing:

> Just over half of the studies reviewed herein provided positive evidence regarding the ability of HIV CT to motivate the adoption of risk-reducing practices. The findings from the remainder of the studies, however, suggest that HIV CT does not have a positive impact on risk-reducing behavior. The pattern of findings varied depending on the population being studied – the most consistent evidence for the beneficial effects of HIV CT came from studies of heterosexual HIV-serodiscordant couples.70

The authors pointed out that, although the patterns of findings varied somewhat according to the population being studied, the research methods employed in each study, and their limitations, may also have significantly influenced the results of the studies reviewed.71 Generally, because HIV counselling and testing has multiple goals (reducing risky behaviour, reducing negative psychological reactions to testing, facilitating referral to AIDS-oriented services, etc), evaluating its effectiveness is a complex task, and the ability of studies to measure the effect of counselling and testing without bias has been called into question.72 Despite the limitations, however,

> there is no question that HIV CT *can* and *does* motivate behavior change in some individuals. What is also clear, however, is that HIV CT does not always lead to behavior change, nor is it equally successful in influencing behavior across a wide

> range of settings and populations.73

Apart from motivating behaviour change in some individuals, knowledge of a person’s HIV infection can assist HIV prevention in other ways. For example, scientific studies have shown that mother-to-infant HIV transmission can be reduced very significantly if seropositive women learn their HIV status early during pregnancy and begin antiretroviral therapy.74 In addition, persons receiving a regimen of HIV 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.75 Finally, there is hope that the new treatments, if administered very shortly after exposure to HIV, can reduce the risk of seroconversion.76

## Conclusion

Clearly, 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."77 In 1998, there can be no doubt that

> [v]oluntary HIV testing accompanied by counselling has a vital role to play within a comprehensive range of measures for HIV/AIDS prevention and support, and should be encouraged. The potential benefits of testing and counselling for the individual include improved health status through good nutritional advice and earlier access to care and treatment/ prevention for HIV-related illness; emotional support; better ability to cope with HIV-related anxiety; awareness of safer options for reproduction and infant feeding; and motivation to initiate or maintain safer sexual and drug-related behaviours.78

The new therapies are profoundly affecting the AIDS epidemic79 and it could be said, as some have expressed it, that "[w]e are at a defining moment in the epidemic of HIV infection and AIDS."80 Indeed, the availability of better therapies and our rapidly expanding knowledge of the molecular biology of HIV are creating new opportunities to control the HIV/AIDS epidemic. Few would contest that it is essential to reexamine the Canadian approach to HIV testing and confidentiality in order 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 benefitting from new treatments. Health Canada estimated that approximately 11,000 to 17,000 persons, or about 30 to 40 percent of the estimated 36,000 to 42,000 Canadians living with HIV infection at the end of 1996, were unaware of their infection.81 This has led the Bureau of HIV/AIDS, STD and TB, Laboratory Centre for Disease Control, to state that, "[g]iven these data, and the fact that new treatments are available for HIV infection, it may be time to review HIV testing in Canada."82

However, the question whether the new developments warrant a major departure from the "general principle governing HIV antibody testing in Canada"83 and the utilization of more coercive public health approaches remains extremely controversial.

## A Shift to More Coercive Measures?

In the first decade of the epidemic, the prevalence of stigmatization of and discrimination against people with HIV/AIDS, particularly with regard to 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. This policy 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 through education and prevention programs, and gay organizations would have been unwilling to cooperate with public health officials in reaching them.84 As has been pointed out, the term "AIDS exceptionalism," coined by some advocates of HIV surveillance and name reporting to refer to the fact that traditional intrusive public health measures have not been systematically applied to HIV infection, is actually an unfortunate misnomer.85 While few would dispute the proposition that the public health profession's approach to HIV control has differed in important respects from strategies applied to certain earlier diseases, the monochromatic depiction of recent public health practice as "exceptionalist" ignores the complexity of the history of public health and structures public policy debates in potentially misleading ways.86 Indeed, the public health response to all infectious diseases has not been uniform, since there is no indication that a one-size-fits-all approach to all public health problems is effective. There is no natural or authentic approach to public health crises – history reveals that each epidemic produced unique public health policies "that were partly political, partly scientific, and somewhat inexplicable."87 It is therefore wrong to portray the voluntarist strategy of dealing with HIV/AIDS as an extraordinary rupture with prior practice, without acknowledging the important degree to which voluntarist principles have often informed the public health approaches to previous epidemics.88

Throughout the 1990s the appropriateness of the voluntary approach to public health measures has been called into question by those who are persuaded that "conventional" public health measures – such as routine involuntary HIV testing and contact tracing – would be more successful than voluntary measures in preventing the transmission of HIV and providing earlier treatment to people with HIV.89 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, the calls for coercive public health measures have been renewed. In the United States, for example, Tom Coburn, a Republican representative to the Congress from Oklahoma, introduced a bill to establish confidential HIV reporting nationwide, the HIV Prevention Act of 1997.90 The bill also makes provision for testing people accused of sexual offences and for testing patients before performing an invasive medical procedure, and it encourages states to criminalize the intentional transmission of HIV. Proponents of a shift to more coercive public health measures 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.

Those who urge caution and argue that the voluntary approach to public health measures retains its validity raise several issues to support their position. First, they point out that 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." As the author of a recent cover article on the subject in *The Atlantic Monthly*, who himself argues for an end to HIV exceptionalism, observes:

> Exceptionalists also point out, correctly and bitterly, that the hatred directed toward homosexuals, and the discrimination they experience at the hands of anti-gay conservatives, among others, are responsible in the first place for the very exceptionalist policies that conservatives like Coburn now so strongly oppose.91

Second, they point out that HIV still primarily targets marginalized populations fearful of government institutions. Indeed, it could be said that in Canada it is now targeting populations that are even more marginalized and vulnerable than gay men were in the 1980s, such as, for example, injection drug users, Aboriginal people, young gay men, and prisoners. Would a shift toward more coercive measures really assist efforts to curb the spread of HIV in these populations, or would it rather create new barriers? Would such measures not drive these populations further underground, making them even harder to reach through education and prevention programs, and less likely to cooperate with public health officials?

Third, they point out that 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 most marginalized in Canadian society, including injection drug users and Aboriginal people, the populations in which HIV infection is currently spreading most rapidly.

Fourth, they point out that in 1998, as in the 1980s and early 1990s, educational strategies to encourage behaviour modification must remain the centerpiece of HIV-prevention efforts. As Isbell has expressed it, "[t]he 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."92

Finally, they point out that there is not necessarily a conflict between public health and individual rights. Instead, the 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.

The following sections examine these arguments in more detail.

## Discrimination Continues

In recent years it has been suggested, both directly and indirectly, that HIV/AIDS-related stigma and discrimination either are not as prevalent as before or need not be taken into consideration in developing policy and programs pertaining to HIV/AIDS. The current debate in the United States about "HIV exceptionalism" is a useful example of this trend.

What is true is that, as the HIV/AIDS epidemic nears the completion of its second decade, the early societal panic about AIDS has diminished. The federal and several provincial human rights commissions have adopted policies interpreting disability or handicap provisions to protect people with HIV against discrimination. For example, the Policy on AIDS adopted by the Canadian Human Rights Commission in May 1988 states that HIV infection should be regarded as a "disability" under the Canadian Human Rights Act and that persons who are not infected may also have a remedy against discriminatory practices; a statement by the Ontario Human Rights Commission emphasizes that all persons infected or suspected of being infected with HIV, or who have HIV–related illnesses, including those who are asymptomatic, are protected by the *Ontario Human Rights Code*; and in British Columbia, the Human Rights Council, ruling on the complaint of *Biggs & Cole* v *Hudson*,93 found that persons who are HIV–seropositive or are "perceived to be infected" should receive the protection afforded by the British Columbia Human Rights Act. In November 1993, a Canadian court ruled for the first time that asymptomatic HIV infection qualifies as a disability for the purposes of discrimination law,94 a decision later confirmed by the Québec Human Rights Tribunal.95 In addition, more and more Canadians know someone who lives with HIV or has died of HIV-related complications, prominent celebrities have announced that they are HIV-positive, and AIDS activists have won broad admiration in many quarters of society. These developments "have somewhat lessened fears that the inevitable result of infection with HIV was complete social isolation."96

### Extent of Stigma and Discrimination

Nevertheless, discrimination against people with HIV/AIDS remains pervasive in Canada. The kinds and the impact of HIV-related stigma and discrimination experienced by people with HIV/AIDS and those affected by the disease at this time in the epidemic in Canada have been documented in *HIV/AIDS and Discrimination: A Discussion Paper*.97 The Paper provides ample evidence that stigma and discrimination continue to be pervasive, reinforcing once again the call for laws, policies, programs, and practices that address the causes and the effects of HIV-related stigma and discrimination.98Based on a review of the academic and scientific literature, reports produced by governmental and nongovernmental agencies, and other literature,99 as well as on interviews with a selection of people with HIV/AIDS, organizations comprised of people with HIV/AIDS, organizations providing services to people with HIV/AIDS or those affected by HIV/AIDS, and the comments of participants in a national workshop on discrimination and HIV/AIDS held on 15 January 1998, the Paper concludes that, in 1998, stigma and discrimination associated with HIV/AIDS are still pervasive, but that the forms they take and the context in which they are experienced have changed since the early days of the epidemic. According to the Paper, these changes have serious implications for people with HIV/AIDS and people affected by HIV/AIDS. It notes the following key aspects of the current situation, as expressed by participants in the national workshop:

- The epidemic of HIV infection is expanding among diverse populations, many of them marginalized within Canadian society. While some aspects of HIV-related discrimination are the same for all these populations, in other ways the experience and impact of discrimination are unique to the various identities that are assumed by or assigned to people living with or affected by HIV/AIDS. The most marginalized among people with HIV/AIDS experience many layers of stigma and discrimination. They also have the least resources or support in seeking redress.

- The restructuring of the health system has meant that fewer programs will be available with a specific focus on HIV/AIDS. This could lead to a systemic neglect of needs that are unique to or disproportionate among people with HIV/AIDS or the populations most affected by HIV/AIDS. At the same time, organizations that provide specific services to people with HIV/AIDS or populations affected by HIV/AIDS are faced with increasing demands, which they must meet with the same level of resources or reduced resources. The difficulty of meeting these demands is all the greater when the populations that need to be served are different; one program will not fit all.

- The advent of protease inhibitors and combination therapies has been accompanied by new risks for people with HIV/AIDS. There is a prevailing sense that people with HIV/AIDS can now lead "normal" lives, and a tendency to become more restrictive in determining whether people with HIV/AIDS qualify for disability benefits. The fact that people with HIV/AIDS are still vulnerable to stigma and discrimination is forgotten in these discussions. In many ways, the era of combination therapies has exposed people with HIV/AIDS to a greater threat of discrimination. One participant in the workshop stated: "I was able to remain invisible living with HIV until two years ago. Now I have to carry my bag of medications around all the time — I am always visible. I carry my stigma around."100

- The era of combination therapies is also raising new concerns about the ethics of informed choice in treatment decisions made by people with HIV/AIDS. There are reports that people feel pressured by their physicians to begin treatment with the latest

> generation of HIV drugs, and of instances where people have been denied services or fear losing their physician if they refuse to begin treatment. There are also questions about equity in treatment and access to care for marginalized populations, and about the extent to which they are provided with the supports that may be necessary to assist them in maintaining the complicated regimens of combinations of drugs.
>
> • While discrimination is still pervasive, it has become more subtle and less explicit. In the past, for example, people may have been fired outright when it was discovered they were HIV-positive. Today they may be laid off for what are ostensibly other reasons, or they may be harassed and pressured to the point that they quit their jobs or go on disability. Fear of being identified at work and of losing their job in fact prevents some people from taking HIV-related medications, as a study among people with HIV/AIDS in Montréal found.101

The Paper concludes that, even as the epidemic changes, stigma and discrimination continue to have an enormous impact on the lives of people with HIV/AIDS.

This conclusion is supported by a study recently undertaken in the United States, which showed that, "although its manifestations have changed in some respects during the 1990s, AIDS stigma persists in the United States."102 The study assessed the prevalence of AIDS stigma in the US, and compared current levels with those assessed in a 1990-91 survey.103 In telephone interviews with a national sample of English-speaking adults (n=1712), questions were asked about affective reactions to people with HIV/AIDS, beliefs about them, levels of comfort with them, intentions to avoid them, attitudes toward AIDS policies, and other AIDS-related attitudes and beliefs. The study showed that

> substantial majorities support mandatory testing of immigrants, pregnant women, and people from so-called high-risk groups. Compared to 1991, fewer people would avoid a person with HIV/AIDS in various hypothetical situations, but approximately one-fourth expressed discomfort about such contact. The proportion of the public believing that HIV can be transmitted through casual contact has increased since the early 1990s; more than 40 percent now overestimate the likelihood of HIV transmission through sharing food utensils, coughing or sneezing, or similar routes. Despite demographic changes in the population of people with HIV/AIDS during the past decade, the public still generally associates AIDS with gay and bisexual men. Antipathy is strongest toward people with HIV/AIDS who are gay or bisexual, and those infected through multiple sexual partners or injection drug use.104

## No Redress

To make matters worse, there is little or no redress for those discriminated against: it has been said that "the [human rights] commissions are useless, experience with them has been negative, delays and bureaucracy are incredible, and the understanding of the issues is appalling."105 Very few of the people living with HIV/AIDS who experience discrimination seek redress in the courts and human rights tribunals. Generally, as de Bruyn points out,106 there are a number of grave concerns about the limitations of human rights legislation and procedures as a means to protect people with HIV/AIDS or populations affected by HIV/AIDS from discrimination.

Many are frustrated with lengthy delays in processing complaints, failure to investigate complaints, the small number of complaints that are referred to a tribunal, and the relatively modest remedies that tribunals provide. Human rights commissions, for their part, are understaffed, underfunded, and overworked.107 They cannot take on every complaint, but must prosecute those that they believe will be most likely to advance human rights. One of the issues here is the inadequate funding of human rights commissions by governments. Another is the inadequacy of systems that cannot handle the myriad of individual complaints that come forward. The result is justice denied for many complainants, as Michelle Falardeau-Ramsay, Chief Commissioner of the Canadian Human Rights Commission, recently observed in a trenchant comment:

> We have to devise a system where it won’t take five years to get remedial action, because it’s far too long. We don’t want to be dealing with the grandchildren of the complainant. I prefer to deal with the complainants themselves.108

In addition, it is generally recognized, by human rights commissions as well as their critics, that procedures designed to deal with individual complaints are not well-suited to preventing discrimination or addressing systemic discrimination.109 In a partial effort to rectify this, human rights commissions issue policy statements setting out standards that, if followed, will prevent discrimination. These include the policies on HIV/AIDS cited above. But human rights commissions do not have the resources or authority to be more proactive. They are not able, for example, to audit policies and practices of employers so as to determine whether these policies and practices discriminate directly or indirectly.110 Moreover, some forms of discrimination, such as discrimination against poor people, are not even covered under human rights legislation. As Falardeau-Ramsay states:

> One of the shortcomings of almost all Canadian human-rights laws ... is that they ignore poverty and homelessness as grounds for discrimination.111

This has obvious relevance to many people with HIV/AIDS and many populations affected by HIV/AIDS.

Another issue is that there is concern that a narrower definition of disability may be applied to exclude people who are HIV-positive but asymptomatic, although HIV infection is currently recognized as a disability within the meaning of human rights legislation in Canada. In the United States, a number of courts have taken the view that HIV infection per se is not a disability.112 The courts have placed the burden of proof on the plaintiff to demonstrate that his/her HIV status is an impairment that substantially limits a major life activity, as stipulated in the *Americans with Disabilities Act*. This assessment "often focuses heavily on factors unrelated to whether or not the individual *requires* protection from discrimination,"113 although in real life the very perception that one is HIV-positive can lead to discrimination, regardless of one's level of impairment. The most recent decision from a human rights tribunal in Canada, as mentioned above, affirms that asymptomatic HIV status constitutes a "handicap" within the meaning of human rights law. Importantly, the Supreme Court of the United States also recently ruled that asymptomatic HIV infection may be covered as a disability by the *Americans with Disability Act*.114 Nevertheless, developments in this area need to be carefully followed to ensure that people with asymptomatic HIV do not lose the human rights protection they need.

Finally, people with HIV/AIDS are often discriminated against not only on the basis of their HIV status, but also because they are drug users, gay, Aboriginal, etc. This raises particular concerns for two of the populations currently most affected by HIV, injection drug users and Aboriginal people. In 1996, approximately half of the estimated 3000 to 5000 HIV infections that occurred in Canada were among injection drug users.115 With regard to Aboriginal people, while there is a lack of solid information about HIV/AIDS among them, it is nevertheless "clear that some Aboriginal communities are at increased risk for HIV infection because of their low socioeconomic status and high rates of sexually transmitted diseases."116

While human rights legislation and human rights commissions in Canada have afforded protection to people who have been or are dependent on alcohol or drugs, in an environment that regards drug use as a choice, a vice, and a crime, considerable education and advocacy will be required to ensure that the rights of drug users are protected and that drug addiction is recognized as a disability. Coercive approaches to treatment and exclusion of drug users from social benefits not only discriminate against drug users. They are unlikely to induce drug users to discontinue using, and are likely to increase the risk of harm from drug use.

For Aboriginal peoples, human rights legislation and procedures may not be particularly useful or inviting as a way to address discrimination.117 Many Aboriginal people will not even consider lodging a complaint because they are worn down by racism, do not think things will change, or are afraid of the consequences. In addition, the human rights system does not reflect Aboriginal values and is in many ways alien to Aboriginal ways of resolving differences. Furthermore, s 67 of the *Canadian Human Rights Act* exempts any provision of the *Indian Act*, or any provision made under or pursuant to that Act, from the provisions of the *Canadian Human Rights Act*. Included in the provisions of the *Indian Act* is the authority conferred on band councils to enact by-laws and band council resolutions that could potentially or inadvertently discriminate against people with HIV/AIDS. Finally, jurisdictional distinctions between Aboriginal peoples create considerable confusion about what human rights legislation applies in a given situation. For these reasons, a recent review of the situation concluded that "recourse to human rights legislation is not the best approach to reducing discrimination around HIV/AIDS for Aboriginal people."118

## Populations Affected

Discrimination is a particularly serious issue in some of the populations in which HIV is currently spreading most rapidly: injection drug users, Aboriginal people and, generally, the poorest and most marginalized in Canadian society.

With regard to Aboriginal people, a recent discussion paper concluded:

> Aboriginal people living with or affected by HIV/AIDS experience discrimination in many of the same forms as non-Aboriginal people do. What differentiates HIV/AIDS-related discrimination against Aboriginal people is the history of oppression and cultural devastation meted out to First Nations, Métis and Inuit communities. The deplorable level of health and social problems in the Aboriginal community represents a failure of human rights in Canada.
>
> The stories of discrimination told by those consulted [in the preparation of the paper] suggest that discrimination relating to HIV/AIDS and Aboriginal people comes from a variety of sources and takes many forms. Misunderstandings and denial about HIV/AIDS are often reinforced by other forms of discrimination, such as discrimination against two-spirited people, women, drug users, and Aboriginal people generally. Finally, it finds its roots in a history of oppression, racism and colonialism.
>
> The systemic and individualized discrimination experienced by Aboriginal people generally, and by Aboriginal people living with or affected by HIV/AIDS in particular, contributes to the disproportionate impact of HIV/AIDS on Aboriginal communities. The risk factors associated with HIV transmission are over-represented among Aboriginal people. The prevalence of such risk factors reflects, again, the disturbing historical relationship between Aboriginal people and Canadian society, governments and institutions.119

People who have acquired HIV through injection drug use live with a double stigma. A study of public attitudes in Australia in 1990 found that drug users who contracted HIV through needle sharing attracted the most blame (92 percent), the least sympathy (18 percent), and the most calls for them to pay for their own treatment (70 percent).120 Similarly, a random-sample survey conducted in the United States in 1990-91 found that 20.5 percent of the respondents thought that "people who got AIDS through sex or drug use have gotten what they deserve."121

The stigma of drug use is reinforced by the illicit status of drug use in law, and by the application of coercive measures, including police surveillance, criminal prosecution, and criminal penalties, against users of illegal drugs. Many drug users are socially and economically disadvantaged. A study of 582 injection drug users in Toronto found that 12.7 percent had an elementary school education, that 72.2 percent had a high-school education, that only 22.5 percent were permanently employed, and that only 36 percent lived in their own residence, while the rest lived in a shelter (14 percent), a room rented on a daily or weekly basis (16 percent), or had no fixed address (11.5 percent).122 Similarly, among injection drug users enrolled in a recent study in Vancouver, 81 percent had less than a high-school education, 62 percent were living in unstable housing, and 28 percent had a high level of depression.123

The marginalized status of drug users profoundly affects the way they are treated by other individuals and by society as a whole. Drug users find that they are denied the legal protections, health services, and social supports that others enjoy, and drug users with HIV/AIDS often encounter difficulties when they seek drug treatment, health care, or social support.124 Of particular relevance in the context of this report is access to antiretroviral therapy. There is considerable fear that HIV-positive drug users will not be offered the current standard of treatment for HIV infection because it is assumed that they will not be able to maintain the demanding drug regimens.125 This fear was confirmed in a recent study showing that HIV-positive injection drug users are perceived by physicians to be less adherent to medications and, generally, that physicians' perceptions of HIV-positive injection drug users "may pose a significant barrier to treatment for these patients."126

### Conclusion

Contrary to what some have suggested, HIV/AIDS-related stigma and discrimination continue to be prevalent and there is often little, if any, redress for discrimination suffered. Decisions about the direction that policy and programs should take in response to the changing epidemic and new developments must continue to be based on, among other considerations, a full analysis and assessment of the impact of stigma and discrimination on the people infected and affected by HIV/AIDS.

## Marginalized Populations

Authorities adhered to voluntarist strategies during the 1980s due, in large measure, to the recognition that HIV primarily targeted marginalized populations fearful of government institutions. In Canada, gay men, who often lacked legal protection against discrimination and were heavily stigmatized in society, were hardest hit.127 Since then, the epidemiologic changes that have occurred have not altered the central characteristic of AIDS as a disease of marginalized groups. Indeed, they have rather accentuated it. As mentioned above, HIV is spreading most rapidly among the poorest and most marginalized in Canadian society –

among those who are most subject to discrimination and have least access to the new treatments,128 populations that may be even more stigmatized than gay men were in the 1980s. Decisions about the future direction of public health’s response to HIV must take this into account. A shift toward more coercive measures could hinder rather than assist efforts to curb the spread of HIV in these populations, driving people in these populations further underground, making them even harder to reach through education and prevention programs, and less likely to cooperate with public health officials. As Burris has pointed out, testing policies "have not yet addressed the social fears of poor people, people alienated from the legal system, and people whose social risk often comes from the law itself (such as sex workers and drug users)."129

## Treatments No Panacea

With the advent of protease inhibitors and combination therapies, many people with HIV/AIDS are living longer and enjoying better health. However, it is questionable whether the advances in the medical management of HIV/AIDS have been "so dramatic as to require official application of the disease-control interventions routinely employed for curable conditions such as TB or syphilis."130 Many problems remain and there is still a long way to go in the quest for an effective treatment. While studies have established the rationale for prescribing combinations of effective medications, including a protease inhibitor to keep viral replication persistently below detectable levels,131 there are many unknowns, "such as the best time to begin combination therapy, the duration of benefit of this approach, possible harm related to inducing drug resistance, and long-term toxicity."132 In addition, once people decide to take combination therapy, it is (as far as we know at this point) a lifetime commitment to a complicated drug-taking regimen with far-reaching consequences on the daily life of the individual: "Individuals must be psychologically and emotionally prepared for the implications of HAART."133 Finally, some physicians are reporting that a significant portion of their AIDS patients cannot tolerate the new drugs,134 can’t stick to the difficult medication regimen, or show no signs of improvement.

### Side Effects

Patients taking the new drugs have emphasized that the optimism reported by scientists should be tempered by the daily suffering of people trying to stay on these treatments.135 Some people experience side effects so severe that they discontinue the treatments even as they see their viral load drop. Other people, particularly those in early stages of the disease, feel perfectly healthy before they start taking the treatments, and find it especially difficult to cope with the many side effects that negatively affect their quality of life. The treatments end up being seen as causing, rather than preventing, illness and discomfort.136 Side effects can include hair loss, kidney stones, nausea, diarrhea, skin rashes, liver dysfunction, and neurological damage. Recently, additional side effects have began to be reported, including elevated triglycerides and the development of visceral fat deposits around the abdomen and upper back. Related to the accumulation of visceral fat on the torso is the wasting occurring around the legs and arms.137 This condition, lipodystrophy, and related metabolic changes may have serious implications for the cardiovascular health of people following protease inhibitor–containing regimens and were not anticipated in the clinical trials that led to the approval of these drugs. One person who discontinued the treatments said:

> My blood work got much better, but the side effects were horrific. I stopped taking the protease inhibitors after three months. ... I work full time, I couldn't spend my entire day having to be in close proximity to the toilet because of constant diarrhea. I couldn't function.138

### Adherence

Other people – estimated at one-third of those who go on a combination therapy regimen139 – end up missing so many doses that the treatment becomes ineffective. A broad spectrum of people find adherence difficult if not impossible to manage. A December 1997 survey by Gay Men's Health Crisis (GMHC), a New York City–based organization for people with HIV/AIDS, revealed that three-quarters of the GMHC clients surveyed had missed doses in the previous three months, nearly one-third in the previous week, and one-tenth on the day of the survey.140 Women were most likely to cite "child care and family obligations" as the reason for falling off their regimen, while gay men were most likely to cite "stress, anxiety and depression" and heterosexual men were most likely to simply say that they had forgotten to take the treatments. Another finding was that, although all respondents said that they had discussed protease inhibitors with their physician, almost one-fifth said that the physician did not clearly explain side effects, resistance, or other consequences of non-adherence.141 A survey undertaken in San Francisco's General Hospital confirmed the findings of the New York City survey, showing that one-fifth of 164 participants admitted to having missed one or more doses within the last three days.142 Data from Canadian studies also show that people taking antiretroviral drugs commonly experience difficulties with taking the drugs as prescribed.143 Results of a national survey of 400 people with HIV in the United States suggest that adhering to HIV treatment regimens may be more difficult for HIV patients who feel well. Over 44 percent of respondents with CD4+ counts above 300 cells/mL reported missing a dose in the last week compared with 30 percent of respondents with CD4+ counts below 300 cells/mL. Results further indicate that younger respondents are more likely to skip their HIV medication.144

One person who stopped his triple combination therapy said that in order "to succeed with these drugs, I had to be emotionally ready to do this for the rest of my life, and I hadn't done that work yet."145 He acknowledged that he had always felt that it would be difficult to adhere to a regimen that he had to follow more than twice a day,

> but I originally agreed to go on the triple combo because I was convinced the data warranted trying it, and I was caught up in the flow – everybody was talking about

> it and doing it. ... But the feeling of being trapped by this difficult regimen, as well as the constant nausea and diarrhea, created severe depression. I found myself accidentally missing or forgetting dosages. I would either completely forget, or I would get up and make breakfast so I could take my meds with my meal and then not remember if I had already taken them or not.146

## Resistance

While this person voluntarily stopped taking triple combination therapy, others – particularly injection drug users, as mentioned above – are not offered such therapy in the first place,147 most often because physicians fear that they would be unable to follow the strict regimen, with potential negative consequences not only for the individual patient, but also for the public through the spread of a virus resistant to many drugs. Already, there is preliminary evidence that a small but significant number of people have contracted viruses that are at least partially resistant to some of the drugs. These people have never been on drug therapy and are contracting the resistant viruses from the people who infect them.148

## Drug Failure

In addition to the severe side effects and the problem of non-adherence, for an increasing percentage of people for whom combination therapy worked initially, the benefits simply do not last: "People do quite well for six months, eight months or a year, and after a while, in a significant proportion, the virus starts to come back."149 It has been estimated that, when these cases of "viral breakthrough" are accounted for, the failure rate of the new drug cocktails may be as high as 50 percent.150 Generally, studies suggest that patients who have the most durable response are those who are just beginning treatment as compared with those who have been using therapy for years.151

## Future Treatment Options

There is also the possibility that patients who decide to treat with HAART now may potentially be foreclosing on the possibility of more effective treatment options in the future:

> Patients who followed the advice of clinicians in the late 1980s and early 1990s and were treated sequentially with AZT, 3TC and other early reverse transcriptase inhibitors discovered later that they had effectively "used up" several drugs in the anti-HIV arsenal, often with very limited effect. As a result the issue of immediate treatment upon an HIV diagnosis is not clear.152

## Access

Finally, access to the new treatments is a significant problem in Canada. Data from the Ontario

Observational Database and the British Columbia Centre for Excellence in HIV/AIDS indicate that patients incur substantial out-of-pocket expenses for deductibles, complementary therapies, and other health-related costs associated with HIV infection.153 In addition, broader health-care issues have an impact on access, with provinces looking at ways to reduce the cost of paying for prescription drugs through reference-based pricing or other cost-cutting mechanisms. As more antiviral drugs are approved - a slow process154 – it will become increasingly difficult to ensure that they are placed on provincial formularies. Finally, access to the new treatments is a seemingly insurmountable problem for many poorer countries,155 leading to renewed calls for increased prevention efforts and the development of a prophylactic vaccine.

## Conclusion

Two years after the Vancouver International Conference on AIDS, at the 1998 12th World AIDS Conference in Geneva, developments since 1996 were summarized as follows:

Protease inhibitors and combination therapy still figure largely on the agenda, although the stir they caused in Vancouver is clearly missing. Early discussions reflected how the promise of the new treatments has proven itself for many people since Vancouver. However, early hopes of viral eradication and triumph over the virus have been tempered somewhat by a daunting list of problems associated with combination therapy. Issues such as viral resistance, drug interactions, drug toxicity and side effects, as well as problems connected to patient non-adherence have found no easy solution in Geneva.156

In conclusion, while it is true that for some people with HIV/AIDS the new treatments have produced near-miraculous results in enhanced health and low (to the point of virtually undetectable) viral load, there is still no cure for AIDS, and fears persist that the virus may evolve to accommodate these medications as it has done with prior medications. Hope remains strong that the protease inhibitors may prove more effective in the long run than did AZT and its nucleoside analogues, but "the word now is watchful waiting."157 A recent article in a US magazine for people with HIV/AIDS also urges caution:

> Over the course of the epidemic, PWAs have swallowed a hell of a lot of pills. And stomached even more hype from drug companies, particularly when products are new and data few. All too often, early claims – echoed by corporate reps, journalists, researchers and even activists – turn out to be exaggerated or just plain false. And sometimes when a cheerleading statement is first made, the data already contradict it. ... Was the ‘80s rush-to-treat a tragic error? Hard to say. But if history has a pattern, you might want to think twice –unless you’re desperate and out of options – before jumping on the first study or news story; hold out for long-term studies with meaningful results.158

Of course, the potential medical benefits to the patient, as well as the public health interest in reducing rates of HIV/AIDS-related disease, support strategies to improve access to early intervention. However, many problems and unknowns remain and, 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. Decisions about the direction that policy and programs should take in response to the changing epidemic need to take these differences and limitations into account.

## Behaviour Modification

In 1998, as in the 1980s, strategies to encourage behaviour modification remain the centerpiece of HIV-prevention efforts. As mentioned above, the sexual and drug-related behaviours that place individuals at risk of HIV infection are unchanged from the 1980s and retain their central features: "they are extremely private, closely intertwined with personal identity, difficult to change, and often poorly understood."159 As Isbell has noted,

> [i]n the absence of effective treatments capable of rendering HIV-positive individuals noninfectious, public health authorities have little choice but to invest in sensitive, noncoercive educational strategies to promote risk reduction.
>
> ... the essentially unaltered public health character of HIV argues against the application of traditional disease-control interventions that ignore the ways in which HIV differs from TB and syphilis. By extension, the enduring uniqueness of HIV militates in favor of communitarian strategies calculated to empower communities to develop (through the careful assistance of public health authorities) culturally appropriate interventions to encourage behavior change."160

## The AIDS Paradox

> Safeguarding the human rights of persons with AIDS is vital not only on ethical and legal grounds but for pragmatic reasons. It is a necessity, not a luxury, and it is not a question of the "rights of the many" against the "rights of the few."161

Those who promote a shift toward more coercive measures often argue that there is a conflict between the protection of public health and the rights of people with HIV/AIDS or affected by the disease, and that individual rights must take a back seat if the battle against the spread of HIV is to be effective. However, rather than impeding the protection of public health, "several years of experience in addressing the HIV/AIDS epidemic have confirmed that the promotion and protection of human rights is an essential component in preventing transmission of HIV and reducing the impact of HIV/AIDS."162 In the vast majority of cases, policies that respect the rights of those infected and affected are also most effective in protecting and promoting public health. The following text, excerpted from the Guidelines on HIV/AIDS and Human Rights adopted at the Second International Consultation on HIV/AIDS and Human Rights, explains the interaction between protection of human rights and protection of public health:

> 72. ...The protection and promotion of human rights is necessary both to protect the inherent dignity of persons affected by HIV/AIDS and to achieve the public health goals of reducing vulnerability to HIV infection, lessening the adverse impact of HIV/AIDS on those affected and empowering individuals and communities to respond to HIV/AIDS.
>
> 73. In general, human rights and public health share the common objective to promote and to protect the rights and well-being of all individuals. From the human rights perspective, this can best be accomplished by promoting and protecting the rights and dignity of everyone, with special emphasis on those who are discriminated against or whose rights are otherwise interfered with. Similarly, public health objectives can best be accomplished by promoting health for all, with special emphasis on those who are vulnerable to threats to their physical, mental or social well-being. Thus, health and human rights complement and mutually reinforce each other in any context. They also complement and mutually reinforce each other in the context of HIV/AIDS.
>
> 74. One aspect of the interdependence of human rights and public health is demonstrated by studies showing that HIV prevention and care programmes with coercive or punitive features result in reduced participation and increased alienation of those at risk of infection.163 In particular, people will not seek HIV-related counselling, testing, treatment and support if this would mean facing discrimination, lack of confidentiality and other negative consequences. Therefore, it is evident that coercive public health measures drive away the people most in need of such services and fail to achieve their public health goals of prevention through behavioural change, care and health support.
>
> 75. Another aspect of the linkage between the protection of human rights and effective HIV/AIDS programmes is apparent in the fact that the incidence or spread of HIV/AIDS is disproportionately high among some populations. Depending on the nature of the epidemic and the legal, social and economic conditions in each country, groups that may be disproportionately affected include women, children, those living in poverty, minorities, indigenous people, migrants, refugees and internally displaced persons, people with disabilities, prisoners, sex workers, men having sex with men and injecting drug users – that is to say groups who already suffer

> from a lack of human rights protection and from discrimination and/or are marginalized by their legal status. Lack of human rights protection disempowers these groups to avoid infection and to cope with HIV/AIDS, if affected by it. [note deleted]
>
> 76. Furthermore, there is growing international consensus that a broadly based, inclusive response, involving people living with HIV/AIDS in all its aspects, is a main feature of successful HIV/AIDS programmes. Another essential component of comprehensive response is the facilitation and creation of a supportive legal and ethical environment which is protective of human rights. This requires measures to ensure that Governments, communities and individuals respect human rights and human dignity and act in a spirit of tolerance, compassion and solidarity.
>
> 77. One essential lesson learned in the HIV/AIDS epidemic is that universally recognized human rights standards should guide policy-makers in formulating the direction and content of HIV-related policy and form an integral part of all aspects of national and local responses to HIV/AIDS.

For those citizens, political leaders, and public health officials who still question what human rights have to do with a successful strategy to contain the spread of HIV, Justice Michael Kirby has the following answer:

> However imperfect our understanding of the tools of behaviour modification, this much at least seems clear. To have a chance of penetrating into the mind of an individual, so that he or she secures the knowledge essential to change behaviour at a critical moment of pleasure-seeking, it is imperative to win the trust of that individual. Only in that way will their attention be captured in a manner that will convert words and information into action. Pamphlets and posters, homilies and sermons are only of minor use in this regard. What is needed is the direct supply of information by a source regarded as trusted, impartial and well intentioned, so that, by repeated messages of this kind, a general awareness about the existence of HIV can be translated into individual daily conduct.
>
> The paradox is that laws which criminalise particular target groups (sex workers, homosexuals, injecting drug users, &c) may appear to be a suitable response. They are often attractive to the public and therefore to distracted politicians who are anxious to be seen to be doing something in the face of the grave challenge to public health that HIV presents. But experience teaches that such responses have little impact on the containment of an epidemic of this nature. They actually tend to have a negative impact on behaviour modification because they place targeted groups beyond the reach of the requisite information. They undermine

> the creation of the supportive social and economic environment in which effective strategies can be prosecuted.
>
> Thus the HIV paradox teaches, curiously enough, that one of the best strategies of behaviour modification which will actually work to reduce the spread of HIV, by enhancing and sustaining self-protection, is to be found in measures that positively protect the targeted groups and uphold the rights of individuals within them. In those countries where there has been a measure of success in achieving and sustaining behaviour modification, and thereby reducing the spread of HIV infections, such strategies have been adopted ... .
>
> To those who find the HIV paradox unconvincing or even offensive, two answers may be given. The first is that of practicality. No other strategy has been shown to work. Without effective behaviour modification HIV will continue to spread rapidly, causing enormous personal suffering and devastating economic and human loss. By 1987, most informed health officials, led by the World Health Organization, had come to recognize the force of the HIV paradox. However, their endeavour to supplement public campaigns and health prevention efforts with attention to human rights has only been partly successful. The effort must continue.
>
> The second justification for the strategy which I have described takes me back to fundamental human rights. They are important, not because they are contained in the international constitutions or laws. Their importance lies in the fact that such rights are basic for every human being for no reason other than the humanity and unique individuality of each of us. I once explained, to a law school in the USA, the practical reasons for supporting a strategy protective of the rights of individuals especially at risk of HIV infection. A young law student rebuked the judge. He told me that I had forgotten the main reason. This was that we accord every human being that person’s human rights because it is our duty and their right. When epidemics are about, human rights tend to go out of the window. But even in times of epidemic, departures from respect for fundamental human rights must be controlled by law. They must be limited to measures that are strictly proportional and necessary. They must be compatible with the other objectives of a democratic society.164

In conclusion, while officials may require the legal authority to employ coercive measures in the event that they prove *necessary* to protect the public health, in the vast majority of cases the imperatives of individual rights and public health are mutually compatible – there is no either-or dichotomy between these two realms.

# 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.165

This Report recognizes at the outset that, given the rapid speed with which HIV treatment and the disease itself change, every important social and legal policy about HIV must be under constant reexamination. There are no permanent answers. 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, be removed.

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. Generally, the AIDS crisis is far from over and AIDS "is far from being a chronic disease like many others."166 In the face of this reality it would be best, as Bayer has said,

> to recognize the real challenge and to assure that the politics of public health reflect a commitment to disease prevention, the protection of the vulnerable, and a respect for the right of privacy. In short, the goal is to make health policy effective and just.167

**Return to the top of this page**

**Return to Table of Contents**

---

ENDNOTES

23 Somerville & Gilmore, supra, note 9.

24 R Bayer. Editorial Review – Ethical and Social Policy Issues Raised by HIV Screening: The Epidemic Evolves and So Do the Challenges. *AIDS* 1989; 3: 119-124.

25  Ibid; OLRC, supra, note 13 at x.

26  Bayer, supra, note 24.

27  Parts of this section are based on the key commentary written by W Flanagan on the first draft of *HIV Testing and Confidentiality: A Discussion Paper*.

28  Bayer, supra, note 24 at 119, with many references.

29  See supra, note 13.

30  See, supra, note 8.

31  See infra.

32  Supra, note 8 at 38.

33  For a good summary, see WJ Kassler. Advances in HIV Technology and Their Potential Impact on Prevention. *AIDS Education and Prevention* 1997; 9(Suppl B): 27-40.

34  WJ Kassler et al. On-Site, Rapid HIV Testing with Same-Day Results and Counseling. *AIDS* 1997; 11(8): 1045-1051 at 1045.

35  Centers for Disease Control and Prevention. Update: HIV Counseling and Testing Using Rapid Tests – United States, 1995. *Morbidity and Mortality Weekly Report* 27 March 1998.

36  Health Canada. *HIV/AIDS Epi Update: HIV and AIDS among Women in Canada.* Ottawa, May 1998.

37  See A Rachlis, DP Zarowny. Guidelines for Antiretroviral Therapy for HIV Infection. *Journal of the Canadian Medical Association* 1998; 158(4): 496-505.

38  See M Huijer. Ethical Implications of the Medical and Existential Uncertainty Related to New Antiretroviral Therapies. Abstract no 44129, 12th World AIDS Conference, Geneva, 1998.

39 See also *Understanding the Impact of New Treatments on HIV Testing. Summary of a January 28-30, 1998, Henry J Kaiser Family Foundation Forum*. The Foundation, 1998.

40  RO Valdiserri. HIV Counseling and Testing: Its Evolving Role in HIV Prevention. *AIDS Education and Prevention* 1997; 9 (Suppl B): 2-13 at 10.

41 See supra, note 8 at 38.

42  D Sanford. AIDS Hasn't Left, but a Future Is Back. One Man's Account. *The Globe and Mail* 23 November 1996, at D1.

43  See, eg, for Canada, British Columbia Civil Liberties Association. *AIDS Discrimination in Canada: A Study of the Scope and Extent of Unfair Discrimination in Canada against Persons with AIDS, and Those Known or Feared to Be HIV Positive.* Vancouver: The Association, 1989; for the United States, LO Gostin. The AIDS Litigation Project. A National Review of Court and Human Rights Commission Decisions, Part II: Discrimination. *Journal of the American Medical Association* 1990;

263(15): 2086-2093; for Australia, New South Wales Anti-Discrimination Board. *Discrimination – The* Other *Epidemic. Report of the Inquiry into HIV and AIDS Related Discrimination*. The Board: 1992; for a general overview, R Cohen, LS Wiseberg. *Double Jeopardy – Threat to Life and Human Rights. Discrimination against Persons with AIDS*. Cambridge, MA: Human Rights Internet, 1990.

44 Valdiserri, supra, note 40 at 2.

45 For a discussion of HIV/AIDS-related stigma, see de Bruyn, supra, note 6, with many references.

46 Somerville & Gilmore, supra, note 9 at x.

47 Valdiserri, supra, note 40 at 3, with reference to Centers for Disease Control. Additional Recommendations to Reduce Sexual and Drug Abuse-Related Transmission of Human T-Lymphotropic Virus Type III / Lymphadenopathy-Associated Virus. *Morbidity and Mortality Weekly Report* 1986; 35: 152-155.

48 R Bayer. Public Health Policy and the AIDS Epidemic. An End to HIV Exceptionalism? *New England Journal of Medicine* 1991; 324(21): 1500-1504 at 1501.

49 In his response to the *Discussion Paper*, dated 24 June 1997, Hendriks argues that the right not to know is embedded in the right to private and family life and has gained official recognition in the European Declaration on the Promotion of Patients' Rights.

50 Somerville & Gilmore, supra, note 9 at vii.

51 D Higgins 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.

52 RJ Wolitski 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 at 53.

53 World Health Organization. *Statement from the Consultation on Testing and Counselling for HIV Infection*. Geneva: WHO Global Programme on AIDS, 1992, at 7.

54 K Phillips, J Stryker. What Is Testing's Role in HIV Prevention? Website of the Center for AIDS Prevention Studies, University of California at San Francisco. Section Prevention Fact Sheets.

55 SM Hammer et al. A trial comparing nucleoside monotherapy with combination therapy in HIV-infected adults with CD4 cell counts between 200 to 500 per cubic millimeter. *New England Journal of Medicine* 1996; 335: 1081-1090; SM Hammer et al. A controlled trial of two nucleoside analogues plus indinavir in persons with human immunodeficiency virus infection and CD4 cell counts of 200 per cubic millimeter or less. *New England Journal of Medicine* 1997; 337: 725-733; RM Gulick et al. Treatment with indinavir, zidovudine, and lamivudine in adults with human immunodeficiency virus infection and prior antiretroviral therapy. *New England Journal of Medicine* 1997; 337: 734-739; CC Carpenter et al. Antiretroviral therapy for HIV infection in 1997: updated recommendations of the International AIDS Society–USA panel. *Journal of the American Medical Association* 1997; 277: 1962-1969.

56 L Neergaard. AIDS Patients Developing Fat Deposits on Face, Bodies. *The Globe and Mail* 22 June 1998, at A6.

57 W Immen. AIDS Drugs Show Surprising Success. *The Globe and Mail*, 8 May 1997, A1 and A8, at A8. See also G Deutsch, A-M Robert, C Tsoukas. Impact of HAART in a Major AIDS Treatment Facility. 7th Annual Canadian Conference on HIV/AIDS Research, 1998. Abstract no 458P; RS Hogg et al. Improved Survival Among Men and Women on Triple

Antiretroviral Therapy. 7th Annual Canadian Conference on HIV/AIDS Research, 1998. Abstract no 443P.

58 Centers for Disease Control and Prevention. *Morbidity and Mortality Weekly Report* 19 September 1997; 46(37).

59 AS Perelson et al. HIV 1 dynamics in vivo: virion clearance rate, infected cell life-span, and viral generation time. *Science* 1996; 271: 1582-1586.

60 C Gorman. The Disease Detective. *Time* 30 December 1996/6 January 1997, 24-31 at 30.

61 Ibid.

62 It must be emphasized that the question of when to begin therapy remains controversial. See, eg, Community AIDS Treatment Information Exchange (CATIE). 12th World AIDS Conference. Interim Report. Toronto: CATIE, at 2 (also available at www.catie.ca).

63 DD Ho. Time to Hit HIV, Early and Hard [Editorial]. *New England Journal of Medicine* 1995; 333: 450-451.

64 Rachlis & Zarownny, supra, note 37 at 498.

65 J Antalek. The Lazarus Effect – Protease Inhibitors: A Return to Health? *Q San Francisco* March/April 1997, 30-33 at 30.

66 Ibid.

67 D Savage. The AIDS Crisis Is Over. *The Ottawa XPress* 7 August 1997,
at 8-9.

68 Supra, note 54.

69 Supra, note 51.

70 Wolitski et al, supra, note 52 at 65.

71 Ibid.

72 See D Miller, AJ Pinching. HIV Tests and Counselling: Current Issues. *AIDS* 1989; 3(Suppl 1): S187-S192.

73 Wolitski et al, supra, note 52 at 65.

74 C Peckham, D Gibb. Mother-to-child transmission of the human immunodeficiency virus. *New England Journal of Medicine* 1995; 333: 298-302; SA Fiscus et al. Perinatal HIV infection and the effect of zidovudine therapy on transmission in rural and urban counties. *Journal of the American Medical Association* 1996; 275: 1483-1488. For more recent studies, see the excellent overview by LM Mofensen. Treatment as Prevention: Mother to Child Transmission. Plenary session PL1.2 at the 12th World AIDS Conference, Geneva, 29 June 1998, with reference to four recent prospective studies from North Carolina, New York, France, and British Columbia showing that transmission in untreated women ranged from 20 to 32 percent, while transmission in zidovudine-receiving women was only 3 to 5 percent. However, the use of highly active antiretroviral therapy may produce significant postnatal side effects in babies. See P Lorezi et al. Safety of Combined Therapies in Pregnancy. 12th World AIDS Conference Geneva, 1998, abstract no 32453, and infra, the section on HIV testing of pregnant women in the chapter on mandatory testing at 132-150.

75 R Royce et al. Sexual Transmission of HIV: Current Concepts. *The New England Journal of Medicine* 1997; 336: 1072. See also O Gostin, JW Ward, AC Baker. [Sounding Board] National HIV Case Reporting for the United States. *The New England Journal of Medicine* 16 October 1997; 337(16): 1162-1167 at 1162.

76 Update: Provisional Public Health Service Recommendations for Chemoprophylaxis after Occupational Exposure to HIV. *Morbidity and Mortality Weekly Report* 1996; 45(22): 468-472.

77 C Marwick. Home Testing Kits for HIV Apt to Get FDA Approval. *Journal of the American Medical Association* 1995; 273 (12): 908-909 at 909.

78 Joint United Nations Programme on HIV/AIDS. UNAIDS Policy on HIV Testing and Counselling. Geneva: UNAIDS, August 1997, at 1.

79 Gostin, Ward, Baker, supra, note 75 at 1162.

80 Ibid at 1162-1163.

81 Health Canada. *HIV/AIDS Epi Update: HIV Testing among Canadians: An Estimated 11,000–17,000 Current HIV Infections May Not Be Diagnosed*. Ottawa, May 1998.

82 Ibid.

83 Supra, note 8 at 38.

84 R Bayer. AIDS: Human Rights and Responsibilities. *Hospital Practice* 1994; 29(2): 155-164 at 155.

85 American Civil Liberties Union. HIV Surveillance and Name Reporting. A Public Health Case for Protecting Civil Liberties. ACLU, October 1997.

86 MT Isbell. AIDS and Public Health: The Enduring Relevance of a Communitarian Approach to Disease Prevention. *AIDS & Public Policy Journal* 1993; 8(4): 157-176 at 165.

87 Ibid at 164, with reference to S Burris. Testing, Disclosure, and the Right to Privacy. In: S Burris et al (eds). *AIDS Law Today: A New Guide for the Public*. New Haven: Yale University Press, 1993, 115-149; J Duffy. *The Sanitarians: A History of American Public Health*. Urbana: University of Illinois Press, 1990; E Fee. Sin Versus Science: Venereal Disease in Twentieth-Century Baltimore. In: E Fee, DM Fox (eds). *AIDS: The Burdens of History*. Berkeley: University of California Press, 1988, 121-146.

88 See also C Hanssens. Inventing "AIDS Exceptionalism." New York, NY: Lambda Legal Defense AIDS Project News & Views, 28 February 1998.

89 Bayer, supra, note 84. See also Bayer, supra, note 48.

90 Burr, supra, note 3 at 66.

91 Ibid at 67.

92 Isbell, supra, note 86 at 163.

93 (1988), 9 CHRR D/5391 (BC Human Rights Council).

94 *Hamel v Malaxos*, 25 November 1993, no 730–32–000370 929, Small Claims Court, Joliette, unreported. See also D Patterson. Québec Court Finds Asymptomatic HIV Infection a Charter "Handicap." *Canadian HIV/AIDS Policy & Law Newsletter* 1994; 1(1):1, 3-4.

95 *Québec Human Rights Commission* v *Dr G G*, QHRT, Québec, no 200–53–000002–944, 11 April 1995, Rivet J. See also B Guillot-Hurtubise. Dentist Found Guilty of Discrimination. *Canadian HIV/AIDS Policy & Law Newsletter* 1995; 1(4): 1, 14-15.

96 ACLU, supra, note 85.

97 Supra, note 6.

98 Previously, in 1989, a study of discrimination against people with HIV/AIDS had concluded that "AIDS discrimination is a serious problem" (British Columbia Civil Liberties Association, supra, note 43); in 1992, NAC–AIDS had reported that violations of human rights in the context of HIV infection occur in Canada and that they "are widespread" (NAC-AIDS. *HIV and Human Rights in Canada*. Ottawa: The Committee, 1992).

99 A working bibliography of approximately 500 items was selected from the available literature. The academic and scientific literature was identified from citations and by searching such databases as AIDSline, Medline, LegalTrac, and Sociofile.

100 For a study of the social and economic impact of anti-HIV drugs on people with HIV, see J Grimshaw et al. *"I Feel Like I've Got a Future." The Social and Economic Impact of Anti HIV Drugs on People with HIV*. London, UK: The Terrence Higgins Trust, 1998.

101 Y Jalbert. Triple-Drug Therapy and Return to Work: Results of a Québec Survey. *Canadian HIV/AIDS Policy & Law Newsletter* 1998; 3(4)/4(1): 13-15.

102 Herek & Capitanio, supra, note 6.

103 GM Herek, JP Capitanio. Public Reactions to AIDS in the United States: A Second Decade of Stigma. *American Journal of Public Health* 1993; 83(4): 574-577.

104 Ibid.

105 See R Jürgens. *Legal and Ethical Issues Raised by HIV/AIDS: Literature Review and Annotated Bibliography*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1995, at 13.

106 Supra, note 6 at 97ff.

107 On this and what follows, see DG Casswell. *Lesbians, Gay Men, and Canadian Law*. Emond Montgomery Publications Ltd, 1996, at 51.

108 M Philp. Rights Panels Losing to Abuse, Commission Says. *Globe and Mail* 25 March 1998, at A3.

109 WW Black. *B.C. Human Rights Review. Report on Human Rights in British Columbia.* Vancouver: Ministry Responsible for Multiculturalism and Human Rights, 1994, at 14-19, 29-31; Philp, supra, note 107.

110 De Bruyn, supra, note 6 at 98, with reference.

111 Philp, supra, note 108.

112 R Jürgens. Your Health is Back. Now You May Lose Your Protection against Discrimination. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 3-5, citing WE Parmet, DJ Jackson. No Longer Disabled: The Legal Impact of the New Social Construction of HIV. *American Journal of Law & Medicine* 1997; 23(1): 8-43.

113 Jürgens, supra, note 112 at 3.

114 *Bragdon v Abbott*, 1998 WL 332958 (25 June 1998).

115 Health Canada. *HIV/AIDS Epi Update. HIV/AIDS Among Injection Drug Users in Canada*. Ottawa, May 1998.

116 Health Canada. *HIV/AIDS Epi Update. HIV/AIDS Epidemiology Among Aboriginal People in Canada*. Ottawa, May 1998.

117 For what follows, see S Matiation. *Discrimination, HIV/AIDS and Aboriginal People*. Montréal: Canadian HIV/AIDS Legal Network, 1998, at 13-29.

118 Ibid at 45.

119 Ibid at 31-32.

120 New South Wales Anti-Discrimination Board, supra, note 43 at 68.

121 Herek & Capitanio, supra, note 103 at 575.

122 P Millson et al. Prevalence of Human Immunodeficiency Virus and Associated Risk Behaviour in Injection Drug Users in Toronto. *Canadian Journal of Public Health* 1995; 86(3): 176-180.

123 Strathdee et al. Needle Exchange Is Not Enough: Lessons from the Vancouver Injecting Drug Use Study. *AIDS* 1997; 11(8): F59-F65 at F61-F63.

124 For an overview, see D McAmmond. *Care, Treatment and Support for Injection Drug Users Living with HIV/AIDS. A Consultation Report*. Health Canada, March 1997.

125 For an analysis of the legal and ethical implications, see Canadian HIV/AIDS Legal Network. *HIV, Injection Drug Use, and Care, Treatment and Support: Legal and Ethical Issues. Report on the Consultation*. Montréal: The Network, 1998.

126 A Green et al. Physician Perceptions of HIV(+) IDUs as Barriers to Treatment. 7th Annual Canadian Conference on HIV/AIDS Research, April/May 1998. Abstract no 125.

127  For a comprehensive analysis of the history and current situation of gay and lesbian legal issues and HIV/AIDS, see Fisher et al, supra, note 20.

128  See, eg, DD Celentano et al. Self-Reported Antiretroviral Therapy in Injection Drug Users. *Journal of the American Medical Association* 1998; 280(6): 544; SA Strathdee et al. Barriers to Use of Free Antiretroviral Therapy in Injection Drug Users. *Journal of the American Medical Association* 1998; 280(6): 547.

129 S Burris. Driving the Epidemic Underground? A New Look at Law and the Social Risk of HIV Testing. *AIDS & Public Policy Journal* 1997; 12(2): 66-78 at 67.

130  Isbell, supra, note 86 at 161.

131  R Steinbrook. Battling HIV on Many Fronts. *New England Journal of Medicine* 1997; 337(11): 779-781 at 779, with many references.

132  Ibid.

133  Communication received from R Kort, Manager, National Programmes, Canadian AIDS Society, dated 26 August 1998.

134  See Gorman, supra, note 60.

135  See Immen, supra, note 57 at A1.

136  M Lenz. Länger leben heißt nicht besser leben. *Süddeutsche Zeitung*, 28 August 1997, at 8.

137  K Dong et al. Changes in Body Habitus in HIV+ Women After Initiation of Protease Inhibitor Therapy. 12th World AIDS Conference, Geneva, 1998, abstract no 12373; E Bernasconi et al. Metabolic Changes in HIV-Infected Patients Treated with Protease Inhibitors. 12th World AIDS Conference, Geneva, 1998 abstract no 12375; RK Walli et al. Peripheral Insulin Resistance Leading to Impaired Glucose Tolerance in HIV-1 Infected Patients Treated with Protease Inhibitors. 12th World AIDS Conference, Geneva, 1998, abstract no 41177.

138  D Gorden, director of communications for the San Francisco AIDS Foundation, cited in Antalek, supra, note 65.

139  Estimate by Dr J Montaner, director of AIDS research at the University of British Columbia and St Paul’s Hospital, Vancouver, as reported in Immen, supra, note 57.

140  Protease Inhibited. *POZ* March 1998, at 31.

141  Ibid.

142  Ibid.

143  See, eg, J Austin et al. A Study of Antiretroviral Drug Taking Behaviour in Persons Living with HIV/AIDS. 7th Annual Canadian Conference on HIV/AIDS Research, 1998. Abstract no 438P; R Carson et al. Drug Compliance in Patients Starting Saquinavir. 7th Annual Canadian Conference on HIV/AIDS Research, 1998. Abstract no 435P; V Montessori et al. Aggressive Therapy of Intravenous Drug Users with Primary HIV Infection. 7th Annual Canadian Conference on HIV/AIDS Research, 1998. Abstract no 442P; see also J Gray et al. Incomplete Care Experiences of Gay Men as Young Adults (Ages 28 to 40) Can Influence Adherence to Antiretroviral Therapy. 7th Annual Canadian Conference on HIV/AIDS Research,

1998. Abstract no 165P; S Laframboise et al. The Health Care Experiences of HIV-Positive Transgendered Persons Can Influence Adherence to HIV Therapies. 7th Annual Canadian Conference on HIV/AIDS Research, 1998. Abstract no 180P; C Perpête et al. Treatment Adherence: An Analytical Approach. 7th Annual Canadian Conference on HIV/AIDS Research, 1998. Abstract no 405.

144  Community Prescription Service. HIV Patients in Better Health Least Likely to Adhere to Treatment Regimens. New York, NY, Press release of 8 June 1998.

145  P Wilson, former director of public policy for AIDS Project Los Angeles, cited in Adhere Say. *POZ* March 1998, at 79.

146  Ibid.

147  D Sontag, L Richardson. Doctors Withhold H.I.V. Pill Regimen from Some. *The New York Times* 2 March 1997, at A1.

148  M Munro. Once-Promising AIDS Drugs Failing. *The Vancouver Sun*, date unknown, citing Dr J Montaner.

149  Sontag & Richardson, supra, note 147, citing Dr A Fauci, Director of the US National Institute of Allergy and Infectious Diseases.

150  Ibid.

151  Ibid.

152  Communication received from R Kort, supra, note 133.

153  See, eg, D McMurchy, R Palmer, R Throop. Who Pays for Antiretroviral Therapy in Ontario? 7th Annual Canadian Conference on HIV/AIDS Research, 1998. Abstract no 174P.

154  See, eg, Immen, supra, note 57, at A8.

155  See, eg, UK NGO AIDS Consortium. *Access to HIV Treatments in Developing Countries. Interim Report*. London, UK: The Consortium, 1997.

156  CATIE. *12th World AIDS Conference. Interim Report*. Supra, note 62.

157  *Lesbian/Gay Law Notes* January 1997, with reference to an article by L Keen in the 13 December issue of the *Washington Blade*.

158  MJ Huisman. Mistrust and Consequences – Telling Antiretroviral Fact from Fiction is no Game Show. *POZ* July 1998, at 130.

159  Isbell, supra, note 86 at 163.

160  Ibid.

161  Centre for Human Rights, Geneva. *Report of an International Consultation on AIDS and Human Rights* (Geneva, 26-28 July 1989). New York: United Nations, 1991 (HR/PUB/90/2).

162  Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS. *HIV/AIDS and Human Rights. International Guidelines*. United Nations, New York and Geneva, 1998, at 39 (HR/PUB/98/1).

163  J Dwyer. Legislating AIDS Away: The Limited Role of Legal Persuasion in Minimizing the Spread of HIV. *Journal of Contemporary Health Law and Policy* 1993; 9: 167.

164  M Kirby. Human Rights and the HIV Paradox. *The Lancet* 1996; 348: 1217-1218. Reprinted in *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 50-52.

165  ACLU. *HIV Surveillance and Name Reporting*, supra, note 85.

166  Lenz, supra, note 136, citing U Meurer, director of programs for people with HIV/AIDS, Deutsche AIDS Hilfe (German AIDS Society).

167  R Bayer. HIV Exceptionalism Revisited. *AIDS & Public Policy Journal* 1994; 9(1): 16-18 at 18.

**Return to the top of this page**

**Return to Table of Contents**

# HIV Testing and Confidentiality: Final Report

**Prepared by Ralf Jürgens**

**ISBN 1-896735-16-9**

---

# CONSENT

In light of the new developments in treatment and prevention mentioned above – but also in light of the persisting discrimination and unresolved issues and ongoing questions regarding the new treatments – this chapter reexamines the minimum conditions necessary to meet the legal and ethical requirements for voluntary HIV testing. Of particular concern here is the question whether a physician must obtain a patient's *specific* informed consent before an HIV test can be legally administered, or whether a physician can rely upon a patient's implied or tacit consent to perform an HIV test, so long as the patient provides the *general* consent necessary to obtain a blood sample for diagnostic purposes.

The chapter first summarizes the recommendations made by Canadian organizations since 1986 (History). It then briefly examines the current situation, noting that HIV testing without specific informed consent is not infrequent in Canada (Current Situation). The chapter considers whether, because of the changing nature of AIDS, physicians should no longer have to obtain a patient's specific informed consent before an HIV test can be legally administered (Assessment). It concludes that, recent developments notwithstanding, the arguments for specific informed consent remain as pertinent as they ever were. Indeed, it can be argued that obtaining specific consent to testing is ethically and legally required. The chapter concludes that, as a general rule, HIV testing in Canada should only be undertaken with the specific informed consent of the person being tested (Recommendations). Finally, the chapter analyzes whether any exceptions should be made to that general rule. It concludes that there are two exceptions: (1) the testing of donors of blood, organs, semen, or similar bodily products; and (2) testing performed as part of an anonymous (unlinked) HIV screening program for epidemiological or research purposes, provided the Guidelines on Ethical and Legal Considerations in Anonymous Unlinked HIV Seroprevalence Research are followed (Exceptions). The chapter does not address the question whether – as a further exception to the general rule requiring informed consent of the person being tested – mandatory or compulsory testing of specific groups of the population, such as pregnant women, newborns, health-care workers, prisoners, etc, is justified. This question is addressed in the chapter on mandatory or compulsory HIV testing.

# History

## Canada

Organizations in Canada that have studied the issues raised by HIV testing since 1986 – in particular, the CBA-Ontario, NAC-AIDS, the Royal Society of Canada, the F/P/T Advisory Committee on AIDS, the Parliamentary Ad Hoc Committee on AIDS, the Ontario Law Reform Commission, the AIDS Committee of Ottawa, the Canadian Public Health Association, and the Canadian Medical Association –have all concluded that HIV testing should generally only be undertaken with the voluntary, informed and specific consent of the person being tested.168 As stated by the Royal Society of Canada, "[i]ndividuals seeking testing should be fully informed of the risks and benefits of the test and should give informed consent before being tested.169 Specifically, as the third edition of the CMA *Counselling Guidelines for HIV Testing* states,170

- 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 for 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.171

## International Developments

The Canadian recommendations are consistent with recommendations in other countries that insist that testing must only be undertaken if voluntary, ensuring informed consent and confidentiality.

The issue of non-consensual diagnosis first gained prominence in the HIV/AIDS context when the British Medical Association passed a motion in 1987 stating that "testing for HIV antibodies should be at the discretion of the patient's doctor, and should not necessarily require the consent of the patient." After concerns were expressed about legal liability, the Association obtained a legal opinion warning that non-consensual HIV testing could expose doctors to liability for assault or negligence.172 Subsequently, other medical bodies obtained legal opinions that, for different reasons, generally endorsed the view that the law requires doctors to obtain patients' specific consent to HIV testing.173 This view now enjoys considerable support.174

In Australia, the Legal Working Party of the Intergovernmental Committee on AIDS has recommended the introduction of a legal provision requiring specific informed consent to HIV testing,175 together with the establishment of a Medical Ombudsman or Health Complaints Authority in each jurisdiction to investigate health complaints. Similarly, the New South Wales Anti-Discrimination Board,176 as well as the New South Wales Ministerial Review HIV/AIDS Legal Working Party,177 have recommended the introduction of an "informed consent" provision, although this has been rejected by the Health Department on the basis that the common law "adequately addresses these concerns."178 Other examples include the national AIDS policies in Switzerland and the Netherlands that also seek to ensure that testing is always voluntary, with the informed consent of the person being tested.179 In France, a Circular adopted in October 1987, summing up the conditions for voluntary HIV testing in the health-care setting, states that patients must be informed in advance of HIV testing, and their free consent obtained.180

## Current Situation

Despite the consensus expressed in the above recommendations that HIV testing should only be undertaken with the informed and specific consent of the person being tested, it is becoming more and more apparent that individuals seeking medical services are sometimes tested for HIV without their knowledge or permission:

There are reports of physicians and hospitals in Ontario having performed HIV antibody tests without obtaining specific informed consent, relying instead on the implied consent to treatment and blood tests that hospital patients typically provide. This is often called "routine" HIV antibody testing – that is, testing without the specific informed consent of the patient [references omitted].181

Two incidents that occurred in a Montréal hospital in 1995 illustrate the problems raised by "routine" testing.182 In the first case, a man was admitted to Notre-Dame Hospital after suffering an epileptic seizure. Soon after his arrival he was tested for HIV without his knowledge and consent. One week later, he was told by a neurologist that he was HIV-positive and suffering from an AIDS-related neurological disorder. The neurologist then abruptly left the room without providing any further information or counselling. It was only the next day that the patient was offered counselling and psychological support. One month later, the patient gained access to his medical file and discovered that, while he had indeed been tested for HIV, the results of the test had come back five days after the doctor had told him that he was HIV-positive and that he had in reality tested negative.

In a second case, only a few weeks after the first, another patient at Notre-Dame Hospital was tested for HIV without his consent. The patient learned about the test and the positive result weeks after the test. As in the first case, the doctor offered no counselling or information. She simply referred him to a clinic and wished him well.

Unfortunately, such cases cannot be regarded as isolated breaches of patients' rights limited to a particular hospital. In 1995, many of the over 60 individuals and organizations consulted during Phase I of the Network/CAS Project on Legal and Ethical Issues Raised by HIV/AIDS expressed their concern about the fact that HIV testing was frequently being undertaken without obtaining the specific informed consent of the person being tested. According to David Thompson, the Montréal lawyer who represented the two patients tested at Notre-Dame Hospital, individuals admitted to hospitals are routinely being tested for HIV without their consent.183 A report prepared by the Centre for Bioethics of the Clinical Research Institute of Montréal contains testimony that tends to confirm this.184 A study of women living with HIV in Montréal showed that one of eight white, non-injecting, drug-using women, and one of four Haitian women and women of African origin participating in the study had been tested for HIV without their knowledge.185 In their submission to the OLRC, the AIDS Committee of Ottawa reported that it knew of doctors who routinely neglected to seek the consent of patients before testing for HIV.186 In addition, a survey of Québec doctors revealed that a third of the physicians participating in the survey approve of testing for HIV without the patient's authorization.187 Finally, many of the people interviewed for the discussion paper on *HIV Testing and Confidentiality: Issues for the Aboriginal Community*188 reported concerns that HIV testing in Aboriginal communities was often being undertaken without the specific informed consent of the person tested.189

HIV testing in the absence of patient knowledge has been a problem also in other countries. For example, a study investigating privacy issues relating to HIV/AIDS carried out in 32 organizations in five Australian and New Zealand cities showed that "surreptitious HIV testing for diagnostic purposes remains a problem."190 This was consistent with a study of Western Australian doctors that revealed that 74 percent of doctors questioned did not believe that patient consent was always necessary before ordering HIV tests.191 In South Africa, the Law Commission was told by members of the public, health-care workers, and AIDS organizations that "many patients are subjected to HIV tests without proper informed consent at public and private health care facilities."192

What motivates doctors to test patients without their consent? Many US hospitals have said that concern about transmission from patient to health-care providers constitutes one factor.193 Some doctors feel that, in order to be able to protect themselves, they need to know patients' HIV status, contrary to the principle that precautions need to be applied universally. In addition, some doctors may want to exclude HIV without unnecessarily worrying a patient. Generally, many do not seem to understand why HIV testing should be treated differently from other medical tests. One doctor, responding to legal opinion that specific consent to HIV testing may be legally required, wrote:

> When will all this nonsense end? Has an anaemic patient to be asked for informed consent and submitted to counselling before a specimen of blood is taken to exclude leukaemia? Has every middle-aged smoker to be told before he consents to chest radiography that the film might show lung cancer? AIDS is a horrible disease, but so was tuberculosis and so is lung cancer. How can there be any hope of controlling AIDS while the leaders of the medical profession actively discourage its diagnosis?194

## Assessment

> In light of the serious consequences of a patient learning that he or she is HIV infected, there is no reason not to insist on informed consent before any blood or other body fluid is taken for testing for the AIDS antibody.195

> *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 in the early 1990's. *It is therefore wrong and misguided to view HIV testing as "routine" and as no longer requiring the safeguards of confidentiality, counseling, and consent* [emphasis in original].196

> Potential ostracism as a result of testing demands that a number of safeguards be adopted in any situation where an individual is to be tested for the presence of HIV antibodies. Informed consent enables a person to determine whether the test can address his motives for being tested.197

Although it is possible to appreciate that some doctors are asserting that it is time to "return AIDS to the medical mainstream"198 and to allow for testing without specific consent, it is important at this juncture to resist the pressure for routine testing. Clearly, the benefits from testing for the individual have increased dramatically. However, the potential harms remain significant:

> For many reasons HIV-related testing is easily distinguished from most standard blood tests. Of prime importance is the fact that the personal, social, and financial consequences of being identified as HIV-infected can be severe.199

As Turkington has pointed out, testing for HIV is unlike testing for cholesterol or other conditions in the blood that involve no significant risk of adverse consequences to the subject if the condition is known. According to him, "comparing testing for cholesterol with testing for HIV is like comparing firecrackers to the hydrogen bomb."200 Field also emphasizes that, "just as AIDS is like no other disease we have known, potential consequences of testing to detect HIV antibodies are unparalleled in our society":

> Testing can have enormous consequences that reverberate throughout all spheres of life. The knowledge by other parties that an individual tested HIV positive, or merely the knowledge that an individual was tested at all ... can cause serious harms.201

As shown above,202 in 1998 HIV-related stigma and discrimination remain pervasive in Canada and, in many ways, HIV/AIDS remains different from other diseases: whereas most illnesses produce sympathy and support from family, friends and neighbours, people with HIV or AIDS continue to suffer stigma and discrimination. Given that the possibility of stigmatization and of discrimination continues to be an ever-present threat to the social well-being of people with HIV, the arguments for specific informed consent remain as pertinent as they ever were. This has recently been acknowledged in the International Guidelines on HIV/AIDS and Human Rights, according to which, "apart from surveillance testing and other unlinked testing done for epidemiological purposes, public health legislation should ensure that HIV testing of individuals should only be performed with the specific informed consent of the individual."203

Further, as pointed out by Bayer, even though the clinical picture has improved dramatically, the moral grounds for insisting on informed consent before HIV testing have not changed. It is an established principle of medical ethics that competent adults have the right to determine which treatments they undergo, and the right to terminate such treatments. By extension, this principle – which limits the paternalistic authority of the physician in the interest of the patient – gives competent adults the right to determine whether they want to undergo testing that would serve as the basis for commencing treatment.204 As Magnusson has said:

> Control over what happens to one’s tissue after it has been removed from the body is consistent with the growing recognition of the importance of patient autonomy, both in law and ethics. If patients have the right to refuse medical treatment and the right to be fully apprised of material risks associated with treatment, they would also seem to have the right to veto ... unwanted and

> sensitive diagnostic investigations. This argument makes sense if the doctor–patient relationship is regarded as one in which the doctor has a duty to act primarily in the patient's interests, rather than his or her own.205

In addition, from an ethical perspective, as Magnusson points out,

> surreptitious HIV testing does create difficulties for the individual doctor. If the patient tests positive, the doctor will be placed in the difficult position of having to inform the patient of a distressing result obtained surreptitiously. ... Failure to tell a patient that he or she has been diagnosed as HIV-positive is clearly unethical.206

The issue of whether specific and informed patient consent to HIV testing is *legally* required is a matter of some dispute and has not been decided by a Canadian court. The issue was left open by the Court of Appeal of Ontario in *Canadian AIDS Society* v *Ontario*:

> With respect to the appellant's submissions based upon the *Charter of Rights and Freedoms*, we are prepared to assume, for the purpose of deciding this appeal, that Wilson J. was correct in determining that there was no consent to the testing of the samples in question. Our hesitancy to make a finding on the issue of consent, where it appears unnecessary to the ultimate decision, stems from the difficulty in differentiating between the legal obligations in 1984 and 1985, when the donations of blood were made, and the developing sense of moral obligation to have informed consent as revealed in subsequent debate directed to the AIDS issue. *It is better that the issue of whether this sense of a moral obligation is a legal one be decided in a case which depends upon this issue for its result* [emphasis added].207

However, it would seem that obtaining specific and informed consent is also legally required. In particular, it has been argued that the fiduciary quality of the doctor–patient relationship, which requires doctors to show a high degree of loyalty to their patients, requires that doctors obtain specific patient consent to "such tests as the reasonable person in the patient's position would wish to be informed of specifically, and counselled over, as well as such tests as the doctor should reasonably be aware that the specific patient would wish to be informed of specifically or counselled over."208 In applying this test, the conclusion reached is that an HIV test should generally not be performed without specific and informed patient consent, because of the stigma attached to the test results, the potential for discrimination and loss of privacy, and the importance for the test subject of pre-test counselling.209 This is consistent with the conclusion reached by Stoltz, who, after reviewing Canadian jurisprudence on the right to give or refuse consent to medical treatment and professional guidelines for physicians that have clarified the standard of care expected of physicians when conducting HIV testing, concludes that "a physician who conducted an HIV test on a patient without meeting the basic elements of the doctrine of informed consent as prescribed in detail by the *CMA Guidelines* would be vulnerable to both a civil action for damages by the person so tested, as well as prosecution for professional misconduct by his or her licensing body, for the failure to meet adequate standards of practice."210

To ensure that, in practice, physicians fulfil their legal and ethical obligations and undertake testing only with the specific informed consent of the person being tested, the OLRC has recommended that a comprehensive, HIV-specific statute governing HIV-related testing and the protection of HIV-related information be enacted and that the statute provide that no HIV-related test be performed without the voluntary, specific, and informed consent of the patient.211 Legislation that requires a patient's informed consent to HIV testing and prescribes fines or other penalties for the contravention of these laws already exists in some states in the US and in Australia. New York State, for example, requires written proof of the informed consent of a patient before the laboratory processes an HIV test request.212 In Australia, the *HIV/AIDS Preventive Measures Act* 1993 of Tasmania requires that an HIV test shall not be performed without the (specific) consent of the test subject.213

Adoption of policies at the hospital level can also contribute to ensuring that the importance of obtaining a patient's specific and informed consent to HIV testing is understood. Such policies should explicitly exclude HIV testing from general consent to medical testing, specifying that HIV testing should only be undertaken with the specific informed consent of the person being tested.

One respondent to the *Discussion Paper* recommended that a standard consent form be drawn up and

> systematically given to every Canadian undergoing HIV testing for their perusal and signature. The contents of the written form could act as a stimulus for patients who did not receive adequate counselling to ask the appropriate questions. The signed form could be filed in the patient's file or could be forced to be attached to the requisition accompanying the blood sample. In the case of anonymous testing, the patient could simply "sign" their identity code. Because hospital policies and recommendations ... are non-binding and obviously ignored in some cases, this may offer a greater level of compliance.214

# Recommendations

> **1.1 Recent developments notwithstanding, the arguments for specific informed consent remain as pertinent as they ever were. As a general rule, HIV testing in Canada should only be undertaken with the specific informed consent of the person being tested.**
>
> **1.2 Hospitals and colleges of physicians should adopt policies on HIV**

> **testing specifying that HIV testing should only be undertaken with the specific informed consent of the person being tested.**
>
> **1.3 Physicians should routinely offer information about HIV-antibody testing to all patients, but never test without specific informed consent, for two reasons: potential harms from testing, and respect for the autonomy of patients.**

# Exceptions

These recommendations notwithstanding, there may be situations in which exceptions to the principle that no HIV-related test should be performed without the voluntary, specific, and informed consent of the patient could be justified. This section identifies two such situations.

## Testing of Donors

The mandatory HIV testing of donors of blood, organs, tissue, ova, semen, or other human body parts and fluids has been universally endorsed as an essential and effective means of preventing the spread of HIV.215 Although the current test will not detect all HIV-positive donors, the introduction of HIV testing has nonetheless greatly improved the safety of the blood supply.

> **1.4 The general rule that HIV testing in Canada should only be undertaken with the specific informed consent of the person being tested does not apply to the testing of donors of blood, organs, semen, or similar bodily products. In all cases of donations, prospective donors should be informed before the performance of the test that an HIV-related test will be conducted, and given adequate information about the nature and purpose of the test.**

## Testing for Research Purposes

A more controversial issue than the testing of donors of blood, organs, semen, or similar bodily products is whether epidemiological screening should be allowed without informed consent.

With the introduction of a test for HIV in 1985, it became possible to investigate how widespread the epidemic had become and to monitor how patterns of infection were evolving. Information of this kind is of great value in designing, implementing, and monitoring programs for the prevention and control of HIV. Voluntary or compulsory testing cannot provide this information because it provides a flawed view of the prevalence of HIV in the population. In a voluntary testing regime, those who are at highest risk of HIV infection and people who are otherwise marginalized in society may be over- or under-represented in the group of individuals tested. Similarly, mandatory testing or screening will not provide information of sufficient accuracy or completeness for public health surveillance purposes, as persons at risk of HIV infection may selectively avoid contact with health services or testing activities, creating unpredictable participation bias.216

Therefore, as an alternative to voluntary or mandatory testing of individuals for epidemiological research, unlinked anonymous screening (UAS) programs have been undertaken. UAS, also known as "blinded" testing, is performed by systematically testing samples of blood left over after having been collected and tested for medical reasons other than testing for HIV.

## History

### International Developments

In the United States, research using UAS provoked little controversy when first proposed,217 and was first undertaken in 1986.218 In the United Kingdom, Sir Richard Doll, chair of the Subcommittee on Epidemiology of the British Medical Research Council's Working Party on AIDS, proposed such research in 1987.219 Initially, objections were raised in the medical, ethical, and legal communities. A compromise was reached to allow UAS to proceed, with a well-publicized opting-out provision,220 and in 1988 the United Kingdom began a series of studies using UAS.221 Studies have also been carried out in Australia, and "have provided useful epidemiological information about the spread of HIV into the heterosexual community."222 In 1989, WHO endorsed the use of UAS in the gathering of epidemiological data on HIV and stated that the following criteria must be observed if UAS is to be carried out:223

> - Prior to implementing UAS, it is essential to conduct a thorough discussion of the ethics of UAS in the social and cultural context of the country where it is to be implemented. If it is against established national public health policy, UAS should not be implemented. If the proposal for UAS originates in one country but is conducted in another, it should be reviewed by both an ethical review committee in the country of origin, as well as its equivalent in the host country.
>
> - Specimens for UAS should have been taken with appropriate consent for other purposes. To take blood primarily or solely for UAS would raise serious ethical concerns. The volume of blood taken should be the minimum necessary and should be, at most, only marginally greater than that required for the other tests for which the blood was originally obtained.
>
> - No information should be requested in addition to that normally collected for the primary purpose for which the blood specimen was obtained.

- All data that could potentially identify the individual must be removed from the specimens set aside for UAS before they are tested by the laboratory.

- Protocols for UAS should be carefully reviewed to ensure that there is no possible way in which test results could be traced back to individuals; that studies are designed to maximize the likelihood of obtaining data useful for surveillance purposes; and that staff are trained to adhere to the UAS protocol, and supervised to avoid breaches of anonymity.

- Voluntary testing (confidential or anonymous) with counselling should be available wherever possible to populations in which UAS is being carried out, so that those individuals who wish to know their HIV-infection status can do so.

- The resources devoted to UAS should be commensurate with its value for surveillance, as one part of a comprehensive HIV/AIDS prevention and control program. UAS should not detract from other important public health objectives.

- Health-care providers should be made aware that the specimens drawn by them from patients may be used for unlinked anonymous HIV screening.

- In areas with low HIV prevalence, pooling of sera collected for UAS might be considered.

In addition, WHO suggested that the following questions be considered to ensure that the criteria and the standards of the surveillance program are respected: How will the public be informed of UAS in a way that they will not be deterred from using health-care services where specimens may be obtained for UAS? How will health-care providers and the public be informed and assured of the appropriateness and anonymity of UAS? How will services be targeted to population groups found to include HIV-positive individuals? What information (eg, age and sex) will be retained with the blood sample, given the need to guarantee anonymity and yet obtain the most useful data for surveillance purposes? And finally, how will UAS findings be presented in order to reinforce other HIV/AIDS prevention and control activities?

In Australia, as reported by Magnusson, the Australian Health Ethics Committee circulated a discussion paper in 1993 that considered ethical issues relating to use of human tissue in research. The discussion paper recommended against obtaining "blanket" consent from patients for research using their tissue, preferring instead that institutional ethics committees consider research proposals on a case-by-case basis. It recommended that the committees decide whether to waive a requirement of "informed consent," taking into account the type of issue involved, the nature of the research, whether the patient or family might have an interest in the research results, whether seeking consent might cause needless anxiety, and the possibility of commercial application.224

## Canadian Developments

In October 1987, NAC–AIDS recommended that federal health authorities undertake or support the collection of seroprevalence data through UAS.225 In 1988, the Royal Society of Canada, the National Health Research and Development Program and the Federal Centre for AIDS proposed the execution of UAS studies. In particular, the Royal Society of Canada identified UAS as the preferred avenue for achieving the goal of HIV epidemiological surveillance.226

### *The Federal Guidelines*

In October 1988, the Federal Centre for AIDS struck a working group to establish guidelines for the use of UAS in research. The group identified the following advantages of using the unlinked research design: it provides accurate estimates of the prevalence of HIV infection by avoiding the self-selection bias inherent in all voluntary studies, is non-invasive, ensures personal privacy since test results cannot be linked to individuals, and is cost-effective.227

The working group felt that the ethical and legal concerns raised by UAS would not preclude its use, provided certain requirements could be met. In 1991, the working group reconvened and modified the guidelines, establishing that:

- Universal access through the health-care system to individual voluntary testing under prescribed conditions of informed consent, counselling before and after testing, and confidentiality would be a prerequisite. People whose leftover serum may be included in unlinked population studies must have access to appropriate diagnostic services to obtain information concerning their HIV-antibody status.

- Only leftover serum routinely obtained for other purposes would be used.

- Records would be permanently unlinked before testing, so that it would be impossible at any time to identify individual test results.

- No information that might lead to the identification of individuals would be used. No sample small enough to identify individuals would be reported. Careful consideration must be given to balancing the public health need to know with the risks and benefits to any subgroups that might be identified through data analysis.

- Study populations would be informed of the research through clear and balanced communication with the public. Individual informed consent would not be relevant, since the research would be using leftover serum samples. It would be impossible to link test results to any individual. Data would be generated on a population, not on the individuals who constitute the population.

- Refusals undermine the value of unlinked research by introducing an unknown statistical bias. It is not ethically necessary to include a provision basis for an individual opting out of unlinked HIV seroprevalence research. However, spontaneous refusals should be honoured in the interests of long-term public support for unlinked research.

- Health-care personnel would be informed about the unlinked HIV seroprevalence research.

- An appropriate contact number of the research or public health authority would be readily available so that patients and health-care personnel could discuss the research and any spontaneous refusals.

- The research would have to meet the approval of the relevant institution’s ethics review committee.

- Careful justification would be required for the conduct of unlinked HIV seroprevalence research in target populations vulnerable to discrimination. Benefits to the group must clearly outweigh the potential harm. Careful consideration must be given to the communication of results. Representatives from target populations should be involved in this decision-making process.

- All these requirements would apply to the use of banked serum samples in unlinked HIV prevalence research.228

### *Other Approaches*

In 1991, Sharpe and the Ontario Ministry of Health proposed other ways of approaching UAS. Sharpe recommended that an individual’s informed consent should be a prerequisite for HIV testing, even in the case of UAS. Exceptionally, however, this requirement could be waived if, on application to a Provincial Health Ethics Monitoring Committee, a compelling public interest for overriding informed consent could be shown. Ideally, the committee’s decision-makers would be representative of both the general public and the particular group targeted for UAS.229

The Ontario Ministry of Health recommended that, while informed consent need not be obtained from the subjects of UAS studies, the subjects be provided with "specific information" about the seroprevalence study; and that, if a subject chooses to "opt out" of the study, that choice be respected. This recommendation flowed from the Ministry’s finding that although a requirement of informed consent may jeopardize the accuracy of the epidemiological research, individuals still have the right "to know what will happen to their bodily fluids and parts when removed if something other than what one would reasonably assume would normally be done is planned."230

With regard to UAS studies in Aboriginal communities, the Joint National Committee on Aboriginal AIDS Education and Prevention recommended in 1990 that they "be undertaken within Aboriginal communities but that these studies be contingent on the approval of the community."231 More recently, a discussion paper on UAS studies in aboriginal communities commissioned by the 2-Spirited People of the 1st Nations (the TSPFN paper) raised numerous objections to such studies, saying that they involve an "unwarranted breach of medical research principles," exploit vulnerable populations, do not provide accurate, meaningful, and relevant data, "involve the conscription of individuals into research studies," and may lead to the discrimination of sub-populations surveyed.232 The paper summarizes the results of a survey of Aboriginal views and perspectives on the moral, social, ethical, and legal implications of blind HIV studies in Aboriginal communities. According to the 83 survey participants, HIV surveillance data should not be collected by Health Canada without personal consent; chiefs and councils or provincial/ territorial organizations cannot authorize Health Canada to undertake blind HIV testing of an Aboriginal population area; "individuals and the community are the best persons to authorize this form of HIV surveillance"; and, generally, the benefits of blind HIV testing in Aboriginal communities may not outweigh the negative aspects, "which include racism, discrimination, harm to various groups, and the creation of mistrust and barriers to Aboriginal access to mainstream health services."233 In addition, the paper questions whether the Federal Centre for AIDS guidelines on UAS research are up-to-date, pointing out that "ethical and legal guidelines will shift with each new clinical or medical breakthrough in the treatment of HIV/AIDS infection." Finally, people consulted in the preparation of the 1998 discussion paper on *HIV Testing and Confidentiality: Issues for the Aboriginal Community*234 also expressed many concerns, reflected in the following comments:

> There is frustration among Aboriginal people about control over HIV research and data on Aboriginal populations. There is scepticism about whether these studies will benefit Aboriginal people.
>
> There is concern that blind studies could create another avenue for discrimination against Aboriginal people and groups within Aboriginal communities such as pregnant women, two-spirited people and drug users.
>
> Testing should be based on community needs and interests. Blind studies do not help individuals who have HIV and they can divide the communities in which they are conducted.235

Since 1996, "to more fully involve Aboriginal people in the design, implementation, collection, interpretation, and dissemination of HIV/AIDS epidemiological information so that prevention and care programs for Aboriginal people may be better targeted and evaluated,"236 Health

Canada has supported three activities to involve Aboriginal people in the process of HIV/AIDS information collection: an annual Aboriginal HIV/AIDS Surveillance and Research Meeting, the development of an Aboriginal Working Group to advise Health Canada on HIV-related surveillance and research issues, and the dissemination of HIV/AIDS information to Aboriginal communities. In particular, the LCDC Aboriginal Working Group on HIV/AIDS Surveillance and Research has developed a draft ethical evaluation checklist which was submitted to the 1998 3rd Annual Aboriginal HIV/AIDS Surveillance and Research Meeting.237 The checklist is based on different work in progress, namely the Code of Research Ethics of the First Nation and Inuit Regional Health Survey Project, the Code of Research of the Kahnawake Schools Diabetes Prevention Projects, and the Model Tribal Research Code developed by the American Indian Law Center Inc. Its purpose "is to provide a set of questions that may be asked of the HIV/AIDS study proponents by the regional/local Aboriginal health authorities and a set of considerations which these authorities may want to ask during its deliberations." The draft checklist reads as follows:

> Principles of a code of ethics
>
> 1. Studies must require informed and voluntary participation of communities.
>
> 2. Discussion with the potential participants at the beginning must reinforce that they can withdraw from the study at anytime and also that the community owns the research in conjunction with the researchers.
>
> 3. Researchers must guard against real and perceived coercion of participants in the studies.
>
> 4. Study protocols must be reviewed and approved by an ethics committee which would be comprised of representatives of the intended study group.
>
> 5. The use of data without specific informed consent is not acceptable.
>
> 6. The use of data for other than what it was intended for is not acceptable.
>
> 7. Protection of study participants must consider the implication of post-research use and findings.
>
> 8. Strong security measures during data collection and analysis.
>
> 9. All research is to be conducted within legal requirements defined by laws on privacy and confidentiality.
>
> 10. Researchers must take every measure to minimize the negative impact

the studies might bring on individuals and the community.

11. Researchers must enhance capacity of Aboriginal people in doing research.

## Ethical Review Questions

1. What is the goal and the purpose of the project?

2. Who are the targeted populations? (Does this current project acknowledge various sub or high risk populations within the larger study population ? How can these groups be reflected when collecting and analysing data?)

3. Why do you think the project is needed?

4. What are the expected benefits of the project?

- To the participating subjects

- To the community as a whole (please describe the skills the community will develop by being involved with your project; Will the project bring some education and prevention programs or direct support programs to the community?)

- To the society as a whole

5. What are the anticipated negative outcome of the project?

- To the participating subjects

- To the community as a whole (to what extent can you determine community reaction or bias to HIV/AIDS issues pertaining to the targeted populations? To what extent might other social issues influence HIV/AIDS problems in Aboriginal communities? Have other projects been performed within the last few years ? If yes, what are the reactions and participation rates?)

- To the society as a whole

6. How will you evaluate the project?

7. Community participation:

a) Have you consulted with the community?

b) Have the involved community been reasonably informed via such mechanisms as Band or Tribal Council Resolutions and public announcements via radio, posters in strategic locations, community information sessions and educational training for community staff?

c) Have you utilized the first languages spoken within the targeted populations in radio announcements?

d) What measures of HIV/AIDS education have been delivered to the targeted populations, prior to this research project ? Have they been provided more recently in any strategic manner, including more captive audiences who might otherwise not attend community sessions? How educational messages are selected for this purpose?

e) Have you taken time and effort to educate political and community leaders before we engage in this particular project?

f) Has the community had the opportunity to review and comment on the research proposal prior to being developed?

g) Have you formed an ethics committee comprised of members from the community,

h) What mechanisms are in place to provide some transparency and address negative reactions or criticisms, and offer assurances that ownership rests with the Aboriginal community/leadership?

i) What procedures will maximize the interpretation and analysis of collected data?

- Are you using the same measuring stick, if so, what are we comparing Aboriginal data to?
- Have you allowed community analysis to indicate how and where this data might influence community programming?
- Have you clearly outlined how comparing Aboriginal to non-

> Aboriginal might create stigma or tainted analysis? How can language be used or changed to avoid further stigmatization?

*Current Situation*

As of April 1998, 90 HIV prevalence and incidence studies had been conducted in Canada, 30 of which involved UAS.238 However, in Ontario, UAS studies effectively came to a halt following public statements by the then provincial Minister of Health in which she expressed her disapproval of testing for HIV without informing those who test positive.239 In Québec, UAS studies came to a halt for a different reason: Article 22 of the province's new Civil Code, which entered into force on 1 January 1994, provides that "[a] part of the body, whether an organ, tissue or other substance, removed from a person as part of the care he receives may, [only] with his consent or that of the person qualified to give consent for him, be used for purposes of research."

## The Debate

> The design of an HIV surveillance methodology should maximize the likelihood of obtaining useful and accurate epidemiological information about the distribution of HIV infection in the community. Simultaneously, the design should minimize the likelihood of adverse individual or community consequences.240

UAS programs have remained controversial, for three reasons:

- the lack of informed consent to testing for HIV: according to some, informed consent is necessary even if test results are unlinked;

- those testing positive are not informed of their test results: particularly in light of the availability of promising new treatments, some say that this is unethical; and

- the harm that could arise if a study indicated a high incidence of seropositivity in a particular group, or if a group surveyed was so small as to allow for identification of particular participants as being HIV-positive.

The underlying conflict is between the ethics of epidemiological research and the ethics of clinical intervention.241

### Informed Consent

Undertaking UAS would appear to be contrary to the principle that no person should be tested without their informed consent. Blood samples tested in a UAS survey are drawn for other purposes; the possibility of their being screened for HIV is not mentioned to the patients.

Therefore, the patients’ consent extends only to testing for the purposes of which they were made aware and to which they agreed.

On the other hand, one could argue that by virtue of the anonymity of UAS (the decoupling of the individual and the test result), consent is not required because testing cannot harm the individual whose blood sample is tested; no one has to learn of their serostatus against their will. It may further be argued that UAS should raise no ethical objections because the rights of individuals over their body products do not extend this far – the surplus blood used for UAS should be considered a form of waste. It has been said that no one would be justified in opting out of a properly designed UAS "anymore than a pacifist should expect a guarantee that their aluminum drink cans returned for recycling must never be used to produce weapons."242 Unlinking the test effectively means that no individual, as an individual, has to participate in the test and therefore has no grounds on which to object. The object of the test is a sample, not a person.

Many, however, remain unconvinced by such arguments. For them, consent is a "strong" right and is never irrelevant.243 Consequently, any derogation from this principle would have to have a very compelling justification. In some countries, such as the Netherlands, UAS studies have been halted because individual rights are seen as too important to be compromised in this way.244 In Australia, blind neonatal heel-prick studies have been condemned, and the head of the New South Wales Anti-Discrimination Board is on record as saying "that as a matter of principle the committee is opposed, fundamentally, to the testing of any person without their knowledge ... and consent."245

Critics of UAS have pointed out several curious ironies in the justifications offered by the supporters of blinded studies. First, they find it odd that individuals are said to have no rights over their "surplus" body fluids, yet for some reason the community at large can claim for itself the right to decide what happens to the "surplus" body fluids. Second, they point out that some supporters of UAS, fearful of biasing their survey samples, see no need for – or even any possibility of – allowing individuals to opt out of blind surveys. At the same time, they feel that it is necessary to inform the public about the use to which samples are put. As David Coburn of the Patients’ Rights Association of Ontario said, "[i]t is an unhappy ethical dilemma then to claim to want to inform and yet not really to inform nor permit choice."246

## Knowledge of HIV Status

> With the existence of improved clinical drugs ... the pressure to stop blind screening has increased. ... The argument is that it is morally difficult for the state to indirectly know an individual’s HIV status when a treatment exists. As Levine states, "Now that there are grounds for advising those who may be infected with HIV to seek testing and early therapeutic intervention, the pressure is building to unblind seroprevalence studies for this purpose."247

Some say that the anonymity of UAS – the very feature that according to others justifies exempting UAS from the requirement of informed consent – is what makes UAS ethically wrong. The unlinking of test results from their subjects means that those testing HIV-positive will not learn of their serostatus, "coldbloodedly leaving them in the dark" and depriving them of the opportunity to seek medical advice and to modify their behaviour to avoid passing the virus to others.248 The situation is sometimes compared to the infamous experiment conducted in Tuskegee, Alabama, in which poor, African-American men were tested for syphilis but not told if they were infected, so that the progression of the disease when left untreated could be studied.249

Those who support UAS counter that, as long as there is universal access to voluntary HIV testing, individuals who wish to know their serostatus can do so. But critics of UAS reply that some people may not suspect that they have been exposed to HIV and as a result do not seek testing: they may have no other way of finding out that they are living with HIV. This has led to calls for relinking identifying data to the test results so that no one will have the "benefit" of having their serostatus "withheld" from them. In October 1995, Governor Pataki of New York State, in response to a lawsuit, announced a plan to transform the state’s UAS program for testing newborns for HIV into a testing regime that allows the linking of test results to the individuals.250 A similar situation developed at the federal level. A bill was introduced in Congress that would have replaced UAS monitoring of HIV in newborns with a program of mandatory testing. The representatives who introduced the bill found it morally objectionable that the CDC conducted testing that did not allow HIV-positive babies to be identified and treated. Although the bill was eventually modified, the CDC abandoned its seroprevalence studies of newborns at the end of 1995.251

In Canada, calls for relinking identifying data to HIV test results so that no one will have the "benefit" of knowing their serostatus "withheld" from them are also not new. Many months into the Commission of Inquiry into the Blood Supply in Canada (the Krever Inquiry), it was discovered that the Canadian Red Cross Society had, before the HIV test became available, collected blood samples from donations in the Toronto area for the purpose of studying the incidence of hepatitis B in the blood supply. Because it anticipated that a similar study might one day become possible for HIV, the Red Cross kept 175,000 blood samples. No action was taken, however, until the Krever Inquiry revealed the existence of these samples. Despite expert advice, the decision was taken not only to carry out testing of the samples for HIV, but also to link the results and inform the test subjects of their serostatus. CAS went to court to prevent this, arguing that it would amount to compulsory HIV testing of individuals without their consent. The judge disagreed, stating that "[t]he fact that some of the donors whose blood is found to be HIV positive might object to being told of that fact because of the effect that might have on them, cannot overcome the need to do whatever is necessary to prevent the spread of what has been described as an epidemic."252 CAS appealed the decision, but the appeal was dismissed in a decision rendered on 29 November 1996. However, as mentioned above, in its decision, the Ontario Court of Appeal did not decide on the issue of consent.253

## Harm to Participants

Harm could arise if the group surveyed in a study was so small as to allow for identification of particular participants as being HIV-positive,254 or if a study indicated a high incidence of seropositivity in a particular group that could lead to discrimination against all members of the group.

With regard to the latter issue, the report of the OLRC maintained that data collected from properly conducted epidemiological studies are extremely important for the purposes of targeting prevention efforts and planning for future health-care services, and "justify any indirect harm to populations or demographic areas."255 In contrast, while they agree that UAS research is important, the Federal Centre for AIDS guidelines – as mentioned above – emphasize that careful justification is required for the conduct of such research in target populations vulnerable to discrimination:

> Benefits to the group must clearly outweigh the potential harm. Careful consideration must be given to the communication of results. Representatives from target populations should be involved in this decision-making process.256

With regard to UAS studies in Aboriginal populations, the TSPFN paper reports fears that UAS may create panic and hysteria in Aboriginal communities, promote racism and further stigmatize Aboriginal people, prompt "witch hunting" and harm (discrimination, marginalization, and violence) to Aboriginal gay and bisexual men and to Aboriginal women who have multiple sex partners, and weaken Aboriginal trust and use of health-care services.257

### Assessment

> Data on the prevalence, incidence, and distribution of HIV infection in a population can be used to monitor the spread of the infection, to increase knowledge of the mechanisms of transmission, to assist in the design of public health measures to prevent the spread of the disease, to evaluate the effectiveness of current interventions, and to plan for the provision of services. Collecting information for such purposes is almost universally regarded as essential to improving society's ability to cope with this epidemic.258

Unlinked anonymous screening or testing for HIV infection is not directed to the individual, but has as its objective the public health surveillance of HIV infection. It is an epidemiological method for measuring HIV prevalence in a selected population with the minimum of participation bias. By minimizing participation bias, UAS offers a distinct epidemiological advantage over voluntary or mandatory HIV testing for the public health surveillance of HIV infection. If properly conducted anonymity is not endangered, and the individual cannot be identified.259

## Informed Consent

The issue of the extent to which persons have the right to control bodily fluids and parts raises a number of very complex issues well beyond the scope of this Paper. Nonetheless,

> in the case of anonymous unlinked seroprevalence studies, where a blood sample has already been extracted for other purposes, will be discarded if not used for the study, and cannot be linked to any individual, it is not clear that the subject has a significant claim to retain all rights to control this blood sample. Moreover, this claim appears even less significant once it is weighed against the very substantial interest the public has in accurately assessing seroprevalence rates.260

Accordingly, as stated by the OLRC, it is doubtful whether a compelling argument can be made that subjects should have to provide informed consent, or be provided with "specific information" about a seroprevalence study and with an opportunity to "opt out" of the study. Such arguments are made even less compelling "by the well established fact that this procedure will compromise the quality and accuracy of the data obtained, because the persons most likely to be infected are the ones most likely to ‘opt out.’"261 However, spontaneous refusals should be honoured, as established by the revised Federal Centre for AIDS guidelines.262

## Knowledge of HIV Status

The argument that unlinked anonymous seroprevalence studies are immoral because the unlinking of test results from their subjects means that those testing HIV-positive will not learn of their serostatus, "coldbloodedly leaving them in the dark," is not convincing. As long as such studies are only undertaken where people have universal access to voluntary HIV testing, offered in conjunction with assurances of informed consent, adequate counselling and confidentiality, ethical and legal concerns raised by UAS would not necessarily preclude its use. Obviously, as demonstrated above, potential benefits from testing for individuals have increased, and people should be encouraged to be tested and seek treatment if they test positive. However, the objective of encouraging people to be tested voluntarily, with their informed consent (by making acceptable testing options easily accessible to them, by educating physicians to encourage patients to be tested, etc), should be distinguished from the entirely different but equally valid objective of obtaining data on prevalence, incidence, and distribution in a population (by conducting UAS research). As Magnusson has said:

> The legitimate objective of public health surveillance should not be confused with case-finding [reference omitted]. If surveillance is the objective, anonymous, nonconsensual testing may be necessary to eliminate the bias introduced by

> voluntary participation in prevalence studies.263

UAS research has a goal independent of voluntary individual testing and cannot serve both functions. A strong argument can therefore be made in favour of anonymous, unlinked prevalence testing for epidemiological purposes involving non-consensual use of human tissue. However, "voluntary, linked testing is a better alternative where statistical biases are unlikely to be significant, since this respects patient autonomy and enables direct intervention when HIV carriers are identified."264 In addition, in some Aboriginal communities in Canada, the requirement that "universal access to individual voluntary testing under prescribed conditions of informed consent, pre-test and post-test counselling, and confidentiality" is available, is not met – as shown in the discussion paper on HIV testing and confidentiality in Aboriginal communities, which identified numerous barriers to accessible testing.265

### Harm to Participants

> It must be recalled that although anonymous population surveys offer the greatest protection to the individuals who are involved, they do not offer complete protection to the population from which the samples were obtained. Even disclosure of anonymous data pertaining to a population could subject its members to negative repercussions. This is particularly so if the population is sufficiently small that the actual identities of the seropositive persons could be inferred. Care must therefore be taken to minimize these effects.266

If they are done properly – to protect anonymity, no study should include so small a sample of subjects that an individual's identity might be inferred, nor should any data that could similarly lead to their identification be kept – epidemiological or research studies cannot harm any *individual*. However, there is a danger that members of vulnerable *populations* or *groups* will suffer discrimination as a result of UAS studies showing an unusually high incidence of HIV infection. In-depth discussions involving vulnerable populations, researchers and funding agencies need to take place "to explore ethical and community issues, barriers and facilitators of HIV research."267 This is consistent with the 1997 *UNAIDS Policy on HIV Testing and Counselling* that encourages community involvement in sentinel surveillance and epidemiological surveys:

> HIV testing conducted for these purposes is usually anonymous and unlinked, and may not require individual consent. However, the findings of such surveys are of great community concern, and so communities need to have a sense of "ownership" of the process. Community consent should be secured before surveys are conducted, and the community should be involved in the survey and have access to the results.268

With regard to UAS studies involving Aboriginal people, the TSPFN paper and the discussion paper on HIV testing and confidentiality in Aboriginal communities are evidence of the wide range of concerns about undertaking UAS in Aboriginal communities. Most people consulted for the papers seemed to agree that there are benefits to blind studies as a method for gathering information about HIV/AIDS. One respondent to *HIV Testing and Confidentiality: A Discussion Paper* pointed out that UAS studies are important because, thus far, the lack of available data on seroprevalence in small, isolated Aboriginal communities contributes to the general opinion among many Aboriginals that HIV/AIDS has not yet reached their villages. As the respondent said: "The potential harm of not knowing about seroprevalence rates is the silent swift spread of HIV once it does arrive, if it is not already there."269 However, people consulted for the papers emphasized that better knowledge about HIV prevalence is of little use as long as HIV programs and testing facilities are not available. They stressed the need to encourage and facilitate testing based on informed consent, appropriate counselling, and confidentiality, saying that this would be more directly beneficial to Aboriginal communities and should be given priority.270 In conclusion,

> [a]nonymous unlinked HIV-seroprevalence research involving Aboriginal people should be based on the principle of Aboriginal control over and ownership of research and data. Aboriginal AIDS organizations and others in the Aboriginal community, particularly those with HIV/AIDS expertise, should direct the design of guidelines for the conduct of HIV-seroprevalence research involving Aboriginal people. Such guidelines should seek to avoid stigmatization and discrimination of specific groups involved in blind studies.271

## Recommendation

> **1.5 The general rule that HIV testing in Canada should only be undertaken with the specific informed consent of the person being tested does not apply to testing performed as part of an anonymous (unlinked) HIV screening program for epidemiological or research purposes, provided the Guidelines on Ethical and Legal Considerations in Anonymous Unlinked HIV Seroprevalence Research are followed.**
>
> **However, increased efforts must be made to reduce the potential for discrimination against groups or populations targeted by this research. In particular, before an anonymous (unlinked) HIV screening program is undertaken in a particular population, community consent should be secured. Researchers and community leaders and members must undertake all necessary steps to ensure that communities understand the advantages and disadvantages of this type of research and take ownership of the research process and outcome so that the results can be usefully applied to programming and policy with respect to HIV/AIDS.**

**Anonymous unlinked HIV-seroprevalence research involving Aboriginal people should be based on the principle of Aboriginal control over and ownership of research and data. Aboriginal AIDS organizations and others in the Aboriginal community, particularly those with HIV/AIDS expertise, should direct the design of guidelines for the conduct of HIV-seroprevalence research involving Aboriginal people. Such guidelines should seek to avoid stigmatization and discrimination of specific groups involved in blind studies.**

**Return to the top of this page**

**Return to Table of Contents**

---

# ENDNOTES

168 See, eg, CBA–Ontario, supra, note 7; NAC-AIDS, supra, note 8 at 38; F/P/T Advisory Committee, supra, note 11; Parliamentary Ad Hoc Committee on AIDS, supra, note 12 at 42 (recommendation 34); OLRC, supra, note 13; ACO, supra, note 14; CPHA, supra, note 15 at 15.

169 Royal Society of Canada, *Summary Report*, supra, note 10 at 13.

170 Canadian Medical Association. *Counselling Guidelines for HIV Testing*. Ottawa: The Association, 1995.

171 Ibid at 5-6.

172 RS Magnusson. Specific Consent, Fiduciary Standards and the Use of Human Tissue for Sensitive Diagnostic Tests and in Research. *Journal of Law and Medicine* 1995; 2: 206-232 at 210, with reference to Human Immunodeficiency Virus (HIV) Antibody Testing. *British Medical Journal* 1987; 295: 911. This chapter draws extensively from Magnusson’s work on consent.

173 Ibid, with reference to K Keown. The Ashes of AIDS and the Phoenix of Informed Consent. *Modern Law Review* 1989; 52: 790.

174 Magnusson, supra, note 172, with reference to A Grubb, D Pearl. *Blood Testing, AIDS and DNA Profiling: Law and Policy*. Bristol: Family Law, 1990, at 3-27; C d’Eca. Medico-Legal Aspects of AIDS. In: D Harris, R Haigh (eds). *AIDS: A Guide to the Law*. London: Routledge, 1990, at 8-10; J Hamblin. Health Care: Rights and Responsibilities. *Law Society Journal* 1992 (May): 66 at 67; WT West. Assault and Battery – Testing for "AIDS." *Justice of the Peace* 22 December 1990, at 812; J Godwin et al. *Australian HIV/AIDS Legal Guide* (2nd ed). Sydney: Federation Press, 1993, 181-182; A Orr. AIDS: Adapting the Law. *New Law Journal* 1988; 138: 388 at 389; MS Swartz. AIDS Testing and Informed Consent. *Journal of Health Politics, Policy and Law* 1988; 13: 607; P Wilson. Testing the Boundaries of Consent. *New Law Journal* 1994; 144: 574.

175 Magnusson, supra, note 172 at 212, with reference to Department of Health, Housing and Community Services. *The Final Report of the Legal Working Party of the Intergovernmental Committee on AIDS*. November 1992, para 2.4. See also TDM Zeegers Paget. *AIDS and Public Health Measures: A Global Survey of the Activities of Legislatures 1983-1993*. Proefschrift, Rijksuniversiteit Groningen, 1996, at 99, with reference to Department of Community Services and Health. *Consultation paper No 5: report of the working panel on testing for HIV/AIDS*. Canberra: Commonwealth of Australia, 1989, at 5, 22.

176 New South Wales Anti-Discrimination Board, supra, note 43 at 40.

177 New South Wales Ministerial Review HIV/AIDS Legal Working Party. *The Courage of our Convictions: HIV/AIDS: The National Strategy and the Laws of New South Wales*. 1993, at 14.

178 *Fighting the Other Epidemic*. Report of the New South Wales Attorney-General's Committee on the Monitoring and Implementation of the Anti-Discrimination Board Report on HIV and AIDS Related Discrimination. 1993, at 16-17, 42.

179 Zeegers Paget, supra, note 175, with reference to TDM Zeegers Paget. Droit et sida: perspectives aux Pays-Bas. In: J Foyer, L Khaiat (eds). *Droit et sida: comparaison internationale*. Paris: CNRS éditions, 313-340.

180 Zeegers Paget, ibid at 102, with reference to Circular DH/DGS of 28 October 1987 on the screening of hospitalized patients for the human immunodeficiency virus. *International Digest of Health Legislation* 1988; 39(1): 31-32.

181 OLRC, supra, note 13 at 21.

182 See J Borra. Faith Test. *Hour* [Montréal], 30 March 1996.

183 Ibid.

184 D Roy (ed). HIV Infection and AIDS, Ethical-Legal Issues 1991, A Report. Montréal: Centre québécois de coordination sur le SIDA, 1991, at 11.

185 C Hankins et al. HIV Testing Experience of Women Living with HIV. Abstract presented at the Second International Conference on the Biopsychosocial Aspects of HIV Infection, Brighton, England, July 1994. See also C Hankins. HIV Counselling and Testing Issues for Women – Testing Experiences of HIV+ Women, Montréal. In: *Women and HIV National Workshop. A National Workshop to Enhance Networking and Collaboration between the Affected Community, Educators, Health and Social Service Professionals, and Researchers*. Montréal: Group for Action-Research, McGill AIDS Centre, 1995, 17.

186 ACO, supra, note 14 at 15.

187 RA Paiement. La perception du SIDA par les médecins québécois. *BULLETIN* 1990; 30(4): 19.

188 Matiation, supra, note 19.

189 Ibid at 5.

190 RS Magnusson. Testing for HIV without Specific Consent: A Short Review. *Australian and New Zealand Journal of Public Health* 1996; 20(1): 57-60, with reference to RS Magnusson. Specific Consent, Fiduciary Standards and the Use of Human Tissue for Sensitive Diagnostic Tests and in Research, supra, note 172.

191 Ibid, with reference to DI Grove, JB Mulligan. Consent, Compulsion and Confidentiality in Relation to Testing for HIV Infection: the Views of WA Doctors. *Medical Journal of Australia* 1990; 152: 174.

192 South African Law Commission. Discussion Paper 68, Project 85. *Aspects of the Law Relating to AIDS*. Pretoria: The Commission, 1996, at xix, para 18.2.

193 CE Lewis, K Montgomery. The HIV-Testing Policies of US Hospitals. *Journal of the American Medical Association* 1990; 264(21): 2764 at 2765.

194 Magnusson, supra, note 172 at 225, with reference to I Grant. Consensus on HIV Testing. *British Medical Journal* 1988; 297: 356.

195 M MacKinnon, K Cottrelle, H Krever. Legal and Social Aspects of AIDS in Canada. In *AIDS: A Perspective for Canadians –Background Papers*, supra, note 10, 347-373 at 372.

196 Roy, supra, note 184 at 54.

197 Field, supra, note 17 at 46-47.

198 Bayer 1989, supra, note 24 at 121.

199 OLRC, supra, note 13 at 23.

200 Magnusson, supra, note 172, with reference to RC Turkington. Confidentiality Policy for HIV-Related Information: An Analytical Framework for Sorting Out Hard and Easy Cases. *Villanova Law Review* 1989; 34: 871
at 892.

201 Field, supra, note 17 at 45.

202 See supra, pp 19ff.

203 *HIV/AIDS and Human Rights. International Guidelines*, supra, note 162 at 12.

204 D Miller, AJ Pinching. HIV Tests and Counselling: Current Issues. *AIDS* 1989; 3(Suppl 1): S187-S192 at S189.

205 Magnusson, supra, note 190 at 58.

206 Ibid.

207 (1996) 31 OR (3d) 798.

208 Magnusson, supra, note 172 at 231.

209 Ibid.

210 L Stoltz, L Shap. *HIV Testing and Pregnancy: Legal and Ethical Issues*. Prepared by the Joint Project on Legal and

Ethical Issues of the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society, for Health Canada. Ottawa: Health Canada, forthcoming.

211 OLRC, supra, note 13 at 27.

212 New York HIV and AIDS Related Information Law, NY Code §§2780-2787 at §2781.

213 Magnusson, supra, note 172 at 212.

214 Response to the *Discussion Paper* by the CLSC Métro AIDS Intervention Centre, Montréal, dated 22 July 1997.

215 See, eg, Parliamentary Ad Hoc Committee on AIDS, supra, note 12 at 42 (recommendation 34); CPHA, supra, note 15.

216 WHO 1992, supra, note 53 at 2.

217 R Bayer. The Ethical Dimensions of HIV Testing. In: J Mann et al (eds). *AIDS in the World. A Global Report*. Cambridge, MA & London, UK: Harvard University Press, 1992, 747-759 at 757.

218 Federal Centre for AIDS Working Group on Anonymous Unlinked HIV Seroprevalence. Guidelines on Ethical and Legal Considerations in Anonymous Unlinked HIV Seroprevalence Research. *Canadian Medical Association Journal* 1990; 143 (7): 625-627 at 626.

219 R Doll. A Proposal for Doing Prevalence Studies of AIDS. *British Medical Journal* 1987; 294: 244.

220 For more details, see R Bayer et al. The American, British, and Dutch Responses to Unlinked Anonymous HIV Seroprevalence Studies: An International Comparison. *AIDS* 1990; 4: 286.

221 S Cook. Go-Ahead for Mass AIDS Tests. *The Guardian* 24 November 1988.

222 Magnusson, supra, note 190 at 58, with references.

223 Paraphrased or quoted from World Health Organization. *Unlinked Anonymous Screening for the Public Health Surveillance of HIV Infections – Proposed International Guidelines*. Geneva: WHO Global Programme on AIDS, 1989 (WHO/GPA/SFI/89.3).

224 Magnusson, supra, note 190 at 60.

225 Federal Centre for AIDS, supra, note 218 at 625.

226 Royal Society of Canada, supra, note 10.

227 Federal Centre for AIDS, supra, note 218 at 626.

228 Paraphrased or quoted from Revised Guidelines on Ethical and Legal Considerations in Anonymous Unlinked HIV Seroprevalence Research. *Canadian Medical Association Journal* 1992; 146(10): 1743-1744 at 1744.

229 G Sharpe. The Ethics and Legality of Seroprevalence Studies. *Health Law in Canada* 1991; 11(4): 102 at 111.

230 Ontario Ministry of Health. *HIV Seroprevalence Report*. Toronto: The Ministry, 1991 at 53, cited in OLRC, supra, note 13 at 73.

231 Joint National Committee on Aboriginal AIDS Education and Prevention. *Recommendations for a National Strategy on Aboriginal AIDS Education and Prevention*. Ottawa: Health and Welfare Canada, 1990, Recommendation 9 at 39.

232 Watershed Writing and 2-Spirited People of the 1st Nations. A Community-based Discussion Paper on: The Social, Moral, Ethical and Legal Implications of Conducting Blind Seroprevalence Studies in Aboriginal Communities. Toronto: 2-Spirited People, 1996.

233 Ibid at 4.

234 Matiation, supra, note 19.

235 Ibid at 7.

236 M Nguyen et al. Involving Aboriginal Communities in HIV/AIDS Surveillance and Research. 12th World AIDS Conference, Geneva, 1998. Abstract no 44269. See also K Barlow et al. Involving Aboriginal Communities in HIV/AIDS Surveillance and Research. 7th Annual Canadian Conference on HIV/AIDS Research, Québec, 1998, abstract no 150P.

237 Aboriginal Working Group on HIV/AIDS Surveillance and Research. Ethical Review Checklist for Support or Approval of Research Proposals on Aboriginal People. Draft. Ottawa: LCDC, 1998.

238 Health Canada. *Inventory of HIV Incidence/Prevalence Studies in Canada*. Ottawa, April 1998.

239 Communication with A Bowlby, AIDS Bureau (Ontario), on 23 August 1996.

240 WHO 1989, supra, note 223 at 1.

241 Magnusson, supra, note 190 at 58.

242 HE Emson. The Ethics and Legality of HIV Prevalence Studies: A Contrary View. *Health Law in Canada* 1992; 12(4): 95.

243 D Coburn. Individual and Community Rights in Anonymous Unlinked HIV Seroprevalence Research: A Response to Dr Emson. *Health Law in Canada* 1992; 12(4): 97.

244 R Bayer. Ethical and Social Policy Issues Raised by HIV Screening: The Epidemic Evolves and so Do the Challenges. *AIDS* 1989; 3: 119 at 123. See also 2-Spirited People, supra, note 232 at 19.

245 Cited in 2-Spirited People, supra, note 232 at 21. See also Magnusson, supra, note 190 at 57, with reference to Proposal for Secret AIDS Tests Attacked. *Sydney Morning Herald* 1 April 1995, at 3.

246 Emson, supra, note 242 at 99.

247 2-Spirited People, supra, note 232 at 22, with reference to C Levine. AIDS and the Ethics of Human Subjects Research. In F Reamer (ed). *AIDS and Ethics*. New York: Columbia University Press, 1991, 77-105 at 84.

248 Don't keep AIDS victims in the dark. *USA Today* 21 January 1987.

249 Bayer refutes this analogy. See *HIV/AIDS: International Perspectives on Legal Issues and Human Rights*. Washington: National Council for International Health, 1995, at 29-33.

250 R Jürgens. New York Policy on HIV Testing of Newborns. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(2): 15.

251 S Reese. CDC Ends AIDS Tracking of Newborns, Mothers. *Star Tribune*, 31 December 1995, at 3E.

252 *Canadian AIDS Society* v *Ontario* (1996), 25 OR 3rd 388.

253 Supra, note 207.

254 In its submission to the OLRC, ACO alleged that such a situation occurred in Ontario when a UAS-style survey was conducted in several teaching hospitals. The study permitted the results to be linked to the individual hospital the women came from. The effect of this, it was argued, was that once the results were published, individual women who had given birth in one of the studies' hospitals were suddenly "suspect" as members of a scientifically and artificially created "risk group" (ACO, supra, note 14 at 4).

255 OLRC, supra, note 13 at 74-75.

256 Revised Guidelines, supra, note 228.

257 Supra, note 232.

258 OLRC, supra, note 13 at 72.

259 WHO 1989, supra, note 223 at 2.

260 OLRC, supra, note 13 at 74.

261 Ibid.

262 Revised Guidelines, supra, note 228 at 1744.

263 Magnusson, supra, note 190 at 58, with reference to HF Hull et al. Comparison of HIV-Antibody Prevalence in Patients Consenting to and Declining HIV-Antibody Testing in an STD Clinic. *Journal of the American Medical Association* 1988; 260: 935; K Krasinski et al. Failure of Voluntary Testing for Human Immunodeficiency Virus to Identify Infected Parturient Women in a High-Risk Population. *New England Journal of Medicine* 1988; 318: 185.

264 Magnusson, supra, note 190 at 58.

265 Matiation, supra, note 19 at 13-15.

266 R Fraser et al. Public Health Imperatives of HIV Infection and AIDS in Canada. In: *AIDS: A Perspective for Canadians – Background Papers*, supra, note 10 at 141.

267 2-Spirited People, supra, note 232 at 17, with reference to K Hankins. *HIV Infection of Childbearing Women in Aboriginal Populations in Northern Québec*.

268 *UNAIDS Policy on HIV Testing and Counselling*. Geneva: UNAIDS Policy Statement, August 1997.

269 Supra, note 214.

270 Matiation, supra, note 19 at 9.

271 Ibid at 10.

**Return to the top of this page**

**Return to Table of Contents**

# HIV Testing and Confidentiality: Final Report

**Prepared by Ralf Jürgens**

**ISBN 1-896735-16-9**

---

# ACCESS TO HIV TESTING

Voluntary testing, with the specific informed consent of the person being tested, has been almost unanimously supported in Canada. However, while for most Canadians access to different forms of HIV testing is fairly easy, problems continue in several areas: women continue to find it difficult to access testing in their doctor's office; Aboriginal people face greater barriers to accessible testing than most other Canadians; and, in some provinces, anonymous testing is not available.

While there is consensus that access to testing must be improved, there has been considerable debate about how voluntary testing should be done:

- The first question, debated since HIV testing became available, centres on the availability of anonymous testing. This question will be addressed in this chapter.

- The second question, which has become controversial more recently, centres on counselling: is pre- and post-test counselling always required? This question will be addressed in the next chapter.

- The third question is intimately connected both with the issues discussed in this chapter and with the second question and concerns the availability of new testing technologies that (1) make HIV testing in the privacy of one's home possible, without pre- and sometimes even post-test counselling; and (2) allow for the provision of HIV test results within ten to fifteen minutes. What are the benefits and potential risks of the availability of such tests? While the new technologies have the potential to increase people's access to HIV testing, they raise many other issues and will be discussed separately, in the chapter on new testing technologies.

This chapter first summarizes the recommendations concerning access to testing made by Canadian organizations since 1986 (History). The chapter then examines the current situation with regard to access to HIV testing (Current Situation). The chapter goes on to emphasize the importance of increasing access to testing for all Canadians and, in particular, for women and Aboriginal people. The chapter then discusses the benefits of making different testing options, including anonymous (and/or flexible non-nominal272) testing available, pointing out that evidence indicates that anonymous testing programs (and/or flexible non-nominal programs such as that available in British Columbia) encourage some people to be tested for HIV who would otherwise delay testing or choose not to be tested. In addition, it explores whether the case for making anonymous (and/or flexible non-nominal) testing available may have become weaker because of two new developments: the availability of new treatments that are likely to encourage people testing HIV-positive to immediately seek medical help (and thus forego anonymity); and the development of home tests kits that make testing in the anonymity of one's own home possible (Assessment). The chapter concludes that barriers to access to testing urgently need to be removed; that the availability of new treatments only underscores the importance of the availability of a variety of voluntary, high-quality, bias-free testing options, including anonymous (and/or flexible non-nominal) HIV testing facilities; and that development of home test kits has not made anonymous (and/or flexible non-nominal) HIV testing facilities superfluous (Recommendations).

## Terminology

There is often confusion between anonymous and other forms of testing.

- *Anonymous testing* is a testing procedure whereby HIV-antibody test 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.273

- *Non-nominal* testing is testing in which results can be linked to the person being tested by a code (which does not include personal identification of the person being tested) known by the person being tested. The physician also knows the identity of the person being tested, but the results of the test remain confidential and the name of the person testing positive is not reported to public health authorities.

- *Nominal* testing is testing in which the results are linked to the person being tested by a personal identifier.

## History

> The AIDS movement and its supporters advocated the use of anonymous testing. Codes rather than names would be used so that no records identifying individuals would be kept which could be reported to authorities. Public health officials generally opposed anonymous testing as they saw compulsory nominal reporting as a prerequisite for further interventions to assist the infected and prevent transmission. At the core of this debate was the issue of whether testing was to inform the state of the names of the infected (compulsory nominal) or to inform those whose health was at stake (anonymous).274

There is consensus in Canada that people should have easy access to HIV testing. This consensus is best expressed in a recommendation of the Canadian Public Health Association, according to which "[a]ll Canadians should be aware of and have access to a variety of voluntary, high-quality, bias-free testing options, including confidential nominal testing, non-nominal testing and anonymous testing."275 In addition, the Association recommended that all testing options be made available and accessible at a variety of sites, including rural and Aboriginal communities, and that appropriate and scientific methods of evaluation be used to ascertain the efficacy and usefulness of the different types of testing. Finally, it emphasized the importance of ensuring access to testing for women who are at risk for HIV infection.

No consensus has, however, been reached on the issue whether access to HIV testing should include access to anonymous testing. The Working Group on Confidentiality in Relation to HIV Seropositivity of the Federal/Provincial/ Territorial Advisory Committee on AIDS opposed the introduction of anonymous testing, stating that, "[a]s a general public health principle, anonymous testing is ... less optimal than nominal testing as it may impede adequate post-test counselling and prevent notification, especially when a ‘duty to warn’ might otherwise exist."276 Most other organizations have, however, acknowledged the advantages of making anonymous testing available and recommended that – where this has not already been done – the options for testing be expanded to include anonymous testing. For example, the Canadian Bar Association – Ontario endorsed the availability of anonymous testing sites, stating that it was persuaded that there are "a certain number of individuals in the at risk community [sic] who are so distrustful of government and of the health care profession that even with respect to confidentiality of the result, [they] would not come forward to be tested even though they so desired, for fear that their privacy would not be respected."277 The Royal Society of Canada also supported anonymous testing and expressed concern about the fact that, in some provinces, existing public health legislation may not allow it:

> [T]he perception that test results are not always kept confidential deters many people from seeking tests. Unless the purpose of identifying the approximately 30,000 seropositive individuals in Canada is to isolate them, there is no reason to name them.
>
> Whether the test is nominal or anonymous, the knowledge of a positive test is likely to change a person's behaviour. However, since anonymous testing may be more acceptable to those tested and achieves many epidemiological goals, *provincial reporting laws should be amended to allow anonymous tests* [emphasis added].278

The AIDS Committee of Ottawa went so far as to say that anonymous testing of individuals "is the only acceptable and legal way of designing a testing regime." In addition, ACO pointed out that, while availability of anonymous testing is extremely important, it is not a "panacea":

> Anonymity should be extended beyond the test site and the reporting site to fully protect the human rights of PLWAs. At the present time it is necessary to disclose one's status to obtain Unemployment Insurance and family benefits. It is necessary to disclose one's name and address to gain access to experimental drug trials. It is usually necessary to disclose one's status to get accommodation in the workplace. The Red Cross has been ordered to disclose the HIV status of individuals. None of these things should be happening.279

Those writing about access to testing for Aboriginal people in Canada have made recommendations that are largely consistent with those reported above. For example, in 1990 the Joint National Committee on Aboriginal AIDS Education and Prevention recommended that access to confidential and free HIV testing be made available to all Aboriginal people across Canada.280 In 1998, Matiation reported that many of those consulted during the preparation of his discussion paper said that anonymous testing should be available to Aboriginal people across the country. They suggested that access to anonymous testing facilities would be of significant benefit to Aboriginal people and pointed out that, although anonymous testing sites may be available in most major cities, they are inaccessible to Aboriginal people living in more remote communities. In addition, it was reported by those consulted that some Aboriginal people may not feel comfortable using mainstream testing facilities; others might prefer to see a non-Aboriginal practitioner or testing site in order to increase the sense of anonymity. Kevin Barlow, then National Coordinator of the Canadian Aboriginal AIDS Network, expressed support for the availability of options for Aboriginal people who wish to be tested anonymously whether they live on or off reserve, in remote communities or in cities.281 Matiation concluded that, due to the continued prevalence of discrimination and denial, provincial and territorial health providers and the Medical Services Branch "must work together to provide accessible options for anonymous testing for Aboriginal people to the greatest extent possible."282 This is consistent with the views expressed in a 1996 article on anonymous HIV testing in the Canadian Aboriginal population, which concludes that "anonymous HIV testing is appropriate for the aboriginal population."283

However, the participants at the National Workshop on HIV Testing and Confidentiality in Toronto in March 1997 failed to reach consensus about whether anonymous testing needs to be made available "in various locations in each province and territory," as had been suggested in *HIV Testing and Confidentiality: A Discussion Paper*.284 Some participants favoured a system of flexible non-nominal testing as adopted in British Columbia. They suggested that, in practice, such a system allows those who seek anonymous testing to be tested anonymously, while providing better epidemiological data. In addition, they pointed out that such a system has been well accepted in British Columbia, including by the communities of people affected by HIV/AIDS, who do not seem to have expressed serious concern about the lack of (official) availability of anonymous testing. However, other participants stressed that, while people may be able to obtain an HIV test anonymously in British Columbia, the onus lies on them to make the test anonymous – which means that access to such testing is reduced. All participants agreed that, at a minimum, flexible non-nominal testing should be available in all provinces and territories, and that the option of providing (always the same) invented identifier should be offered to all those presenting for testing at clinics where no PIN number is required.

# Current Situation

While most Canadians have fairly easy access to HIV testing, problems continue in several areas: women continue to find it difficult to access testing in their doctor’s office; Aboriginal people face greater barriers to accessible testing than most other Canadians; and, in some provinces, testing options are restricted.

## Access to Testing for Women

As de Bruyn has pointed out, there are a number of ways in which practices of HIV testing and counselling among women are, on the one hand, influenced by stigma and discrimination or, on the other hand, fail to take stigma and discrimination into account.285 Women’s access to HIV testing is adversely affected, first of all, by perceptions that *only* men who have sex with men, drug users, and sex workers are at risk of HIV infection. Such perceptions have prevented women from seeking HIV testing.286 They have also led physicians not to offer HIV testing and counselling to women whom they do not perceive to be at risk for HIV infection.287 This was a common complaint in the consultations undertaken for *HIV/AIDS and Discrimination: A Discussion Paper*.288 As de Bruyn has put it:

> The outcome for women is serious. Bias due to perceptions of risk, along with failure to recognize symptoms of HIV disease in women, can result in delayed diagnosis and delayed treatment for women.289

Second, women’s access to HIV testing has been adversely affected by the fact that some women (who are not pregnant) have even been dissuaded by their doctors from being tested. Counselling guidelines establish that counsellors should not attempt to talk people out of being tested, even when they – based on the discussions with the counsellor – appear to be at low risk.290 Nevertheless, women have often been refused testing on the assumption that they are not at risk,291 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.292

Third, testing and counselling for women has been closely associated with prenatal care. As stated in the submission of the Canadian HIV/AIDS Legal Network to the Parliamentary Sub-Committee on HIV/AIDS,

> [o]ne striking feature of the debate on women and HIV/AIDS is its frequent preoccupation with women as mothers or as future mothers; it is comparatively rarely concerned about the women themselves and the many problems they face in dealing with HIV/AIDS. For example, while the issue of compulsory testing of pregnant women or of women of childbearing age is hotly debated, women who are not pregnant or of childbearing age still report that they find it difficult to access HIV testing. This raises the issue of whether there is less concern about the welfare of women than for that of their children or potential children. It will be necessary to ensure that women's needs and their "knowledge and ... varying life situations are systematically taken into consideration in the formulation of responses to the epidemic": so far, few, if any, policies and programs developed in response to HIV/AIDS "are related to women's real-life situations."293

The issues of HIV infection, pregnancy, and preventing HIV transmission to the child are important to women, and, given the benefits of early detection for both the woman and her child, it should be standard practice to offer HIV testing to pregnant women.294 Nevertheless, as de Bruyn points out,

> to associate HIV testing only or primarily with prenatal care is discriminatory. It precludes the provision of HIV testing, diagnosis and care to women who are not considering or seeking to have a child, and ignores the value of HIV testing for a woman in her own right, apart from her decision to have a child.295

Finally, another barrier lies in the fact that women often live in situations of abuse and economic dependence and are fearful of the potential consequences of testing. Indeed, women testing HIV-positive may experience additional negative consequences, consequences that most men testing positive do not have to deal with. For example, one study showed that 52 percent of women who tested positive feared that their partners would leave them once they notified them of the test result; and 12 percent expected to be assaulted – half of them were indeed subjected to violent acts by their partner.296

## Access to Testing for Aboriginal People

Aboriginal people can receive HIV testing off reserve from any provincial or territorial institution or clinic that can conduct the test, including hospitals, doctor's offices, and anonymous testing clinics, where available. In addition, a small number of testing clinics or programs specifically designed for Aboriginal people are available in some Canadian cities such as Vancouver and Toronto.

On reserve, Aboriginal people can generally be tested for HIV at the community health centre by a community health nurse (CHN). Most reserve communities have a CHN and health centre, although in some smaller communities the CHN may divide time between a number of communities. The Medical Services Branch of Health Canada (MSB), which administers health services on reserve, recommends non-nominal testing. "Anonymous testing will generally not be offered, but may be made available in some circumstances, at the decision of the region."297

However, in many ways, Aboriginal people face greater barriers to accessible HIV testing than most other Canadians. As Matiation points out, "access to testing can be compromised by a number of factors, including remoteness and the cost of accessing testing facilities from distant locations, confidentiality concerns in small communities, and the cultural inappropriateness of mainstream facilities for some Aboriginal people."298

Matiation identified the following barriers to accessible testing:299

> In some parts of the country an Aboriginal person may have to travel long distances at great expense to take advantage of an anonymous testing facility, or even to get tested at a local health centre. The period between taking a test and getting the result is generally much longer in rural and reserve communities than in major cities and may require two expensive trips, one for the test and one for the result. Further, many communities are visited by a health nurse only sporadically. In these circumstances, the chance that a person will get tested or, having been tested, return to the health centre to get the result, is reduced.
>
> Many people consulted expressed concern that there are barriers to testing in facilities within a small community. People may be reluctant to use the local health centre due to confidentiality concerns. In some communities, a health centre capable of performing the test may not be available and a person may be referred to a larger centre. Many people in smaller Aboriginal communities lack the resources to get to a testing facility in a larger centre. As a result, few Aboriginal people living in rural areas are being tested [reference omitted].

> Access to testing for Aboriginal people may also be compromised in cities. Some of the people consulted expressed concern that mainstream facilities do not reflect cultural differences between Aboriginal and non-Aboriginal people. Culturally based differences can make mainstream facilities and services less accessible to Aboriginal people.
>
> In many cities Aboriginal AIDS organizations are available to provide support to Aboriginal people who wish to be tested. Many of these organizations are under severe demands for their services and lack sufficient funding to respond to the needs of all those who approach them. Aboriginal testing facilities are also available in a small number of cities. It was reported that the testing clinic operated by Vancouver Native Health is very well-used, suggesting that Aboriginal-specific clinics are needed.
>
> Some of those interviewed expressed concern that some communities may not provide adequate HIV/AIDS programs and services, including HIV testing services, after assuming control over the administration of health services through health transfer initiatives, particularly given the limited transfer of funds from MSB [the Medical Services Branch] involved in the process [reference omitted]. It is important that HIV/AIDS issues be made a priority in all Aboriginal communities and that communities look to Aboriginal AIDS organizations, Aboriginal AIDS workers, and MSB for expertise in the delivery of HIV programs and services. First Nations and Inuit governments have a central role to play in the development of accessible HIV testing options for Aboriginal people.

In addition, according to Matiation, a continuing lack of HIV/AIDS education in many Aboriginal communities is contributing to the problem of access to testing for Aboriginal people.

## Access to Different Testing Options

### Canada

In all provinces and territories, nominal and/or non-nominal testing is available. Anonymous testing, however, is not available in all provinces and territories.

The following provinces expressly provide for HIV testing on an anonymous basis:

- Newfoundland, where anonymous testing is provided through public health nurses rather than through designated clinics;300

- Nova Scotia;301

- Québec, where the first anonymous testing clinics were established in 1987. Two such clinics were opened in Montréal, one in Sherbrooke, and one in Québec City. Since 1995, all regions have anonymous testing facilities, for a total of over 75 in 1996;302

- Ontario, where anonymous testing for HIV has been offered since 1985 at the Hassle Free Clinic in Toronto. However, technically it became legal only when, in 1990, public health regulations were amended to exempt certain authorized clinics from the requirement of reporting the names of people who test HIV-positive to public health authorities. Pre-test counselling and collection of epidemiological data are mandatory and are preconditions for the processing of a test sample. Evaluation of the program has shown that client satisfaction is very high. Monitoring of the program is continuing, with efforts being focused on trying to establish the effectiveness of anonymous testing in encouraging high-risk persons to be tested;303

- Saskatchewan;304 and

- New Brunswick, where anonymous testing became officially available at seven sexual health centres across the province on 20 July 1998, as part of a one-year pilot project. An evaluation will assess the effectiveness of offering anonymous testing in enhancing early detection and access to treatment for people with HIV, as well as in reducing risk behaviours and HIV transmission through pre- and post-test counselling.305 Before then, anonymous HIV testing was not officially available. In practice, if undertaken at clinics where the presentation of a health insurance card or other identification is not required, and if the person tested gave a false name, the test could be made effectively anonymous. However, the onus was on the person being tested to make it so.306

In the remaining provinces and territories, anonymous testing is technically not allowed. However, in actual practice it can sometimes be obtained despite existing reporting requirements:

- Prince Edward Island only provides nominal and non-nominal testing. All laboratory requisitions are coded and reported. 80 percent of the tests are reported on a non-nominal basis and 20 percent are reported nominally.307 In his response to the *Discussion Paper*, Dr Lamont Sweet, Chief Health Officer of Prince Edward Island, stated that "it is questionable whether PEI has sufficient demand to warrant a special local anonymous testing unit." He continued by saying that there is excellent cooperation with the Nova Scotia anonymous testing clinic and that most people seeking anonymous testing in Prince Edward Island probably prefer to go out-of-province to be tested because the Island is so small and they feel that truly anonymous testing would not be possible.308

- In the Northwest Territories309 and Yukon,310 persons being tested can give a false name "or any kind of code,"311 making the test anonymous.

- In Manitoba, anonymous testing is not encouraged, but can be arranged informally by negotiation with health-care providers if the patient insists on anonymity (otherwise, testing is done on a non-nominal basis).312

- At Alberta's STD clinics, HIV testing "can be done anonymously if a patient requests it." In practice, the number of cases in which patients do so has decreased in recent years.313

- British Columbia does not offer anonymous testing, but promotes flexible non-nominal testing to all providers of HIV testing.314 Nearly all testing undertaken at public health clinics (and some testing undertaken by physicians, although the majority of tests done by them are identified by patient name) is non-nominal. When tested for HIV, people are asked to use their initials and date of birth as codes, which allows for elimination of duplicate positive test results from the same person and thus for adequate monitoring of the spread of HIV in the province. It also allows for calling back the clinician who undertook the test to obtain, if necessary, missing demographic and risk-factor information, and to enquire about whether partner notification efforts have been made. However, the system is flexible: people tested in public health clinics who do not have to provide their PIN number can give a false name and false date of birth to eliminate any risk that a positive result may ever be traced back to them. People who decide to provide a false name and date of birth are, however, encouraged to use the same name and date of birth if they test again, for disease surveillance purposes.315

## International Developments

Internationally, anonymous testing is widely available. In the United States, as of 1996, 19 states had enacted statutes that guarantee individuals the right to anonymous HIV testing, and more had made anonymous testing available without having enacted statutes guaranteeing it. At the same time, some states were considering phasing out their anonymous testing programs, under pressure to take more aggressive public health actions to prevent the spread of HIV.316 As of May 1997, 10 states had eliminated anonymous testing.317 However, in the vast majority of states anonymous testing remains available. Interestingly, even most of the states in the US that require reporting HIV cases by name maintain the option of anonymous HIV testing. As of October 1997, only eight of the 28 states requiring name reporting did not have anonymous testing available, all of them states with relatively low HIV prevalence.318 A National HIV Testing Coalition has developed "Ten Guidelines for HIV Testing" asking, among other things, that "all states receiving CDC funding must maintain anonymous HIV testing sites accessible to the entire population."319

In Europe, a 1997 survey of 48 countries of the World Health Organization's European Region showed that free anonymous HIV testing is available in 37 of the 43 countries that returned the study questionnaire.320

# Assessment

The availability of new treatments for HIV infection raises a number of challenges. Primarily, it underscores the importance of providing accessible testing facilities for all Canadians (coupled with accessible treatments for those testing positive). In order to encourage people to seek testing (and treatment), they require easy access to low-threshold testing facilities.

## Access to Testing for Women

[C]ountries should give special consideration to increasing women's voluntary access to them [HIV testing and counselling services]. ... Regardless of the presence of risk factors ... women should not be coerced into testing, or tested without consent. Instead, they should be given all relevant information and allowed to make their own decisions about HIV testing, reproduction and infant feeding.321

A variety of initiatives need to be undertaken in order to increase women's access to testing:

> First, in order to encourage women to seek testing, they need to be made aware that they may be at risk of HIV. Increased education that focuses specifically on women needs to be undertaken.

Second, if a woman's desire to be tested is ignored or dismissed by her physician, her access to HIV testing may effectively be barred. Therefore, there is a need for a more sensitive approach to the assessment of a woman's risk of HIV infection, and for education and training directed at increasing doctors' awareness of the potential vulnerability of women to HIV infection. As Cullingworth stated in her response to the *Discussion Paper*:

> Another important initiative is the need to educate doctors – to challenge their assumptions about the "type" of woman who may be at risk, and about the symptoms women experience.
>
> For many women, public education will not reach them –either because they are "protected" in their homes, and think they are in monogamous relationships; therefore, a doctor's office may, for some women, be the only place they have the opportunity to have their awareness raised. Doctors can – and should – play a really critical role in increasing access to testing for women, rather than blocking access.322

In addition, the broader problems of abuse and economic dependence of women need to be addressed in order to create a climate where women will be less fearful of the potential consequences of testing.

Finally, rather than focusing efforts to increase access to testing for women nearly exclusively on pregnant women – which makes it seem as if there is less concern about the welfare of women than for that of their children or potential children – it will be necessary to ensure that efforts encompass all women and take their needs, knowledge, and various life situations into consideration: testing policies need to be related to women’s real-life situations.

## Access to Testing for Aboriginal People

The Aboriginal Nurses Association of Canada makes education the central recommendation of its report on HIV/AIDS and Aboriginal women, stating that "a broad-based education program must be developed to prevent the potentially devastating spread of HIV/AIDS throughout Canada’s Aboriginal community."323 Matiation agrees, saying that

> [e]ducational resources that reflect the values, experiences, culture and languages of Aboriginal communities are imperative in overcoming fear, denial and discrimination related to HIV/AIDS and HIV testing. HIV/AIDS education may reduce concerns about confidentiality in small communities and encourage people to get tested.324

In particular, Matiation emphasizes that medical practitioners must continue to be educated about HIV/AIDS and trained to provide testing that is voluntary, confidential, and accompanied by skilled counselling. According to him, this would increase the comfort level around HIV testing, and may prevent situations where doctors refuse to give an HIV test because a person is not perceived to be at risk, and/or refuse to be part of care, treatment and support initiatives.325

Matiation further suggests that mobile HIV testing units may be useful in overcoming some of the barriers to accessible testing for Aboriginal people, particularly problems of remoteness, concerns about confidentiality, and issues related to cultural difference.

## Access to Different Testing Options

[A]nonymous testing is seen as a testing procedure that maximizes the number of persons who will come forward for testing and counselling, particularly those who are at the highest risk of infection. Maximizing the testing and counselling of such persons ensures that more HIV-infected individuals will make use of their treatment options when it is most beneficial to do so – before symptoms develop [references omitted].326

As mentioned above, nominal and/or non-nominal testing is available in all Canadian provinces and territories. The question that remains to be addressed is whether anonymous testing should also be available.

## Benefits of Making Anonymous Testing Available

The benefits of making anonymous testing available have been discussed in great detail in the literature.327 In particular, there is evidence that:

- availability of anonymous testing encourages people to be tested for HIV;
- availability of anonymous testing encourages particularly those at greatest risk to be tested;
- elimination of existing anonymous testing facilities may have a detrimental effect; and
- anonymous testing facilities often offer "best practice" pre- and post-test counselling.

### Encouragement of Testing

Numerous studies undertaken in Canada, the United States, and elsewhere suggest that availability of anonymous testing encourages people to be tested.328 For example, a study of people seeking testing at Toronto’s Hassle Free Clinic revealed that 30 percent of people tested at the Clinic said they would not have chosen to be tested if anonymous testing had not been available.329 Another example is a US study showing that residents of US states that provide anonymous testing and have strict rules protecting the confidentiality of HIV test results are more likely to have been tested than those living in states without such policies.330 Concerns about being tested in the absence of anonymous testing persist: in 1998, during a community consultation on surveillance needs, participants from across Canada mentioned that in the absence of anonymous testing, people were often still hesitant to be tested, "particularly in smaller communities and rural areas, even if they knew they had been at risk."331

### Encouragement of Those at Greatest Risk

In particular, studies have shown that persons at greatest risk of HIV infection are more likely to undergo testing for HIV if the testing is anonymous.332 Anonymous testing facilities attract greater numbers of seropositive clients. A good example of this is the fact that, while only 1.5 percent of all tests in countries of the World Health Organization European Region responding to a recent survey were undertaken anonymously, these tests accounted for 8.5 percent of positive tests in 1996.333 In addition, anonymous testing facilities attract people who would otherwise have delayed being tested or never have gone for testing, fearing discrimination and loss of confidentiality.

## Detrimental Effects of Elimination of Anonymous Testing

The authors of a study carried out in North Carolina have suggested that efforts to abolish anonymous testing could deter people from seeking testing. From 1985 to 1991, North Carolina offered both anonymous and nominal testing in all of the state's 100 counties. However, in 1991, a decision was taken to phase out anonymous testing. After considerable public opposition, a compromise was reached according to which anonymous testing was discontinued in 82 counties, but retained in 18; confidential testing remained available statewide; and permanent abolishment of anonymous testing was contingent on evidence that the loss of such testing would not adversely affect HIV testing rates. On 1 January 1993, anonymous testing resumed in all 100 counties by court order.334

The study assessed the impact of the 1991-92 restriction of anonymous testing on HIV test-seeking. It showed that testing increased statewide throughout the study period as AIDS awareness grew. However, counties that retained anonymous testing saw a 64 percent increase, while counties that ended anonymous testing saw only a 44 percent increase.

Counties that ended anonymous tests saw a 12.4 percent decrease in testing of gay men and a 3.1 percent decrease in testing of intravenous drug users (in counties that retained anonymous testing, gay and bisexual men accounted for ten percent of all tests, compared to four percent in counties that ended anonymous testing). In addition, in counties that ended anonymous testing, a disproportionate number of people declined the test after receiving counselling (0.50 percent versus 0.16 percent in counties that retained anonymous testing). Finally, people tested nominally were more likely not to receive their results than those tested anonymously (21.3 percent versus 8.7 percent).

According to the authors of the study, the association between availability of anonymous testing and a greater increase in testing "could be causal or either partially or wholly due to unmeasured differences between the two types of counties."335 However, the authors suggested that "circumstantial evidence" from the study supports the conclusion that the elimination of anonymous testing had a detrimental effect, a conclusion supported by evidence from other studies.336 Therefore, the authors concluded, "[t]hose making policy decisions affecting the availability of anonymous testing must take into account possible consequences for high-risk and/or vulnerable persons."337

Another study that analyzed the closing of anonymous test sites in North Carolina using some more data also found "evidence that anonymous testing was important to a relatively small (but important) group of persons"338 and concluded that "eliminating anonymous testing in 82 counties in North Carolina appeared to cause a small decrease in testing among some possibly high-risk men."339 However, the study also produced different findings,340 such as that partner notification was more successful if the index case was tested confidentially than if the index case was tested anonymously: more partners were named, notified and counselled after confidential testing than after anonymous testing.341 This second study emphasized that, while eliminating anonymous testing had a relatively small effect on testing and on partner notification, it had a large effect on the relationship between the advocacy community and the public health department. It suggested that a policy that strongly encourages confidential testing while maintaining the availability of anonymous testing may maximize the effectiveness of both testing and partner notification. Alternatively, it suggested that the acceptability of confidential testing could be enhanced by removing possible barriers (ie, using unique identifiers as opposed to names for HIV reporting, strengthening anti-discrimination policies and laws).342

### Counselling

Finally, anonymous testing services not only encourage people to come forward for testing, particularly when they are at high risk of HIV, but also provide "best practice" pre- and post-test counselling. Personnel at anonymous testing services (and at other dedicated HIV testing clinics) have developed an invaluable expertise in providing counselling, and there is evidence that some people prefer anonymous testing services because of the quality of the counselling available. The provision of counselling at anonymous testing clinics is seen as a cost-effective way of promoting the reduction of risky behaviour in a population that, despite years of public education campaigns, remains highly ignorant of HIV-prevention issues. That the emphasis on preventive counselling at anonymous testing clinics is indeed reaping benefits is demonstrated by the evaluation of Ontario’s anonymous testing clinics, which is showing that people who test repeatedly at these clinics are more successful at staying HIV-negative than those tested elsewhere.343

## Concerns about Making Anonymous Testing Available

Despite the benefits of making anonymous testing available, 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; and is expensive. In addition, they express concern about the fact that some of the people tested in anonymous testing facilities never return to pick up their results: "Anonymous testing does not allow health departments to locate seropositive patients who fail to return for test results and to provide them with prevention services such as counseling, partner notification, and referral for therapy."344

### Collection of Epidemiological Data

Although this is heavily disputed – a dispute that will be analyzed in more detail below – nominal reporting is not essential for the usefulness of information for epidemiological purposes:345

> [T]he need is for consistent and accurate data in a form that enables the spread of HIV to be monitored. Relevant data would include demographic information about the age, sex, and geographic location of an infected person, as well as information about how that person is thought to have been exposed to the virus, and about the person’s previous testing history in order to prevent duplication of reporting. *Personal identifying information is not relevant for epidemiological purposes* [emphasis added].346

In addition, there is the question whether accurate epidemiological data can be obtained through the collection of data from voluntary testing. For determining seroprevalence data, properly conducted epidemiological research studies are more useful, since there is evidence that the self-selecting nature of voluntary testing may present a distorted picture of the prevalence of infection in the population (see supra, the section on UAS studies, and infra, the chapter on reporting).

Finally, as mentioned above, 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 of maintaining this option may outweigh the potential negative impact on the collection of epidemiological data.

### Partner Notification

The concern most frequently voiced in relation to anonymous testing involves partner notification. Partner notification is entirely voluntary when an individual tests anonymously. Anonymous testing by its nature does not permit the identification of the HIV-positive individual, and health-care workers are unable to reach unsuspecting partners who may be at risk. Several studies undertaken in the US have examined "the substantially reduced yield of partner notification associated with anonymous testing"347 and it has been said that "[w]hen persons who prefer anonymous testing over the confidential mode are diverted from confidential testing because anonymous testing is readily available, there are public health costs associated with that exercise of preference."348

However, as pointed out by Hamblin and Somerville, the

> relationship between contact tracing [partner notification] and compulsory case reporting is far from clear, as contact tracing can be carried out by infected persons themselves or by their physicians without any need for case reporting. It is only when public health officials wish to carry out or to supervise the contact tracing and are justified in using such an approach, that any form of compulsory case reporting can be justified for contact tracing. And even then, case reporting

> need not be nominal, because reporting by code or some other means can still provide the link to the infected person needed for contact tracing.349

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, making intervention by public health authorities superfluous; 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; index persons and their partners should have full access to available services independent of their willingness to cooperate with partner notification activities."350

The Canadian approach suggests that "some form of partner notification should be implemented in every jurisdiction in Canada,"351 which, in the context of anonymous testing, can mean encouraging HIV-positive individuals to notify partners of their possible exposure to HIV, without the direct involvement of health-care providers (for more detail, see infra, the chapter on partner notification).352

### Cost

Anonymous testing programs need not be expensive. Indeed, evaluation of one particular Canadian program, the Ontario anonymous testing program, has shown that the cost of an anonymous test in Ontario is less than half ($44) the cost associated with providing the test through a physician in private practice ($100).353

### Return Rate

Contrary to what some have suggested, the experience of existing anonymous testing programs in Canada suggests that the vast majority of people who test anonymously do return to learn their test results. For example, in Ontario, results are picked up by more than 90 percent of clients of anonymous testing clinics.354 In addition, the problem of some people’s failure to return for test results and post-test counselling is not restricted to anonymous testing programs. A study conducted in Oregon that offered clients the option of anonymous or nominal HIV testing found that 94 percent of clients who received pre-test counselling and testing returned for their test results and post-test counselling. This proportion was almost identical for both the anonymous and the nominal testing groups.355 In North Carolina, people tested nominally were even more likely not to receive their results than those tested anonymously: in counties offering a choice between nominal and anonymous testing, 30 percent of those testing nominally, but only 8 percent of those testing anonymously, did not receive their results. Among those who tested positive, the percentages not receiving results were nearly identical.356 Admittedly, in the latter study many of those who were tested nominally and did not return for their results may have been tested routinely during the course of an examination for sexually transmitted diseases, not because they were specifically seeking HIV testing. This may have been the main reason why they did not return for their results, "presumably because they are less interested in their results, and possibly because they expect the clinic to contact them if the tests are positive."357 Nevertheless, the study shows that most people who are tested anonymously do receive their test results.

While the concern that some of the people tested in anonymous testing facilities never return to pick up their results is legitimate, the problem clearly is not exclusive to the provision of anonymous testing services – although, in the end, people who test anonymously "are less likely to get their test results than people seeking the test who leave their name and address because [in the latter case] health care workers can contact infected people who do not return for their results."358 A relevant question is: would (some of the) people who do not return for their test results at anonymous testing clinics have chosen to be tested at all if anonymous testing had not been available? Generally, it is doubtful whether the fact that some people at anonymous clinics do not pick up their test results warrants closing these clinics. One must weigh the benefit of offering a low-threshold testing facility against the benefit of being able to follow up on people who test positive and do not pick up their test result.

One way to encourage patients at anonymous testing clinics to return is to ensure that pre-test education and counselling is as comprehensive as possible and that the waiting period between testing and receipt of the result is kept to a minimum.

## Evaluation

Available evidence indicates that there are benefits to making anonymous testing programs available, and that these benefits outweigh the concerns expressed with regard to such programs. In order to encourage as many people as possible to learn their HIV status, such programs should therefore be available to all Canadians as part of a variety of voluntary, high-quality, bias-free testing options. Where they are not available, Canadians should at a minimum have access to flexible, non-nominal testing, such as is offered in British Columbia. The latter form of testing may have many of the benefits of anonymous testing, particularly if the option of providing a false name and date of birth is widely known and offered to people at the time of testing in clinics where patients do not have to provide a PIN. At the same time, it may allow for better collection of epidemiological data.

## Reevaluation

This conclusion, however, may have to be reevaluated in light of two developments: the availability of new treatments, and the commercialization, in the United States, of home test kits that make testing possible in the anonymity of one’s own home.

### Availability of New Treatments

It could be argued that, because of the availability of new treatments, offering anonymous (or flexible non-nominal) testing services is no longer necessary. Indeed, people testing positive have an interest in seeking medical care as soon as they find out that they are HIV-positive. As soon as they enter a doctor’s office, however, anonymity is no longer possible: medical information related to their HIV status will remain confidential, but a patient cannot remain anonymous. In addition, it could be argued that HIV/AIDS should be "normalized" and that people testing positive need no longer fear the discrimination they faced earlier in the epidemic.

However, these arguments are not entirely convincing. It has already been shown (see supra, in the Background chapter) that discrimination remains a priority concern for people testing positive in Canada and that they have every reason to fear being subjected to stigmatization and discrimination. The new treatments notwithstanding, for many people, particularly those who believe themselves at risk, the decision to be tested for HIV remains a very difficult one to make. People may still want to be tested anonymously or have the option of providing a false name, and then decide themselves when to give up anonymity and seek medical help. Making available the option of anonymous (or flexible non-nominal) testing has not become unnecessary; it will continue to encourage people to be tested, or to be tested earlier.

## Home Testing for HIV

Home test kits make testing in the anonymity of one’s own home possible. However, even if such kits do become available to Canadians, they cannot and should not replace, but complement, anonymous (or flexible non-nominal) testing services. There are many reasons for this. Most important, anonymous (or flexible non-nominal) testing is undertaken with pre- and post-test counselling, while the lack of adequate counselling is one of the primary concerns about home testing. Indeed, as shown above, it is often at anonymous (and other dedicated) testing clinics that the counselling provided is most adequate and constitutes a real and important opportunity to prepare people for their test results and enable them to better care for themselves and their partners.

Second, home test kits are not free. In the United States, the approved tests cost US$39.99 (Home Access) and US$49.99 (Home Access Express – results available in three days),359 which for many of those most vulnerable to contracting HIV and at need of finding out about their HIV status – such as injection drug users, street kids and, generally, the poor and marginalized –represents an important barrier to accessing such testing. Unless testing is provided for free, it is entirely unrealistic to assume that those most in need of accessible and anonymous testing will indeed be able to avail themselves of testing.

Further, in contrast to the home sample collection tests that have been approved in the US,360 some tests (the current generation of true home tests that have not been approved in the US) are screening tests, not diagnostic tests. This means that, were these tests approved, people who tested positive would still need to confirm their result by seeking "conventional" testing.

People would therefore only have access to truly anonymous testing if anonymous testing clinics where they could confirm the results of a home test were available.

### Previous Concerns Moot

> Anonymous testing, a matter of great debate in the past, should ... be a much less controversial option in the future.361

As shown above, the new developments (availability of new treatments and of home test kits) do not make the option of anonymous (or flexible non-nominal) testing unnecessary. In addition, because of the new developments, some of the objections against making anonymous testing available have become even less persuasive. In particular, this is true for the concerns regarding contact tracing:

> Previously, the concern (reasonable or not) was that persons with HIV could test anonymously, and health care professionals would have no means to identify those persons with HIV who might continue to place others at risk. These professionals would then be unable to take appropriate action, such as counselling or in some cases contact tracing. Now that there are effective interventions for HIV infection, invariably almost all persons with HIV will seek treatment, including those who test anonymously. As this ongoing treatment cannot logistically be provided anonymously, there should no longer be any concern that there would be absolutely no means for health care providers to identify and counsel those who may continue to present a serious risk to others. In short, these new treatments for HIV infection make the old debate about [problems created by] anonymous testing largely moot. Because anonymous testing encourages people to seek testing (and treatment if necessary), an essential public health goal, it can only be endorsed as a useful public health strategy.362

## Conclusions and Recommendations

The availability of new treatments for HIV infection underscores the importance of making all Canadians aware of, and providing them with access to, a variety of voluntary, high-quality, bias-free testing options, including anonymous testing or, at a minimum, flexible non-nominal testing.

The provision of anonymous (or flexible non-nominal) HIV testing facilities remains important. The benefits of offering these options are proven and outweigh existing concerns. In particular, numerous studies indicate that the availability of anonymous testing encourages people to be tested. In particular, people at greatest risk of HIV infection are more likely to undergo testing for HIV if the testing is – or can be rendered – anonymous. In addition, the availability of new treatments does not make the option of testing anonymously superfluous. Because of the continued stigma attached to HIV/AIDS and the often justified fear of discrimination resulting from a positive test result, some people may still refrain from being tested or will delay a decision to be tested in the absence of a guarantee of initial anonymity. Finally, even if home test kits that make testing in the anonymity of one's own home possible do become available to Canadians, the option of testing anonymously (with, generally, publicly funded HIV counselling and testing services) will remain important: many of those most at risk will not be able to afford to buy home test kits, and the quality of the counselling offered is not comparable to that of anonymous testing facilities.

The availability of anonymous testing – at anonymous testing facilities and/or at facilities offering flexible non-nominal testing – needs to be widely advertised, waiting periods need to be reduced, and ongoing evaluation should be undertaken.

Finally, a special effort needs to be undertaken to remove barriers to testing for women and Aboriginal people.

> **2.1 The availability of new treatments for HIV infection underscores the importance of making all Canadians aware of, and providing them with access to, a variety of voluntary, high-quality, bias-free testing options, including anonymous testing or, at a minimum, flexible non-nominal testing.**
>
> **2.2 The availability of anonymous testing – at anonymous testing facilities and/or at facilities offering flexible non-nominal testing – needs to be widely advertised, waiting periods at such facilities need to be reduced, and ongoing evaluation should be undertaken.**
>
> **2.3 Barriers to testing, in particular for women, need to be removed. There is a need for a more sensitive approach to the assessment of a woman's risk of HIV infection, and for education and training directed at increasing doctors' awareness of the potential vulnerability of women to HIV infection. In addition, the broader problems of abuse and economic dependence of women need to be addressed in order to create a climate where women will be less fearful of the potential consequences of testing. Finally, rather than focusing efforts to increase access to testing for women nearly exclusively on pregnant women – which makes it seem as if there is less concern about the welfare of women than for that of their children or potential children – it will be necessary to ensure that efforts encompass all women and take their needs, knowledge, and various life situations into consideration.**
>
> **2.4 Barriers to HIV testing for Aboriginal people need to be removed. Provincial, territorial, federal, 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, including anonymous or, at a minimum, flexible non-nominal testing.**

**HIV/AIDS education for Aboriginal communities should continue to be emphasized in order to help reduce stigmatization related to HIV testing.**

**Mobile testing units should be examined for their potential to overcome some of the problems related to HIV testing and Aboriginal communities.**

**Return to the top of this page**

**Return to Table of Contents**

---

ENDNOTES

272 See infra, the description of British Columbia's testing system in the "Current Situation" section.

273 OLRC, supra, note 13 at 98.

274 A Sears. The Politics of HIV-Related Testing: A Review Essay on the Ontario Law Reform Commission *Report on Testing for AIDS. The Windsor Review of Legal and Social Issues* 1993; 4: 157-163 at 160.

275 CPHA, supra, note 15 at 15.

276 F/P/T Advisory Committee, supra, note 11 at 44.

277 CBA–Ontario, supra, note 7 at 41.

278 Royal Society, *Summary Report*, supra, note 10 at 13. Other organizations supporting the availability of anonymous testing have included the Parliamentary Ad Hoc Committee on AIDS (supra, note 12 at 42 (recommendation 34)) and the Ontario Law Reform Commission (supra, note 13 at 111).

279 ACO, supra, note 14 at 14.

280 Supra, note 19 at 13, with reference to recommendation 10 at 40.

281 Personal communication with Kevin Barlow, 8 August 1997.

282 Matiation, supra, note 19 at 13.

283 A Lin-In Tseng. Anonymous HIV Testing in the Canadian Aboriginal Population. *Canadian Family Physician* 1996; 42: 1734-1740 at 1739.

284 Jürgens & Palles, supra, note 2 at 74 (conclusion 2.2).

285 De Bruyn, supra, note 6 at 74.

286 LA Jackson, P Millson, L Calzavara 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 at 20-21.

287 KA Phillips et al. HIV Counseling and Testing of Pregnant Women and Women of Childbearing Age by Primary Care Providers: Self-Reported Beliefs and Practices. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1997; 14(2): 174-178.

288 De Bruyn, supra, note 6 at 74-75.

289 Ibid, with reference to Phillips et al, supra, note 287; Jackson et al, supra, note 286 at 22.

290 Ontario Ministry of Health. *HIV Antibody Testing: Guidelines for Pre- and Post-Test Counselling in Anonymous Testing*. Toronto: The Ministry, June 1992, at 3.

291 Ibid at 3; communication with K Nallanagagam, Hassle Free Clinic (Toronto), on 23 August 1996; communication with J Cullingworth, Voices of Positive Women (Toronto), on 2 September 1996.

292 S Lawless et al. Dirty, Diseased and Undeserving: The Positioning of HIV Positive Women. *Social Science and Medicine* 1996; 43(9): 1371-1377 at 1373.

293 R Jürgens. HIV/AIDS and Discrimination: A Brief to the Sub-Committee on HIV/AIDS of the House of Commons by the Canadian HIV/AIDS Legal Network. Montréal: Canadian HIV/AIDS Legal Network, 15 May 1996 (also available on the Network's website at www.aidslaw.ca), with reference to E Reid. Gender, Knowledge, and Responsibility. In: JM Mann, DJM Tarantola, TW Netter (eds). *AIDS in the World*. Cambridge, MA: Harvard University Press, 1992, at 657–667.

294 See, infra, the section on HIV Testing of Pregnant Women, in the chapter on Mandatory Testing.

295 De Bruyn, supra, note 6 at 75.

296 HIV in Women Conference: Women Seek Greater Influence in Reseach, Prevention Policies. *AIDS Policy & Law* 1995; 10(4): 9.

297 Medical Services Branch. *Guidelines for the Delivery of HIV/AIDS Programs and Services*. Ottawa: Health Canada, March 1995, at 35.

298 Matiation, supra, note 19 at 13.

299 Ibid at 13-14.

300 Communication with C Donovan, Medical Health Officer, Eastern Newfoundland, on 29 August 1996.

301 Communication with Dr Blaikie, Medical Health Officer, Central Region (Nova Scotia), on 30 August 1996.

302 See MSSS, Centre québécois de coordination sur le sida (Direction générale de la Santé publique) et Direction de la recherche et de l'évaluation (Direction générale de la Planification et de l'Évaluation). «Dépistage», *Rapport de la consultation réalisé pour le bilan de la phase 3 et l'élaboration de la phase 4 de la Stratégie québécoise de lutte contre le sida*, November 1996, at 45-49.

303 Communication with A Bowlby, AIDS Bureau (Ontario), on 23 August 1996.

304 Communication of 28 August 1996.

305 Communication with Caroline Ploem, 21 August 1998.

306 Communication with C Olivier, AIDS New Brunswick, on 23 August 1996. See also J Goltz, J Noble. New Brunswick Needs Anonymous HIV Testing. Fredericton: AIDS New Brunswick, 1996.

307 Communication with Dr Sweet on 10 January 1997.

308 Response to the *Discussion Paper*, dated 22 May 1997.

309 Communication with A Corveau on 27 August 1996.

310 Communication with P Mandel on 29 August 1996.

311 Response to the *Discussion Paper* by Dr FI Gilchrist, dated 9 June 1997.

312 Communication with P Matusko, AIDS Program Coordinator, Public Health Branch, Manitoba Health, on 2 September 1996.

313 Communication with Dr B Larke on 21 August 1998.

314 Communication received from Dr D Patrick, 24 August 1998.

315 Communication with Dr D Patrick, 20 August 1998.

316 J Maxwell et al. The Need for Anonymous Genetic Counseling and Testing. *American Journal of Human Genetics* 1996; 58: 393-397 at 394, with reference to R Doughty. The Confidentiality of HIV-Related Information: Responding to the Resurgence of Aggressive Public Health Interventions in the AIDS Epidemic. *California Law Review* 1994; 82(111): 132-133.

317 HIV Testing Action Coalition. *Statement of the National HIV Testing Action Coalition on the Necessity for Maintaining Anonymous HIV Testing Sites in All States*. The Coalition, 21 May 1997.

318 AIDS Action Committee of Massachusetts and AIDS Action Council of Washington DC. *Creating an Effective Public Health Response to the Changing Epidemic: Moving to HIV Surveillance by Unique Identifier and Other Non-Name Based Surveillance Systems.* Boston & Washington DC: The Committee and the Council, October 1997, with reference to AIDS Project Los Angeles. *HIV Surveillance: Proposals for the New Era of the HIV Epidemic*, Summer 1997.

319 HIV Testing Action Coalition, supra, note 317.

320 European Centre for the Epidemiological Monitoring of AIDS. *HIV/AIDS Surveillance in Europe*. Saint-Maurice, France: The Centre, Quarterly Report no 56, 1997/4, at 41.

321 *UNAIDS Policy on HIV Testing and Counselling*, supra, note 78 at 1.

322 Response to the *Discussion Paper* by Jane Cullingworth, dated 22 July 1997.

323 Aboriginal Nurses Association of Canada. *HIV/AIDS and Its Impact on Aboriginal Women in Canada*. Ottawa: Minister of Health Canada, March 1996, recommendation 9.0 at 44.

324 Matiation, supra, note 19 at 14.

325 Ibid.

326 OLRC, supra, note 13 at 99.

327 For an overview of studies on anonymous and confidential HIV testing, see the ACLU paper on *HIV Surveillance and Name Reporting*, supra, note 85, appendix III.

328 I Hertz-Picciotto, J Goltz, J Noble. HIV Test-Seeking Before and After the Restriction of Anonymous Testing in North Carolina. *American Journal of Public Health* 1996; 86(10): 1446-1450 at 1448, with reference to LJ Fehrs et al. Trial of Anonymous Versus Confidential Human Immunodeficiency Virus Testing. *Lancet* 1988; ii: 379-382; WD Johnson, FS Sy, KL Jackson. The Impact of Mandatory Reporting of HIV Positive Persons in South Carolina. In: *IV International Conference on AIDS*; June 1988; Stockholm, Sweden. Abstract 6020; SM Kegeless et al. Mandatory Reporting of HIV Testing Would Deter Men From Being Tested. *Journal of the American Medical Association* 1989; 261: 1275-1276; SM Kegeless et al. Many People Who Seek Anonymous HIV-Antibody Testing Would Avoid It under Other Circumstances. *AIDS* 1990; 4: 585-588; P Phanuphak et al. Thailand's First Anonymous Alternative Test Site: A Lesson for Asian Countries. In: *VII International Conference on AIDS/III STD World Congress*; July 1992; Amsterdam, The Netherlands. Abstract MoC 0061; G Ohi et al. Notification of HIV Carriers: Possible Effect on Uptake of AIDS Testing. *Lancet* 1988; ii: 947-949; L Paringer et al. The Impact of Risk, Knowledge, and State Regulatory Policy on Testing Decisions. *Inquiry* 1991; 28: 226-235; Centers for Disease Control and Prevention. Comparison of Anonymous and Confidential Registrants for HIV Testing. *Morbidity and Mortality Weekly Report* 1993; 29 January: 53-56.

329 L Gardner, R Trow. Anonymous Testing Considered Essential, Good Follow-up Results. In: *VI International Conference on AIDS*; June 1990; San Francisco, Calif. Abstract Th.D.831.

330 KA Phillips. The Relationship of 1988 State HIV Testing Policies to Previous and Planned Voluntary Use of HIV Testing. *AIDS* 1994; 7: 403-409.

331 T Yovetich. *Community Consultation on Surveillance Needs. Final Report*. Ottawa: Canadian AIDS Society, June 1998, at 5.

332 Hertz-Picciotto et al, supra, note 328, with reference to T Hoxworth et al. Anonymous HIV Testing: Does It Attract Clients Who Would not Seek Confidential Testing? *AIDS Public Policy Journal* 1994; 9: 182-189; TL Cheng et al. Confidentiality in Health Care: A Survey of Knowledge, Perceptions and Attitudes Among High School Students. *Journal of the American Medical Association* 1993; 269: 1404-1407; Kegeless et al 1989, supra, note 328; Phanuphak et al, supra, note 328; Ohi et al, supra, note 328; HF Hull et al. Comparison of HIV-antibody Prevalence in Patients Consenting to and

Declining HIV-antibody Testing in an STD Clinic. *Journal of the Americal Medical Association* 1988; 260: 935-938; WJ Kassler et al. Anonymous vs Confidential HIV Testing in North Carolina. In: *VIII International Conference on AIDS/III STD World Congress*. July 1992, Amsterdam, The Netherlands. Abstract PoC 4818; T Myers et al. Factors Affecting Gay and Bisexual Men's Decisions and Intentions to Seek HIV Testing. *American Journal of Public Health* 1993; 83: 701-704; J Browne et al. HIV Anonymous Testing – Does It Make a Difference? In: *IX International Conference on AIDS/IV STD World Congress*. June 1993, Berlin, Germany. Abstract PO-C28-3249 (a study conducted after the expansion of anonymous testing services in Ontario); G Godin et al. Understanding the Intention of Gay Men to Take the HIV Antibody Test. In: *IX International Conference on AIDS/IV STD World Congress*. June 1993, Berlin, Germany. Abstract PO-C25-3223; J Reardon et al. Are HIV-infected Injection Drug Users Taking HIV Tests? *American Journal of Public Health* 1993; 83: 1414-1417. See also New Brunswick Needs Anonymous HIV Testing. Fredericton: AIDS New Brunswick, 1996, with reference to AIDS Bureau, Ontario Ministry of Health. Anonymous HIV Testing Evaluation – January 1992 to June 1993. Toronto: AIDS Bureau, June 1993; Nova Scotia Department of Health. Four Month Progress Report on the Anonymous Testing Program in Nova Scotia. Halifax: The Department, November 1994. In contrast, in Québec, initial evaluation of anonymous testing facilities has revealed that the facilities have thus far failed to attract those at greatest risk of HIV. This may be due to many factors that remain to be examined, including the lack of awareness among those at risk of the existence of the facilities.

333 *HIV/AIDS Surveillance in Europe*, supra, note 320 at 41.

334 *ACT-UP Triangle* v *Commission for Health Services*, State of North Carolina, in the General Court of Justice, Superior Court Division, File
No 94CVS05480.

335 Hertz-Picciotto et al, supra, note 328 at 1448. Counties that retained anonymous testing were more urban and had more AIDS cases than the other counties, and residents probably were more aware of the epidemic.

336 Ibid.

337 Ibid at 1449.

338 Response to the *Discussion Paper* by TA Peterman, dated 24 June 1997.

339 WJ Kassler et al. Eliminating Access to Anonymous HIV Antibody Testing in North Carolina: Effects on HIV Testing and Partner Notification. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1997; 14: 281-289 at 288.

340 See also M Moser. Anonymous HIV Testing (letter to the editor). *American Journal of Public Health* 1998; 88(4): 683.

341 Ibid at 286.

342 Ibid, with reference to KA Phillips. The Relationship of 1988 State HIV Testing Policies to Previous and Planned Voluntary Use of HIV Testing. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1994; 7: 403-409.

343 Communication with A Bowlby, supra, note 303.

344 WJ Kassler et al, 1997, supra, note 339 at 282.

345 OLRC, supra, note 13 at 91, with
reference.

346 J Hamblin, M Somerville. Surveillance and Reporting of HIV Infection and AIDS in Canada: Ethics and Law. *University of Toronto Law Journal* 1991: 41; 224-246 at 236.

347 Kassler et al, supra, note 339; RE Hoffman et al. Comparison of Partner Notification at Anonymous and Confidential Test Sites: HIV Test Sites in Colorado. *Journal of Acquired Immune Deficiency Syndrome and Human Retrovirology* 1995; 8: 406-410; Landis et al. Results of a Randomized Trial of Partner Notification in Cases of HIV Infection in North Carolina. *New England Journal of Medicine* 1992; 326: 101-106.

348 Moser, supra, note 340.

349 Supra, note 346 at 237. Anonymous testing is not an absolute barrier to partner notification programs: two states in the US have reported successful programs when index case patients are tested anonymously (Hertz-Picciotto et al, supra, note 328 at 1448, with reference to AT Pavia et al. Partner Notification for Control of HIV: Results after Two Years of a Statewide Program in Utah. *American Journal of Public Health* 1993; 83: 1418-1424; EM Blankenship et al. HIV Partner Notification with an Anonymous Testing System. In: *V International Conference on AIDS*. June 1989, Montréal, Canada. Abstract WDP1).

350 The Members of the Federal/Provincial/Territorial Advisory Committee on AIDS Working Group on Partner Notification. *Guidelines for Practice for Partner Notification in HIV/AIDS.* Ottawa: Health Canada, January 1997, at 6.

351 Ibid at 4.

352 OLRC, supra, note 13 at 95.

353 Ontario Ministry of Health, AIDS Bureau. *Anonymous HIV Testing Evaluation, January 1992 to June 1993*. Toronto: The Ministry, November 1994, at 7.

354 Ibid at 17.

355 OLRC, supra, note 13 at 99, with reference to Fehrs et al. Trial of Anonymous versus Confidential Human Immunodeficiency Virus Testing. *Lancet* 1988; ii: 379 at 381.

356 Hertz-Picciotto et al, supra, note 328 at 1448.

357 Response to the *Discussion Paper* by TA Peterman, supra, note 338.

358 Ibid.

359 See www.homeaccess.com. See also D Canedy. Seeking Assurance from a $40 Kit. *New York Times* 21 November 1996, at D1.

360 For a description of the various types of home tests available, see infra, the chapter on new testing technologies.

361 W Flanagan. Comment on M Palles. HIV Testing and Confidentiality – Draft, with reference to W Flanagan. Equality Rights for People With AIDS: Mandatory Reporting of HIV Infection and Contact Tracing. *McGill Law Journal* 1989; 34: 531-602.

362 Ibid.

**Return to the top of this page**

**Return to Table of Contents**

# HIV Testing and Confidentiality: Final Report

**Prepared by Ralf Jürgens**

**ISBN 1-896735-16-9**

---

# COUNSELLING

In Canada and internationally there used to be a consensus that HIV testing should only be undertaken with pre- and post-test counselling. Nevertheless, in practice, people tested for HIV often receive very little or no counselling. In addition, some people have started suggesting that requiring pre-test counselling for all people who seek testing may in fact discourage some people from being tested by "overdramatizing" the testing situation and creating a "crisis" atmosphere around the decision to be tested.

This chapter first summarizes the recommendations concerning counselling made by Canadian organizations and internationally since 1986 (History). The chapter then briefly examines the current situation, pointing out that, in practice, people tested for HIV often do not receive adequate counselling before and after testing (Current Situation). The chapter then critically explores whether, in 1998, counselling is still required before and after an HIV test is undertaken (Assessment). The chapter concludes that pre- and post-test counselling remain important components of HIV testing, that existing counselling guidelines should be regularly updated, and that health-care professionals need to be educated about the need for counselling and about proper counselling techniques (Conclusions and Recommendations).

The chapter does not deal with the concerns related specifically to the development of HIV home test kits, which make testing in the privacy of one's own home possible without pre- and sometimes even without post-test counselling. These concerns will be addressed in the next chapter.

# History

> In order to guarantee the individual benefits from an HIV test, to reduce the fear and occurrence of the negative effects of testing, and to increase the possible public health benefits, counselling has been promoted as an essential element of voluntary testing. Ideally, the counselling process should start before HIV testing occurs to discuss the need for testing, provide accurate information about HIV, clarify technical aspects of HIV testing, discuss past risk behaviours and risk reduction strategies and help explore the implications of the test result, particularly if positive. Counselling after the test should provide emotional support, and help the person to find the most appropriate medical and social care.363

## Canada

Organizations in Canada that have made statements on the issue of counselling – including the National Advisory Committee on AIDS, the Royal Society of Canada, the Federal/Provincial/Territorial Advisory Committee on AIDS, the Canadian Public Health Association, the Ontario Ministry of Health, and the Canadian Medical Association – have all held that it is an important, even essential, component of HIV testing.364 According to guidelines for pre- and post-test counselling in anonymous testing centres released by the Ontario Ministry of Health in June 1992, "[c]ounselling about HIV infection is the most effective way to prevent transmission and to help people who are infected identify the support, strength and resources they need to live with the diagnosis."365 The guidelines continue by saying that counselling

is more important than the test itself. People who seek testing are receptive to information and may be in need of support. The quality of counselling they receive will have a significant impact on their ability to change behavior or live with HIV infection.366

The F/P/T Advisory Committee on AIDS specified that pre-test counselling "should include notification of the limitations and implications of testing, including information regarding nominal reporting of positive test results in jurisdictions where this is required by law," and that "[r]eporting of test results to the tested individual must be done in a manner that reinforces and supplements pre-test information and ensures appropriate post-test counselling."367 Recognizing the importance of quality pre-and post-test counselling, CPHA established that all professionals involved in HIV counselling must adhere to high standards of practice; all counsellors require thorough training to meet standards of competency in counselling about HIV infection and related issues; and, if counselling is to be effective, a better understanding of behaviour-change techniques is essential.368

Specifically with regard to Aboriginal people, the *Guidelines for the Delivery of HIV/AIDS Programs and Services* issued by the Medical Services Branch of Health Canada state that

> counselling should be provided in an environment where the person providing the counselling is sensitive to issues of sexual identity, culture and living conditions. The language and approach should be appropriate to the client.369

## International Developments

As in Canada, individuals and organizations in other countries have held that pre- and post-test counselling are essential components of HIV testing.

For example, the South African Law Commission, in a discussion paper on aspects of the law relating to AIDS, stated that

> [p]re-test counselling is an important part of informed consent in the context of HIV: Testing for HIV/AIDS presents serious medical, legal, ethical, economic and psychological implications. Because HIV is a life-threatening condition reasonable persons or health care workers will, according to established case law, attach significance to the outcome of an HIV test, especially a positive diagnosis. Adequate information on these issues therefore forms an essential part of informed consent. [references omitted]370

In some Australian jurisdictions, pre- and post-test counselling requirements are even imposed by legislation. For example, in Tasmania the *HIV/AIDS Preventive Measures Act* 1993 requires pre-test counselling on the medical and social consequences of being tested and face-to-face post-test counselling about how to avoid HIV transmission in cases where the test is negative. When the result is positive, the patient must be informed in person and counselled in accordance with Departmental guidelines.371 Victoria, New South Wales, and the Northern Territory also require some kind of counselling of persons testing for HIV or, more generally, persons suffering from a sexually transmissible disease.372

In the United States, since early 1985, the Centers for Disease Control and Prevention (CDC) has provided public funds to state and local health departments to support a national HIV counselling-and-testing program, and the importance of providing pre-and post-test counselling has been recognized from the beginning.373

Finally, the Joint United Nations Programme on HIV/AIDS (UNAIDS), in a policy statement released in August 1997, reemphasized that voluntary testing should be provided "in a non-stigmatizing environment," and that "the services should include pre-test counselling (where possible and desired), informed consent, and post-test counselling."374 Similarly, the United

Nations International Guidelines on HIV/AIDS and Human Rights, published in 1998, provide that, "in view of the serious nature of HIV testing and in order to maximize prevention and care, public health legislation should ensure, whenever possible, that pre-and post-test counselling be provided in all cases."375

## Current Situation

Despite the consensus about the importance of providing pre- and post-test counselling, and despite the existence of comprehensive guidelines such as those of the CMA and the Ontario Ministry of Health, most of the over 60 individuals and organizations consulted during Phase I of the Network/CAS Project on Legal and Ethical Issues Raised by HIV/AIDS expressed concern about the fact that many who seek testing for HIV do not receive any or only inadequate counselling. Anecdotal evidence of the lack of counselling was confirmed by a study of 40 HIV-positive women’s experiences and perceptions related to HIV testing, in which 37 (93 percent) of the women interviewed indicated that they did not receive both pre- and post-test counselling; 20 (50 percent) received post-test counselling only, and 17 (43 percent) indicated that they did not receive any counselling.376 Of the 17 women who stated that they did not receive any counselling, eight were tested between 1986 and 1989, five between 1990 and 1992, and four between 1993 and 1994, suggesting that the year of testing may not play a significant role in the type of counselling received. Likewise, of the 20 women who reported that they received only post-test counselling, five were tested between 1986 and 1989, nine between 1990 and 1992, and six between 1993 and 1994.377 The study concluded:

> This raises serious concerns about the counselling process, and suggests that there may be a need for multiple counselling sessions to ensure that women are receiving and understanding HIV-related information. In addition, more education for physicians and other health professionals about the recommended counselling and notification process may be required to ensure that appropriate HIV counselling is provided.378

While the quality of the counselling provided at dedicated testing clinics or by physicians who are experienced in the area of HIV/AIDS is seldom criticized, it has been said that doctors with little experience with HIV/AIDS often do not provide adequate counselling, or do not provide any counselling at all:379 "Some doctors treat the HIV test as if it were a test like any other, tell a patient `You are positive’ and essentially leave it at that."380 In the study of HIV-positive women’s experiences and perceptions related to HIV testing, the women interviewed were not specifically asked about how they were told about their HIV status, but two women, tested in 1988 and 1991 respectively, did indicate that they were told over the telephone, and one woman, tested in 1990, reported that the message was given to her husband.381 Some doctors are aware of their lack of expertise in counselling people who seek testing for HIV: the Hassle Free Clinic in Toronto reports that an increasing number of doctors refer clients to them for counselling and testing.382 Clearly, few incentives exist for doctors who have relatively little experience with HIV in their medical practice to improve their counselling skills. They are required to deal with a myriad of health problems and often do not have – and are not adequately paid for – the time and attention required for effective counselling. Another problem is HIV testing undertaken as part of an application for insurance: stories abound of people who have found out that they are HIV-positive in a letter sent to them from an insurance company.383

Many of those consulted in the process of developing a discussion paper on HIV testing and confidentiality issues for Aboriginal communities also indicated that adequate pre- and post-test counselling is not being provided to Aboriginal people by all health-care practitioners and that the quality of counselling is greater in testing clinics, both in small communities and in cities. For example,

> [a]n AIDS organization in a smaller city with a large Aboriginal population conducted a secret campaign to determine whether counselling was being provided by local doctors. It was found that few doctors provided counselling and that many doctors failed to communicate results to patients.

In another smaller town with a large Aboriginal population doctors have the option of providing counselling or referring persons who seek testing to public health centres. In the latter scenario a person must first visit the public health centre, then go to the doctor for the HIV test, return to the doctor for the result, and go back to the public health centre for post-test counselling. Few people seek testing in this community.

> Some CHNs [community health nurses] and CHRs [community health representatives] are not comfortable with HIV/AIDS issues and do not have adequate counselling skills.384

Finally, problems with the adequacy and quality of counselling are not limited to the Canadian context. According to Valdiserri, concerns about the quality of HIV counselling "have been recurrent throughout the history of this program [the United States HIV CT program],"385 leading him to conclude that programs must "develop quality assurance measures and systems to monitor the provision of counselling and be prepared to take corrective actions when deficits are noted."386 Sikkema and Bissett note that an external review of the CDC's counselling, testing, referral, and partner notification program found that HIV CT did not always follow CDC guidelines or meet CDC standards. Specific findings included: testing and identification of the infected took precedence over counselling in some communities, counselling was often perfunctory or inappropriate, the length of the counselling session was brief and variable, and there was considerable variation in the content of counselling offered, the training of individuals conducting the counselling, and the intensity of the counselling session.387

# Assessment

> Psychological stresses associated with knowledge of seropositivity have yet to be shown to have been reduced for those recently identified [as being HIV-positive].388

Counselling has been defined as

the skilled and principled use of relationships which develop self knowledge, emotional acceptance and growth, and personal resources. The overall aim is to live more fully and satisfyingly. Counseling may be concerned with addressing and resolving specific problems, making decisions, coping with crises, working through feelings and inner conflict, or improving relationships with others. The counselor’s role is to facilitate the client’s work in ways that respect the client’s values, personal resources and capacity for self determination.389

Specifically in the context of HIV, counselling has been defined as "the development of a relationship between a counsellor and a client for the purpose of assessing risk for HIV infection or transmission, developing a plan to reduce risk, and assisting the client to cope with emotional and interpersonal issues related to HIV."390 As Grinstead notes, HIV counselling for behaviour change is sometimes distinguished from counselling for care and support, counselling provided to HIV-positive individuals and their family and significant others. An alternative viewpoint is that both types of counselling have behaviour change as their goal and that both types of counselling can be conducted regardless of the client’s serostatus. In the case of prevention counselling, the goal is behaviour change to prevent the transmission of HIV. In the case of counselling for care and support, the goal is behaviour change to improve the care and comfort of people with or affected by HIV and to decrease behaviours and attitudes that contribute to stigmatization, discrimination, abuse, and abandonment of affected individuals.391

Pre- and post-test counselling have been widely considered to be essential components of HIV testing. Indeed, before treatments for HIV became available, the opportunity for counselling was often seen as the primary reason for state encouragement of testing.392 According to WHO,

> [t]o be beneficial, voluntary HIV testing ... must be ... part of a comprehensive counselling program, in which counsellors provide counselling before a decision is made about testing (pre-test counselling), and provide counselling along with other supportive services (such as the provision of condoms and safer injecting equipment, where appropriate) or referral after testing (post-test counselling).393

Counselling can be a direct vehicle to combat fear, denial, and misunderstanding about HIV, educate people about the importance and nature of safe practices, convey the meaning of test results, and help people to cope with the severe psychological, social, and economic consequences of HIV infection, as well as emotions about death and dying.394 While traditional STD counselling is more likely to be didactic in nature, focusing on treatment regimens, notification of partners, and disease symptoms,395 it has been suggested that HIV counselling should be

> an on-going dialogue and relationship between client and counselor with the aims of preventing HIV transmission and providing psychosocial support for those affected. ... In order to achieve these aims, counselling seeks to encourage and enhance self-determination, to boost self-confidence, improve family and community relationships, and quality of life.396

According to the [US] Centers for Disease Control and Prevention HIV CT Guidelines, optimally, HIV CT should consist of client-centered pre-test and post-test counselling,397 "where client centered is defined as tailoring counseling to the special circumstances of the client (e.g., gender, culture, sexual orientation, age, and level of education); listening to, rather than lecturing, the client; and personalizing risk reduction information to the client."398

## Pre-test Counselling

> Pretest counselling is an educational opportunity and should be viewed as a means to initiate preventive and continuing care. The decision to be tested should always be the choice of the individual patient.399

Ideally, a physician providing pre-test counselling should:

- assess the risk of HIV infection of the person being tested;

- assess the window period;

- provide information about HIV infection and testing, including the meaning of positive, negative and indeterminate test results, and the impact of the window period;

- discuss risk-producing activities and specific ways in which the person can avoid or reduce risk;

- identify testing options available in the region;

- discuss record-keeping by informing the patient that test results and information will be added to the medical record and will be available to other health-care professionals on a need-to-know basis (if the patient objects, anonymous testing should be discussed);

- discuss the issues raised by testing so that the patient has the opportunity to weigh the advantages and disadvantages of being tested and prepare for the potential consequences of a positive or negative test result – testing should be carried out only when the patient considers the advantages to be greater than the disadvantages;

- discuss the confidentiality of test results in relation to office or clinical procedures, communication of results to other health-care officials, partner notification and reporting requirements;

- discuss the stress related to waiting for test results and possible reactions to learning the results;

- determine the timing of testing and arrange a post-test appointment;

- obtain and record informed consent before testing is conducted; and

- provide support and follow-up by encouraging the persons being tested to contact the physician, AIDS service organizations or support groups if they experience intolerable anxiety between the time the blood is drawn for testing and the time they receive their result.400

Most of these steps would be required also if counselling were undertaken by a counsellor in a testing clinic. In addition, counselling needs to be an interactive process – not just the provision of information, but an open discussion of issues, feelings, concerns and reactions:

> Counsellors are expected to bring their own knowledge of counselling skills to the sessions, adapting the information – if necessary – to meet the clients' needs. Counsellors are reminded that culture, language, perception of HIV disease, the person's self-esteem and many other factors will have an impact on how clients understand and are able to act on the information they receive. These should all be taken into account in the counselling sessions.401

## Post-test Counselling

> Post-test counselling involves working with the patient to understand the test result, address psychological reactions to it, promote behaviour changes and assess the need for follow-up and care.402

The CMA counselling guidelines stress that test results, whether positive or negative, "must be given only in person, in a face-to-face interview." They state that informing patients of their test result by telephone is "unacceptable," even when the result is negative, and that it places the physician at risk of liability should disclosure to someone other than the patient inadvertently occur. In addition, the guidelines point out that communicating test results face-to-face permits better appreciation of the patient's reaction and enables adequate counselling.403

Post-test counselling should include

- an assessment of the person's understanding of the test result;
- for persons with a negative or indeterminate test result, a discussion of any need for repeat testing, a review of the ways in which HIV is transmitted, and an assessment of the patient's commitment to risk-reducing strategies;
- for persons with a positive test result, the first post-test visit may be mainly supportive in nature because, after diagnosis, an HIV-positive patient usually cannot absorb much more information. The newly diagnosed patient should receive assistance in deciding if and to whom s/he will disclose her/his HIV status before the second post-test visit (this should include information about the consequences of the Supreme Court decision in *R* v *Cuerrier*404); if necessary, crisis intervention should be provided; and a second post-test visit should be set up to take place as soon after the first visit as possible. Over several more visits, counselling should stress that the patient can remain healthy and productive for a long time; emphasize the importance of medical follow-up, referral when appropriate, and of health promotion and stress reduction in general; include discussion of the reproductive consequences of HIV infection for both men and women, including interventions to reduce mother-to-child transmission; arrange psychological and social support services as needed; encourage self-education on care and treatment and be available to discuss new developments in the management of HIV infection; discuss risk-reduction strategies; and, if necessary, arrange for partner notification.405

It has been said that the nature of HIV presents a unique counselling challenge because clients

> who test positive for HIV effectively face a terminal situation, despite medical advances that promise eventual long-term management of the infection. In addition, anyone infected with HIV can pass these severe consequences on to another. There is no parallel to this complex counseling challenge of simultaneously meeting the emotional support and coping needs of someone dealing with their own mortality and facilitating risk-related behavior change. This complexity distinguishes HIV CT from other health-related counseling situations such as physician-mediated counseling for other STDs, high cholesterol, pregnancy, or even cancer.406

## Continued Importance of Counselling

## Pre-test Counselling

As mentioned above, some people have started suggesting that requiring pre-test counselling for all those who seek testing may in fact discourage some people from being tested by "overdramatizing" the testing situation and creating a "crisis" atmosphere around the decision to be tested. These are the same people who have started suggesting that specific informed consent should no longer be required for testing and, generally, that HIV is no longer unlike other diseases and that the HIV test should be treated like any other test for other diseases. They are concerned that as many people be tested for HIV as early as possible, so that those testing HIV-positive can obtain treatments for HIV and change their behaviour to prevent the transmission of HIV to others.

However, as shown above, stigmatization and discrimination of people with HIV/AIDS in Canada continues because HIV/AIDS continues to disproportionately affect vulnerable, marginalized populations with a long history of discrimination and because the disease continues to be strongly associated with sex and drugs. As a result, the potential social, psychological, and economic harms from testing positive remain significant. In addition, while the new treatments can potentially be very beneficial for those testing positive, access to these treatments continues to be a serious problem, their long-term efficacy is still unproven, and HIV/AIDS is still a terminal disease. In 1998, and likely for many years to come, HIV/AIDS continues to be a disease that is very different from other diseases. It would be a serious mistake to "trivialize" HIV testing and to push people to be tested without providing them with pre-test counselling to discuss the benefits and potential harms from testing. While there can be no doubt that people should be encouraged to be tested, they must be provided with the support that will help them to maximize the benefits from testing for themselves and others, while reducing potential harms.

## Post-test Counselling

Post-test counselling may be even more important than pre-test counselling. Those who test negative need to be counselled about ways to remain HIV-negative. They also need to be informed about the "window period" between actual infection and the time when an HIV test will be able to detect it. If not, they may be falsely reassured by a negative test result. People who test positive typically comprehend little of what is told to them immediately after receiving results; therefore follow-up sessions are essential to help them cope with this news.407

Rather than decreasing the need for counselling, availability of new treatments (and the recent decision in *R v Cuerrier*)408 enhance the importance of counselling. More than ever, counselling 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. In addition, some cautioning may be appropriate:

What we know ... is still incomplete. In a rapidly changing scenario of HIV activity where rumours and hopes quickly take on the gravitas of facts, researchers and clinicians have a vital responsibility to ensure that clinical diagnosis and management decisions are based on scientific procedures and findings that can be fully discussed and analysed. It is increasingly difficult, but at the same token also increasingly important, for counsellors to present a balanced and, if need be, cautious view of current scientific developments when so many others are shouting about the "new clothes of the antiretroviral emperor."409

## Improving Counselling

Pre- and post-test counselling continue to be important, and may even have become more important. However, as many of the respondents to the *Discussion Paper* pointed out, the reality is that outside the established testing clinics staffed with professionals trained to provide testing and counselling services, it will in the vast majority of cases remain up to the individual physician administering the test to provide adequate counselling. As one respondent said, given that counselling can be time-consuming, "it will continue to be the exception rather than the rule."410 It has been suggested that physicians who lack the time to do proper counselling should refer patients requesting HIV testing to a facility providing adequate counselling. While this may be a partial solution for people requesting testing in areas in which testing clinics have been established, it may not be an option for the majority of those seeking testing. In addition, it can be argued that, unless appropriate counselling is provided, people cannot provide *informed* consent to testing. Therefore, every physician providing HIV testing must provide counselling consistent with the CMA counselling guidelines, and sustained efforts need to be undertaken to educate physicians and other health-care professionals about the importance of providing counselling and the recommended counselling process.

At the same time, the expertise available at testing clinics should be acknowledged, and testing and counselling services available there should be supported and promoted. Finally, counselling services available to HIV-negative and HIV-positive people outside the testing context also need to continue to be supported, to offer both care and support as well as prevention advice. An example of such a service is a recently started psychosocial counselling service for HIV-positive gay men offered in Montréal by a community-based AIDS organization, Action Séro Zéro in collaboration with public health (Direction de la Santé publique de Montréal-Centre).411

# Conclusions and Recommendations

Counselling works. In its "Best Practice" collection, UNAIDS recently stressed that "[v]arious studies have proved that good counselling has: assisted people to make informed decisions – such as whether to have an HIV test; helped many other people living with HIV or AIDS to cope better with their condition and lead more positive lives; and helped prevent HIV transmission."412 It continues to be important, and may even have become more important. The preceding discussion has reemphasized the need for it in the context of HIV testing:

> This re-emphasis reflects ... the undeniable fact that changes in the amount and content of medical knowledge associated with HIV have not been matched by improvements in the availability of psychological or welfare support available to those testing positive, nor by amelioration of the adverse psychological consequences attendant on a positive result. Thus, while the grounds, particularly for pretest counselling, has shifted significantly, the essential basis of, need for and nature of the counselling process remains little altered. As before, there is a vital need to recognize that the counsellor in HIV must remain a person offering a trusting, implicitly and explicitly supportive, ongoing and confidential relationship that rises above the rhetoric, the hype, the unrealistic expectations and the hidden agendas embraced by the public discussions to which they, and their patients, are perpetually exposed, whatever their profession.413

**3.1 While the availability of new treatments for HIV infection underscores the importance of removing barriers to access to HIV testing, pre- and post-test counselling should not be seen as barriers to HIV testing. Rather, they maximize the benefits from testing for the persons being tested and for society, while reducing potential harms. Therefore, as a general rule, testing should be undertaken only with quality pre- and post-test counselling, consistent with existing counselling guidelines.**

**3.2 Counselling should be culturally competent, sensitive to issues of sexual identity, developmentally appropriate, and linguistically specific.**

**3.3 The CMA and other existing counselling guidelines should be updated to reflect the many new developments that have occurred in recent years, and should be made widely available.**

**3.4 Health-care professionals need to be educated about the importance of providing counselling, and about the recommended counselling process, in basic and continuing education.**

**3.5 The expertise available at dedicated testing clinics should be acknowledged, and testing and counselling services available there should receive increased support and be widely promoted.**

**3.6 Counselling services available to HIV-negative and HIV-positive people outside the testing context need to be supported, to offer both care and**

**support as well as prevention advice.**

**3.7 When testing individuals for insurance purposes, insurance companies should adhere to the same principles as public health, hospitals and physicians in private practice, including provision of pre- and post-test counselling.**

**Return to the top of this page**

**Return to Table of Contents**

---

## ENDNOTES

363 D Schopper, G Vercauteren. Testing for HIV at Home. What Are the Issues? *AIDS* 1996; 10: 1455-1465.

364 For a detailed review, see Jürgens & Palles, supra, note 2 at 75-78, with reference to NAC–AIDS, supra, note 8 at 38; Royal Society of Canada, supra, note 10 at 371; CPHA, supra, note 15 at 17; F/P/T Advisory Committee, supra, note 11 at 44; CMA, supra, note 170 at 4.

365 Ontario Ministry of Health, supra, note 290 at 3.

366 Ibid.

367 F/P/T Advisory Committee, supra, note 11 at 44.

368 Ibid at 4.

369 Supra, note 297 at 39.

370 South African Law Commission. *Discussion Paper 68 – Project 85 (Aspects of the Law Relating to AIDS)*. Pretoria: The Commission, 1996 (ISBN: 0-621-17550-1), paragraph 17.2; for a summary, see South Africa – National Policy on HIV Testing and Informed Consent Proposed. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 11-12.

371 RS Magnusson. 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 at 346.

372 Ibid at 346-347.

373 For more details, see Valdiserri, supra, note 40; JT Weber. Publicly Funded HIV Counseling and Testing in the United States. *AIDS Education and Prevention* 1997; 9(Suppl B): 79-91; DR Holtgrave et al. The Evaluation of HIV Counseling-and-

Testing Services: Making the Most of Limited Resources. *AIDS Education and Prevention* 1997; 9(Suppl B): 105-118.

374 *UNAIDS Policy on HIV Testing and Counselling*, supra, note 78 at 1.

375 *HIV/AIDS and Human Rights: International Guidelines*, supra, note 162 at 12 (Guideline 3, paragraph 28(c)).

376 Jackson et al, supra, note 286 at 21.

377 Ibid.

378 Ibid at 22, with reference to P Selwyn, R Carter, E Schoenbaum et al. Knowledge of HIV Antibody Status and Decisions to Continue or Terminate Pregnancy among Intravenous Drug Users. *Journal of the American Medical Association* 1989; 261(24): 3567-3571; CMA 1995, supra, note 170.

379 Communication with M Shore, Hassle Free Clinic (Toronto), on 26 August 1996.

380 Communication with J Cullingworth, supra, note 291.

381 Supra, note 286 at 21.

382 Communication with K Nallanagagam, supra, note 291.

383 Comment on the *Discussion Paper* received from J Cullingworth, dated 22 July 1997.

384 Matiation, supra, note 19 at 16.

385 Valdiserri, supra, note 40 at 10.

386 Ibid.

387 KJ Sikkema, RT Bisset. Concepts, Goals, and Techniques of Counseling: Review and Implications for HIV Counseling and Testing. *AIDS Education and Prevention* 1997; 9(Suppl B): 14-26 at 16, with reference to Centers for Disease Control. *External Review of CDC's HIV Prevention Strategies by the CDC Advisory Committee on the Prevention of HIV Infection*. Atlanta: The Centers, June 1994; L Doll, M Kennedy. HIV Counseling and Testing: What Is It and How Well Does It Work? In: G Schochetman, JR George (eds). *AIDS Testing*. New York: Springer-Verlag, 1994, 301-319.

388 Miller & Pinching, supra, note 204 at S191.

389 Sikkema & Bissett, supra, note 387, with reference to L Sherr, S Quinn. HIV Testing, Counseling and Behaviour Change. In: L Sherr (ed). *AIDS and the Heterosexual Population*. Langhorne, PA: Harwood Academic, 1993, 179-197 at 181.

390 OA Grinstead. HIV Counseling for Behavior Change. *AIDS Education and Prevention* 1997; 9(2): 125-132 at 125.

391 Ibid at 125-126.

392 See Field, supra, note 17 at 48.

393 WHO 1992, supra, note 53 at 8.

394 Ibid.

395 W DeJong, L O’Donnell, AD San Doval et al. The Status of Clinic-Based STD Patient Education: The Need for a Commitment to Innovation in Health Communication. *Journal of Health Communication* 1996; 1: 51-63.

396 D Silverman, A Perakyla, R Bor. Discussing Safer Sex in HIV Counselling: Assessing Three Communication Formats. *AIDS Care* 1992; (4): 69-82.

397 Sikkema & Bissett, supra, note 387, with reference to Centers for Disease Control. Technical Guidance on HIV Counseling. *Morbidity and Mortality Weekly Report* 1993; 42(RR-2): 8-17; Centers for Disease Control. *HIV Counseling, Testing, and Referral: Standards and Guidelines*. Atlanta: US Department of Health and Human Services, May 1994.

398 Ibid. See also Valdiserri, supra, note 40 at 8.

399 CMA 1995, supra, note 170 at 8.

400 Ibid at 24.

401 Ontario Ministry of Health, supra, note 290 at 4.

402 CMA 1995, supra, note 170 at 12.

403 Ibid at 12.

404 See supra, note 5.

405 CMA 1995, supra, note 170 at 13-16, and comment on *Discussion Paper* received from CLSC Métro AIDS Intervention Centre, dated 25 July 1997.

406 Sikkema & Bissett, supra, note 387 at 20.

407 Schopper & Vercauteren, supra, note 363.

408 Supra, note 5.

409 Miller & Pinching, supra, note 204 at S192.

410 Supra, note 214.

411 Séro Zéro. Positively Sexual. A psychosexual counseling service for HIV-positive gay men. Montréal: Séro Zéro, 1998.

412 The Joint United Nations Programme on HIV/AIDS. *Counselling and HIV/AIDS: UNAIDS Best Practice Collection: Technical Update*. Geneva: UNAIDS, November 1997. See also ML Kamb et al. A Multi-Center, Randomized, Controlled Trial Evaluating HIV Prevention Counseling (Project RESPECT): Preliminary Results. 11th International Conference on

AIDS, Vancouver, 1996, abstract no Th.C.4380 (a study documenting a significant differential decrease in new STDs, and an increase in condom use, at 6-month follow-up among persons receiving HIV testing (with either two or four sessions of counselling) compared with those receiving HIV testing and only minimal risk-reduction education).

413 Ibid.

Return to the top of this page

Return to Table of Contents

# HIV Testing and Confidentiality: Final Report

**Prepared by Ralf Jürgens**

**ISBN 1-896735-16-9**

---

# ADVANCES IN TESTING TECHNOLOGY

Recent advances in HIV testing technology are increasing 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 test available – antibody tests can be done on blood, saliva, and urine, and blood tests can even be done at home. In addition, rapid tests have become available that can provide test results within 5 to 30 minutes.

Availability of these new testing options raises many issues. This chapter first provides an overview of the developments in the field of HIV testing (Evolution in the Field of HIV Testing). It then focuses on the two developments that are both most controversial and most promising: home testing and rapid testing. It first examines questions related to home testing. It summarizes the developments and recommendations made concerning HIV home testing in Canada, the United States, and internationally (History) and then examines the current situation, pointing out that, while HIV home testing kits have been approved and on sale in the US since mid 1996, no home test for HIV has as yet been approved in Canada (Current Situation). The chapter then critically explores the potential benefits and harms of home tests, and the questions that need to be addressed in Canada before they can be made available (Assessment). The chapter concludes that HIV home test kits, particularly HIV sample collection kits, have great potential benefits, but also potential harms, and advocates a cautious approach to their introduction in Canada (Conclusions and Recommendations).

The chapter then examines questions related to rapid testing. It first summarizes developments in the area of rapid testing in Canada and the US (History). It then briefly examines the current situation, pointing out that, because the situation with regard to rapid tests is evolving so quickly, it is difficult if not impossible to provide an accurate assessment of the current situation (Current Situation). The chapter then critically explores the potential benefits of rapid tests, as well as concerns and questions about them (Assessment). The chapter concludes that serious debate about the choices that the rapid testing technology poses must take place in Canada, and repeats the recommendation that a national workshop on issues raised by the new testing technologies be held (Conclusions and Recommendations).

Apart from describing these tests in the section on Evolution in the Field of HIV Testing, the chapter does not deal with saliva or urine tests. Where they have been approved, many of those tested seem to prefer these tests because they do not involve needle sticks. These tests do not raise the same policy, legal, and ethical issues as home and rapid tests do. They should be approved in Canada once all technical aspects of the tests, such as sensitivity, specificity, reproducibility, stability, etc, have been validated in Canada in comparison with an approved, professional-use system for the collection and testing of blood or any other appropriately validated specimen.

# Evolution in the Field of HIV Testing

The evolution or revolution in the field of HIV testing is the result of technological developments that allow body fluids other than serum or plasma to be used for the detection of HIV antibodies.

## Standard HIV-Antibody Testing

Traditionally, HIV tests have been based on the detection of HIV antibodies in serum/plasma derived from whole blood collected by venipuncture, and hence required trained health-care workers for collection and laboratory facilities for testing. Kassler has described the standard HIV-antibody testing as follows:

Standard HIV antibody testing involves the client having a blood sample drawn by a phlebotomist in a clinical setting, with the blood subsequently being tested in a clinical laboratory to detect the presence of HIV specific antibodies using an enzyme immunoassay (EIA) as a screening test. A negative result is reported if the EIA screening test is nonreactive. A positive result is reported only after the EIA screening test is repeatedly reactive, and confirmed by a more specific, supplemental test such as the Western blot or immunofluorescence assay (IFA). Although the actual testing doesn’t require much time, typically 1 to 2 weeks elapse before results are available. This is because specimens are generally "batched" (i.e., tested in groups) to decrease testing costs, and because time is needed to complete confirmatory testing of reactive EIA samples.414

The major types of screening tests for antibody detection include EIA, agglutination tests, and conjugated colloidal gold assays.415 In general, the EIA is a very sensitive test (ie, high probability that the test will be positive if the specimen is positive). The EIA is usually automated, and batch high-volume testing reduces the cost per test.

## Rapid Tests

Newer, rapid EIA tests have been developed that are simpler to perform, as they require no special equipment other than what is provided in the test kit. These tests can be performed in less than 30 minutes. As Kassler describes, they

> typically involve a flow-through filter device, through which the patient's serum and various washes and reagents are poured. The antigen is on a membrane in the device, and the color reaction occurs on the membrane when anti-HIV antibody is detected.416

Evaluation of some such devices have found sensitivity and specificity (ie, when the specimen is negative, the test will be negative) to be comparable to the standard EIA.417

Because these rapid tests are comparable to the standard EIA, a nonreactive rapid test does not require further confirmation.418 Negative results can be given out at the time of testing, eliminating the need for most people to return for results. As is true of all screening tests (including the EIA), a reactive rapid HIV test result must be confirmed. Currently, confirmation is done by Western blot or IFA, meaning that clients with a reactive test need to return to the clinic once the results of the confirmatory test have been received, one or two weeks after the rapid test. However, studies in countries where more than one type of rapid HIV test is available show that specific combinations of two or more different rapid HIV tests can provide results as reliable as those from an EIA and Western blot or IFA. Therefore, a second rapid HIV test for people whose first rapid HIV test is reactive could significantly improve the predictive value of rapid HIV testing.419

## Tests for Samples Other Than Serum or Plasma

For years, plasma and serum samples (which require venipuncture) have been the standard, but many newer tests have been optimized for noninvasive samples that do not require venipuncture, such as whole blood (also referred to as capillary or fingerstick blood), oral fluids, and urine. Several of these tests have been approved and are available for use. This is a quickly evolving field, with new tests becoming available at a rapid rate. Some of the tests that are not available in Canada have already been approved in the US, and some of the tests that are not available either in Canada or the US are already being marketed in countries where regulations are not as stringent.

The use of body fluids other than blood – such as saliva or urine – for detecting antibodies to

HIV is an attractive alternative for several reasons:

- saliva specimens can be collected or self-collected virtually anywhere – in the home, on the street, in bars;

- non-invasive sampling methods are safer for the subject and for the health-care worker: there is no danger of contamination through unsterilized syringes or needlestick injuries;

- the use of urine specimen has similar advantages, and the infectivity of both saliva and urine seems to be very low.420

## Saliva Tests

Because antibodies to HIV can be detected in the saliva of people with HIV, oral fluids can be used as a noninvasive alternative to blood for HIV testing. Technically, the so-called saliva tests are not really looking for antibodies to HIV in saliva, but in a fluid in the mouth called "oral mucosal transudate." However, the tests are now commonly referred to as saliva tests and will be referred to as such in this Report.421 Oral fluids–based tests have the advantage of ease of collection – medically trained personnel are not needed, there is a reduced risk of needlestick injuries, and oral fluid–based testing may be more acceptable to patients. Oral fluids can be collected using devices including OraSure (Epitope), Omni-Sal (Saliva Diagnostics Systems), Accu-sorb (Avitar), Orapette (Trinity Biotech), and Salivette (Sarstedt). Of these, OraSure was the only device approved by FDA and available for commercial use in the US at the time of writing. The *OraSure HIV-oral specimen collection device*, used to collect oral specimens for use with the HIV-antibody EIA for oral fluid, was approved in December 1994, while the *OraSure HIV-1 antibody Western blot kit*, used to confirm the presence of HIV-1 antibodies in oral samples that are reactive on screening tests, was approved in June 1996.422 Results of a US study using specimens from 3570 subjects collected at 11 different sites showed that OraSure was as accurate as serum testing, providing the correct result or triggering appropriate follow-up testing in more than 99.9 percent of cases (3569 of 3570).423 In addition, the study concluded that: (1) the test would be well-suited for use in a home test kit, in large part because it does not involve the use of needles, which is both safer and more advantageous to individuals with compromised venous access; (2) the collection device is easy to use and portable; (3) the samples remain stable for at least three weeks, which makes the test useful in outreach and developing-world settings; and (4) because training related to saliva testing is minimal, the device reduces the personnel costs associated with gathering samples for HIV testing.424 However, the test is more expensive than the standard blood test, costing about US$35.425

Thus far, the United States is the only country where saliva tests have been approved for initial diagnosis of HIV infection; in other countries, such tests have been used only for surveillance purposes. As pointed out by Schopper and Vercauteren, "[m]ost European countries have reservations about saliva tests for diagnostic purposes."426

In the US, the Whitman-Walker Clinic in Washington, DC was the first major AIDS clinic to announce, in January 1997, that it was switching from the standard blood test for HIV to OraSure as of 1 February 1997.427 Other clinics soon followed.428 In Michigan, the Department of Community Health started making OraSure available to all community-based organizations under contract for HIV prevention services at no cost to the agency. The Department had "one over-arching goal in mind: to increase access to and appropriate utilization of C&T [counselling and testing] services by at-risk populations, especially racial/ethnic minorities and injection drug users."429 Analysis of provisional data suggest that saliva-based testing has been largely successful in this regard.430 In New York State, the Department of Health AIDS Institute's Anonymous HIV Counseling and Testing Program (ACT) conducted an 11-week oral fluid testing implementation and preference pilot study in the summer of 1997. During the study period, all clients at 39 community sites and four correctional facilities were offered a choice of venipuncture or oral fluid testing. A total of 1943 clients participated in the study, 86 percent of whom chose oral fluid testing. Based on "overwhelming client preference and overall staff satisfaction with this testing method,"431 the Department of Health decided to incorporate the use of oral fluid testing into ongoing program services. A choice of testing methods is now being offered to all clients. A policy decision was made to continue to offer both testing methods rather than to switch totally to oral fluid testing, accommodating clients who strongly prefer venipuncture and those who present with HIV-2 risk factors that cannot be detected through current oral fluid testing. Since the conclusion of the study, 73 percent of clients have selected oral fluid testing.432 In New York City, Planned Parenthood started offering OraSure at its three health-care centers in June 1998, after a pilot program using the test saw a 50 percent increase in the number of people who were tested for HIV.433

At the time of writing, saliva tests had not yet been approved for *home* testing, but some unapproved home saliva tests were available that were being sold illegally, especially on the Internet, although they had not been proven to be either accurate or safe to use.434 The Centers for Disease Control and Prevention estimated that an oral HIV-antibody home testing kit may become available to the public in 1998.435

*Rapid* saliva tests had not been approved in the US or in Canada either, but rapid saliva tests are available outside the US and Canada. As Kassler reports, the development of accurate rapid saliva tests has presented a challenge because antibody concentrations are, in general, a thousandfold less concentrated in oral fluids than in serum, and because many rapid test designs use washes or buffers that dilute the sample even further.436

## Urine Tests

Urine offers the same potential as oral fluids for a noninvasive test. A nonrapid EIA that has been optimized for urine has been approved and is commercially available in the US (Calypte HIV-1 Urine EIA, Calypte Biomedical). In addition, on 28 May 1998 the FDA approved the licensing of a Western Blot test that confirms the presence of HIV-1 antibodies in urine samples, also manufactured by Calypte Biomedical. The approval completes the only available urine-based HIV test system in the US. Before the confirmatory test was approved, people with a reactive urine test had to submit an additional blood or oral fluid sample for confirmatory testing.437 The urine test is expected to be attractive to health agencies that do not have access to funds, personnel, or facilities for blood collection and testing. Moreover, a survey conducted by Market Facts, Inc showed that 50 percent of 1000 US citizens interviewed would prefer a urine HIV test over a blood test. More than 80 percent of these people cited fear of needles as the reason for preferring urine tests.

In clinical trials of the Western Blot urine test, the sensitivity was 99.7 percent. The two individuals who tested false negative in the trial were individuals who had AIDS and were on antiretroviral therapy.438

At the time of writing, urine tests were not available for *rapid* or *home* use, and were not commercially available in Canada.

## Home Tests

Until recently, the performance of HIV tests – even those using body fluids other than serum or plasma – were confined to a laboratory setting. Today, HIV tests can be performed at home, and home sample collection and true home tests have become a practical reality.

The term "HIV 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.

It is important to distinguish the two different forms when considering their respective impacts. In the following text, the broad term home testing will only be used where the text refers simultaneously to both forms of testing.

### Home Sample Collection Testing

Under this system (also called home-access testing), a person purchases an over-the-counter HIV test kit and collects her/his sample at home using a home collection kit. The specimen with identification number is then mailed to a testing facility and approximately seven days later the person can call for the result. Depending on the test result, post-test counselling is given either by voice mail (negative result) or person to person (positive result).

Home sample collection kits thus do not provide on-the-spot test results in a matter of minutes, as is the case with home pregnancy tests and home self-tests.

## True Home Tests

True home tests (also called home self-tests or home validated tests) are essentially rapid tests that can be carried out entirely at home without 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. In the context of HIV, if the HIV indicator is negative, a person testing her/himself is encouraged to repeat the test in three to six months. If the HIV indicator is positive (indicated by, eg, a colour change), the person is encouraged in the instructions to visit a physician or an HIV testing clinic for further testing. For obvious reasons, counselling is not an integral part of this system. Although the instructions may urge the user to contact health-care facilities in case of a positive result, it is left to his/her initiative to do so.

Although, to date, no true home HIV test has been approved in the US or Canada, the technology for such tests currently exists. According to Kassler,

> [t]he technical performance requirements for a home HIV test are straightforward: (1) the sample must be easily collected; (2) the test must be simple to perform; (3) the results must be easy to read, preferably with an internal control; (4) the results must be available rapidly; (5) the test must be safe, with minimal infectious waste; and (6) the test must be accurate and perform well in a wide range of environmental conditions.439

As Kassler points out, many rapid tests that use whole blood or oral fluids already meet most of these requirements and have the potential to be adapted for home use. Several that are currently in development can be characterized as true home tests. Some of these prototype tests are cumbersome and not likely to be effective home tests; others are quite elegantly designed and approach the simplicity of home pregnancy tests. It is possible that several applications for approval of these tests will be submitted within the next few years. However, "bootleg" home-self tests have been sold and continue to be sporadically available by mail or telephone order from companies that set up offshore, advertise in underground newspapers or on the Internet, and subsequently disappear when enforcement activities intervene. These illegal kits have not been licensed or evaluated for home use with respect to accuracy, use effectiveness by lay persons, or impact on behavioural outcomes.440 Some of these kits are officially available in other countries, such as Turkey, where they have raised some controversy.441

# Home Testing – Issues and Recommendations

## History

### United States

When the first home test for HIV was developed in the United States, many AIDS activists and the American Medical Association opposed its introduction, and in 1987 the Food and Drug Administration (FDA) refused even to consider it for approval. The controversy was resurrected in 1993, when Johnson & Johnson purchased the rights to the home testing technology from its inventor. Subsequently, Johnson & Johnson launched a vigorous campaign to win FDA approval.442 On 14 May 1996 its home collection kit, the so-called Confide HIV Testing Service (Direct Access Diagnostics), received approval.443 This kit was made up of three integrated components: an over-the-counter home blood-collection kit; HIV-1 antibody testing at a certified laboratory; and a test result centre that provided test results, counselling and referral anonymously.

Those wishing to undergo testing purchased the Confide kit at their local pharmacy or, by calling a toll-free number, had the kit delivered to their home. The kit contained a pre-test counselling booklet, a step-by-step instruction guide, the collection material, and a protective envelope. Using the lancet provided, users pricked their fingers and applied three drops of blood to a special collection card. The card was pre-coded with a unique Personal Identification Number assigned to each kit. The card was then mailed to a testing facility using the postage-paid, pre-addressed envelope. At the laboratory, both enzyme-linked immunosorbent assays and confirmatory tests were performed. After about seven days, the user could call another toll-free number to obtain the test result, punching in a unique code number. Those who tested negative listened to a recording informing them of the meaning of the result and offering them the option of speaking to a counsellor. Positive results were reported by a counsellor, who provided referrals to follow-up clinical services and social-service agencies.444 All components of the testing service were subject to several regulations and were closely monitored by the FDA. Both the testing and counselling facilities needed annual accreditation and HIV testing procedures had to comply with FDA regulations.

A competitor, Home Access Health Corporation, received FDA approval on 22 July 1996 for its so-called Home Access test.445 Soon, both companies started accepting mail orders from across the United States, increased national retail availability, and started national advertising.446 The two companies took different approaches to marketing their tests – Confide was promoted in a serious tone, featuring health-care professionals wearing white laboratory coats, while Home Access advertisements included more controversial themes.447

The Food and Drug Administration had required product sponsors to collect information about users, and asked the Centers for Disease Control and Prevention to analyze this information to help evaluate the impact of HIV home collection in actual practice. In January 1997 Johnson & Johnson released data based on the test cards of the first 30,000 customers who used the test, showing that 99 percent of Confide customers were providing a sufficient quantity of blood for testing; more than 95 percent called and received their results; more than 98 percent of those who received results did so within 15 days of mailing their test cards; and 1 percent tested HIV-positive.448 In May 1997, both Johnson & Johnson and Home Access Health Corporation released results showing that their products had primarily been used by males, most of whom had indicated that their primary risk factor for HIV was heterosexual contact. According to the companies, a "sizable minority" of users had been gay men, while very few users had reported that they had a history of injection drug use.449 Finally, on 1 December 1997 an account of national HIV seroprevalence and demographic data among home test users, which had been reviewed by the Centers for Disease Control, was issued by Home Access Health Corporation.450 The report showed that from inception through June 1997, 152,044 people had used home HIV testing systems. Of these, 148,039 called to receive test results, and 0.9 percent tested positive. Fifty-nine percent of those tested and 52 percent of those testing positive had been tested for the first time by using the home sample collection kit. 78,358 clients were asked to provide anonymous demographic data and risk information during pre-test counselling. Responses by the approximately two-thirds who did provide data showed that bisexual men accounted for 38 percent, heterosexuals for 24 percent, gay men for 20 percent, and injection drug users for 6 percent of users who tested positive. These observations suggest that home sample collection tests are being used by persons at risk for HIV who may not access other testing opportunities. Though not conclusive, the data suggest that concerns about confidentiality may be a motivating factor. Even though the Home Access system is completely anonymous, one-third of users declined to provide any demographic information, and an additional 16 percent elected not to disclose their zip code.451

Phillips answered the question of whether home sample collection tests were expanding access to testing as follows:

> The answer appears to be yes – and no. Many individuals using the home test are new testers and many are from high-risk populations. Few home test users, however, are from minority populations (only 15%) and sales of the tests are much lower than anticipated. In three separate 1995 national surveys, 29–34% of U.S. adults, including those not previously tested, those with less access to testing, and those at-risk for HIV, stated that they would likely use such tests. Reasons for much lower actual use might include the price, differences between intentions and actual behavior, knowledge and trust of the test, and a decline in marketing.452

A study presented at the 12th World AIDS Conference in Geneva on 2 July 1998 that examined the utility of home HIV test services in public health settings in the US concluded that "an HIV home test service is most useful in outreach settings because a larger proportion of persons learn their HIV status when they use a home testing service," and that it "may also be useful in anonymous settings where many people fail to return for results."453

Thus far, there is limited evidence about the consequences of receiving test results over the phone. A review of the call log in which Home Access counsellors summarize their telephone interactions with users revealed that, although most users who test negative receive a recorded counselling message, 12 percent elect to speak to a counsellor. Among those who received positive results, 23 percent claimed to have an existing source of care, 65 percent accepted referrals for medical and psychosocial services, 5 percent hung up without receiving phone counselling, and one caller expressed suicidal ideation. Generally, it "is unknown if home testing facilitated or impeded access to medical care or affected changes in risk behavior."454

Some AIDS service organizations continued expressing concerns about the home collection tests after having tested them. For example, one 25-year-old woman who described her experience with the test in an issue of *Bridges* remarked that her

> entire pre- and post-test experience with Confide was completely automated (with an extremely vague definition of the window period). I listened as the recording went on in a monotone, basically reading verbatim the HIV/AIDS booklet included in the kit, for ten minutes before I had the opportunity to speak to a live counsellor.455

She continued by saying that she "should have stayed with the computer," because her "counsellor" was "impersonal and vague," did not ask any clarifying questions to assess her age, needs, risks or knowledge, and had no "awareness of the information I was forced to listen to before I had the opportunity to speak with her."456 She added:

> This traumatic counselling session ended with another plug for using Confide for my follow-up test since "only confidential testing is available in your area." Knowing this to be false, I pressed for a referral in San Francisco for anonymous testing. She gave me a number for the Department of Public Health, which (surprise) was a wrong number... My experience with Confide was appalling and I am nervous and scared when I think of other young people believing it is a safe and easy way to find out their HIV status.457

While the young woman’s experience with Home Access was better, she was still hesitant to promote its use without an accompanying counselling session from an outside source, saying that she was concerned about the possibility of "a young person finding out their result in such an impersonal and potentially destructive manner."458

A 24-year-old man who tried both kits also expressed criticism, particularly with regard to counselling and referrals received. He concluded that, for both tests,

> the counsellors did not have enough information about the virus, progression, the "neat new drugs" protease inhibitors, or local service. More to the point, it is not possible for these people to have local information unless they are to spend time working in the communities which they aim to profit from. The operators did not even attempt to ascertain my mental state prior to giving me the result. Neither of them determined that I was a young person, addressed issues such as testing for other STD's and hepatitis, vaccination against other diseases, or asked why I had initially decided to take the test.459

In response, the companies noted that such examples are atypical and that they had received positive reports from many customers.460 In particular, Dr Branson of the Centers for Disease Control and Prevention reported that the counsellors employed by the test makers get "good marks."461

On 26 June 1997 Johnson & Johnson announced that its Confide testing kit was being "withdrawn from the market, effective immediately, due to lack of consumer demand."462 According to the company, "consumers simply have not shown a high level of interest in using the Confide service."463 The reasons for Johnson & Johnson's withdrawal from the market have, however, remained controversial. Some have maintained that Confide is no longer produced because the FDA was not satisfied with the product, while other simply say that Johnson & Johnson was not aggressive enough in its marketing.464

Other US companies have applied for FDA approval of their home collection kits,465 but at the time of writing only Home Access was marketing its test in the US. Plans to distribute "almost $100,000 worth" of free home collection kits to community partners of the [US] National AIDS Fund were announced in January 1998.466

As mentioned above, several versions of home self-test kits, although they have not yet been approved by the FDA, are also being promoted in the United States,467 and at least one company, SmithKline Beecham, is seeking approval to market to consumers its home saliva test.468

The Centers for Disease Control and Prevention "plans to continue monitoring utilization of home collection and the post-marketing studies currently underway, to help ensure this system provides effective links to prevention, services and care."469

## International Developments

Several governments, including those of Australia,470 Austria, France, Germany, Japan, the Netherlands, Switzerland, and the United Kingdom, have stated that the public use of diagnostic tests for determination of the HIV serostatus of an individual should not be done without pre- and post-test counselling.471 In the United Kingdom472 and Austria, legislation currently prohibits the sale or supply of HIV test kits or any component of such kits to members of the public. However, times are changing and other countries may follow the US in the near or distant future and approve over-the-counter home sample collection kits.

In a policy statement on HIV testing and counselling of August 1997, "addressed to national authorities" and "meant to facilitate the development or strengthening of national policies on the subject,"473 UNAIDS urges countries to "[s]trengthen quality assurance and safeguards on potential abuse before licensing commercial HIV home collection and home self tests."474 UNAIDS continues by saying:

> HIV home collection tests ... and home self-tests offer the advantages of enhanced access and anonymity. However, these tests may have serious negative consequences, especially if they are not connected with confirmatory testing, and with counselling and care services, or if they are applied coercively to spouses, sex partners, and people seeking employment, entitlements or services. Licenses for commercial "home" tests should be continuously reviewed and test uses monitored.475

Also in 1997, the Swiss AIDS Commission adopted a position statement regarding the introduction of home tests.476 The Commission concluded that there was no acute need for the authorization of home tests in Switzerland, and that availability of such tests would have negative consequences for HIV surveillance. The Commission recommended to continue assessing the evolution of home tests with a view to allowing their introduction once they meet the standards set by currently available tests and there is a clear need for them. The Commission added that it would be preferable if Switzerland could harmonize its policy regarding home tests with that of its neighbours.

In Germany, the Ministry of Health intervened in August 1997 to prohibit the sale of an HIV home test that had not been approved by the relevant authorities.477

## Canada

While HIV home sample collection testing kits have been approved and on sale in the United States since mid 1996, no home test for HIV has as yet been approved in Canada. However, as early as July 1993 Health Canada organized a workshop on home HIV self-test kits. Its purpose was to gather perspectives on home testing from representatives working at the federal, provincial, and community levels, before receiving any application by a manufacturer for a home testing device. Two issues were seen as the driving force behind the need for discussions: the advance in HIV-antibody detection technologies; and the push by insurance companies to use such tests. It was reported that Canadian insurance companies have used saliva-based tests to "screen applicants for HIV" and that applicants whose test indicated possible HIV infection have been advised by the insurance companies that they should have a confirmatory blood test done. As pointed out by participants at the meeting, this represents more than just "screening" applicants and contravenes provincial health legislation: it is not permitted in Canada to use saliva tests as a diagnostic tool.

The issue received renewed attention when in May 1996 a US-based company named 1-888-444-TEST Inc held a press conference in Toronto to publicize, and market to Canadians, their mail-order, saliva-based, home self-test kit for HIV. The test kits, priced at $90 for a set of two, were offered for "personal use." The company was violating federal regulations by offering the kits before they had even been submitted for evaluation of their reliability. The Health Protection Branch (HPB) of Health Canada asked the company to cease all activities and submit an application for pre-market evaluation in order to obtain a Notice of Compliance. According to media reports, an official of the company announced that the company would submit the test to Health Canada for testing.478

Most Canadian organizations that have addressed the issues raised by such tests have expressed a number of serious concerns, sometimes flatly rejecting their introduction. When, in 1993, CPHA established the principle that "[a]ll Canadians should be aware of and have access to a variety of voluntary, high-quality, bias-free testing options, including confidential nominal testing, non-nominal testing and anonymous testing," the Association explicitly added that "[t]his does not include home test kits or other types of testing that fail to offer quality control or an opportunity for pre- and post-test counselling."479 In 1997, CPHA somewhat softened this position in a resolution adopted at its Annual General Meeting. However, CPHA urged Health Canada "to consider approving HIV home collection kits only if they meet the criteria of testing accuracy and reliability, confidentiality and the availability and offering of pre and post test counselling."480 In addition, CPHA resolved that "any company that performs the HIV test on samples collected with home collection kits in Canada be required to report HIV seropositivity to provincial and territorial health departments."481 The Canadian Medical Association has been concerned mainly with the counselling aspects of home testing, stressing that the "introduction of rapid simple testing does not decrease the need for quality assurance in the testing methods and the training of those carrying out counselling and testing."482 A very strong stand against home testing was taken by the Board of Directors of the Canadian AIDS Society in a resolution stating that "CAS does not support the use of home test kits." The Board recommended that the use and sale of such kits "be banned" in Canada, citing concerns about the limited accuracy of some of the kits, the lack of appropriate counselling and support, the fact that individuals may be coerced into being tested or be tested without their consent, and the fact that individuals would have to pay for the kits, while "HIV testing is part of the publicly funded health care system" and "individuals should not have to pay for HIV testing."483

## Current Situation

In Canada, the sale of in vitro diagnostic devices (IVDDs) for the detection of HIV infection is governed by the *Food and Drugs Act* and the *Medical Devices Regulations*. All medical devices offered for sale in Canada must meet the requirements of sections 3 and 19-21 of the *Food and Drugs Act* and parts I-III of the *Medical Devices Regulations*. IVDDs for the detection of infection by HIV are classified as Class IV, the highest risk class. As a result, manufacturers are subjected to the most stringent regulatory requirements.

The *Medical Devices Regulations* stipulate that all manufacturers must obtain an authorization before offering for sale IVDDs for the detection of infection by HIV in Canada. Authorization for sale, in the form of a licence, can be obtained by submitting, to the Director: evidence of quality assurance; evidence of safety and effectiveness; and a copy of all labels and package inserts to be used in connection with the device.

In accordance with the Regulations, the Medical Devices Bureau will accept, review and evaluate submissions for over-the-counter HIV home test kits for their scientific merit. Appropriate preclinical studies and clinical trials will have to validate all technical aspects of the kits, such as sensitivity, specificity, reproducibility, stability, etc, in comparison with an approved, professional-use system for the collection and testing of blood or any other appropriately validated specimen. Other issues of safety and effectiveness directly related to the use of the test, such as comprehension of the instructions by consumers, safe handling, etc, will also have to be validated by data obtained from a properly designed clinical trial conducted in the target population. In accordance with section 32(4)(k) of the "new" *Medical Devices Regulations* (promulgated 1 July 1998), "detailed information on investigational testing conducted on the device using human subjects representative of the intended users and under conditions similar to the conditions of use" must be provided.

In cases where the safety and effectiveness of the kit has been substantiated, in accordance with section 36 of the *Medical Devices Regulations* the Therapeutic Products Program (TPP) will issue a medical device licence.

With regard to the sale or advertisement of "mail-order HIV home test kits" (mailed from within or from outside Canada) that have not received a medical device licence (as in the case of 1-888-444-TEST Inc), TPP considers this a violation of sections 26 and 27 of the *Medical Devices Regulations*. In such cases TPP has, "and will continue, to take appropriate compliance action to stop this practice."484 In contrast, when private Canadian citizens purchase HIV home test kits outside Canada and bring them back for their personal use, this is not considered a violation of the *Food and Drugs Act* and of the *Medical Devices Regulations*, provided there is no attempt to distribute the kits.

As of October 1998, no home test for HIV had been approved for sale in Canada. In interviews on 30 August 1996 and on 11 September 1998, Dr Choquet of the Medical Devices Bureau of HPB said that, for confidentiality reasons, Health Canada could not reveal if any company has applied for review of its home test for approval. According to Choquet, the approval process for HIV test kits typically takes about one year.485

## Assessment

As expressed by Schopper and Vercauteren, the "current reluctance of several governments of industrialised countries to approve HIV home collection and home self-test kits for open marketing may be due to fear that the potentially negative consequences of this new technology could be more important than its positive effects."486 This section therefore explores the main arguments used by proponents and opponents of home testing.

### Claimed Benefits

Proponents of home testing have argued that it has many potential benefits. They say that home testing expands the availability of testing, increases access to anonymous testing, is less invasive than conventional tests, and has positive impacts on public health.

#### Expansion of Testing

Advocates of home testing for HIV have stated that there is an urgent need for a new mode of testing. They point out that, despite the establishment of sites for anonymous HIV testing, many people are reluctant to come forward and be tested: nearly one-half of all HIV-positive Americans did not get tested until they were within a year of being diagnosed with AIDS-related illness, and approximately one-third were within two months of an AIDS diagnosis when they first tested positive.487 In addition, studies have shown that many people with HIV and many who practice risky behaviours have never been tested,488 and that those who have been tested do not always return for their results.489

In Canada, there has been little investigation of how HIV-antibody testing is actually being applied in practice. One study of the testing behaviour of Canadians was presented at the XI International Conference on AIDS in 1996.490A nationwide telephone survey was conducted to determine how many people had been tested, what kind of people they were, why they decided to be tested, and where they went to have it done. About one-quarter of Canadians aged twenty to fifty had been tested for HIV, nearly half of them in the last two years. People were more likely to go for testing if they were young, poorer, unmarried, and a resident of a large metropolitan centre. Of particular note is the fact that only 11 percent had been tested non-nominally, whereas 78 percent were tested at a doctor’s office or in a hospital setting. The most common reason given for getting tested was to monitor general health (40 percent for men, 32 percent for women), followed by concern that they were at risk of infection (30 percent for both men and women). None of the 259 women and only three of the 237 men reporting they were tested said they had tested HIV-positive.

In January 1997, questions on sexual risk behaviour and HIV testing were added to the Canada Health Monitor, a Canada-wide random digit dialing telephone survey of people 15 and over. Preliminary results presented at the 1998 Canadian Conference on HIV/AIDS Research indicated that 19 percent of men and 17 percent of women had ever been tested for HIV. Of these, 42 percent of men and 35 percent of women had been tested within the year prior to the survey. Generally, rates of testing were higher among those who engaged in risk behaviours compared to those who did not engage in such behaviours. This was most evident among men who had had anal intercourse with another man in the last year, 100 percent of whom reported having been tested for HIV.491

A study of HIV-positive women's experiences and perceptions related to HIV testing showed that testing is often not initiated until well after infection.492

Finally, as mentioned above, Health Canada recently estimated that 11,000 to 17,000 people, or about 30 to 40 percent of the estimated 36,000 to 42,000 Canadians living with HIV infection at the end of 1996, were unaware of their infection.493

According to proponents of home testing, the anonymous character and convenience of this type of testing will encourage more people to come forward for testing:

Now, for the first time, testing for HIV can be done anonymously from the convenience of one's own home. No appointment is necessary, and there is no need to take time off work. You can test whenever it's convenient for you.494

However, those who take a cautious approach to the introduction of home testing point out that only very limited data exist on people's attitudes to home sample collection kits; and no data exist to substantiate the often-made claim that "people want" true home test kits. In one US study conducted in 1992,

- 29 percent of all respondents, and 42 percent of respondents deemed "at risk" of HIV infection, said they would be very or somewhat likely to use home sample collection tests; and

- 22 percent of all respondents, and 31 percent of those deemed "at risk" of HIV infection, said they would choose home sample collection testing over all other testing options.495

People were more likely to say that they would use a home sample collection test if they were male, younger and non-white, and had less than a university education, a lower income, risk factors for AIDS, or a self-perceived risk of AIDS.

Furthermore, these results need to be read with caution: people surveyed were not told about the cost of the test, nor were they asked about their reasons for preferring home collection testing.

In 1996 *The Advocate*, a US magazine targeting a gay readership, conducted an informal poll. Fifty-two percent of (an unknown number of) respondents said they would be more likely to get tested if they could use a home sample collection kit, while 42 percent responded that availability of the kits would make no difference, and six percent said they were not sure.496

### Increased Access to Anonymous Testing

At present, anonymous testing is not easily accessible to all Canadians. Indeed, as noted above, it is only available in certain provinces at certain designated clinics. For some people, especially those living in remote areas and/or in provinces where anonymous testing is currently not offered, getting to these centres is simply not feasible. A home test might offer them the only opportunity to be tested anonymously. This was also expressed at the National Workshop on HIV Testing and Confidentiality in Toronto in March 1997, where a participant from Atlantic Canada emphasized that for many Canadians living in rural areas home sample collection testing may provide a valuable alternative to existing, insufficient testing options.497

Generally, concerns about the social risk of HIV testing continue to influence testing decisions. For example, in one US survey, among people at risk for HIV who had not been and did not plan to be tested, 50 percent indicated they would get tested if no one else could find out the results.498 Those most likely to report they would be tested if no one else could find out their results included women (particularly women living with partners), African Americans, younger people, and those with lower income. Kassler concluded that

> [h]ome sample collection testing may provide a viable alternative for those concerned about their privacy. Potential users of home sample collection testing include persons who may feel intimidated by attending a public clinic or embarrassed by face-to-face contact, residents of rural areas who may not have convenient access to testing sites or who might want to avoid being seen at a local public clinic, the physically disabled, and those who have responsibilities such as job or school that make it difficult to attend a clinic.499

While home sample collection tests do offer increased access to anonymous testing, home self-tests are currently only screening tests: a person who tests positive will have to seek confirmatory testing, which would be done through drawing of blood and would not be anonymous unless undertaken in an anonymous HIV testing clinic.

### Less Invasive than Conventional Tests

The new kits are less invasive than traditional testing methods; they require only a few drops of blood from a pinprick, or a swab of saliva. Some have suggested that this will increase people's willingness to be tested. For example, a European multi-centre study of prostitutes showed that many who refused to allow their blood to be drawn for HIV testing would consent to the taking of a saliva sample;500 and a Canadian study found that offering the option of testing with saliva collection kits, as an alternative to drawing blood, increased the willingness of intravenous drug users to submit samples from 69 to 83 percent.501

The new test kits might also be the only testing option for those who, for religious reasons, object to the drawing of blood.

### Positive Impact on Public Health

Proponents of home testing have argued that the main benefits of increased access to and use of HIV tests would be earlier treatment, decreased costs, and decreased sexual transmission of HIV. As Donna E Shalala, Secretary of the US Department of Health Services, put it,

> [t]oo many [people] do not know their HIV status. Knowledge is power, and power leads to prevention. The availability of a home test should empower more people to learn their HIV status and protect themselves and their loved ones.502

#### *Earlier Treatment*

> Early access to treatment based on early knowledge of HIV status will be of benefit to the individual if and where such services are available.503

There can be no doubt that early knowledge of HIV positivity can be beneficial, particularly where access to treatments is provided – which, even in Canada, remains a significant problem.

#### *Decreased Costs*

It has been suggested that the availability of home testing might reduce demand for, and costs associated with, testing at publicly funded testing sites:

The main arguments are that HIV-negative persons would only need one test, done at home, with little or no counselling, thus reducing human resource and overhead costs. In addition, people would pay themselves at least for the first test, thus reducing public sector cost mainly in instances where governments provide HIV tests free of charge.504

As stated by Frerichs,

> [o]nly about two percent of individuals who come to government testing and

> counselling centers are HIV-positive. Money that is spent on the many HIV-negative individuals cannot be spent on treatment for HIV positives. Money that is spent on HIV-negative individuals cannot be spent on extended care for persons harbouring the virus. So by supporting a system in which only two percent coming in are HIV-infected, we are spending an enormous amount of money on HIV-negative individuals that could be reallocated in more effective ways to slow down the epidemic.505

In another text, he concludes that

> [i]t is too expensive and inefficient for most countries to offer clinic-based diagnostic testing to people who have not been previously screened with HIV indicators. ... The savings from not testing and counselling endless numbers of HIV negative persons would be spent on better serving those who are infected, including long-term follow-up, education and support.506

However, this view neglects to take into consideration the benefits of voluntary counselling and testing to those who are negative: counselling may be especially important for those who are negative but have engaged in risk behaviours. In addition, it neglects to consider that state-funded testing sites will remain important even if home test kits do become available (see supra, the chapter on Access to HIV Testing).

It has further been suggested that, for many persons, home sample collection testing may offer more convenience than clinic or office-based services. Kassler points out that obtaining an HIV test, even a "free" one, costs time and money. In the US, one study estimated the average costs to the clients attending public testing sites in one city at US$41 per test.507 This represents the value of their time traveling, waiting and being seen in the clinic, valued at the average hourly wage rate for the area, and the transportation cost incurred for pre-test and post-test visits. Thus, although concern has been raised that people with low incomes may be dissuaded by the retail price of US$30 to $40 for home sample collection kits, Kassler suggests that the cost of this type of home testing may actually be comparable to what is currently being "spent" by people tested for HIV. He concludes that, although "clients of public clinics may receive more services and thus more value for their expenditure, for some consumers, the time savings, the added convenience of obtaining the kit by a toll-free telephone call or at the corner drug store, and the flexibility of choosing the time and place to be tested may be more important."508

### *Decreased Sexual Transmission*

It has been suggested that the availability of HIV home testing would lead to a decrease in sexual transmission of HIV. This is based on the assumption that more people will be tested sooner and, once they find out that they are HIV-positive, will not engage in unsafe behaviours;

couples "could screen each other for the presence of HIV antibodies and then act on the findings"; or partners could "quietly" screen each other.509

## Questions and Concerns

> Overall the risks and potentially negative consequences of the home test should be expected to be much greater in situations where the powerless are not well protected by law and regulations, where the status of women is not equal to that of men, where quality control of medical devices and procedures is difficult, where regulations are not enforced, where literacy rates are low, and where health services are either scanty or difficult to access.510

Support for home sample collection testing appears to have grown considerably over the past years, while support for true home tests remains mitigated. A number of questions and concerns remain to be addressed, some of which are relevant only in the context of true home tests, some in the context of both types of tests: the extent to which testing will have a beneficial impact on public health; the tests' accuracy; the lack of adequate counselling; the potential for abuse, particularly for women in relationships of unequal power; the effect on existing testing services; and issues of confidentiality. In addition, concerns have been voiced by Aboriginal people consulted for a recent discussion paper on *HIV Testing and Confidentiality: Issues for the Aboriginal Community*.511

### Impact on Public Health

[The effectiveness of] testing as a preventive or behaviour modification strategy remains unclear. This is particularly true of any kind of HIV antibody testing being performed without pre and post-test counselling.512

Would availability of home testing really have a beneficial impact on public health, as claimed by proponents of home testing? As stated by Schopper and Vercauteren,

> [a]lthough nobody would deny the potential benefits of HIV testing for the individual, its public health impact remains a contentious issue. Overall the evidence for the impact of HIV testing in bringing about behaviour change is mixed. It has been shown that voluntary counselling and testing (VCT) can enhance safer sexual behaviour in discordant couples if both partners are tested and counselled. However, on a public health scale little change in behaviour has been documented in heterosexuals if they are tested alone. ... In addition, some studies have documented an increase in risky behaviours after testing in HIV-negative persons. The major problem is that there are only few reliable data from epidemiologically sound studies, and that there may be many confounding variables, such as the quality of the counselling provided with the testing, the

> initial risk perception of the individual, the attitude of family members or the social environment. Thus after ten years of experience with HIV testing ... we are not able to draw definite conclusions about the role of HIV testing in controlling the further spread of HIV. The main argument for making HIV tests widely available and accessible remains that every person should have access to information about her own health status in order to make informed personal choices about HIV prevention and care [references omitted].513

Additionally, some oppose the introduction of home testing on the basis that it would further hamper efforts to control the HIV epidemic through partner notification and other public health measures. As Kassler states:

> Health departments are concerned about the impact of home sample collection testing on their ability to fulfill their essential roles of disease surveillance and the delivery of prevention services. Many state health departments rely on the posttest counseling session to offer infected persons partner notification services, follow-up counseling, referral to clinical and support services, and, where mandated, to report HIV infection for surveillance purposes. ... Concerns exist that persons who use home sample collection testing may not access the health care system, thus delaying needed treatment for themselves and hindering important public health activities. In addition, many states conduct laboratory-based surveillance, and unless persons who test positive using home sample collection tests seek additional confirmatory testing, the effectiveness of this system could also be hindered.514

### Accuracy

The accuracy of some of the new testing methods remains controversial. As pointed out by Schopper and Vercauteren, a number of issues relate to the accuracy of the tests, including their sensitivity and predictive value; quality of the test at the time of use depending not only on the manufacturer, but also on transport and storage at the sales point and at home; quality of the sample collected; understanding of the window period; and, more generally, the level of education needed to correctly understand the testing procedure.515

For home self-tests there are additional issues such as errors of manipulation if done by lay persons; interpretation of results and action to be taken for confirmatory testing.516

Some of the new tests, particularly home sample collection tests, are accurate and reliable: for example, the FDA based its approval of the Confide test on studies showing that 99.95 percent of HIV-negative and 100 percent of HIV-positive samples were correctly identified;517 and people from various backgrounds were able to follow the kit's instructions well enough to obtain a sample suitable for testing.518 The Home Access test also performed well in clinical trials, demonstrating 100 percent sensitivity and 100 percent specificity of subject-collected dried blood spot samples compared with phlebotomist-collected venous blood samples.519 In contrast, the accuracy of some of the new tests that could potentially be used as home self-tests has not yet been evaluated extensively, nor has their reliability been confirmed if performed by lay persons. At best, current rapid tests have comparable performance of a standard EIA. Thus, as mentioned above, the first generation of true home tests will probably be screening tests and will not provide confirmed results. The technology does not exist for two-stage rapid tests, which could provide both screening and confirmatory test results. Even with the accuracy of an EIA, a larger number of false positive results can be expected. Assuming a specificity of 99.5 percent and an HIV prevalence among users of one percent, the positive predictive value of a home screening test would be 67 percent – 33 of 100 positive tests would be false positives. With a lower prevalence of 0.1 percent, the predictive value drops to 17 percent, and 83 of 100 positive tests would be false positives.520

Of particular concern is that data on accuracy of tests are usually obtained under optimal conditions by trained technicians and may not always reflect a real-life situation:

> The accuracy of simple rapid tests that require subjective interpretation is closely linked with training. Non-trained operators such as lay persons can easily misinterpret test results. Kit inserts from strongly promoted home self-tests ... claim high reliability, although virtually no external data are available. It is clear that these statements should be validated by independent studies.521

### Lack of Counselling

> As a male that’s been living with HIV for fourteen years, I cannot imagine testing myself. I can’t. I mean, you [Dr Frerichs] likened it to a woman doing a breast check, but that woman went into her doctor, was shown how to do it, was told all the consequences of it, it could be benign, it could be malignant, she was counseled. Now to me, counseling is what has kept me alive, the positive attitude, and the help and support. But to throw it out and say here, test yourself, I think we’re really asking for trouble.522

There are serious concerns about the possible negative consequences of the absence of pre-test counselling for both home sample collection and true home tests; the absence of post-test counselling for true home tests; and the fact that post-test counselling for home sample collection tests is provided over the phone, either by voice mail (negative result) or person to person (positive result).

As discussed above, as a general rule HIV testing should not be undertaken without pre- and post-test counselling. In addition, it has been argued that post-test counselling over the phone cannot be as effective as person-to-person counselling: in post-test counselling sessions, a counsellor has to be alert to testees' emotional reactions to their test results. This is especially important when clients test positive, as this can cause a great deal of emotional distress and result in panic and suicidal thoughts. In the moment of shock, clients may simply hang up the phone, thus foreclosing any opportunity of helping them to deal with their reactions. Finally, counsellors rely heavily on visual clues such as body language to direct their counselling.523 Such nuances would be lost over the telephone.

In contrast, proponents of HIV home testing argue that pre-test counselling is not essential and that counselling after home testing

could be provided more efficiently through telephone contact, which would be cheaper and guarantee anonymity. Persons who test positive would be referred to and/or take themselves the initiative to contact appropriate health services.524

Further, responding to the argument that person-to-person counselling is essential because of the risk of suicide upon learning of a positive test result, some say that suicidal thoughts are more closely linked to the onset of symptoms than to the positive test result itself.525

Finally, it has been claimed that telephone counselling might actually be superior in quality to the face-to-face counselling many people currently receive. One commentator has said that

> corporate sponsors of home testing products can train counsellors specifically to engage in full-time HIV counselling. The potential superiority of telephone counsellors would be derived from their specific training as HIV counselors and from the experience they would receive from performing that function on a full-time basis. Both training and experience can provide professionals with a level of expertise difficult to replicate among physicians engaged in more diversified activities.526

Proponents of home testing insist that telephone counselling be evaluated against actual practice, not idealized standards.527 While admitting that face-to-face counselling provided in specialized testing clinics may indeed be more effective than telephone counselling, they recall that most Canadians are tested by their doctors, many of whom may not have much experience with, or time for, counselling: telephone counselling may be an improvement on the support that most people who are tested are receiving in practice.528 Others point to the success of suicide hotlines as evidence that telephone counselling can be effective in crisis situations.529

However, Schopper and Vercauteren caution against such arguments, pointing out that there would have to be some type of quality control of the telephone counselling process, and that

> it is not clear who would provide this service and pay for it. If this is the

> responsibility of the test manufacturer, as has been suggested, the incentive to train, supervise and maintain qualified counsellors is limited, if this is not linked to a periodic accreditation system.530

### Potential for Abuse

Those who support home testing argue that the possibilities for abuse may not be very different from those that already exist, and that a potentially beneficial technology should not be banned because it may be abused.531 A better approach, they argue, would be to minimize the potential misuse of home tests by enacting or strengthening laws that punish those who test people against their will or without their knowledge.

However, concerns remain: the ease with which home tests can be forced by one person on another and the easy, rapid access to results, either in the home or by phone, makes them attractive and convenient for those who might want to test others without their consent. According to Schopper and Vercauteren, there are at least two reasons why home testing would be more amenable to abuse than laboratory-based testing: it is easier to do under coercion; and there is less guarantee of confidentiality, as the result is directly available in the home or through a telephone call.

In addition, true home tests that provide an immediate result

> could be used directly at border controls, by future employers and by sexual partners with little or no consent of the person tested. Given the level of persistent discrimination and stigmatization in many countries, this potential for abuse is worrisome.532

This has led some to recommend that, where true home tests become available, "the enactment and enforcement of laws and regulations to protect people from coerced testing and to punish physical violence that results from such efforts is essential."533

### Impact on Current Testing Procedures

Another cause for concern is the effects that availability of home tests may have on existing testing options. It has been argued that increasing reliance on home testing would relieve the burden on present testing facilities and allow resources to be redirected to other sectors such as prevention and research. However, authorities could be tempted to allow publicly funded testing options to wither away in an attempt to economize. Further, a study of HIV testing in an Australian state where a user fee was introduced for HIV tests suggests that when the burden of paying for testing shifts to the individual, the numbers of people seeking testing decrease, even if testing is still offered free of charge at certain sites.534

## Confidentiality

A variety of concerns with regard to confidentiality have been raised:535

- if a person buys a home 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, name and address must be provided so that the test can be mailed;
- when the test is paid for by credit card, the charge for the test will appear on the credit card statement;
- the garbage collector or neighbours may see the packaging from the test kit in the garbage, if it is not well hidden away; and
- in a home test 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 over the phone – emphasizing the importance of ensuring that nobody but the person tested sees the card with the number.

In addition, at the National Workshop on HIV Testing and Confidentiality in Toronto in March 1997, concerns were raised about customer databases that companies distributing the test kits could build up and that could be misused.

## Concerns Expressed by Aboriginal People

Although they mostly fall within the above categories, it is nevertheless useful to mention separately concerns raised by Aboriginal people. As Matiation writes, most of the people consulted for his paper "do not support home testing as an alternative for Aboriginal people who wish to be tested for HIV."536 The concerns of those consulted are reflected in the following statements:537

> Most concerns focused on the lack of counselling associated with the self-test and the lack of appropriate counselling for Aboriginal people with home collection testing.
>
> One person expressed the view that test users would likely be well-educated individuals who can afford to buy them and that home testing would not be used by street-involved people or most people living on reserve, where the tests would likely be inaccessible.

> Concerns were expressed about the possibility for error. One person who works in an Aboriginal AIDS organization indicated that two individuals appeared at the clinic having tested positive with the home test kits they obtained in the United States. Further tests indicated that both were in fact HIV-negative.
>
> Concerns were also raised about the language of instruction provided with home test kits and whether people with low literacy levels would be able to follow the instructions and understand the information about HIV provided with the kits.
>
> Home testing kits may not assure anonymity in smaller communities where rumours about who bought a test kit or received one from the local health centre might spread as rapidly as information about who was tested at the health centre.

One participant in the consultations undertaken by Matiation stated that home testing kits could be disastrous for Aboriginal people, saying:

> There is a disproportionately high suicide rate in the Aboriginal community. Without accessible counselling, particularly counselling that reflects the experiences of Aboriginal people, there are concerns about whether the home test would encourage an Aboriginal person to find support or drive that person to depression and denial. The response of different Aboriginal people to test results will certainly vary. Based on the comments of those consulted about a lack of confidentiality in small communities, the effects of discrimination and racism, and the prevalence of health and social problems experienced by too many Aboriginal people, a positive test result received in isolation will more often have devastating consequences [reference deleted].538

Matiation concluded that the potential benefits from home testing do not outweigh the concerns, that home testing kits are no replacement for face-to-face, culturally reflective pre- and post-test counselling and HIV/AIDS education material delivered by Aboriginal people for Aboriginal people, and that home testing should "not be used as an excuse for a lack of emphasis on establishing testing facilities that are accessible to all Aboriginal people in Canada."539

## Lessons from Home Pregnancy Tests

As pointed out by Schopper and Vercauteren, the only other home self-test to detect a health condition – as opposed to monitoring an already diagnosed health condition such as high blood pressure or diabetes – that has been widely used is the home pregnancy test. Of course, the consequences of a positive HIV test are quite different from those of a positive pregnancy test:

> Learning that one is pregnant can be viewed in a variety of ways. Such news could be taken as positive or negative depending on a wealth of factors like economic status, social status, housing status, employment status, health status etc. Furthermore, were a woman to view being pregnant as a negative situation she could affect this reality in a number of ways through adoption, abortion or an attempt to change her circumstances in various ways.540

Nevertheless, some of the lessons learned from pregnancy tests could be useful when considering HIV home tests. In particular, studies have shown that test results will be on average less accurate when a test is done by a lay person; the user needs to be well educated to understand operating procedures and optimal timing of the test; and the user needs to have immediate access to health services for confirmation of test results and/or care.541

## Possible Responses

> I guess we would all agree that people should have access to information that enables them to control their lives. But at the same time, we need to acknowledge that external conditions can make the same technology favorable or dangerous. If we want to abide by the Hippocratic principle of first do no harm, we must ensure that the benefits of a new technology outweigh its negative consequences.542

### Regulation and Its Limits

Those who argue that the potential harms from making home collection and/or home self-testing available far outweigh the potential benefits may argue that their introduction into the Canadian marketplace should be blocked. However, although the law is broad enough to forbid most attempts at advertising these products to Canadians, little can be done to hinder individuals from purchasing them outside Canada and bringing them back for personal use:

> [I]t appears that the United States will soon adopt a policy in favour of home HIV testing. This may render moot the question in Canada, as it is likely impossible to completely block the use of such a test in Canada. The advertising and sale of the test in Canada could be prohibited, but likely Canadians could easily access the test either in the United States, or by mail from the United States.543

### Establishing Preconditions for Approval

Another possible approach would be to adopt a policy that would allow the sale of those home testing kits that meet a set of criteria designed to minimize their potentially harmful effects. Manufacturers would have to demonstrate that their kits offer accuracy and standards of counselling comparable to those expected from conventional HIV tests. Perhaps if home testing kits were first offered on a limited trial basis we could better assess their risks and benefits. Bayer et al suggest that, as a condition of government approval of home test kits, post-marketing studies be carried out, including a comparison of home testing with current practices, not idealized standards; demographic information on test users, information about the quality of telephone counselling, and data on consumer satisfaction; a comparison with face-to-face encounters; and a consideration of the effects on the existing system of public testing and counselling.544

### Schopper and Vercauteren's Approach

According to Schopper and Vercauteren, a cautious approach to the evaluation of home test kits for HIV should be taken. While acknowledging that the new testing technologies may have enormous merits and may in many ways change our approach to the HIV epidemic,

> we need to acknowledge that many technical, psychological and social questions remain unanswered. Given the nature of HIV infection – lifelong, incurable and fatal – and the stigma attached to it, it would seem irresponsible to provide these new tests to lay persons for self-testing before answering at least some of the most essential questions.545

These questions relate to both forms of home testing, but may in some cases have to be addressed separately:

- What is the intrinsic accuracy of the currently available HIV home sample collection and true home tests?
- What is their reliability if used by lay persons, including timing after risk behaviour?
- What is the probability that persons identifying themselves as HIV-positive through home testing will not seek confirmatory testing, and what would be the consequences of not seeking such testing?
- How cost-effective is home sample collection or true home testing as compared with clinic-based testing?
- What is the demand for and acceptability of these tests in different sociocultural environments?
- What are the expressed needs and fears of potential users?
- What is the importance of providing counselling before and after the test? Does it depend on the result being positive or negative?

- How can post-test counselling be provided in low-resource settings?

- What action will individuals take after receiving an HIV test result at home?

- What is the potential for abuse in different settings and how can it be prevented?

Schopper and Vercauteren suggest that relatively small-scale qualitative and quantitative research studies may enable us to provide some answers, and that the experience with the home sample collection test kits that have been approved in the US should be monitored closely. In addition, they suggest that some minimum requirements that must be fulfilled for any tests be defined, including the following:

- any test marketed as a self-test must have an internal control mechanism that validates the test result;

- no test should be marketed in another country before having been approved by the regulatory body of the country of production, as there is a danger that low-quality tests would be brought onto the market in developing countries with weak or no regulatory bodies; and

- clear guidelines must be provided with the test on how to confirm a positive result.

## Conclusions and Recommendations

> Because of the serious nature of the test and so as to maximise prevention and care goals, public health law should ensure, whenever possible, that pre-and post-test counselling is provided in all cases of HIV testing. With the introduction of home-testing, States should ensure quality control, maximise counselling and referral services for those who use such tests, and establish legal and support services for those who are the victims of misuse of such tests by others.546
>
> Let us base our policy decisions not on the availability of the technology, but on the sound scientific data and consultation with consumers, including persons living with HIV and AIDS. Above all, the science, and not the technology, should drive us.547

Availability of HIV home testing has potential benefits – in particular, it can provide another confidential and readily available means to encourage people at risk to seek HIV testing and, if necessary, treatment – but also has potential harms. Contrary to what has been stated by former US Surgeon General C Everett Koop,548 home test kits are certainly not the "single most important weapon we can employ in the fight against AIDS." Indeed, this statement is more a reflection of the failure of AIDS policy in the US – a country that emphasizes testing as a prevention strategy, while other prevention strategies that have been proven to significantly reduce levels of infection, such as needle exchange programs, have not been implemented for political reasons – than a sign of the effectiveness of home test kits. It is also a reflection of the widespread but unproven belief that testing equals prevention, an approach that is all the more dangerous when it leads to a neglect or de-funding of those prevention efforts that have proven successful, such as counselling, education, provision of wide access to preventive means such as condoms and sterile needles, and, generally, community-based efforts to prevent the further spread of HIV.

In the last years, we have learned more and more about home sample collection tests, but at present we clearly do not know enough about true home HIV testing. At the same time, individuals can already import home sample collection tests into Canada for their own use. How should Canada approach the many issues raised? The main concerns will be the absence of face-to-face counselling, the risk of abuse, the impact on existing testing facilities, and the accuracy and reliability of the tests. All these concerns apply to true home tests, and most of them, although often to a minor extent, also apply to home sample collection tests.

Of the concerns, the one related to the accuracy and reliability of the tests can be easily addressed: those applying for authorization of home test kits for sale in Canada have to prove that their kits meet the technical standards set by existing approved tests. It seems safe to assume that at least some home test kits – in particular, home self collection tests – will meet these standards, and that there will be no reason to oppose their sale in Canada on the basis that they are inaccurate or unreliable. Other kits will not be able to meet these standards, and will not receive the Notice of Compliance required for their sale in Canada. The other concerns, being less technical in nature, are more difficult to deal with. In the end, accurate and reliable home test kits should be allowed for sale in Canada if their potential benefits outweigh their potential harms. People providing counselling, those who have tested positive, and those caring for and working with them, including representatives of Aboriginal communities in Canada, will have to be consulted if we are to be able to better assess the potential impact of making home testing available in Canada. They will be best equipped to answer some of the questions raised by Schopper and Vercauteren, and can assist in the design and carrying out of the studies that will provide the answers to those questions. Of particular need for study is the potential effect of permitting HIV testing with only telephone counselling (home sample collection) or no counselling at all (true home test). They will also be able to assist in finding ways to reduce the potential harms from making home testing available by, for example,

- requiring that all home test kits sold in Canada be accompanied by a Canadian-developed information brochure that would address issues normally raised in pre- and post-test counselling;

- monitoring the counselling provided over the phone to ensure that it meets appropriate quality standards;

- addressing the risk of abuse by reemphasizing the need for informed, specific consent to HIV testing, by providing support for those who are victims of the misuse of such tests by others, and by establishing severe penalties and quick complaint mechanisms in cases of violations;

- renewing the commitment to the provision of free testing and counselling at a variety of state-sponsored testing clinics, advertising their services, and decreasing, as far as possible, delays at such clinics;549 and

- renewing the commitment to prevention efforts that have proven successful, such as counselling, education, provision of wide access to preventive means such as condoms and sterile needles and, generally, community-based efforts to prevent the further spread of HIV.

The organization of a national workshop on issues raised by the new testing technologies, that includes people providing counselling, those who have tested positive, those caring for and working with them, representatives of Aboriginal communities, but also the federal and provincial and territorial health ministries, researchers, and HIV test manufacturers, should be considered. The workshop would help to provide answers to the questions raised by Schopper and Vercauteren, could assist in the design and carrying out of the studies that would provide the answers to those questions, and could assist in finding ways to reduce the potential harms from making home testing available. In addition, it could address issues raised by the availability of the other new forms of testing, such as rapid testing, and saliva and urine tests.550

> **4.1 Home test kits are devices with potential benefits for individuals, unproven benefits for society, and commercial interests behind them. Their introduction – particularly that of true home testing – carries risks that need to be better assessed before they are made widely available in Canada. Decisions about their introduction should not be based on the availability of the technology, but on sound scientific data and consultation with consumers, including people with HIV and AIDS.**
>
> **4.2 Home test kits that meet a set of criteria designed to minimize their potential harmful effects should be allowed for sale in Canada. In particular, manufacturers need to be able to demonstrate that their kits meet the technical standards set by existing approved tests and that counselling provided over the phone is adequate.**
>
> **In addition, measures should be implemented that would reduce the**

**potential harms from making home test kits available, such as (1) addressing the risk of abuse by reemphasizing the need for specific informed consent to HIV testing, by providing for support for those who are the victims of misuse of such tests by others, and by establishing severe penalties and quick complaint mechanisms in cases of violations; (2) renewing the commitment to the provision of free testing and counselling at a variety of state-sponsored testing clinics, advertising their services, and decreasing, as far as possible, delays at such clinics; and (3) renewing the commitment to prevention efforts that have proven successful, such as counselling, education, provision of wide access to preventive means such as condoms and sterile needles, and, generally, community-based efforts to prevent the further spread of HIV.**

**4.3 Serious consideration should be given to first offering home test kits on a limited trial basis and to requiring, as a precondition of approval, that post-marketing studies be carried out by independent researchers.**

**4.4 A national workshop on issues raised by the new testing technologies, that includes people providing counselling, those who have tested positive, those caring for and working with them, representatives of Aboriginal communities, representatives of the federal and provincial and territorial health ministries, researchers, HIV test manufacturers, and others concerned, should be held to further discuss the issues addressed in this Report and to attempt to reach a consensus and develop a research agenda on the various new testing technologies.**

# Rapid Testing: Issues and Recommendations

**(For additional information and an update on this section, see the Legal Network’s report, *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*, available at http://www.aidslaw.ca/Maincontent/issues/testing.htm).**

## History

### United States

When HIV testing was first implemented in the US, the US Public Health Service guidelines recognized the value of reporting preliminary positive results:

If additional more specific test results are not readily available, persons in high-risk groups [sic] with strong repeatedly reactive ELISA ... results can be counseled, before any additional test results are received regarding their probable infection status, their need for medical follow-up, and ways to reduce further transmission.551

However, as the availability of supplemental tests increased and the results of these tests could be reported on the second visit, subsequent guidelines recommended that

> no positive test results be given to clients/patients until a screening test has been repeatedly reactive on the same specimen and a supplemental, more specific test such as the Western blot has been used to validate these results.552

Because these recommendations precluded providing results from positive screening tests, including rapid tests, the market for rapid tests in the US was too small to justify the cost and time necessary to obtain FDA approval.553 As a result, although many of the rapid tests used around the world have been developed by US manufacturers, few if any of these manufacturers were pursuing FDA approval. At the time of writing, the Single Use Diagnostic System (SUDS) HIV-1 test was the only rapid test licensed by the FDA that was available for clinical use in the US.

In October 1997, the US Centers for Disease Control (CDC) and the US Association of State and Territorial Public Health Laboratory Directors (ASTPHLD) conducted a workshop to discuss rapid HIV testing, the potential health benefits and risks of reporting provisional rapid-test results, and the feasibility of changing the recommendations for reporting HIV test results. The purpose of the meeting was to discuss those recommendations "in light of technological advances in rapid screening tests, data that suggest that prevention efforts could be improved by more rapid turnaround of test results, and increased health benefits that may be afforded by more quickly initiating new, effective therapies for HIV."554

At the workshop, participants agreed that it is optimal to follow the 1989 Public Health Service algorithm for HIV testing, which recommends confirmatory testing before reporting reactive HIV test results to minimize the risk of reporting false-positive results.555 However, they agreed that exceptions are warranted

> when the health benefit of reporting HIV-rapid-test results offsets the potential risk for reporting false-positive rapid-test-results (e.g., patients who fail to learn their HIV status because they do not return to receive their test results). Rapid HIV tests also can assist health-care providers who must make immediate decisions about initiating HIV prophylaxis (e.g., caring for health-care workers after occupational exposures and for pregnant women in labor who have not been tested or whose results are not available.

In addition, they agreed that (1) health-care providers who choose to give patients test results from rapid HIV tests must ensure both high-quality testing and appropriate counselling; (2) laboratories must institute rigorous quality control and quality assurance plans, including participation in proficiency testing; (3) all persons with a first-time positive HIV test result should have another specimen collected and tested according to the currently recommended algorithm; and (4) decisions about whether to use rapid tests should be based on a combination of the prevalence of HIV in a community and return rates for test results:

> For example, in settings of high prevalence where a low percentage of persons return for their results (e.g., STD clinics), use of rapid tests will be most beneficial. In comparison, rapid tests may be less beneficial in settings of low prevalence where return can be ensured (e.g., most practitioners' offices). Other settings require individual consideration.556

Meeting participants also agreed that it is extremely important for counsellors to explain in detail, before the test is given, the likelihood that the rapid HIV test represents the client's true HIV-infection status. Counselling should emphasize the importance of confirmatory testing and be "responsive and interactive in communicating the probability of infection to those clients with reactive HIV rapid tests."557 The meeting report notes that when explaining a reactive HIV rapid test to clients, counsellors should use phrases such as "a good chance of being infected" or "very likely infected" to communicate the probability of infection, and further qualify these phrases on the basis of an individual assessment during counselling of the client's risks.558 When conveying a reactive rapid-test result, counsellors should consider both the HIV prevalence in their setting and an assessment of each client's individual risks.

On the basis of the findings from the workshop and of studies demonstrating the efficacy of rapid tests, the Public Health Service

> recommends an alternative approach to HIV testing: health-care providers should provide preliminary positive test results before confirmatory results are available in situations where tested persons benefit. This recommendation is based on research demonstrating that persons who receive preliminary results understand the meaning of the result and prefer rapid testing. When additional rapid tests become available for use in the United States, the PHS will re-evaluate algorithms using specific combinations of two or more rapid tests for screening and confirming HIV infection.559

The push for adopting this "alternative approach to HIV testing" came from studies that showed that rapid testing can result in an increase in the number of people learning their HIV status. A study undertaken in Dallas, Texas, at an anonymous testing clinic and a sexually transmitted disease clinic concluded that "[r]apid, on-site HIV testing was feasible, preferred by clients, and resulted in significant improvement in the number of persons learning their serostatus, without increasing the costs or decreasing the effectiveness of counseling and testing."560 In addition, a report published in March 1998 by the Centers for Disease Control and Prevention concluded that

> the use of a rapid test with same-day results for HIV screening in clinical-care settings can substantially improve the delivery of CT [counselling and testing] services. Because most persons who are tested are not infected, they can receive counseling and learn their HIV status in a single visit. In addition, providing preliminary positive results also increases the number of infected persons who ultimately learn their infection status and can be referred for medical treatment and additional prevention services.561

This conclusion is based on an analysis of the comparison of the current counselling and testing procedure and the rapid test currently available in the US (Single Use Diagnostic System (SUDS) HIV-1 Test), based on the number of HIV tests conducted and the HIV prevalence reported from publicly funded testing sites in CDC’s 1995 client record database. Publicly funded counselling and testing programs in the US conduct approximately 2.5 million HIV tests each year, but in 1995 25 percent of those testing HIV-positive and 33 percent of those testing HIV-negative at publicly funded clinics did not return for their result. The analysis showed that, using the rapid test, during 1995:

- a total of 697,495 more people would have learned their HIV status;

- approximately two million people whose rapid-test results were negative would have learned their HIV status without a second clinic visit;

- an additional 8170 people (22 percent of all positive tests performed in 1995) would have received confirmed positive results;

- an additional 1115 HIV-positive people who did not return for confirmed results would have been given a reactive rapid-test result and received counselling about the likelihood of being HIV-positive and the need for behavioural changes; and

- 8301 HIV-negative people would have received preliminary false-positive results after a reactive rapid test, representing 0.4 percent of the 2.1 million tested for HIV but 18 percent of those who would have received an initial reactive result; because of the differences in HIV prevalence at different types of testing sites, the proportion of people given a reactive rapid-test result who were truly positive ranged from 46 percent at family planning clinics to 88 percent at drug-treatment programs.562

Since March 1998, when the "alternative approach" to HIV testing was adopted, CDC, in collaboration with other organizations, has been developing guidelines on the implementation and quality assurance of rapid HIV testing. CDC is also revising its guidelines for HIV counselling, testing, and referral to incorporate new information about counselling as well as new developments in testing technology.

In July 1998, AIDS activists in the US called for doctors, clinics and hospitals to begin using rapid HIV tests "immediately."563

### Canada

After receiving a submission pursuant to Part V of the *Medical Devices Regulations* in April 1997, Health Canada authorized the first rapid test, but only for laboratory use, in May 1998.564 According to its manufacturer, the MedMira Rapid HIV Screen Test is reliable (sensitivity at 96.3 to 100 percent and specificity at 99.6 to 100 percent) have been found to be equivalent to conventional ELISA tests), inexpensive (the test costs about $5), quick (taking only three minutes), easy to administer (it can test whole blood, serum, or plasma), requires no laboratory equipment or refrigeration, and detects both HIV-1 and HIV-2.565 An application to the US FDA was under review at the time of writing, and MedMira has stated that the company already has sales contracts for several million units of the test.

## Current Situation

Because the situation with regard to rapid tests is evolving so quickly, it is difficult if not impossible to provide an assessment of the current situation. New developments risk making that assessment out-of-date within weeks of the time of writing.

In the United States, as mentioned above, only one rapid test (the Single Use Diagnostic System for HIV-1 – SUDS) was available at the time of writing. This test has sensitivity and specificity similar to those of EIA and provides results within 15 to 30 minutes, but has several limitations. In particular, it is classified as a test of moderate complexity (eg, it requires a laboratory with centrifuge), detects only HIV-1, and several factors, including temperature and centrifuge speed, can affect test results.566 However, with the new US recommendations on the use of rapid testing, it is likely that more second-generation rapid tests will soon become available. These tests require little or no equipment, can be performed on serum, plasma, or whole blood, which can be collected by using the finger-stick method, provide results in two to five minutes, detect HIV-1, HIV-2, and HIV-1 group 0, and make possible the use of different combinations of rapid tests that may allow for same-day confirmation of reactive test results,567 as recommended by the World Health Organization.568

In Canada, the only rapid test that has been approved is the MedMira Rapid HIV Screen Test. However, as mentioned above, it has been approved for laboratory use only. At the time of writing, clinical trials of other rapid tests were starting in Canada, to assess their accuracy and performance in clinics and public health settings. However, in these trials participants will not be given their test result before confirmatory testing has been undertaken.569

## Assessment

In the US, there has been much debate about rapid testing and it has been said that "[a]mong the advances in HIV testing technologies, rapid testing perhaps has the most potential to change how C&T [counselling and testing] is provided to clients."570 The March 1998 Public Health Service recommendations on rapid testing are the first indication of this change. As mentioned above, the recommendations do not currently allow for widespread use of rapid testing, but only for (1) use in public clinics, such as STD clinics and anonymous testing and counselling sites; (2) post-exposure assessment; and (3) perinatal settings for women who are at risk but have not been tested previously.571 However, there is an expectation that second-generation rapid tests will soon become available in the US, and that they will allow for same-day confirmation of reactive test results. It is likely that the Public Health Service recommendations will then be changed again and will allow for – and probably encourage – the widespread use of these tests.

Canada and other Western industrialized countries are, as usual, taking a more cautious approach – probably a reflection of the fact that, while they strongly encourage voluntary testing, they (can afford to) rely less on HIV testing and counselling as HIV prevention methods because political barriers to implementing other HIV prevention measures, such as needle exchange programs, have at least in part been overcome. In addition, the fact that so many people in the US do not return for their HIV test results is, at least in part, due to the fact that HIV testing is routinely undertaken in many STD clinics. Some of the people tested did not seek out HIV testing in the first place, and it is therefore hardly surprising that a higher number will not return for their test results. In contrast, in Canada HIV testing clinics have achieved higher return rates, at least in part because the primary purpose of people attending these clinics is to be tested for HIV.

### Potential Benefits

Kassler et al have summarized the potential advantages of using on-site, rapid HIV testing as follows:

- clients can receive counselling that is relevant to their HIV status on the same day they come in;

- client satisfaction with the process can be improved because they receive their results sooner;

- more clients receive their test results, since most do not have to return for their results and post-test counselling;

- clinics are able to provide negative results at less cost, since only one visit is needed.572

In addition, it has been argued that appropriate uses for rapid tests include post-exposure assessment (testing the source patient to whom, for example, a health-care worker has been exposed), and perinatal settings for women who are at risk but have not been tested previously.573

### Convenience and Client Satisfaction

In the study that evaluated the use of a rapid test in a public testing site with a high prevalence of infection, most of the clients preferred the rapid test over conventional testing. Ninety-two percent of clients surveyed liked receiving their HIV results on the same day they were tested, and 89 percent understood the meaning of their test results. Of those previously tested, 88 percent responded that they preferred the rapid test.574

In Canada, an informal survey concerning the introduction of rapid HIV test kits was sent by email to 159 Vanguard participants on World AIDS Day 1997. Sixty-six participants responded. Most were very supportive of the idea of getting faster test results, felt that this would encourage more people to get tested, and would alleviate the anxiety that people currently experience in the two-week waiting period. However, several people said that until the rapid tests are "fully tested for accuracy," patients should not be given the results of the rapid test until the results of the standard blood test are available.575 Finally, many were concerned that the introduction of rapid test kits could lead to home testing: "While a few people liked the idea of home testing, the majority were very opposed to it, warning of the dangers of people testing positive at home without any counselling or support."576

### More Clients Receive Test Results

The debate over the use of rapid tests is being fueled by data indicating that follow-up for HIV tests is often poor. In some public settings in the US, many clients fail to return for test results and post-test counselling. Since rapid tests allow the provision of results and result-specific counselling on the day of the initial visit, such tests could potentially increase the efficiency of HIV counselling and testing.577

However, as noted above, follow-up for HIV tests in Canada is better than in the US, making this argument weaker in the Canadian context.

### Reduced Costs

While the individual test kit may be more costly than the per-test cost of the EIA, an analysis done in 1996 by Farnham and his colleagues indicated that rapid HIV testing is more cost-effective than the current EIA-based system because of the number of people who actually learn their results.578 In other words,

> although EIA is less expensive, it is a waste of money to perform lab tests if the person tested never learns the test results, if two clinic visits are required to get test results, or if the clinic has to send field staff to locate people for test results.579

However, this statement neglects the value of counselling. It is not a waste of money to provide pre-test counselling, even if a person does not return to receive her/his test result, and it has not been conclusively established that providing pre- and post-test counselling during the same clinic visit immediately before and after testing is as effective as providing such counselling during two separate visits.

### Other "Appropriate" Uses

The suggestion that appropriate uses of rapid tests could include post-exposure assessment and perinatal settings raises many legal and ethical issues. In the US, Minkoff and Sullivan have recently made "the case for rapid HIV testing during labour." They point out that, for women who receive no prenatal care, the "first and only opportunity to have counseling and testing for HIV occurs when they are admitted during labor."580 After discussing the benefits of administering intrapartum and neonatal zidovudine, they conclude that "it is reasonable to assume that *some* benefit would result from intrapartum and neonatal zidovudine."581 They continue by saying that,

[u]nfortunately, until women without prenatal care (or with care but without the offer of a prenatal test for HIV) are "captured" in some manner, there will continue to be a sinecure [sic] into which none of the benefits of zidovudine can flow. If pediatric HIV infection is to be eradicated in the United States, innovative approaches will have to be developed that address the needs of this population.582

To make intrapartum therapy a potential intervention for women with no prenatal care, rapid tests would have to be used. The authors suggest that, the limitations of the current tests notwithstanding,

> some women may need and want to consider therapy while awaiting confirmatory testing. Those women might need to be told initially that the confirmatory test is being done to rule out an HIV infection and that in their circumstance infection cannot yet be ruled out. They would then have the option of receiving therapy while awaiting definitive results. In the absence of any significant evidence of harm from an abbreviated course of zidovudine, the small chance of unnecessary treatment (treatment of women with positive preliminary but negative confirmatory test results) may be a reasonable risk for a woman to assume.583

The authors do acknowledge that, before such an approach is implemented, consideration must be given to the ethics of discussing HIV tests and antiretroviral therapy with women who are in labour. They admit that "this is not the ideal circumstance in which to provide counseling," and that an argument could be made that merely making the offer is a violation of standards of informed consent. However, they say that

> depriving women of the right to consent to be tested and treated for HIV, if such therapy could potentially spare their children lethal infections, may represent more of an assault on autonomy than a discussion of testing would entail. Women untested and untreated, who deliver children who eventually succumb to HIV, may not be grateful that they were not burdened with the difficulties of decision making during labor."584

The authors conclude that, while the ideal situation would be to institute systems to ensure both prenatal care and access to prenatal HIV testing for all women, meanwhile "the reality of unknown HIV status during labor needs to be confronted." In their opinion, developing a system for offering HIV tests in the intrapartum period, "using a good faith effort to ensure an informed process of consent, is reasonable." In such a manner, "all newborns would be provided with an opportunity to benefit, to at least a partial degree, from the reduced rates of mother-to-child transmission associated with the use of zidovudine during pregnancy."585

In Canada, for many reasons, the percentage of women receiving no prenatal care is lower than in the US. In addition, the potential benefits for the newborn of administering, as suggested in the US, an abbreviated course of zidovudine to the women would have to be more carefully weighed against the potential harms to the mother. Finally, the issue of whether a woman could indeed provide fully informed consent to testing for HIV during labour is not the same – as is implied in the article – as the issue of whether a woman can provide informed consent to a cesarean section during labour.

With regard to the use of rapid tests for post-exposure assessment, this could indeed provide information useful for the examination of the question of whether the person exposed should start post-exposure prophylaxis (even if this information is not confirmed by Western Blot). The person who is the source of the exposure could therefore be encouraged to submit voluntarily to testing with a rapid test. The question whether this would warrant asking the person who is the source of the exposure to submit to involuntary testing, however, is more complicated. It will be addressed infra, in the chapter on confidentiality.

## Questions and Concerns

The following concerns about rapid testing have been raised:

- the low predictive value of a reactive test result, particularly in low-prevalence settings;

- the effects on counselling and, in particular, the question of how to convey a reactive test result; and

- its potential misuse in a variety of settings.

### Low Predictive Value

In low-prevalence populations, the predictive value of a single positive screening test may be as low as 10 percent.586 It has been said that, while "many physicians understand the value of a low positive predictive value and will counsel their patients/clients appropriately, the possibility exists that other physicians could give misleading information and counsel their patients inappropriately."587

### Counselling of People Testing Positive

The availability of rapid testing is likely to affect couselling in a number of ways. In the absence of same-day confirmatory testing, the greatest challenge will be what to tell a patient with a reactive screening test. As Kassler has said:

Although reporting preliminary positive results from rapid tests may motivate the client to return for confirmed results and additional counseling, and may encourage early adoption of risk-reducing behaviors, those who ultimately prove to be uninfected on confirmatory testing may experience unnecessary psychological distress. Thus, reporting preliminary positive results from rapid tests involves a trade-off.588

For Leviton, what to do about those who screen positive is "the sticking point for public health practice."589 As she expresses it:

> The test information is, after all, preliminary. What should be shared? In what form should it be shared? If rapid testing is implemented, it will not be feasible to selectively withhold the preliminary screening information. The public will be aware that screening results can be made available immediately. If people do not immediately receive information that they are negative, the inference is that they screened positive.590

According to Kassler, there are several considerations in deciding how to communicate the meaning of a reactive screening result: the likelihood that a reactive client is truly HIV-positive (ie, positive predictive value of the test), how best to communicate that probability to the client, and what the client should do in response to a reactive result with respect to health seeking and risk behaviours.591 In evaluations of on-site, rapid testing in public clinics undertaken to date,592 a series of phrases were recommended to communicate to patients the likelihood of their being infected with HIV in the case of a preliminary positive result. When the positive predictive value (PPV) was 81 percent, the terms "probably infected, likely to be infected, a good chance of being infected," or "usually means you are infected" were used. When the PPV was 88 percent, the terms "very likely" (or "highly likely") infected; or "a very good chance of being infected" were used. When the PPV was 97 percent, the terms "most likely infected" or "probably infected" were used. In practice, based on their individual assessment of the client's risks during counselling, the counsellor either strengthened or qualified the phrases used to communicate the probability of infection in the case of a preliminary positive result.593

As mentioned above, CDC has proposed to develop recommended language for providing provisional test results to patients.

### Counselling of People Testing Negative

The compression of pre- and post-test counselling sessions into a single session, with the absence of a two-week waiting period for HIV-negative results, raises the concern that the counselling associated with rapid testing may not be as effective as the standard procedures in promoting HIV risk reduction.594 However, in the study undertaken by Kassler et al using one indirect measure of HIV risk – acquisition of new STD following HIV testing – no difference was found between STD clinic patients counselled using rapid test procedures and patients receiving standard pre- and post-test counselling. This led Kassler et al to conclude that, although "larger trials may be needed to definitively resolve some of these issues, these data indicate that program managers considering the use of rapid testing to improve service delivery can be reassured that counseling associated with rapid testing does not appear to be less effective.595

## Conclusions and Recommendations

According to Kassler,

> [e]nough is known about some of these [new] developments [in HIV testing], such as rapid testing, to recommend their broader use. Rapid tests can provide clinicians timely information to guide patient management. Rapid tests can also be more convenient for clients. Because these tests can provide same-day results, they can expedite counseling for patients in a variety of clinical and public health settings. Rapid tests using finger-stick blood and oral fluids (if and when they are approved) could be administered by professionals in nonclinical settings, bringing testing services to hard to reach, high-risk clients, and facilitating access to other prevention services.596

Similarly, Schopper and Vercauteren have suggested that the new testing technologies could be used in existing voluntary testing and counselling centres to provide clients right away with an indicative test result:

> In case of a positive primary result a blood sample can immediately be drawn to perform further testing for confirmation, making the whole system more client friendly and probably more cost effective. In addition, this approach may reduce the high drop-out rates currently witnessed in some settings after initial counselling and the collection of the blood sample.597

However, various questions need to be distinguished:

- Should the use of a rapid test, provided its accuracy has been proven, be recommended for broader use, and should the results be divulged before confirmatory testing is undertaken?
- If yes, for which uses should the rapid test be used? In public testing clinics? During labour? For post-exposure assessment? In any other situation?
- Should rapid tests only be allowed for broader use in Canada once at least two tests, based on a different antigen preparation and/or different test principle,598 have been approved, so that a reactive rapid HIV test result could be confirmed immediately?

In most cases, a single rapid test does not give an acceptable positive predictive value and should not be used. Even in most of the cases in which use has recently been recommended in the US, (1) the potential benefits are limited; (2) some of the reasons for applying them do not apply, or apply to a lesser extent, in the Canadian context; and (3) legal and ethical issues are not always addressed satisfactorily. The most evident benefit and the least potential harm would result from allowing the (voluntary) use of a rapid test for post-exposure assessment. Clearly, more discussion of these questions is needed in Canada. As Leviton has said,

> we cannot afford ... to avoid the choices that the rapid testing technology poses. Serious debate on these choices is inevitable. This technology, and additional new developments, are upon us and the choices are posed right now.599

As recommended above (recommendation 4.4), a national workshop should be held to further discuss the issues raised by the new technologies, including rapid testing, and to attempt to reach a consensus and develop a research agenda on them.

**Return to the top of this page**

Return to Table of Contents

---

# ENDNOTES

414 WJ Kassler, supra, note 33 at 28, with reference to F Spielberg, WJ Kassler. Rapid Testing for HIV Antibody: A Technology Whose Time Has Come. *Annals of Internal Medicine* 1996; 125: 509-511.

415 Ibid, with reference to Centers for Disease Control. HIV Counseling and Testing Services from Public and Private Providers-United States, 1990. *Morbidity and Mortality Weekly Report* 1992; 41(40): 743, 749-752.

416 Ibid, with reference to Centers for Disease Control, 1992, ibid.

417 Ibid, with reference to K Irwin et al. Performance Characteristics of a Rapid HIV Antibody Assay in a Hospital with a High Prevalence of HIV Infection. *Annals of Internal Medicine* 1996; 125; 471-475; WJ Kassler et al. Performance of a Rapid, On-site Human Immunodeficiency Virus Antibody Assay in a Public Health Setting. *Journal of Clinical Microbiology* 1995; 33: 2899-2902.

418 Kassler, supra, note 33, with reference to Irwin et al, supra, note 417; WJ Kassler et al. The Performance of a Rapid On-site HIV Assay in Uganda: Results of a Field Trial. XI International Conference on AIDS, Vancouver, 1996, abstract no Th.C.4845; Kassler et al, supra, note 417.

419 Centers for Disease Control and Prevention. *Rapid HIV Tests: Questions/Answers*. Atlanta, GA: March 1998.

420 Schopper & Vercauteren, supra, note 363 at 1456 with many references.

421 R Sowadsky. The New Saliva Tests. Available at www.thebody.com/sowadsky/saliva.html

422 Centers for Disease Control and Prevention, National AIDS Clearinghouse. HIV Oral Fluid Tests. In: *Guide to Information and Resources on HIV Testing*, 1997.

423 D Gallo et al. Evaluation of a System Using Oral Mucosal Transudate for HIV-1 Antibody Screening and Confirmatory Testing. *Journal of the American Medical Association* 1997; 277(3): 254.

424 Ibid.

425 Sowadsky, supra, note 421.

426 Schopper & Vercauteren, supra, note 363 at 1459-1460.

427 K Painter. Oral HIV Test Gains Important Support. *USA Today* 15 January 1997; A Goldstein. Whitman Walker Adopts Oral HIV Test Before Other Big AIDS Clinics. *Washington Post* 16 January 1997, at D3; LB Benko. No Needles. *Investor's Business Daily* 2 March 1997.

428 See, eg, D Ott. Camden County to Use New AIDS Test. *Philadelphia Inquirer* 16 April 1997, at B2.

429 L Randall. HIV Counselling and Testing Using Oral Mucosal Transudate. *NASTAD HIV Prevention Community Planning Bulletin* April 1998.

430 Ibid.

431 E Berberian, A Richardson-Moore. New York State's Oral Fluid Testing in the Anonymous Counseling and Testing Program. The Implementation and Preference Pilot Study. *NASTAD HIV Prevention Community Planning Bulletin* April 1998.

432 Ibid.

433 Oral HIV Test Available in NY This Week. *United Press International* 24 June 1998.

434 Sowadsky, supra, note 421.

435 HIV Oral Fluid Tests, supra, note 422.

436 Kassler, supra, note 33 at 30.

437 Ibid, with reference to Calypte. *Food and Drug Administration Summary Basis for Approval*. Bethesda, MD: US Department of Health and Human Services, 1996.

438 FDA Approves First Urine-Based HIV Test System. *The Association of State and Territorial Health Officials HIV/AIDS Update* 1998; 1(8): section 6.

439 Kassler, supra, note 33 at 31.

440 Ibid.

441 L Doganci. Home-Use HIV Test Kits in Turkey. *The Lancet* 1997; 349(9062): 1401.

442 N Freundlich. The Trials of a Home HIV Test. *Business Week* 18 March 1996, at 56.

443 Health Notes. Home Testing for HIV Infection. *United Press International* 15 May 1996.

444 Direct Access Diagnostics. The Confide HIV Home Testing and Counselling Service. Publicity distributed at the HIV & Telemedicine Symposium, Vancouver, 9 July 1996.

445 New Home HIV Test Goes on Sale Nationwide. *Bangor Daily News*, 25 July 1996. For results from the Home Access clinical trials, see AP Frank et al. Anonymous HIV Testing Using Home Collection and Telemedicine Counseling. *Archives of Internal Medicine* 1997; 157: 309-314.

446 M Wilke. J&J's Confide Faces Legal Battle, New Rival. *Advertising Age* 1996; 67(32): 3; C Hutchcraft. AIDS Tests Join At-Home Diagnostics. *Chicago Tribune*, 7 October 1996, at 4-1.

447 C Miller. HIV Kits Target Untested Market. *Marketing News* 1997; 31(2): 1.

448 Confide Results Are Demonstrating Ease of Use and Public Health Benefits. Confide HIV Testing Service, Johnson & Johnson, press release of 16 January 1997.

449 Users Mostly Male, Heterosexual. *USA Today* 12 May 1997.

450 *Home Access HIV Counseling and Testing Report*. Home Access Health Corporation, 1 December 1997 (available at www.homeaccess.com/hicctrpt.html).

451 B Branson. Update: HIV Home Collection Kits. *NASTAD HIV Prevention Community Planning Bulletin* April 1998.

452 K Phillips. The Experience of Home Collection HIV Tests. In: *Understanding the Impact of New Treatments on HIV Testing. Summary of a January 28-30, 1998, Henry J. Kaiser Family Foundation Forum*. Henry J Kaiser Family Foundation, 1998.

453 KE Kruzel. Comparison of a Home HIV Test System to Public Health HIV Test Services. 12th World AIDS Conference Geneva, 1998, abstract no 43143.

454 Phillips, supra, note 452.

455 For a Testing Controversy, Press 1. *Bridges* 1997; 3(1): 3-6 at 5-6. Reprinted in the *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 8-10.

456 Ibid at 6.

457 Ibid.

458 Ibid.

459 Ibid.

460 K Painter. HIV Home Test Kits Catching on But Still Criticized. *USA Today* 12 May 1997.

461 Supra, note 451.

462 Press release by Johnson & Johnson dated 26 June 1997.

463 Ibid.

464 Communication with Patrick Flaherty, then with the Association of State and Territorial Health Officials, Washington, DC, October 1997.

465 R Bayer et al. Testing for HIV Infection at Home. *New England Journal of Medicine* 1995; 332: 1296. See also the revised version of this article in the *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 37-40.

466 National AIDS Fund to Distribute Home Access HIV Home Tests. National AIDS Fund and Home Access Health, press

release of 14 January 1998.

467 Schopper & Vercauteren, supra, note 363.

468 Kassler, supra, note 33 at 32.

469 Branson, supra, note 451.

470 See also Magnusson, supra, note 371 at 342.

471 Schopper & Vercauteren, supra, note 363 at 1460, with references.

472 SM Gore, AG Bird. Letter to the Editor. *The Lancet* 1994; 343: 1295.

473 *UNAIDS Policy on HIV Testing and Counselling*, supra, note 268 at 1.

474 Ibid.

475 Ibid at 1-2.

476 Subkommission Serologie, Immunologie und Virologie (SIV) der Eidg. Kommission für Aids-Fragen (EKAF). Stellungnahme zum Gebrauch von Home Tests für HIV. Berne: Bundesamt für Gesundheit, *Bulletin* 29 (28 July 1997): 4-6.

477 Ministerium Verbietet AIDS-Heimtest. *Süddeutsche Zeitung* 28 August 1997, at 2.

478 W Immen. Mail-Order HIV Saliva Test Raises Concerns. *The Globe and Mail* 13 May 1996.

479 CPHA, supra, note 15 at 15.

480 Canadian Public Health Association. *1997 Resolutions and Motions*. Ottawa: CPHA, 1997, at 3 (Resolution No 7).

481 Ibid at 4 (Resolution No 13).

482 Supra, note 170 at 19.

483 Canadian AIDS Society. Position Statement. HIV Home Testing. Ottawa: The Society, November 1996.

484 Correspondence received from
C Choquet, Health Protection Branch, Health Canada, on 14 November 1996 and on 30 September 1998.

485 Communication with C Choquet, Health Protection Branch, Health Canada, 30 August 1996 and 11 September 1998.

486 Schopper & Vercauteren, supra, note 363 at 1460.

487 P Wortley et al. HIV Testing Patterns: Where, Why and When Persons with AIDS Were Tested for HIV? *AIDS* 1995; 9: 487-492; see also: Testimony before FDA Blood Products Advisory Committee. Washington DC: Centers for Disease

Control and Prevention, 1994, cited in Bayer et al, supra, note 465.

488 DG Berrios et al. HIV Antibody Testing Among Those at Risk for Infection: The National AIDS Behavioral Surveys. *Journal of the American Medical Association* 1993; 270(13): 1576-1580.

489 RO Valdiserri et al. A Study of Clients Returning for Counseling After HIV Testing: Implications for Improving Rates. *Public Health Reports* 1993; 108: 12-18.

490 D Sutherland et al. HIV Testing Behaviour of Canadians. Abstract Mo.C.210, presented at the XI International Conference on AIDS, Vancouver, 1996.

491 Seventh Annual Canadian Conference on HIV/AIDS Research, Québec, 1998, abstract no 239P.

492 Jackson et al, supra, note 286 at 22.

493 *Epi Update,* supra, note 81.

494 Direct Access Diagnostics, supra, note 444.

495 KA Phillips et al. Potential Use of Home Testing. *New England Journal of Medicine* 1995; 332: 1308-1310.

496 Advocate Poll Results. *The Advocate*, 23 July 1996, at 8.

497 Comment by Elaine Sussey, AIDS New Brunswick, at the Workshop.

498 Kassler, supra, note 33 at 33, with reference to KA Phillips et al. Who Plans to Be Tested If No One Else Could Find Out the Result? *American Journal of Preventive Medicine* 1995; 11: 1
561-1562.

499 Ibid.

500 European Working Group on HIV Infection in Female Prostitutes. HIV Infection in European Female Sex Workers: Epidemiological Link with the Use of Petroleum-Based Lubricants. *AIDS* 1993; 7: 401.

501 CJ Major et al. Comparison of Saliva and Blood for Human Immunodeficiency Virus Prevalence Testing. In: British Columbia Centre for Excellence in HIV/AIDS. *HIV/AIDS Research in British Columbia. A Ten Year Retrospective*. Vancouver: The Centre, 1996, 200 at 203.

502 HIV Home Test Could Aid Prevention, Awareness. *The Nation's Health*, July 1996, at 6.

503 Schopper & Vercauteren, supra, note 363 at 1460.

504 Ibid, with reference to SR Salbu. HIV Home Testing and the FDA: The Case for Regulatory Restraint. *Hastings Law Journal* 1995; 46(2): 403-457. See also Bayer et al, supra, note 465.

505 Comment by R Frerichs at the Home HIV Screening Debate, XI International Conference on AIDS, Vancouver, 8 July 1996.

506 R Frerichs. HIV Testing – A Reply. From owner-sea-aids@bizet.inet.co.th, 2 October 1996.

507 Kassler, supra, note 33 at 33, with reference to WJ Kassler et al. On-Site, Rapid HIV Testing with Same-Day Results and Counselling. *AIDS* 1997; 11: 1045-1051 at 1050.

508 Ibid.

509 Schopper & Vercauteren, supra, note 363, with reference to R Frerichs. Personal Screening for HIV in Developing Countries. *Lancet* 1994; 343: 960-962.

510 Schopper & Vercauteren, supra, note 363.

511 Matiation, supra, note 19 at 18-20.

512 M Graydon. Report on the Health Canada (Health Protection Branch) Home HIV Self-Test Kit Workshop, 16 July 1993. Ottawa: Canadian AIDS Society, 23 July 1993.

513 Schopper & Vercauteren, supra, note 363 at 1455, with many references.

514 Kassler, supra, note 33 at 34.

515 Schopper & Vercauteren, supra, note 363 at 1460-1461.

516 Ibid at 1461.

517 HIV Home Test Could Aid Prevention, Awareness, supra, note 502.

518 Home HIV Test Is Found to Be Reliable and Effective. *AIDS Weekly Plus*, 2 October 1995, at 29.

519 Frank et al, supra, note 445 at 311-312.

520 Kassler, supra, note 33 at 34-35.

521 Schopper & Vercauteren, supra, note 363 at 1458, with reference.

522 Person living with HIV, reported in A Picard. Home HIV Test Sparks Hot Debate. *The Globe and Mail*, 10 July 1996, at A5.

523 Communication with M Shore, supra, note 379.

524 Schopper & Vercauteren, supra, note 363 at 1461, with reference.

525 BM Branson, HD Gayle. Home Testing for HIV – It’s Coming. Are You Ready? *International AIDS Society Newsletter*, March 1996, at 4.

526 Salbu, supra, note 504 at 424.

527 See Bayer et al, supra, note 465.

528 For a review of current counselling practices in the US, see Kassler, supra, note 33 at 37-38.

529 Ibid.

530 Schopper & Vercauteren, supra, note 363 at 1461.

531 Salbu, supra, note 504 at 427.

532 Schopper & Vercauteren, supra, note 363 at 1461.

533 MH Merson et al. Rapid Self Testing for HIV Infection. *The Lancet* 1997; 349: 352-353, at 353.

534 EM Stevenson, SC Thompson, N Crofts. HIV Testing and Policy Change, an Analysis Based on Statewide HIV Testing Data. Abstract Mo.C.212, XI International Conference on AIDS, Vancouver, 1996.

535 R Sowadsky. Home HIV Testing – The Good and the Bad. The Body: An AIDS and HIV Information Resource. At www.thebody.com/sowadsky/homehiv.html.

536 Matiation, supra, note 19 at 18.

537 Ibid at 18-19.

538 Ibid at 19.

539 Ibid at 20.

540 Graydon, supra, note 512.

541 Schopper & Vercauteren, supra, note 363 at 1462.

542 Ibid.

543 Flanagan, Commentary, supra,
note 27.

544 Supra, note 465.

545 Schopper & Vercauteren, supra, note 363 at 1462.

546 UNAIDS Guidelines, supra, note 162 at 20.

547 Comment by Dr M Merson at the Home HIV Screening Debate, XI International Conference on AIDS, Vancouver, 8 July 1996.

548 Cited in Bayer et al, supra, note 465.

549 One way to achieve this would be to allow the use of home self-tests within the framework of existing testing and counselling settings.

550 See, eg, Association of State and Territorial Health Officials. *Recommended Actions Resulting from the Workshop: "HIV Home Sample Collection Kits: Maximizing the Public Health Benefits."* Washington, DC: The Association, March 1997.

551 Spielberg & Kassler, supra, note 414 at 510, with reference to Additional Recommendations to Reduce Sexual and Drug Abuse-Related Transmission of Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus. *Morbidity and Mortality Weekly Report* 1986; 35: 152-155.

552 Centers for Disease Control. Interpretation and Use of the Western Blot Assay for Serodiagnosis of Human Immunodeficiency Virus Type 1 Infections. *Morbidity and Mortality Weekly Review* 1998; 38(Suppl 7): S4-S6.

553 Advances in HIV Testing Technology. *The Association of State and Territorial Health Officials HIV/AIDS Update* 1997; 1 (4): section 2.

554 Ibid.

555 CDC, supra, note 552.

556 Centers for Disease Control and Prevention. Update: HIV Counseling and Testing Using Rapid Tests – United States, 1995. *Morbidity and Mortality Weekly Report* 27 March 1998.

557 Centers for Disease Control and Prevention. Rapid HIV Test Enables Same-Day Test Results. *HIV/AIDS Prevention* June 1998, 11, 18, at 18.

558 Centers for Disease Control and Prevention, Update, supra, note 556, with reference to WJ Kassler et al, supra, note 34.

559 Ibid, with reference to Kassler et al, ibid.

560 Kassler et al, supra, note 34 at 1045.

561 Centers for Disease Control and Prevention. Update, supra, note 556.

562 Ibid.

563 LN Neergard. Activists Urge Stepped-Up HIV Prevention. *Dallas Voice* July 1998.

564 See, eg, the press release of 27 May 1998 by MedMira Laboratories Inc, Halifax. Health Canada Authorizes MedMira's Rapid HIV-1 & HIV-2 Screen Test for Sale in Canada.

565 Ibid; K Cox. Maker of Fast AIDS Test Succumbs to Nova Scotia's Lure; and Medmira website at www.medmira.ca/hivin.html.

566 Rapid HIV Tests: Issues for Laboratories. *CDC Issues*, March 1998. See also Kassler et al, Performance of a Rapid, On-Site Human Immunodeficiency Virus Antibody Assay in a Public Health Setting, supra, note 417 at 2901.

567 *CDC Issues*, ibid.

568 World Health Organization. Joint United Nations Programme on HIV/AIDS (UNAIDS) – WHO. Revised Recommendations for the Selection and Use of HIV Antibody Tests. *Weekly Epidemiological Record* 1997; 72(12): 81-88 at 85.

569 Communication with D Patrick, 20 August 1998.

570 New Public Health Service Recommendations on Rapid Testing Results. *NASTAD HIV Prevention Community Planning Bulletin* April 1998.

571 See, eg, Association of State and Territorial Health Officials. *Advances in HIV Testing Technology*. Washington, DC: 1997.

572 Kassler et al, supra, note 34 at 1050.

573 H Minkoff, MJ O'Sullivan. The Case for Rapid HIV Testing During Labor. *Journal of the American Medical Association* 1998; 279 (21): 1743-1744.

574 Kassler et al, supra, note 34.

575 What If You Could Get HIV Test Results in 20 Minutes? Printed in the newsletter for Vanguard participants, Vancouver, April 1998.

576 Ibid.

577 Advances in HIV Testing Technology, supra, note 571.

578 PG Farnham et al. Counseling and Testing for HIV Prevention: Costs, Effects, and Cost-Effectiveness of More Rapid Screening Tests. *Public Health Reports* 1996; 111: 44-53.

579 Centers for Disease Control and Prevention. *Rapid HIV Tests: Questions/Answers*. March 1998.

580 Minkoff & O'Sullivan, supra, note 573 at 1743.

581 Ibid.

582 Ibid at 1743-1744.

583 Ibid at 1744.

584 Ibid.

585 Ibid. See also CDC. Public Health Service Task Force Recommendations for the Use of Antiretroviral Drugs in Pregnant Women Infected with HIV-1 for Maternal Health and for Reducing Perinatal HIV-1 Transmission in the United States. *Morbidity and Mortality Weekly Review* 1998; 47(RR-2): 1-31.

586 See Kassler supra, note 33.

587 Advances in HIV Testing Technology, supra, note 571.

588 Kassler, supra, note 33 at 36.

589 LC Leviton. For Whom Do We Test? What Do We Say? Rapid HIV Screening. *Public Health Reports* 1996; 111(1): 54.

590 Ibid.

591 Ibid.

592 Kassler et al, supra, note 417; Kassler et al, supra, note 418; Kassler et al, supra, note 34 at 1047.

593 Kassler, supra, note 33 at 36.

594 Kassler et al, supra, note 34 at 1050.

595 Ibid.

596 Kassler, supra, note 33 at 38.

597 Schopper & Vercauteren, supra, note 363 at 1462.

598 WHO, supra, note 568 at 85.

599 Leviton, supra, note 589.

**Return to the top of this page**

**Return to Table of Contents**

# HIV Testing and Confidentiality: Final Report

**Prepared by Ralf Jürgens**

**ISBN 1-896735-16-9**

---

# MANDATORY OR COMPULSORY HIV TESTING (Part 1)

[Link to Part 2 of this chapter]

> The value of testing as a strategy to combat AIDS depends completely on how the information from tests will be used. In considering any given testing policy, therefore, it is fundamental to ask what will be done with test results once they are created.600
>
> What makes mandatory testing attractive? "It looks like a quick fix. People still perceive HIV testing as an us–them issue. And it makes constituents think legislators are doing something about the epidemic."601

Despite the consensus that HIV testing should generally be undertaken only with the informed consent of the person being tested, there have been repeated calls for mandatory602 or compulsory603 testing of the entire population or of certain groups of the population.

This chapter examines various proposals for mandatory or compulsory HIV testing of specific populations. The discussion does not canvass every conceivable group that could be tested, or even every group for which testing has been suggested. Rather, it focuses on the proposals for mandatory or compulsory testing that have been most frequently put forward in Canada and that continue to be made. Thus, it analyzes whether mandatory and/or compulsory testing of

- pregnant women;
- newborns;
- prisoners;
- persons accused or convicted of sexual assault;
- prostitutes;
- health-care workers and patients; and/or
- immigrants

is justified. In contrast, it does not analyze whether mandatory and/or compulsory testing of other groups, such as military personnel or employees, would be justified. While in some countries such proposals have been frequent, in Canada the mandatory or compulsory testing of military personnel, employees, and other groups not analyzed in the following text has been infrequently proposed and generally rejected. For example, the Canadian Human Rights Commission's 1996 *Policy on HIV/AIDS* states that HIV-positive people pose "virtually no risk to those with whom they interact in the workplace," and that therefore the Commission does not support pre- or post-employment testing for HIV. According to the Commission, "[s]uch testing could result in unjustified discrimination against people who are HIV positive."604 Similarly, in its response to the *Discussion Paper*, the British Columbia Human Rights Commission said that "the Commission considers that routine HIV screening of employees would violate the [British Columbia *Human Rights] Code*."605

The chapter first provides a short general review of the rationale behind proposals for mandatory or compulsory HIV testing (General Overview). It then summarizes the Canadian approach to mandatory or compulsory HIV testing, in particular the recommendations made in some of the most important reports and policy statements published by Canadian organizations since 1986, and provides a brief overview of approaches taken in other countries (History).

For each of the groups for which mandatory or compulsory testing has been suggested, a section of the chapter analyzes whether such testing is justified. Each section first reviews the recommendations concerning mandatory or compulsory testing made by Canadian and, whenever available, international organizations. It then briefly examines the current situation, pointing out that, while in some countries some forms of mandatory or compulsory testing have been implemented, Canadian policymakers have thus far resisted adopting a policy of mandatory or compulsory testing of people belonging to any of the groups for which mandatory or compulsory testing has been suggested. The section then critically explores whether, because of the new developments, mandatory or compulsory testing of some or all people belonging to those groups has become justified in Canada. The sections conclude that, the new developments notwithstanding, justification for mandatory or compulsory testing remains weak. In some cases, forced testing would serve no clear and valid purpose; in others, its purposes can be achieved through other, less intrusive measures.

## General Overview

As Zeegers Paget points out, mandatory testing programs have been used in combating other communicable and sexually transmitted diseases, such as tuberculosis and syphilis.606 The conditions under which a mandatory testing program is acceptable were defined by the World Health Organization in 1968, as follows:

- the condition being tested should be an important health problem;
- there should be an accepted treatment for patients who test positive;
- facilities for diagnosis and treatment should be available;
- there should be a recognizable latent or early symptomatic stage;
- there should be a suitable test for examination;
- the test should be acceptable to the population;
- the natural history of the condition, including development from latent to declared disease, should be adequately understood;
- there should be an agreed policy on whom to treat as patients;
- the cost of case-finding (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole; and

- case-finding should be an ongoing process and not a once and for all project.607

As Zeegers Paget points out, not all of these ten conditions are fulfilled in the case of HIV/AIDS.608 Nevertheless, worldwide, opinion about HIV-antibody testing has varied widely:

There are those who recommend screening for all: their arguments are irrational and are not based on scientific fact. Others show interest in screening targeted groups: the problem then lies in the choice of the groups and in the motives of that choice, which are subjective as well as objective. Last, we found those who recommend voluntary screening: they defend both human rights and scientific inquiry.609

## Proposals for Forced Testing

As Field points out,

> [i]n AIDS, policymakers have faced a public health crisis of catastrophic proportions: the disease is fatal. No cure or vaccine exists. The number of infected people has been increasing at a geometric rate. These chilling facts and the public reaction to them make legislators want to do something, anything, that can make a difference.610

Initially, in the face of the HIV/AIDS epidemic, proposals for mandatory or compulsory testing were easy to understand. People naturally searched for concrete solutions, and the notion of mandatory testing – coupled perhaps with forced segregation of persons living with HIV or AIDS – had obvious superficial appeal.611 Calls for mandatory or compulsory testing became a common political response to HIV/AIDS, partly because they create the appearance of taking a strong stand against the threats of AIDS. Moreover, there were

> nagging doubts about the credibility of those who denounce forced testing. For example, how can it be better *not* to know who harbours the virus? Are those who reject forced testing trying to protect the individual rights of AIDS carriers at the expense of the public health?612

Over the years, calls for mandatory HIV testing have never stopped. Motivated by a mix of emotions and ideologies, they have "reechoed ..., citing new research findings and targeting different populations."613

## Testing of the Entire Population

Early in the epidemic, some even recommended that the entire population be mandatorily tested for antibodies to HIV. A popular misconception was that widespread or even universal HIV testing could identify "all who carry the virus so that they could be isolated and the uninfected majority could be secure from any risk of transmission."614

However, wide consensus emerged that it would be a mistake to enact laws requiring the entire population to submit to testing: "Concerns for protecting public health support this conclusion, just as concerns for protecting civil liberties do; each goal independently militates against mandatory testing."615 In particular, it was pointed out that

- even if universal testing could be carried out, it could not contain HIV: false negatives and persons still in the latency period when testing was performed would not be detected; repeat testing would be necessary to remedy those errors, and in the meantime those undetected might continue to spread the disease;

- there is a danger that the "uninfected" population would feel a sense of security and not pursue precautions against infection, even though that population could not be entirely secure from HIV-positive persons;

- a universal or widespread testing program does not represent a practicable approach because of the costs it would entail; and, most important,

- the HIV-negative persons in the population are not in fact at risk from HIV-positive persons living in their midst: they can protect themselves against becoming HIV-positive by taking appropriate precautions.

## Testing of So-Called "High-Risk Groups"

Recognizing the problems raised by universal testing of the entire population, some have recommended that mandatory or compulsory testing be limited to members of the so-called "high-risk groups," in particular gay men, injection drug users, and hemophiliacs. However, such proposals were rejected on the basis that HIV is an indiscriminate virus that does not infect people along group lines: it is a high-risk activity, not identification with a group that has a high seroprevalence rate, that causes transmission of the virus. In addition, it was recognized that a mandatory testing program aimed at the so-called "high-risk groups" would face obvious problems in identifying members of the targeted groups: testing would be associated with stigma, and members of "high-risk groups" would be encouraged to go underground. Finally, mandatory testing of these groups would have exacerbated "the sense of us and them – therefore increasing discrimination towards "them" and giving "us" a false and potentially dangerous sense of security."616

## Testing Specific Populations

There is increasingly broad realization that proposals for mandatory testing generally are political rather than health policy proposals; they often are motivated by anti-gay animus or an animus against intravenous drug users and rarely are animated by legitimate public health objectives. As more persons come to realize these facts and also become dedicated to taking AIDS seriously, most of the proposals for testing by group should lose the support of those followers they still have.617

Because there are problems both with forced testing of the entire population and with testing of "high-risk groups," some have called for more targeted mandatory testing programs. As Field points out, one or more of the following four factors seem to underlie the proposals for testing of certain groups: 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 some use that can be made of test results.618

For example, Werdel argued that testing should be required among prisoners, arrested prostitutes and drug users, and those who attend sexually transmitted disease and drug abuse clinics. In his view, "[t]hese groups are not only at a high risk of infection, but they also pose a serious risk to the health of the community" and "are likely to transmit the disease to innocent, healthy members of society."619

Each type of testing proposal raises a unique set of policy issues, and therefore must be considered separately. For example, proposals to test all pregnant women raise different concerns and implications from proposals to test all prisoners.

## Views

> Most calls for mandatory testing could succeed only by playing upon public ignorance about the disease.620

Mandatory or compulsory testing, whether of the entire population or of specific groups, is generally opposed "because it is unlikely to lead to changes in behaviour necessary to impede the spread of AIDS, and because of the potential for invasion of privacy and discrimination."621 According to Persky, forced testing might locate a minuscule proportion of the "endangered population," but this would likely be offset by a larger proportion of the endangered population being "scared off" by the prospect and consequences of mandatory measures.622 In the words of the American Civil Liberties Union, "civil liberties defects aside, mandatory testing seems destined to be counterproductive, irrationally wasteful of public funds, or both."

This is consistent with WHO’s Statement from the [1992] Consultation on Testing and Counselling for HIV Infection, which emphasizes that "[m]andatory testing and other testing without informed consent has no place in an AIDS prevention and control programme."623 The

Statement continues by saying:

> There are no benefits either to the individual or for public health arising from testing without informed consent that cannot be achieved by less intrusive means, such as voluntary testing and counselling.

Public health experience demonstrates that programmes that do not respect the rights and dignity of individuals are not effective. It is essential, therefore, to promote the voluntary cooperation of individuals rather than impose coercive measures upon them.

Furthermore, testing programmes 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 and discrimination directed at HIV-infected people, individuals who believe they might be infected tend to go "underground" to escape mandatory testing. As a result, those at highest risk for HIV infection may not hear or heed education messages about AIDS prevention.
>
> • Testing without informed consent damages the credibility of the health services and may discourage those needing services from obtaining them.
>
> • In any testing programme, there will be people who falsely test negative – for example, because of laboratory error or because they are infected but have not yet developed detectable antibodies to HIV. Thus, mandatory testing can never identify all HIV-infected people.
>
> • 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. Examples are health care workers who do not follow universal precautions when all hospital patients are tested, and clients of sex workers who do not use condoms when they believe that all prostitutes are being tested.
>
> • Mandatory testing programmes are expensive, and divert resources from effective prevention measures.624

Other international organizations have made similar statements. For example, the Council of Europe adopted a recommendation stating that "in the absence of curative treatment, and in the view of the impossibility of imposing behaviour modification and the impracticability of restrictive measures, compulsory screening [is] unethical, ineffective, unnecessarily intrusive, discriminatory and counter-productive."625 The Joint United Nations Programme on HIV/AIDS (UNAIDS), in its 1997 Policy on HIV Testing and Counselling, also expressed its opposition to mandatory testing stating that "HIV testing without informed consent and confidentiality is a violation of human rights."626 Moreover, the Policy continues by saying that

> there is no evidence that mandatory testing achieves public health goals. UNAIDS therefore discourages this practice. HIV testing in which the individual’s identity is linked to the test result must not be done without the individual’s informed consent.627

Finally, the International Guidelines on HIV/AIDS and Human Rights recommend that HIV testing only be performed with the specific informed consent of the individual tested, and that "[e]xceptions to voluntary testing would need specific judicial authorization, granted only after due evaluation of the important considerations involved in terms of privacy and liberty."628

## General Principles

> With any scheme for testing, it is important to identify the intended goal – what the test result will be used for.629
>
> HIV antibody testing must be carried out in such a way as to respect and protect, to the greatest extent possible, both the individual being tested and the community. Compulsory testing represents an invasion of individual rights, including of autonomy and privacy. Because we live in a free society, any implementation of compulsory testing must be ethically justified, and this remains a relevant consideration even where such testing is permitted or required by law. The use of coercive measures to obtain information provided by HIV antibody testing, or behaviour change through HIV antibody testing, is unacceptable unless it is clearly justified. Justification for compulsory HIV antibody testing requires fulfilling the necessary, but not necessarily sufficient, condition that benefits outweigh harms, and that these are sufficiently important to justify inflicting the harms involved.630

There are several general principles that should guide consideration of all testing proposals:631

- First, the purpose of testing must be ethically acceptable.632 Protecting public health and preventing transmission of HIV are acceptable purposes, while denying needed services and expressing disapproval of certain groups are not.

- Second, the proposed use of test results must contribute to the program’s goal.

- Third, the test program must be the least restrictive or intrusive means for attaining the program’s purpose.

- Fourth, 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: "The central question posed by this epidemic is whether we will be able to maintain our traditional values and principles while dealing with a threat to our very existence."633

Similarly, Somerville and Gilmore have pointed out that, before deciding how and when someone or a population should be tested for HIV antibodies, the ethical implications of such testing must be fully examined.634 The general concepts that guide ethical analysis of HIV-antibody testing include respect for persons, non-maleficence, beneficence, and justice. From these concepts, Somerville and Gilmore identify seven principles that need to be satisfied before testing of any individual, group, population or community can be proposed, recommended or implemented:635

> 1. The rights of everyone in a society where implementation of HIV antibody testing is being considered must be respected, and exceptions which invade any of these rights must be fully justified;
>
> 2. Testing, and interventions that result from HIV antibody testing, must be the least invasive, least restrictive, likely to be effective measures reasonably available to accomplish the valid objectives of HIV antibody testing;
>
> 3. Expected benefits of HIV antibody testing must exceed the potential harm or harm that might result from HIV antibody testing, and harmful consequences of HIV antibody [testing] must be minimized;
>
> 4. Testing must be applied fairly and must not wrongfully discriminate against anyone or any group in the population being tested;
>
> 5. There must be a reasonable risk of HIV infection in the population being tested;
>
> 6. Methods used in testing must be of the highest technical standards that are reasonably available;
>
> 7. Testing must be likely to result in effective measures

> to control or interrupt HIV transmission or the consequences of HIV infection.

# History

## Canada

> The major players in the struggles around Canadian AIDS policies have generally agreed on one thing, that HIV-related testing should be voluntary. Mandatory testing offers little or nothing in the way of genuine health benefits at an enormous cost, both in dollar values and in terms of the well-being and human rights of those subjected to it. A commitment to voluntary testing and consistent opposition to mandatory testing has produced a rare occurrence in the hard-fought politics of AIDS – consensus.636

In Canada, the approach to HIV testing has been very cautious, recognizing that testing has potentially great benefits, but also great harms for the individual being tested and that, in addition, benefits for the community until recently were limited and questionable. Policymakers did not give in to the temptation of creating the appearance of taking a strong stand against the threats posed by the epidemic by implementing forced testing programs. They understood that taking such a course of action would have had little impact on the spread of HIV in Canada and that, instead, implementing effective HIV prevention programs, including such controversial measures as needle exchanges, was warranted. Consequently, there have been hardly any calls for testing of the entire population. In addition, although there have been calls for the widespread mandatory or compulsory testing of certain groups or populations, such as prisoners, sex workers, pregnant women, and health-care workers, all major reports dealing with the issue – including those of the Canadian Bar Association, the National Advisory Committee on AIDS, the Royal Society of Canada, the Parliamentary Ad Hoc Committee on AIDS, the Ontario Law Reform Commission, the AIDS Committee of Ottawa, and the Canadian Public Health Association637 – have rejected such an approach. They ruled out any practice of testing of certain populations without their specific consent and concluded that mandatory or compulsory testing schemes would not further any particular public health objective. They noted that HIV was unlike other infectious diseases, where a testing and treatment regime might significantly reduce the spread of infection, because there were no effective treatments to cure HIV infection or significantly reduce the infectivity of people with HIV. Moreover, the reports noted that mandatory or compulsory testing schemes would have the effect of driving away from the health-care system those most at risk of HIV infection and most in need of prevention education.

According to NAC-AIDS, compulsory HIV-antibody 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." An analysis of the benefits and harms of compulsory testing to the individual being tested, to the community, and to society in general led the Committee to conclude that at "this time, in Canada, compulsory HIV antibody testing is unwarranted." In particular, the Committee pointed out that, while compulsory testing might offer some benefits, harms can be numerous and include

discrimination, disadvantage, stigmatization or isolation of the population, community, organization or institution to which HIV infected persons belong; the costs of testing and of its consequences; and the danger that compulsory testing may increase risk-producing behaviour, or avoidance of testing by those at increased risk of being exposed to or infected with HIV. Moreover, compulsory testing could seriously harm Canadian society by disrupting or damaging the ethical and legal norms on which it is currently established.638

However, the Committee accepted that there may be rare exceptions to the general principle according to which compulsory (or mandatory) testing is unwarranted, and stated that these exceptions must be examined on a case-by-case basis.639

Finally, the Committee made specific recommendations with respect to the testing of certain population groups (recipients of blood products, pregnant women, people about to be married, residents of areas where HIV is endemic, heterosexuals, homosexuals, prostitutes, injection drug users, health-care personnel, prisoners, immigrants, etc) or in certain situations (when applying for insurance, seeking health care or employment, or being evaluated for adoption). The Committee came to the conclusion that compulsory or mandatory testing – with the exception of testing of blood, organ, tissue, ovum, or sperm donors – was unwarranted in all cases. The Ontario Law Reform Commission reached the same conclusion, but, like the Canadian Bar Association-Ontario,640 was willing to grant insurance companies the right to perform mandatory HIV-related tests on applicants.641

According to the Royal Society,

> [a]ny proposal for mandatory testing raises the conflict between individual rights and societal benefits. As a general principle, measures respecting individual rights are preferable to restrictive ones conceived for the protection of society. Only when the threat to society or to the very existence of society is real and imminent, as for example in times of war, may the rights of the individual have to yield to the interests of society. We believe that AIDS now poses no such threat.642

The Society pointed out that, unless AIDS should create such a national emergency in Canada that the federal Parliament could pass extraordinary public health legislation, decisions about mandatory testing in Canada would be made by the provinces; that current provincial legislation does not authorize the mandatory testing of the whole population; that mandatory blood tests would affect several rights and freedoms guaranteed constitutionally by the Canadian Charter, such as the right to liberty and security of the person and the right to be free from unreasonable search or seizure; that mandatory blood testing would produce an enormous body of confidential information with a large risk that the information would be misused; and that mandatory testing of defined groups is discriminatory, "since it would impose tests on some but not others."643

In 1993, the Canadian Public Health Association recommended that, if necessary, all interested parties (eg, physicians, community AIDS groups, public health workers, government officials, legal counsel) be brought together to discuss and clarify any exceptions to voluntary testing and to address other outstanding testing policy issues.644

There have been no suggestions in Canada of mandatory testing of Aboriginal people and no one consulted by Matiation during the preparation of his discussion paper expressed any concern that such a course of action would be proposed. As Matiation says:

> It would be shocking if it ever were. Nonetheless, issues regarding mandatory or compulsory testing are of special concern to Aboriginal people because of their overrepresentation among some groups for which such testing has been proposed, such as prisoners, IV drug users, and – in many cities – sex workers. Aboriginal AIDS organizations and activists need to remain vigilant against proposals for mandatory or compulsory testing [footnote deleted].645

## International Developments

A survey of laws and policies on HIV testing undertaken by Zeegers Paget shows that internationally only two jurisdictions have adopted law or policy allowing for most of their population to be tested without consent.646 While Cuba has indeed implemented a testing program for a large part of its population, in Mongolia a legal instrument allowing for testing on a large scale was adopted in 1989, but such testing was not undertaken.647 Other jurisdictions have adopted mandatory or compulsory testing programs for some groups in the population. For example, in 1987 the conservative government of the German *Land* of Bavaria introduced Circulars ordering mandatory HIV testing for prostitutes, intravenous drug users, or anyone else suspected of carrying HIV.648 Applicants for civil service jobs were also required to submit to testing. The Bavarian courts later decided that the Circulars could legally be extended to compel a person to be tested for HIV even on the grounds of a merely "slight suspicion" of infection.649 These measures were widely criticized, but in actual practice the power to force testing was exercised in a very limited way. No compulsory testing and reporting and no large-scale screenings were ever organized in the end.650

In the United States, in the early days of the HIV/AIDS epidemic, the public health response was marked by what some have referred to as a "voluntarist consensus," that is, a rejection of past methods of disease control based on coercion.651 In this vein, thirty-six states had by the end of 1991 passed legislation requiring the informed consent of an individual to HIV testing.652 Still others passed specific statutes to ensure the confidentiality, at least to some extent, of HIV test-related information. In some US jurisdictions, counselling became a mandated component of testing schemes.653 Over time, however, this consensus began to give way to mounting calls for a more aggressive, coercive approach to HIV-antibody testing. At the federal level, the US government embarked on a program of screening all new recruits and active duty personnel in its armed forces for HIV.654 The State Department, Peace Corps, and Job Corps also instituted compulsory HIV testing for foreign service personnel.655 These compulsory testing programs have been upheld by the Courts as constitutionally valid.656 Numerous mandatory testing programs have been instituted at the state level. Many US states have at one time or other compelled members of certain groups of people to be tested for HIV. For example, Illinois required HIV testing as a precondition for receiving a marriage licence; Florida mandated the testing of pregnant women for sexually transmitted diseases, including HIV; numerous states allowed for the mandatory testing of individuals convicted of or charged with sex-related crimes; by the end of 1988, fourteen states had introduced mass testing of prisoners for HIV; and Nevada, where prostitution is state-regulated, required all sex workers to be tested.657

Currently, mandatory tests are imposed, for example, on US military and foreign service personnel, immigrants, and certain sex offenders.658 Some states also permit nonconsensual HIV testing of patients in limited circumstances. An Alabama statute, for example, allows testing without consent if: (1) the patient is at "high risk" of infection; (2) knowledge of the patient’s serologic status is necessary for medical care; or (3) knowledge of serologic status is needed for the protection of health-care personnel. A federal district court found the "high risk" classification to be unconstitutional because a patient could be arbitrarily classified, but upheld the other two classifications.659 Many states allow compulsory testing to determine the HIV status of a patient in the event of an injury to a health-care worker, emergency response employee, or corrections officer that poses a risk of HIV transmission.660 In August 1998, California Governor Wilson even signed a bill that specifically provides for the testing of a deceased individual’s blood without consent in order to learn whether an emergency health-care worker has been exposed to HIV.661 Finally, New York has enacted a law requiring mandatory testing of newborns.

In Australia, federal government policy advocates voluntary HIV testing.662 As Magnusson reports, early demands for broad population screening have not been followed, and HIV testing remains, in most cases, voluntary. However, compulsory HIV testing is required by legislation at both state and federal levels in some circumstances. For example, applicants for migration to, or for permanent residency in, Australia, as well as some other categories of applicant, have been required to undergo HIV testing since December 1989. The compulsory testing of defence forces recruits and selected classes of serving personnel has also been authorized since 1989. The Tasmanian *HIV/AIDS Preventive Measures Act* 1993 authorizes compulsory or mandatory testing in a variety of circumstances, including where a person has been charged with a crime of a sexual nature and where "the testing of a person is necessary to determine the treatment of someone else whom the person may have infected."663 In Victoria, the Health

Department may order a person to be tested where he or she has exposed a medical practitioner, nurse, dentist, ambulance officer, police officer, or prison officer to the risk of infection.664 Like the Tasmanian provision, "this would authorize HIV testing following needlestick injuries suffered by ambulance officers and HCWs [health-care workers] and after physical assault upon prison guards and police, although the Tasmanian provision is not limited to these categories of people."665

In South Africa, it has been recommended that HIV testing always be undertaken only with the informed consent of the person being tested. Recently, in August 1998, the Labour Portfolio Committee of the South African Parliament accepted amendments to the forthcoming *Employment Equity Act*. HIV has been included as a prohibited ground of discrimination in the Act, and a section has been added according to which "[t]esting of an employee to determine that employee’s HIV status is prohibited unless such testing is determined to be justifiable by the Labour Court."666

# Testing of Pregnant Women

Prior to 1994, those interventions known to reduce the risk of perinatal HIV transmission were limited to the prevention of HIV transmission to women of child-bearing years, the deferral of pregnancy by HIV-positive women, and the termination of pregnancies by HIV-positive women.

In 1994, the interim results of US Pediatric AIDS Clinical Trial Group Protocol 076 (ACTG 076) demonstrated that the administration of zidovudine (ZDV) to HIV-positive pregnant women and their infants could reduce the anticipated rate of perinatal HIV transmission by approximately two thirds – from 25.5 percent to 8.3 percent. Subsequent experience confirming the interim results of ACTG 076, and achieving even lower rates of perinatal HIV transmission, has stimulated debate within the Canadian and international medical communities and public health circles as to how best to offer HIV testing to pregnant women so that those who might benefit from antiretroviral chemoprophylaxis to reduce the risk of perinatal HIV transmission can be made aware of its availability, benefits, risks and unknowns.

The questions raised by HIV testing of pregnant women are addressed in detail in *HIV Testing and Pregnancy: Legal Issues* (the "Pregnancy Paper"), prepared as another component of the Joint Project on Legal and Ethical Issues Raised by HIV/AIDS,667 on the basis of an examination of the medical and legal parameters of the policy debate. Based in large part on the analysis undertaken in the Pregnancy Paper, this section will provide only a brief overview of some of the issues raised by HIV testing of pregnant women.

## History

The debate about HIV testing of pregnant women has changed significantly since the release of ACTG 076 in 1994.

## Before 1994

Initially, knowledge about HIV and pregnancy was scarce. Evidence suggested that about one-third of babies born to women who were HIV-positive prior to pregnancy would be HIV-positive themselves, and there was fear that pregnancy might accelerate the development of AIDS in women who were HIV-positive but asymptomatic. In addition, breast-feeding by HIV-positive women was discouraged because of the potential for HIV transmission. Due to a lack of information, the potential use of mandatory HIV testing was limited. As expressed by Field,

[w]hile states undoubtedly have a strong interest in decreasing the number of children born with HIV infection, it is unclear how mandatory testing of pregnant women would serve that goal. Once a woman is pregnant, the test can help contain HIV only if it leads to abortion.668

Field continued by saying that "the spectre of the state encouraging or requiring abortion based on positive test results is a frightening one indeed." According to her, mandatory testing should not be contemplated: first, because the child of an HIV-positive woman is more likely to be HIV-negative than to be HIV-positive; and second, because requiring abortion would run counter to a woman’s fundamental right to make decisions concerning procreation. There was general consensus that testing without informed consent offered no advantage over voluntary testing and counselling programs designed to assist women in making decisions about childbearing and/or breast-feeding. As stated by WHO,

> [t]hose women who want to know if they are infected before making such decisions generally would participate in voluntary testing and counselling programmes. Furthermore, not only is it unethical to pressure or force women to make reproductive or breast-feeding decisions for any reason, including their HIV infection status, but those women most likely to be HIV-infected may try to avoid mandatory testing, precisely in order to avoid pressure in such decision-making. Such avoidance may have the additional unwanted result of discouraging pregnant women from attending antenatal services.669

For the same reasons, in Canada, in 1988 NAC–AIDS concluded that mandatory or compulsory prenatal HIV-antibody screening was "not necessary."670 In 1992, the OLRC pointed out that the testing of pregnant women would not significantly further any public health objective to prevent the spread of HIV because, at that time, no available treatment could prevent perinatal transmission or effectively treat asymptomatic HIV-positive infants. Therefore, the Commission concluded that "no exception to a general rule requiring voluntary, specific, and informed consent for all HIV-related testing is justified respecting pregnant women."671 In practice, HIV counselling and testing was most often offered only to pregnant women considered by their physicians to be at risk for HIV, or was provided at the specific request of the patient herself.

## Since 1994

As mentioned above, in 1994 researchers at the US National Institutes of Health and its collaborators announced the interim results from ACTG 076, indicating that antiretroviral medication provided to pregnant women during pregnancy, labour and delivery and to the newborn baby during the first six weeks of life, can dramatically reduce the risk of mother-to-child transmission of HIV infection. ACTG 076 was a randomized, multi-centre, double-blind, placebo- controlled clinical trial sponsored by the US National Institutes of Child Health and Human Development to investigate the effectiveness of ZVD to reduce the risk of perinatal HIV transmission. The pregnant women who participated in the study were HIV-infected, from 14 to 34 weeks gestation, had received no antiretroviral therapy during the current pregnancy, had no clinical indications for antepartum antiretroviral therapy, and had CD4 counts over 200 upon enrolment. The regimen of ZVD administration studied was as follows:

- oral administration of 100 mg ZVD five times daily, initiated at 14-34 weeks gestation and continued throughout the pregnancy;

- during labour, intravenous administration of ZVD in a one-hour loading dose of two mg per kg of body weight, followed by a continuous infusion of one mg per kg of body weight per hour until delivery; and

- oral administration of ZVD to the newborn (ZVD syrup at two mg per kg of body weight per dose every six hours) for the first six weeks of life, beginning eight to twelve hours after birth.

The interim results of the study revealed HIV transmission rates of 25.5 percent within the placebo group and 8.3 percent within the ZVD group. The final results of the study, reported in 1996, were similar: HIV transmission rates of 22.6 percent within the placebo group and 7.6 percent within the ZVD group.672 Other studies have since confirmed these results or achieved even better results, such as four prospective studies from North Carolina, New York, France, and British Columbia, in which transmission in untreated women ranged from 20 to 32 percent, while transmission in ZDV-receiving women was only three to five percent.673

The US Public Health Service (PHS) responded to the 1994 interim results with recommendations that health-care providers recommend the full ACTG 076 regimen to all HIV-positive pregnant women meeting the entry criteria for the study, as well as to women with similar clinical characteristics. The PHS further recommended that specified components of the ACTG 076 regimen be discussed with, and in some cases recommended to, women presenting clinical characteristics more removed from the original entry criteria for the study. It advised, however, that the efficacy of the ACTG 076 regimen could not be considered to have been established for HIV-positive pregnant women with advanced disease, low CD4 lymphocyte counts, or prior ZVD therapy, and that the long-term risks of ZVD used in this manner (for the mother or for the infant, irrespective of the mother's clinical characteristics) were not yet known.

Health Canada was reserved in its endorsement of the application of the ACTG 076 interim results in the Canadian context. The Editorial Comment that accompanied its reproduction of these results concluded:

> Based on this interim analysis of ACTG 076, ZVD therapy in HIV-positive women after their 1st trimester, during delivery, and to infants for 6 weeks thereafter has shown potential for a reduction in vertical transmission of HIV. In the United States, it has been recommended that women meeting the study entry criteria be treated with ZVD according to the protocol. At this time, individual clinicians and their HIV-positive female patients may wish to make treatment decisions on a case by case basis.674

Notwithstanding this cautionary note, Health Canada drew immediate attention to the question of HIV testing in response to ACTG 076:

> This study also has a public health dimension that goes beyond the clinical decision to offer treatment to pregnant HIV-positive women. There are approximately 400,000 live births each year in Canada. HIV seroprevalence studies among pregnant women across Canada suggest that this cohort might include approximately 140 to 150 HIV-positive pregnant women. Since HIV testing programs are the responsibility of provincial and territorial governments, the relevant authorities will have to analyze the most cost-effective approaches for offering testing to pregnant women who might be HIV positive and wish to reduce the risk of HIV transmission to their infants.675

Indeed, as of 1992, NAC-AIDS had already altered its recommendations regarding HIV testing of pregnant women from targeted offers of testing to those women at increased risk of HIV transmission676 to the provision of information about the risk of perinatal transmission and the availability of testing to all pregnant women in Canada.677

In the United States, in 1995 the Public Health Service similarly altered its HIV testing recommendations for pregnant women from a targeted approach, in which HIV testing was offered to pregnant women at increased risk of HIV infection, to a universal approach calling for the counselling of all pregnant women to encourage them to be tested for HIV infection.678 This shift in approach was attributed to both the advances in prevention and treatment of opportunistic infections in HIV-infected adults and children since 1985 and the availability of ZVD therapy to reduce the risk of perinatal transmission.

More recently, the recommendations founded on the results of ACTG 076 have been updated by the PHS.679 The updated recommendations and supporting commentary served three general purposes:

- first, they confirmed the effectiveness of the ACTG 076 regimen in women meeting the entry criteria for the study;
- second, they confirmed the effectiveness of the ACTG 076 regimen in populations of HIV-positive women with advanced disease and receiving prior antiretroviral therapy (clinical characteristics differing from the ACTG 076 entry criteria);680 and
- third, they integrated the ACTG 076 regimen together with the use of aggressive combination drug regimens (highly active antiretroviral treatment or HAART) that constitute the current standard of care in the treatment of women's HIV infection in the US and Canada.

Commentary in support of the updated recommendations emphasized that there were no clinical trials to establish the effectiveness of antiretroviral drugs other than AZT to reduce perinatal HIV transmission. Rather, the purpose of integrating HAART into the ACTG 076 regimen was to maintain an appropriate standard of care for HIV-positive pregnant women rather than abandon them to ZVD monotherapy, characterized as "suboptimal care."681 The guiding principle adopted by the PHS in support of this approach was

the belief that therapies of known benefit to women should not be withheld during pregnancy unless there are known adverse effects on the mother, fetus or infant and these adverse effects outweigh the benefit to the woman.682

Most recently, at the 12th World AIDS Conference in Geneva, it was reported, among other things, that HAART integrated with ACTG 076 is effective at further reducing the rate of perinatal HIV transmission; and that elective caesarian section delivery was also effective in reducing the rate of perinatal HIV transmission, both in ZDV-treated women and in women not receiving treatment.683

At the same time, limitations, risks and unknowns associated with the use during pregnancy of ZVD and other antiretrovirals used in HAART remain significant.

Two primary *limitations* remain associated with antiretroviral chemoprophylaxis integrating the ACTG 076 regimen with HAART to reduce perinatal HIV transmission: HIV transmission is still observed, and – perhaps most importantly – adherence to the therapeutic regime is essential but physically, psychologically and financially demanding and can therefore prove difficult.

With regard to *risks* and *unknowns*, each of the antiretrovirals currently used in HAART present the risk of short-term and long-term adverse effects, quite apart from the complicating factor of pregnancy.684 The US PHS concluded in its 1998 recommendations that, "[t]here are currently minimal data available on the pharmokinetics and safety of antiretrovirals during pregnancy for antiretrovirals other than ZVD."685 The drugs ddI, ritonavir, saquinovir and nelfinovir are classified by the US Food and Drug Administration as Pregnancy Category B, meaning that:

> [a]nimal reproduction studies fail to demonstrate a risk to the fetus, and adequate but well-controlled studies of pregnant women have not been conducted.686

All of the remaining drugs (including ZVD) are classified as Pregnancy Category C, meaning that:

> [s]afety in human pregnancy has not been determined, animal studies are either positive for foetal risk or have not been conducted, and the drug should not be used unless the potential benefit outweighs the potential risk to the fetus.687

Important areas of concern when any of these drugs are used during pregnancy include the changes in drug pharmokinetics attributable to the many physiologic changes associated with pregnancy; the potential for teratogenicity, mutagenicity and carcinogenicity; and the pharmokinetics and toxicity of transplacentally transferred drugs.688

In summary, there is a paucity of data regarding the short-term effects in women and their infants of antiretroviral chemoprophylaxis to reduce perinatal HIV transmission, and almost a total absence of such data regarding long-term effects. While the demonstrated ability of this therapy to reduce the risk of perinatal HIV transmission and its devastating consequences is unquestionably significant, policymakers must therefore equally bear in mind the potential seriousness of known and unknown associated risks. The public health disasters of thalidomide and diethylstilbesterol (commonly referred to as "DES") serve as powerful reminders of the possibility of harm presented by the use of drugs during pregnancy.

## Current Situation

### Canada

As a result of the developments described above, some Canadian provinces and territories have changed their (formal or informal) testing policies with regard to pregnant women, from offering testing only when a particular woman presented risk factors for HIV to routinely offering the opportunity to be tested to every pregnant women, or to making it a part of routine prenatal care. The Canadian Medical Association, the Canadian College of Family Physicians, and the Society of Obstetricians and Gynaecologists of Canada now also recommend offering HIV testing and counselling to all pregnant women.689 No Canadian province or territory has adopted a policy of mandatory HIV testing of pregnant women.

The following is an overview of the provincial and territorial testing policies as of September 1998. However, this information must be read with some caution for two reasons: (1) at the time of writing, some provinces and territories were considering changing their policies; (2) the practice in each province and territory does not always conform to formal or informal policy. In particular, testing without informed consent and, sometimes, even without the knowledge of the pregnant woman, is not infrequent.

### Newfoundland and Labrador

Beginning in 1992, Newfoundland recommended that all pregnant women have an HIV test and that physicians discuss the option of HIV testing with their patients during their prenatal visits. As of 1 April 1997, the Newfoundland Public Health Laboratory implemented a policy of treating the HIV test as routine, meaning that when physicians order "routine prenatal screening" (or use words to that effect) an HIV test is carried out in addition to syphilis, rubella, and hepatitis B. The relevant communication to physicians emphasized that:

> As is the case for all tests and procedures, physicians should ensure their patients know what tests are being done and that they have consented. As well, physicians should be aware of tests ordered on their behalf by a regional nurse. Even if the nurse orders the tests, the responsibility still falls on the physician to ensure the patient is aware of what tests are being done.690

It is clear, in other words, that characterization of the HIV test as routine does not abrogate a physician's obligation to secure informed consent of his/her patient to the test. The communication endorsed the *CMA Guidelines for HIV Testing* as a guide for physicians with respect to prenatal testing procedures, mother-to-child transmission, and pre-test counselling. The new policy requires physicians to specifically state on the requisition if a patient does not consent to any of the tests normally included in routine testing. Alternatively, physicians may requisition specific tests individually rather than using the term "routine prenatal screening."

### Prince Edward Island

In Prince Edward Island, there is no formal policy for testing of pregnant women, but it is recommended that any woman who presents with risk factors for HIV be screened. Pregnant women who present with risk factors are counselled as to the positive and negative effects of HIV testing, offered the option of being tested, and asked to provide informed consent.691 Recently, a recommendation was put forward by the Community Medical Health Committee that PEI adopt a different method of screening pregnant women for HIV.

### Nova Scotia

The May 1994 Guidelines for Antenatal Screening and Testing established by the Reproductive Care Program of Nova Scotia recommended that HIV testing of pregnant women be carried out "as clinical judgment dictates" and that HIV testing of pregnant women requires informed consent and appropriate pre– and post-test counselling in accordance with the CMA Guidelines.692 The guidelines were premised on the assumption that pre- and post-test counselling, in conjunction with education programs, would facilitate "self-identification."

These guidelines are presently under revision to include a new recommendation that HIV testing be offered to all pregnant women and that "women who decline testing in the first trimester or who are known to engage in activities that put them at risk for contracting HIV should be offered testing again in conjunction with other blood work generally done at 24-28 weeks gestation."693 There is no suggestion that the existing recommendation regarding informed consent and the need to adhere to the *CMA Guidelines* will be altered. Other tests recommended for all pregnant women include: haemoglobin, hepatitis B, rubella, syphilis, blood group and Rh type antibody, urine culture, and cervical cytology. None of these is characterized as "routine."

### New Brunswick

New Brunswick has no formal policy for testing of pregnant women. Whether a woman is tested and how the testing is conducted will vary from region to region.

Outside the reproductive health clinic setting, testing of pregnant women is done by physicians on a discretionary basis. It is believed that some physicians may be testing women for HIV as part of the routine prenatal tests without their informed consent.

Based on a seroprevalence study conducted by the University of New Brunswick Faculty of Nursing, doctors were sent a letter suggesting that they offer HIV testing to all pregnant women.

### Québec

In Quebec, a new program, The HIV Infection and Pregnancy Intervention Program, was launched in May 1997. The program aims to offer the opportunity to undergo an HIV test during pregnancy to every pregnant woman and to every woman who wishes to become pregnant. Under the new program, the "indication for HIV testing during pregnancy will no longer be restricted to the presence of risk factors or patient request but will be simply the condition of pregnancy itself or the desire to conceive."694 The program emphasizes that "offering HIV testing and counselling adapted to pregnancy is henceforth part of the medical practice related to monitoring pregnant women or women who wish to become pregnant."695 The program stresses the need for pre- and post-test counselling as well as long-term follow-up by the physician. Discussion of HIV testing should occur as early as possible to permit "a full range of choices." At the first prenatal visit, attending physicians provide pregnant women with information on the advantages and disadvantages of undergoing HIV testing during pregnancy in order to assist them in making a decision about the test and to explain testing conditions. At subsequent visits, physicians conduct HIV risk evaluation, counselling and education as appropriate for each patient. The program emphasizes that women who are found to be HIV-positive require counselling concerning pregnancy interruption or continuation. In order to assist health-care providers in achieving these tasks, a comprehensive kit containing detailed information and suggestions on how to address these issues, as well as a comprehensive list of resources to which the physician can resort for assistance, has been made available. Further, in order to ensure that a woman is not tested without providing specific informed consent, there is a separate requisition form. The form is intended to provide a woman with the opportunity to think about her decision and to discard the form after the medical appointment if she decides not to have the test done. In addition, the kit specifically instructs that if the specific anti-HIV prescription form is not used, the HIV test must be prescribed separately.

## Ontario

Ontario has shifted its policy from a recommendation that "HIV testing *should be discussed* with all pregnant women and all women considering pregnancy" (established by the Chief Medical Officer of Health in 1995) to a policy that "HIV testing *must be offered* to all pregnant women and all women considering pregnancy." At the time of writing, in October 1998, the Ontario Ministry of Health was in the final stages of developing the materials that will accompany public announcement of this change, which was expected shortly.696

The new policy will expressly require that the informed consent of each woman be sought and obtained prior to testing, and that pre- and post-test counselling be provided as part of that process. Ontario is developing its own guidelines to set out minimum standards for the conduct of that counselling.

The HIV test will be added to the current laboratory requisition for prenatal screening (together with hepatitis B, rubella, and syphilis). The requisition requires physicians to check the box or boxes associated with the test results sought. With respect to the HIV test, the requisition will include two prompts: the first will require confirmation that counselling has been provided; the second will require confirmation that the woman has given her informed consent to the test. The Central Public Health Laboratory, which performs all HIV tests in Ontario, will not process an HIV test requisition unless both boxes have been checked in the affirmative. The requisition will further note that HIV testing may be ordered separately using the ordinary serology requisition (ie, for a non-nominal test) or at any anonymous test site.

## Manitoba

Since March 1994, Manitoba Health and the College of Physicians and Surgeons of Manitoba have recommended that HIV testing be offered to all pregnant women regardless of risk factors identified. The policy states that the decision to be tested should be voluntary, based on informed consent, and include adequate pre- and post-test counselling. Guidance with respect to the conduct of the pre- and post-test counselling is provided by Manitoba Health's own *HIV Counselling Guidelines*.697 In December 1997, the Manitoba Advisory Committee on Infectious Diseases confirmed its July 1997 recommendation that this policy should be continued and recommended further that the Manitoba Prenatal Record be revised to allow recording of the HIV test being offered, and accepted or refused.698

### Saskatchewan

In Saskatchewan testing is offered to pregnant women at the discretion of the physician on the basis of perceived risk. According to the College of Physicians and Surgeons of Saskatchewan, all physicians should discuss risk factors with their patients. If a physician then perceives a patient to be at risk, the woman should be counselled and offered the option of being tested.699

### Alberta

In March 1998, Alberta moved from a policy of HIV testing of pregnant women on the basis of risk assessment to a policy of routinely offering HIV testing to all pregnant women as part of "good prenatal care." HIV testing is done unless a woman chooses not to be tested. According to the policy, physicians must nonetheless obtain the informed consent of all women tested, and this process should include pre- and post-test counselling. Other routine prenatal tests presently include rubella, syphilis, Rh factor, and antibodies to red blood cells.700

### British Columbia

In 1994, the British Columbia Ministry of Health issued a bulletin stating that

> it is imperative that all pregnant women be strongly advised to have an HIV test. HIV testing should be done in accordance with the principles of informed consent and with adequate pre and post test counselling.701

Elsewhere in the statement, the policy is described as one of "routine testing." An HIV Counselling Checklist appended to the policy statement sets out essentially the same requirements for pre-and post-test counselling as established by the *CMA Guidelines*.

British Columbia employs a requisition form specifically designed for the purpose of HIV testing rather than incorporating HIV testing into a collection of standard prenatal assays. In addition, the British Columbia Reproduction Program distributes prenatal care record forms used to chart prenatal care by all family physicians and obstetricians that include two prompts: "Has HIV testing been discussed?" and "Has HIV testing been done?"702

In addition to HIV testing, British Columbia recommends that all pregnant women be screened for hepatitis B and syphilis.

### Yukon

Since 1990, Yukon has strongly recommended that counselling and voluntary testing be offered to all pregnant women. A notice stating that all prenatal women were to be tested voluntarily was sent by the Chief Medical Officer of Health to all physicians. Much of the counselling is carried out by the community health nurses and, unlike most other provinces, it is recommended that partners be screened as well.703

### Northwest Territories

Since November 1996 the Northwest Territories has recommended that all pregnant women commencing the second trimester "be particularly considered for testing."704 A guideline provides that the process of HIV testing include:

> discussing the proposed test with the individual and obtaining his/her informed consent (often referred to as pre-test counselling); ... conducting post-test counselling for those with both positive and negative results; and carrying out appropriate follow-up.

## International Developments

In the US,

> most medical and public health experts support voluntary HIV counselling and testing as the most effective strategy for bringing HIV-infected and -affected women and children into care. Experts such as the Federal Centers for Disease Control, the American College of Obstetricians and Gynecologists, and the American Academy of Pediatrics have consistently opposed proposals for mandatory testing of pregnant and childbearing women as unnecessary and potentially harmful to women and their relationships to their health care providers. These medical and public health experts agree that routine counseling and the offer of voluntary testing during prenatal care have been demonstrated to be the most effective way of identifying HIV-infected women and engaging them in care.705

However, an HIV testing provision in the 1996 Ryan White CARE Act Reauthorization Bill706 (the Ryan White CARE Act is the primary source of federal funds designated for the care and support of people with HIV/AIDS in the US) could lead to the adoption of policies on mandatory HIV testing of pregnant women (and/or of newborns). The provision requires the Health and Human Services secretary to determine in 1998 whether newborn HIV testing has become standard medical practice. If such testing has not become routine practice, each state will have eighteen months in which to demonstrate one of the following or lose its Ryan White CARE Act funds: (1) a fifty percent reduction in the rate of new cases of HIV resulting from perinatal transmission (comparing most recent data to 1993 data); (2) HIV testing of at least ninety-five percent of the women who have received at least two prenatal visits prior to thirty-four weeks gestation; (3) a program of mandatory testing of all newborns whose mothers have not undergone prenatal HIV testing.707 Commenting on the provision, McGovern has said that that, "[a]s these benchmarks are virtually impossible to meet, Congress has in effect invited states to impose mandatory testing measures or lose all their Ryan White funding."708 As of the time of writing, no state had legislated mandatory HIV testing of all pregnant women. However, on 1 February 1997, New York State became the first state to approve mandatory HIV-antibody testing of all newborns.709

In other countries, offering every pregnant woman, and not just women perceived to be at risk, the opportunity to be tested has received wide support. In contrast, mandatory testing has been almost universally opposed. For example, a recommended code of best practice on pregnancy and HIV developed in South Africa states that "[v]oluntary HIV testing based on informed consent can empower a woman to make informed choices about her pregnancy." However, it continues by saying that "HIV testing which is conducted without pre- and post-test counselling ... violates a woman’s rights to autonomy, dignity, privacy and bodily and psychological integrity."710 With regard to HIV testing, the code makes the following recommendations:

> 3.1 All pregnant women should be offered an HIV test upon their initial presentation to a health service provider ...
>
> 3.2 A person may only be tested for HIV after she has given informed consent and no person may be subject to a mandatory HIV test. Informed consent may only be given after minimum standards have been observed by the health service provider ... in the pre-test counselling section.
>
> 3.3 HIV testing should be offered as early as possible in the pregnancy to maximise the benefits of early knowledge of HIV status ...711

During the 12th World AIDS Conference in Geneva in June 1998, the International Community of Women Living with HIV/AIDS (ICW) issued a position statement on "the key issues affecting women living with HIV/AIDS." Among other things, the statement expresses ICW’s "total opposition to mandatory testing in all forms" and advocates for "universal pre and post test counselling, testing with informed consent and access to test results."712 A statement on women's HIV testing and care developed in the United States and supported by a long list of organizations and individuals from across the United States also opposes mandatory testing. The statement reads as follows:

> We, the undersigned, support the right of all women to make medical decisions regarding HIV testing and treatment for themselves and their children, as well as their right to the information necessary to make such decisions. All women have the right to linguistically and culturally competent healthcare. This includes thorough and complete counseling regarding HIV testing and treatments, the opportunity for voluntary HIV testing, and access to appropriate HIV care.
>
> We oppose any program of mandatory or coercive HIV testing and/or treatment of pregnant or childbearing women as violative of the fundamental rights of women and their families, and unsupported by medical science or public health principles.
>
> We reject the assertion that measures restricting a woman's right to make an informed choice regarding HIV testing and care for herself and her children are necessary to reduce perinatal transmission or ensure proper treatment for HIV-infected children. A voluntary approach will establish the trust required for the long-term care of the mother and child.713

The International Guidelines on HIV/AIDS and Human Rights point out that

[m]any HIV/AIDS programmes targeting women are focused on pregnant women but these programmes often emphasize coercive measures directed towards the risk of transmitting HIV to the foetus, such as mandatory pre-and post-natal testing followed by coerced abortion or sterilization. Such programmes seldom empower women to prevent perinatal transmission by pre-natal prevention education and an available choice of health services and overlook the care needs of women.714

While not explicitly addressing the issue of HIV testing in pregnancy, the Guidelines state that "[p]ublic health, criminal and anti-discrimination legislation should prohibit mandatory HIV-testing of targeted groups, including vulnerable groups."715 The Guidelines emphasize that "States should ensure that all women and girls of child-bearing age have access to accurate and comprehensive information and counselling on the prevention of HIV transmission and the risk of vertical transmission of HIV, as well as access to the available resources to minimize that risk, or to proceed with childbirth, if they so choose."716

In its policy statement on HIV testing and counselling, the Joint United Nations Programme on HIV/AIDS also states that pregnant women should not be coerced into testing or be tested without consent:

> Women should be offered information on reproductive and infant feeding options and on the use of antiretroviral treatment to reduce the risk of mother-to-child (vertical) HIV transmission. Regardless of the presence of risk factors or the potential for effective intervention to prevent transmission, women should not be coerced into testing, or tested without consent. Instead, they should be given all relevant information and allowed to make their own decisions about HIV testing, reproduction and infant feeding.717

Finally, a European study group on antenatal HIV testing, under the aegis of the European Union, has recently produced a consensus document and recommendations, summarized here:

- Every pregnant women should, as of right, have access to HIV testing and information. The provision of testing without undue obstacles should be mandatory for healthcare providers. The policy for implementation of antenatal HIV testing may be expected to vary between localities, being based on the balance of cost/benefit informed by the hidden prevalence of HIV infection in the pregnant population. Decisions on such matters need to be taken at national and regional levels at "arm’s length" from competing claims for local resources.

- There is a need to deliver appropriate and understandable information to all women. This may require the assistance of ethnic health advocates.

- Women should have access to specialist counselling and have the right to decline such counselling.

- Models of care providing for HIV-infected individuals and family have to precede a testing policy.

- Regular staff training is necessary.

- The ideal situation is for the serostatus of both partners to be known before conception. If not, testing should also be offered to the male partner. In the event of a discordant result, or of only one partner being tested, no decision on third-party disclosure should be taken without full discussion with the woman.

- The situation of "vicarious maternal testing" can also arise postnatally if the serostatus of an infant is determined. Every effort should be made to avoid a conflict of interest between a mother and her baby.

- Consensus may now be achievable that antenatal HIV testing should be positively recommended, in the interests not only of the baby but also of the symptomless woman; and that HIV testing should be regarded as the norm although not compulsory. The right of the woman to refuse testing, intervention, and drug therapy should also be enshrined.718

## Assessment

Four alternative approaches to HIV testing of pregnant women have been considered:

(1) Voluntary HIV testing offered to pregnant women with identified risk factors

This approach calls for HIV testing to be offered to pregnant women who present with a history and/or signs and symptoms that place them at increased risk of HIV infection, as well as all pregnant women who ask to be tested irrespective of the presence or absence of identified risk factors for HIV infection.

The test is performed only with the voluntary, specific and informed consent of each pregnant woman, together with all standard components of pre- and post-test counselling.

(2) Voluntary HIV testing offered to all pregnant women

This approach calls for HIV testing to be offered to all pregnant women irrespective of the presence or absence of identified risk factors for HIV infection.

The test is performed only with the voluntary, specific and informed consent of each pregnant woman, together with all standard components of pre- and post-test counselling.

(3) Routine HIV testing of all pregnant women

This approach calls for HIV testing to be performed on all pregnant women by adding this test to the standard requisition form used to conduct prenatal assays.

In theory, routine testing does not require that the test be performed without the voluntary, specific and informed consent of the pregnant woman tested, and without all standard components of pre- and post-test counselling. In practice, however, the characterization of the test as "routine" may create a presumption on the part of both the physician and the woman concerned that the test will be conducted and may, as a result, diminish the importance attached (by one or both) to a full discussion and consideration of the risks and benefits of testing.

Alternatively, the need for voluntary, specific and informed consent might be overlooked altogether. Instead, the woman’s consent to be tested for HIV might be implied from her presentation to a physician seeking prenatal care and providing a blood sample for "routine bloodwork."

In either case, a woman’s specific refusal to be tested for HIV (sometimes referred to as "opting out" of HIV testing) would be respected.

(4) Mandatory HIV Testing of All Pregnant Women

This approach calls for HIV testing to be performed on all pregnant women by adding this test to the standard requisition form used to conduct prenatal assays.

The test is performed without the voluntary, specific and informed consent of the pregnant woman tested, and without all standard components of pre- and post-test counselling. Should a pregnant woman refuse to be tested for HIV, that choice would not be respected. The test would be performed against her will.

## Legal Parameters

At this time in Canada, which of the above approaches should be adopted? Before turning to this question, an analysis of the current status of Canadian law is necessary because it is essential that any analysis of the relevant medical and scientific facts undertaken to make policy choices in response to these questions be informed by an appreciation of the current status of Canadian law. The following is a brief summary of the main arguments considered in relation to this issue in the Pregnancy Paper.

The Paper first analyzes the right to give or refuse consent to medical treatment and its application in the context of HIV testing, concluding that a physician who conducted an HIV test on a patient without meeting the basic elements of the doctrine of informed consent would be vulnerable to both a civil action for damages by the person so tested, as well as prosecution for professional misconduct by his/her licensing body, for the failure to meet adequate standards of practice.

It then analyzes whether the right of a woman to give or refuse informed consent to HIV testing is restricted or otherwise altered by pregnancy, concluding that the Supreme Court of Canada’s decision in *Winnipeg Child and Family Services (Northwest Area)* v *DFG*719 confirms the inviolability at common law of a pregnant woman’s right to exercise informed consent to a proposed medical intervention that may benefit the fetus she carries, and accept or decline that intervention, free of state compulsion. However, the Paper points out that the Supreme Court did acknowledge the legitimacy of the state’s interest in protecting the health of a fetus to be carried to term and its ability to enact legislation to effect that purpose: "Justice McLachlin stated repeatedly throughout the course of her reasons for judgment on behalf of the Court’s majority that, given the magnitude of the changes to the law sought on the appeal and their potential ramifications, they were best left to the wisdom of the legislature."720 The powers of the legislature, however, are not unlimited. The Paper points out that any legislation intended to authorize the state to compel a pregnant woman to submit, against her will, to a proposed medical intervention in the interests of her fetus would have to comply with the *Canadian Charter of Rights and Freedoms*. The Paper concludes that the enactment of legislation to mandate HIV testing for pregnant women would in all likelihood fail to pass constitutional muster.

## What Policy?

> As treatment with ZDV cannot and should not be coerced, the 076 results do not compel involuntary testing without informed consent and abrogation of patient privacy.721
>
> Compulsory testing could drive women away from seeking prenatal care at all. If you want women to take AZT four times a day for six months, plus take it intravenously during labor, plus give it to their babies for six weeks afterward, is coercion the way you want to start?722
>
> Mandatory testing proposals will not work to improve the well-being of newborns living with or at-risk for HIV because they will not work to improve the well-being of their mothers. They undermine, rather than support, the provider–patient trust relationship that is essential to obtaining appropriate care and services.723

### Who Should Be Offered Testing?

Should HIV testing be offered to all pregnant women, or only to those at increased risk of HIV infection? There seems to be consensus that, at this stage of the epidemic, an approach under which all pregnant women are offered HIV testing is preferable to an approach under which only women considered to be at risk are offered HIV counselling and testing. Several studies have shown that the latter approach fails to identify a high proportion of HIV-positive women.724 Women are frequently not tested either because they are unaware of their risk for HIV infection or because they are reluctant to disclose potentially stigmatizing behaviour. In contrast, offering counselling and testing to all pregnant women will provide the benefits of counselling to all pregnant women and increase the number of women who will agree to be tested.

### Voluntary versus Mandatory Testing

Should HIV testing of pregnant women be voluntary, or should it be mandatory? Only a policy of mandatory testing could ensure that *all* pregnant women seeking prenatal care are tested for HIV. However, testing is not a goal in itself. Even if all pregnant women seeking prenatal care were tested for HIV, this would not and could not ensure that all pregnant women testing HIV-positive would undergo treatment to reduce the risk of transmission to their children: the decision to undergo treatment would remain a voluntary decision, made by a woman herself, after she is made aware of the risks and benefits associated with treatment. Pregnant women have a right to decide whether or not they will take medication even if the decision not to means that their babies will have a higher chance of being born with HIV infection.

In addition, there are many other reasons why a policy of mandatory HIV testing of pregnant women should not be adopted. First, as the analysis in the Pregnancy Paper shows, the enactment of legislation to mandate HIV testing for pregnant women would in all likelihood fail to pass constitutional muster, would not be the least invasive, least restrictive, likely to be effective means reasonably available to accomplish a valid objective for testing of pregnant women.

Second, where voluntary testing programs have been well designed and implemented, they have been demonstrated to be effective. For example, the New York City Health and Hospitals Corporation (HCC) has reported that 90 percent of pregnant women using HCC facilities who receive HIV pre-test counselling voluntarily consent to HIV testing and return for test results.725 Other model programs have also reported very high rates of voluntary testing,726 showing that a range of factors regarding design of the testing and the delivery of counselling can improve testing uptake rates. Before moving to more coercive approaches could ever be justified in Canada, these factors would have to be exhausted as less restrictive approaches.

Third, voluntary testing will maintain a woman’s relationship of trust and confidence in her physician, a relationship that is necessary for open discussion and consideration of risks and benefits of chemoprophylaxis and, if treatment is chosen, adherence to the complex treatment regimen. As McGovern says:

> Physicians who work with HIV-positive women and their children stress the fact that HIV-exposed and infected children require a medical regimen that is complex and demanding. They report that the voluntary cooperation of the mother is the most important factor in the delivery of effective care for both mother and child, and that trust, not coercion, is the key to such cooperation. A voluntary approach best protects the interests of the child [and mother] in receiving important treatment, since a trusting relationship between medical providers and patients is the best way to ensure that patients get the care and treatment they need, and that they comply with doctors’ recommendations.727

The purpose of HIV testing

> is not to label a woman as infected, but to engage her and her child in appropriate health care. This is most likely to occur when a woman feels she has participated in decisions regarding her own and her child's health.728

Fourth, government-mandated HIV testing could

heighten the existing mistrust of the public health system in communities disproportionately affected by HIV, driving some women away from care. Most experts also agree that the threat of mandatory or involuntary HIV testing and/or treatment will drive some women already mistrustful of the health care system even further from care. The fear of improper disclosure of HIV-related information is already a powerful disincentive to HIV testing for many women at risk. Faced with the prospect of mandatory testing, many women may shun medical care because of justifiable fears of discrimination in healthcare, insurance, employment and housing; because of rejection by partners, family, or friends, or even because of domestic violence.729

If adoption of a policy of mandatory testing of pregnant women indeed drove some of the most vulnerable and marginal women away from HIV testing and good prenatal care, this would defeat the object of the policy, undermining the health of the mother and the child with respect to HIV and generally. This risk was recently acknowledged by the province of Alberta which, when it adopted a policy of routine testing of pregnant women, explicitly rejected making HIV testing mandatory, saying that

> [s]ome women may be reluctant to face the reality of a life-threatening illness or be fearful of discrimination or personal abuse if they test positive for HIV. If prenatal HIV testing were mandatory, such women might refuse all prenatal care, to the serious detriment of their own health and the health of their infants. It is believed that women will make the most appropriate decision for themselves and their babies without having to be forced to do so.730

Fifth, "[n]one of the other routine prenatal tests for infectious diseases are mandatory," and the "only mandatory testing of Canadians for HIV and hepatitis is for persons donating blood or organs and tissues."731 Clearly, adopting a policy of mandatory testing of pregnant women would be a major departure from current policy and practice, and would establish a dangerous precedent.

Finally, in contrast to a policy of mandatory testing, a policy of voluntary testing is respectful of the autonomy of the woman, treating her as an end in and of herself rather than a means to an end.

### Is Informed Consent Required?

The next question is whether physicians should be required to secure the informed consent of pregnant women before proceeding with HIV testing, or whether this requirement can be abrogated. As discussed in much detail in the chapter on consent,732 recent developments notwithstanding, the arguments for requiring specific informed consent before an HIV test can legally be undertaken remain as pertinent as they ever were. HIV is still very different from other diseases, requiring that HIV testing be undertaken only with the specific informed consent of the person being tested and only when pre- and post-test counselling is undertaken. There is no reason to make an exception to this principle in the case of testing of pregnant women. Indeed, it would seem that obtaining a pregnant woman’s consent and counselling her before and after the test is particularly important. Testing is not a goal in itself: if it is to be beneficial, a pregnant woman testing HIV-positive will have to accept antiretroviral therapy for her own and – should she decide to continue her pregnancy – for the child’s benefit. Under Canadian law, the decisions to interrupt or continue pregnancy, and to undergo treatment, are voluntary decisions. The sooner a pregnant women 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 – if she continues her pregnancy – her child. In fact, several studies have shown that when pregnant women are informed of the benefits of HIV testing and when testing is recommended by their health-care providers, most accept it.733 In addition, requiring that testing be undertaken only with the woman’s specific and informed consent will enhance the bedrock of confidence and trust necessary for establishing a collaborative relationship with the physician. It will also provide necessary information around prevention that will help HIV-negative women stay negative (which is especially important given that there is evidence that the risk of HIV transmission to the fetus is higher when a women is newly infected during pregnancy or breastfeeding) and will help HIV-positive women avoid reinfection. Therefore,

> we must question why the response of some policy-makers to the development of critical medical interventions is to seek to eliminate or decrease the HIV-related counseling and consent, essentially reducing the degree of information and autonomy afforded pregnant and delivering women. We must question the apparent ease with which policy-makers are willing to establish a different degree of HIV-related consent from pregnant and delivering women than is required from all other people.734

### Should Testing Be "Routine"?

Finally, what does it mean to designate a test as "routine," and should the HIV testing of pregnant women be characterized as such? As explained above, a policy of routine testing calls for HIV testing to be performed on all pregnant women by adding this test to the standard requisition form used to conduct prenatal assays. In theory, routine testing does not require that the test be performed without the voluntary, specific and informed consent of the pregnant woman tested, and without all standard components of pre- and post-test counselling. Indeed, those Canadian provinces that have adopted policies of "routine" testing have all stated that such testing should not be undertaken without informed consent and counselling. In practice, however, the characterization of the test as "routine" may create a presumption on the part of both the physician and the woman concerned that the test will be conducted and may, as a result, diminish the importance attached (by one or both) to a full discussion and consideration of the risks and benefits of testing. Alternatively, the need for voluntary, specific and informed consent might be overlooked altogether. Instead, the woman’s consent to be tested for HIV might be implied from her presentation to a physician seeking prenatal care and providing a blood sample for "routine bloodwork." This danger should not be underestimated, particularly because there is evidence that some pregnant women are already tested without their consent and without receiving counselling. A policy of routine testing could reinforce this practice.

Nevertheless, some believe that adopting a policy of routine testing is necessary. For example, the province of Alberta recently justified its decision to include HIV with other routine tests by pointing to the experience of other Canadian provinces: "Most provinces have recommended that HIV testing be *offered* to all pregnant women, but because it has not been made part of routine, good prenatal care, fewer than half of pregnant women across Canada are actually believed to be screened for HIV."735

However, "routine, good prenatal care" necessitates more than just adding the HIV test to the standard requisition form used to conduct prenatal assays. Indeed, testing a pregnant women for HIV without obtaining her informed consent and without counselling her would not be good prenatal care. In addition, the problem in provinces where current policies are not resulting in a higher number of pregnant women seeking voluntary testing would seem to lie in the fact that physicians do not offer testing to all their patients and fail to provide adequate counselling. If the goal is simply to increase the number of pregnant women tested for HIV, then a policy of routine testing could be successful. However, if the goal is to offer good prenatal care and to ensure that women can make their own informed decision about whether to undergo testing and, if positive, treatment, then designating HIV testing as routine misses the mark. Instead, what would be required is a sustained effort to implement a program of routine counselling and voluntary testing in which *all* women are counselled about the benefits and harms of HIV testing and offered voluntary testing. To ensure that women provide informed consent and receive counselling, prenatal testing requisition forms should require the physician to declare that counselling was provided and be accompanied by an informed consent form signed by the woman receiving testing. Such a program of routine counselling and voluntary testing would likely result in the vast majority of pregnant women being tested for HIV,736 and in addition its benefits would go well beyond increasing the number of pregnant women tested for HIV.

## Recommendations

> The legal and ethical background for HIV testing in Canada requires respect for the conditions of informed consent, pre- and post-test counselling, and confidentiality. As with any other patient, pregnant women and women who are intending to conceive need to fully understand the advantages and disadvantages

> of HIV testing before deciding to undergo the test. The discovery of a seropositive status has important implications for decisions to interrupt pregnancy, to take antiretroviral therapy should pregnancy continue, and to breastfeed – decisions which themselves are voluntary in Canada. The [Québec] provincial programme has been designed to meet the challenge of ensuring that all HIV-infected women who desire to continue a pregnancy are offered effective means to reduce the risk of HIV transmission to their babies while respecting the rights of all pregnant women, the majority of whom will not have HIV infection, to decide for themselves whether or not to be tested for HIV.737

The pressure to test pregnant women for HIV is great. In the rush to respond to the availability of therapy that can significantly reduce the risk of HIV transmission from mother to child, there is a serious risk that the basic rights of the mother will be swept aside. As stated by Cooper, many of the proposed routine or mandatory testing programs may have been put forward with the best intentions, but they also reflect a confluence of the following factors:

1) people generally, and legislators in particular, are just plain tired of AIDS; especially in times of scarce resources, legislators look to take actions that, unfortunately, are not always positive; 2) the voices and needs of women generally ... are not sufficiently valued in the development of policy and the allocation of resources; 3) when children are involved, emotionalism prevails.738

Given the availability of treatment that can reduce the risk of perinatal transmission, there can be little doubt that pregnant women would be well advised to consider undergoing an HIV test. All pregnant women, and not only those considered at risk, should therefore routinely be counselled about the advantages and disadvantages of HIV testing and offered voluntary HIV testing. Those provinces and territories that have thus far failed to implement a program of routine counselling and voluntary testing should do so immediately. Policies should be designed so as to maximize the uptake rate (including the regular evaluation of strategies for effectiveness), and professionals responsible for implementing the policy should be provided with supportive education and training, again to maximize the policy’s effectiveness. To ensure that women provide informed consent and receive counselling, prenatal testing requisition forms should require the physician to declare that counselling was provided and be accompanied by an informed consent form signed by the woman receiving testing. Finally, colleges of physicians and surgeons should take an active role in ensuring that physicians provide good prenatal care, including offering HIV testing to all pregnant women and routine counselling. Adoption and appropriate implementation of such policies is the "least restrictive, least invasive, likely to be effective, reasonably available approach" because there is reason to believe that the vast majority of pregnant women will willingly undergo an HIV test when the risks and advantages of seeking such a test are fully explained to them: when properly informed and supported in their decision-making, pregnant women will do what is best for themselves and their babies without coercion. In addition, a voluntary system has benefits reaching far beyond an increase in the number of pregnant women tested and

> supports the provider–patient trust relationship, allowing a woman to make the best decisions for herself and for her family – regarding testing, use of antivirals, and treatment for herself and her newborn. This is the approach that deserves our support.739

Provinces should resist the temptation of adopting routine *testing* policies and instead adopt policies of routine *counselling*, focusing on ensuring that adequate counselling be provided to all pregnant women, coupled with the offer of voluntary testing. Those provinces that nevertheless designate their policies as "routine testing" policies must ensure that HIV is not simply added to the list of prenatal assays and that women will indeed receive the counselling that is needed to enable them to provide informed consent to HIV testing. Unless they do so, they will fail to ensure provision of good prenatal care. Finally, a policy of mandatory HIV testing for pregnant women would not be justified and would likely be held unconstitutional.

In addition to adopting policies on HIV testing of pregnant women, increased efforts need to be made at all levels to pursue effective strategies to prevent HIV transmission to women.

> **5.1 In all Canadian provinces and territories, programs should be implemented under which all pregnant women – and not only those considered at risk of HIV – are routinely counselled about the advantages and disadvantages of HIV testing and offered voluntary HIV testing. These programs should be designed so as to maximize the uptake rate (including the regular evaluation of strategies for effectiveness), professionals responsible for implementing the policy should be provided with supportive education and training, and the colleges of physicians and surgeons should take an active role in ensuring that physicians offer HIV testing to all pregnant women and provide appropriate counselling. To ensure that women provide informed consent and receive counselling, prenatal testing requisition forms should require the physician to declare that counselling was provided and be accompanied by an informed consent form signed by the woman receiving testing.**
>
> **5.2 Increased efforts need to be made at all levels to pursue effective strategies to prevent HIV transmission to women.**

## HIV Testing of Newborns

The question whether routine or compulsory HIV testing of newborns is justified has rarely been raised in Canada. In contrast, in the United States, the issue has been debated since the late 1980s.

## History

Initially, there was consensus that routine or compulsory testing was not ethically justifiable for at least two reasons. First, testing technology did not permit the routine identification of HIV-positive babies. The enzyme-linked immunosorbent assay test merely reveals the presence of maternal antibody. Since a majority of those born to HIV-positive mothers are, in fact, HIV-negative, this meant that the test provided an inadequate basis for identifying newborns who could theoretically benefit from therapeutic or prophylactic intervention. What the test did do was identify the existence of an HIV-positive mother. As expressed by Bayer, "[c]ertainly before such identification is permitted to occur without consent, it should be necessary to demonstrate more than a theoretical benefit to the infant."740 Second, there was no evidence that anything could be done for HIV-positive babies in the asymptomatic stage that would fundamentally affect their life course.

Some argued that, were a diagnostic procedure for identifying infection in the newborn to be developed and were a therapy for such infants available,

> the clinical foundation would exist for making a claim on behalf of the vulnerable child. Such a claim might well be sufficient to establish the grounds for testing without prior parental consent.741

They argued that the state has the right to treat an infant without parental consent if the infant’s life is at stake, and pointed out that there are already widely accepted instances of compulsory or routine testing of newborns to permit the identification of those in need of special treatment:

> Screening in these instances is held to represent a legitimate exercise of the state’s power to protect the vulnerable. Screening for phenylketonuria is paradigmatic. Early identification is critical so that a special dietary regime can be initiated. The failure to undertake such a therapeutic intervention can be catastrophic for the child. A definitive diagnostic test, a definitive therapeutic intervention, an imperative to act quickly; these are the conditions that provide the empirical and moral grounds for the routine screening of newborns without first seeking parental consent.742

In recent years, it has become possible to identify infection in newborns, and prompt identification and close monitoring of infants with HIV is now seen as essential for optimal medical management.743 For example, guidelines for prophylaxis against pneumocystis carinii pneumonia (PCP) in children now recommend that all children born to HIV-infected mothers be placed on prophylactic therapy at four to six weeks of age.744 In addition, careful follow-up of these children to promptly diagnose other potentially treatable HIV-related conditions (eg, severe bacterial infections or tuberculosis) can prevent morbidity and reduce the need for hospitalization.745 Infants born to HIV-positive women also require changes in their routine immunization regimens as early as two months of age.746

These and other new developments notwithstanding, some people argue that it will never be ethically justifiable to test babies without the mother’s consent because testing the babies means testing their mothers at the same time: women giving birth would be the only group of citizens to undergo HIV testing in the absence of informed consent.747

## Current Situation

Thus far, in Canada there have been no attempts to introduce routine or compulsory HIV testing of newborns. In contrast, in 1996 New York State became the first state in the US to pass legislation making HIV testing of all newborns compulsory.

### Canada

Consistent with the general principle guiding HIV testing in Canada, CMA’s 1995 counselling guidelines emphasize that, "[a]s with adults, testing children for HIV requires informed consent, confidentiality, and pre- and post-test counselling." The guidelines continue by saying that, when the issue of testing an infant arises, both the mother and infant will have a test result and that, therefore, "all issues pertaining to the testing of one of these people also apply to the other."748

### United States

As mentioned above, in May 1996, the US Congress debated an amendment to the Ryan White Care Act – the primary source of federal funds for the care and support of people with HIV – that would have mandated HIV testing for all newborns in the United States. After considerable debate, the proposed amendment was modified: it now requires states, within two years, to either (1) reduce the rate of reported pediatric AIDS cases by 50 percent compared with data from 1993; or (2) have knowledge of the HIV status of 95 percent of pregnant women who obtained prenatal care at least twice prior to 34 weeks of pregnancy. If a state cannot meet one of these two criteria, an 18-month "probationary" period is allowed for it to meet one of the criteria or to implement compulsory HIV testing of newborns. If the state is still unable to meet these requirements, it faces the loss of funding under the Act.749

In June 1996, the New York State Legislature approved compulsory HIV testing of all newborns. The statute came into effect in February 1997. It contains no requirements that the mother receive pre- and/or post-test counselling, that health-care providers attempt first to obtain her consent or attempt to learn whether she already knows her serostatus, deferring all implementation decisions to the State Health Commissioner.

## Assessment

Proponents of compulsory testing for newborns emphasize the potential benefits of testing,750 pointing out the importance of early identification and treatment of HIV-positive newborns. As Dr Martha Rogers, chief of epidemiology in the HIV/AIDS division of the US Centers for Disease Control and Prevention, said:

> We are now having [HIV-positive] children who are becoming teenagers. They can have quite a good life and do things that normal children do.751

Many doctors do not understand why they cannot test a newborn for HIV without the mother's consent. As one New York pediatrician expressed it,

> [i]f I think a child has syphilis or gonorrhea in the eye I can test for it. If I think a child is the victim of abuse I can put the child in the hospital for three days. But if I suspect a child has HIV infection, it can take me two months to get permission for testing.752

As is the case with proposals for mandatory HIV testing of pregnant women, the presumption behind proposals for testing of newborns is that testing must be mandatory because not all mothers can be relied upon to act in the best interest of their child or fetus. Therefore, it is argued that the state must have the power to intervene in the child's care.753

State intervention to compel the medical treatment of a child against the wishes of the parents is not without precedent in Canada. Although courts generally defer to the parents' judgment of what is in the best interests of the child's health, occasionally a judge will intervene to impose medical treatment. On numerous occasions the courts of Canada have exercised their *parens patriae* jurisdiction – that is, the inherent right of the State to care for those who cannot care for themselves – to order life-saving blood transfusions for sick children despite the parents' objections on religious grounds.754 However, this power is narrowly construed:

Though the scope ... of the *parens patriae* jurisdiction may be unlimited, it by no means follows that the discretion to exercise it is unlimited. ... It is a discretion ... that must at all times be exercised with great caution, a caution that must be redoubled as the seriousness of the matter increases.755

In addition, the problem remains that HIV testing of a newborn also reveals the HIV status of the mother; the potential harms for the mother of being identified as HIV-positive are significant. Finally, mandating testing of newborns misses the mark:

> Testing newborns means that HIV-infected mothers have lost the opportunity to choose treatment for themselves or to prevent HIV infection of their infants. Only prenatal testing affords this dual opportunity.756

## Conclusion and Recommendation

Unlike programs directed at offering voluntary HIV testing and counselling to all pregnant women – coupled with voluntary treatment, if necessary – testing of newborns does not have the benefit of substantially reducing the risk of transmission from mother to baby, except to the extent that a positive test might indicate a need to discontinue breastfeeding in order to prevent any further risk of transmission, assuming transmission has not already occurred. Therefore, it has been said that mandatory newborn testing is the "wrong answer to the wrong question":757

> The right question is: How can we offer appropriate counseling to all women and engage them voluntarily to learn their HIV status? If they are HIV-positive, how do we ensure that they receive needed care for themselves and potential interventions to prevent transmission to their fetus and, finally, that they provide care for their infants? ... With appropriate resources given to education and health care delivery, the desired goal of early identification and treatment of HIV-infected infants can be accomplished without mandatory newborn screening.758

Rather than implement compulsory testing of newborns, we need to encourage pregnant women to voluntarily undergo testing and – if they are HIV-positive – to consider taking treatments that will benefit them and reduce the risk of transmission to their infants. Women who tested positive during pregnancy (or before), as well as women who refused HIV testing during pregnancy, but are considered to be at risk by their health-care provider, should be asked to consent to testing of their newborns. Refusals should generally be respected. Testing of an infant without the parent’s consent may, however, exceptionally be justified in a few circumstances, when a court decides that it is necessary, effective and the least invasive and restrictive means available to achieve the aim of benefitting the infant. This could be the case, for example, when a physician has reason to suspect that a child suffers from an HIV-related illness, the parents’ and the child’s HIV status are unknown, the parents refuse to give consent to testing, and knowing the child’s HIV status would be necessary to decide how the child’s illness could best be treated.

> **6. Routine or compulsory testing of newborns is unwarranted. Rather, all pregnant women should be offered voluntary testing and counselling and, if HIV-positive, be encouraged to consider taking treatment that will benefit them and reduce the risk of transmission to their infants (see Recommendation 5).**

# HIV Testing of Prisoners

The mandatory or compulsory testing of inmates in correctional facilities and prisons has been debated since the HIV-antibody test was developed in 1985. In 1996, the debate was re-fueled by the release of a report on HIV/AIDS and prisons published by the Network and CAS.759

## History

### Canada

In Canada, it is generally agreed that involuntary testing of prisoners would not be consistent with the provisions of the *Canadian Charter of Rights and Freedoms*. In this regard, the prison policy of Newfoundland and Labrador explicitly says:

> No person may be forced to submit to an HIV Antibody test. Such a test may only be administered by a medical professional if the patient provides informed consent. Any attempt to coerce an inmate to submit to the test in the absence of consent may not only be a violation of fundamental human rights under the *Charter of Rights* (the right to "life, liberty and security of the person" and the right to be "secure against unreasonable search or seizure") but may also be regarded as an offence under the *Criminal Code*.760

This has been acknowledged by the Commissioner of the Correctional Service of Canada (CSC) who, responding to a question by Reform Party MP Ringma at a hearing of the Parliamentary Sub-Committee on HIV/AIDS on 26 November 1996, said that the Service had asked the Department of Justice for an opinion about whether compulsory or mandatory testing of inmates would be legal. He continued by saying that "the opinion we have so far is that in both general legislation and several sections of the Charter there are some potential difficulties."761

Nevertheless, from time to time there have been claims that prisoners should be mandatorily or compulsorily tested for HIV. In September 1996, Reform MP Art Hanger and Jorge Escola, president of Québec's prison guards union, argued that, instead of providing prisoners with access to the means that would enable them to protect themselves against contracting HIV in prisons –such as condoms, bleach, methadone maintenance programs, and sterile injection equipment – prisoners should be mandatorily tested for HIV and segregated if HIV-positive.762 In April 1997, the Reform Party's Justice Campaign leader Randy White again proposed mandatory HIV testing of all prisoners.763

However, most Canadian organizations that have analyzed the issues raised by testing of prisoners have agreed that testing should only be done on a voluntary basis, with the informed consent of the inmate. One of the few documents recommending involuntary testing of inmates was released in June 1993 by the Progressive Conservative Caucus Committee on Family Issues. The Committee made a recommendation to "[a]mend the *Corrections and Conditional Release Act* to require all federal penitentiary inmates with a record of sexual, violent, or drug offences to consent to HIV-antibody testing, and to disclosure of the test results under certain conditions, in order to qualify for any form of release prior to the end of their sentences."764 According to the Committee's report, the legislative initiatives it proposed were "designed to help protect the public from being assaulted by dangerous HIV-infected federal inmates, and to ensure that the necessary information is readily available to victims in the event that such assaults occur." Inmates whose past record included certain specified offences, who wished to be eligible for any form of conditional release, statutory release, or escorted temporary absences or work release programs, would be "required to consent" to HIV-antibody testing. The report further stated:

> They would thus undergo voluntary testing,[the use of the term "voluntary testing" in this context is inappropriate: any testing that is a prerequisite for an inmate to be eligible for conditional release, statutory release, or escorted absences or work release programs is, in fact, mandatory testing or even occult compulsory testing] or they would be detained until the expiry of their sentences. The inmate would further be required to consent to the disclosure of the test results, at the discretion of the institutional head, to a qualified medical practitioner on a confidential basis. The consent would cover disclosure for valid medical purposes involving the physical or emotional health of any person who may be exposed to HIV because of the actions of the inmate while on release.765

Such proposals have, however, been rejected by NAC-AIDS, the Ontario Law Reform Commission, the Royal Society of Canada, the Expert Committee on AIDS in Prisons and other organizations that have analyzed the issues raised by testing of prisoners.766 These organizations have all recommended that testing only be done with the informed consent of the inmate, stressing that

- it would not be legitimate to distinguish between the prison population and other identifiable groups for the purposes of mandatory testing;

- mandatory testing would not improve efforts to prevent the spread of HIV in prisons; and

- instead, prisoners need to be provided with the means necessary to act responsibly and to protect themselves and others, such as access to voluntary testing, education, counselling, condoms, bleach, sterile needles, methadone maintenance and other drug treatment.

With regard to the first point, the Royal Society emphasized that prisoners who have been convicted of offences are sentenced to a loss of liberty, but do not lose all their rights. Therefore, the Society said, prisoners' "rights not to be subjected to mandatory testing should be evaluated using the same principles as applied to others in Canada."767

With regard to the second point, the OLRC pointed out that it was not clear "how the identification of HIV-infected inmates will significantly improve efforts to prevent the spread of infection in [prisons]."768 The Commission concluded "that no exception to a general rule requiring voluntary, specific, and informed consent for all HIV-related testing is justified respecting inmates in correctional institutions."769 The Royal Society of Canada also concluded that mandatory testing would not protect correctional officers, stating that they have "other, more effective means to protect themselves."770 According to NAC–AIDS,771 mandatory or compulsory testing would be justified only in individual cases, when such testing would be the least restrictive, least invasive, likely to be effective means reasonably available to assist in preventing a person from forcibly or non-consensually exposing others to HIV within the prison. In its 1994 Report on HIV/AIDS in Prisons, the Expert Committee on AIDS and Prisons strongly opposed any proposals for mandatory or compulsory testing of all or certain groups of inmates. The Committee was concerned that "benefits from such testing are very limited and questionable, while harms include breach of a person’s right to inviolability, self-determination, autonomy, privacy and confidentiality, and the risk of discriminatory and other harmful treatment."772 Instead, ECAP recommended that testing be readily accessible to all inmates in federal correctional institutions at their own request; that testing always be voluntary and accompanied by pre-and post-test counselling; that inmates have access to HIV testing from health-care personnel as well as from primary-care or community clinic personnel who are independent of the prison system; and that all inmates have access to anonymous HIV testing.

With regard to the third point, many of the organizations that have analyzed the issue of testing of inmates have concluded that measures such as better education and access to condoms, bleach and sterile needles would be better suited to reducing HIV transmission in prisons than mandatory or compulsory testing. For example, the OLRC concluded that "[t]argeted HIV education campaigns and programs directed towards the special needs of inmates and correctional institution officials, including the availability of condoms and bleach, are the best means currently available to reduce transmission within this setting."773 Similarly, NAC-AIDS stated that "[t]here are strong ethical obligations, indeed imperatives, to provide prisoners with the means necessary to act responsibly, and to protect themselves and others."774 According to the Committee, this includes "ensuring prisoners have free and easy accessibility to condoms, education, and counselling about HIV infection and transmission, HIV antibody testing that is voluntary, and that efforts are made to encourage safe sexual conduct and to prevent sharing of injection equipment during drug use."775 The Royal Society of Canada also emphasized that voluntary testing, education, counselling, condoms, drug treatment programs and facilities for decontaminating syringes should be made available to prisoners to encourage responsible behaviour in prisoners. Because of the harm that may be inflicted on a stigmatized prisoner, the Society further stressed that confidentiality "must be guarded in the prison setting."776 Finally, the Prisoners with HIV/AIDS Support Action Network,777 the Expert Committee on AIDS in Prisons778 and the Joint Network/CAS Project779 released reports urging the prison systems to adopt comprehensive strategies to deal with the many issues raised by HIV/AIDS and drug use in prisons, including access to condoms, bleach, sterile injection equipment, and methadone maintenance treatment.

## International Developments

Although rarely recommended and not adopted in Canada, mandatory or compulsory testing of inmates has been introduced in some prison systems in the United States and internationally. For example, the US Federal Bureau of Prisons tests certain classes of inmates, including a random selection of five percent of incoming inmates, all inmates who are involved in community activities, and all inmates at least 60 days before they are discharged. In addition, 18 states in the US conduct mandatory testing, paradoxically mainly in areas of low HIV prevalence,780 according to information provided by the American Civil Liberties Union's National Prison Project: Alabama, Colorado, Georgia, Idaho, Iowa, Michigan, Mississippi, Missouri, Nebraska, Nevada, New Hampshire, North Dakota, Oklahoma, Rhode Island, South Carolina, Texas, Utah, and Wyoming.781 Prisons that test inmates usually have some form of case-by-case segregation policy for those found to be HIV-positive. Some prisons segregate only those who have developed symptomatic HIV-related disease. A very small number of prisons segregate all HIV-positive inmates.782 However, such coercive measures have been undertaken by a small minority of prison systems and have been nearly unanimously condemned. In particular, the World Health Organization's *Guidelines on HIV Infection and AIDS in Prisons* state that "compulsory testing of prisoners for HIV is unethical and ineffective, and should be prohibited." The Guidelines continue by saying that

> [v]oluntary testing for HIV infection should be available in prisons when available in the community, together with adequate pre-and post-test counselling. Voluntary testing should only be carried out with the informed consent of the prisoner. Support should be available when prisoners are notified of test results and in the period following.783

In 1997, the United Nations Programme on HIV/AIDS reemphasized that "[i]nformed consent should always be obtained before any testing for HIV takes place."784 Finally, the International Guidelines on HIV/AIDS and Human Rights state that prison authorities "should prohibit mandatory testing, segregation and denial of access to prison facilities, privileges and release programmes for HIV-positive prisoners."785

In addition, it should be noted that many of the prison systems that had introduced coercive measures – such as involuntary testing and, sometimes, segregation – in the 1980s, have since abandoned these measures, acknowledging that they were costly and inefficient. For example, a number of states in the US, such as New York State, Connecticut, and Maryland, that at one time maintained separate AIDS housing, have long since desegregated their prisoners with HIV.786 In Australia, HIV testing of prisoners was authorized in all jurisdictions, either specifically or through general provisions, but New South Wales, for example, repealed the regulation requiring this in 1995 and now operates an induction program for new prisoners that offers voluntary HIV and hepatitis testing.787 In 1996, the Western Australian Government was found in breach of the federal *Disability Discrimination Act* 1992 because of prison policies that segregated HIV-positive prisoners and had them imprisoned in maximum-security prisons.788 Western Australia had required that all male prisoners living with HIV or AIDS be imprisoned at a maximum-security prison and accommodated in the Infectious Diseases Unit of the prison infirmary. Responding to complaints from two prisoners, the Human Rights and Equal Opportunity Commission of the state took evidence from a number of doctors on whether the regime was necessary and about the impact of the regime on the prisoners. It concluded that the "system of segregation must be condemned" and that "the segregation and close supervision of HIV positive prisoners is wrong because it denies those prisoners what should be seen as a right, namely, the right to medical confidentiality." In addition, the Commission held that "segregation and close supervision of HIV positive prisoners is wrong because it leads to affected prisoners being stigmatized." The Commission ordered the State of Western Australia to pay the prisoners AUS$8000 and $3000 respectively, as compensation for having been unlawfully segregated. After the ruling was released, Western Australia announced that it would from now on treat prisoners with HIV or AIDS on the basis of their security rating and behaviour rather than their HIV status.789 In Europe, mandatory testing has now been abandoned in nearly all countries, and steps have been taken to reinforce the confidentiality of voluntary test results.790

Rather than compulsory or mandatory testing of prisoners, international policies and guidelines – as the Canadian ones –recommend other measures to reduce the spread of HIV and other infectious diseases behind bars, such as educating prisoners and staff about HIV, training staff in the use of universal precautions, and giving inmates access to condoms, bleach, sterile injection equipment, etc.791 The International Guidelines on HIV/AIDS and Human Rights state:

> Prison authorities should take all necessary measures, including adequate staffing, effective surveillance and appropriate disciplinary measures, to protect prisoners from rape, sexual violence and coercion. Prison authorities should also provide prisoners (and prison staff, as appropriate), with access to HIV-related prevention information, education, voluntary testing and counselling, means of prevention (condoms, bleach and clean injection equipment), treatment and care and voluntary participation in HIV-related clinical trials, as well as ensure confidentiality ...792

In addition, it has been recommended that control over prison health be transferred to public health authorities. As UNAIDS has pointed out, some countries have already introduced such a change in prison health administration, with positive results.793

## Current Situation

In all Canadian prison systems, testing for HIV is undertaken only voluntarily. Support for this policy is nearly unanimous. In addition, in some prison systems testing by outside personnel and agencies is available, such as in some provincial prisons in British Columbia and Québec. In his response to the *Discussion Paper*, Mr Demers, Assistant Deputy Minister, Ministry of Attorney General of British Columbia, said that his Ministry supports anonymous testing "as it may increase the number of persons who will seek testing and, therefore, counselling and treatment."794 In Québec, the report on the evaluation of counselling and testing services offered in two provincial prisons in Montréal –a prison for men and a prison for women – concluded that "maintaining, even improving, access to HIV testing and counselling services is justified ... in all provincial correctional establishments."795 In the two prisons studied, testing and counselling services have been offered since 1994 by the local public health clinic. The evaluation showed that they reach a clientele at high risk of HIV infection:

- 52 percent of the men and 56 percent of the women who used the services had injected drugs during the 12 months before imprisonment;
- 10 percent of the men and 67 percent of the women had engaged in prostitution;
- 8 percent of the men and 46 percent of the women had both risk factors; and
- 41 percent of the men and 34 percent of the women had sexual partners who were injection drug users.

In addition, the evaluation showed that many of the clients reached had not used counselling and testing services on the outside: 63 percent of the male and 43 of the female clients were taking their first HIV test. The report suggested ways to further improve testing and counselling service in prisons. It concluded that

> we need to reach those who continue, inside prison, to expose themselves to the risks of HIV infection. In particular, access to the means of protecting oneself (sterile syringes, condoms, methadone maintenance treatment, etc) have to be made available as part of a general HIV prevention strategy in prisons.796

At the federal level, CSC accepted the recommendations related to HIV testing released by its Expert Committee on AIDS in Prisons in 1994.797 In particular, the Service agreed to pilot-test anonymous testing in one institution.798 In the spring of 1995, CSC went even further and the Commissioner of CSC, with the approval of the Solicitor General, instructed CSC to initiate the implementation of anonymous HIV testing in *all institutions*.799 A National Working Group was established to assist in the implementation,800 but work on the initiative was later suspended. Finally, on 1 December 1997, the Service, as part of an announcement of "new" measures to combat the spread of HIV and other infectious diseases in federal penitentiaries,801 promised "greater efforts to promote widespread HIV/AIDS testing as well as the introduction of an anonymous testing project to be piloted in one designated federal correctional institution."802 This re-announcement of CSC's first commitment – made over three-and-a-half years ago – is effectively a breach of the 1995 promise to initiate anonymous testing in all institutions, and hardly a "new" measure to combat the spread of HIV, as it has been called by CSC. Nevertheless, after years of inaction, there is new hope that CSC will undertake activities to make testing more accessible and acceptable to inmates. However, it remains to be seen whether, after a successful pilot project, anonymous and/or flexible non-nominal testing by outside personnel and agencies will become more widely available. As the 1996 report on HIV/AIDS in prisons produced by the Network/CAS Project on Legal and Ethical Issues Raised by HIV/AIDS emphasized, making such testing available to inmates "will allow those who have so far been reluctant to be tested because of concern that test results will not remain confidential to come forward for testing."803

This is particularly important because anecdotal evidence strongly suggests that some prisoners continue to be reluctant to access HIV testing offered through prison health care. Most recently, this was confirmed when prisoners in one federal institution demanded that anonymous testing be made accessible to them after there had been rumours about a potential outbreak of HIV and hepatitis C at that institution. Many inmates feared that they might have contracted HIV and hepatitis C and wanted to know their HIV and hepatitis status, but did not want to be tested by the prison health-care staff for fear of self-identifying as injection drug users. In the end, CSC allowed an outside physician to come into the institution and undertake testing.

With regard to other measures to reduce the spread of HIV behind bars, there has been some progress over the last years in most, but not all, Canadian prison systems. For example, condoms and more recently bleach and, to a limited extent, methadone maintenance treatment have become accessible to inmates in an increasing number of prisons. However, all prison systems continue to fall far short of the recommendations made in Canada and internationally.804

## Assessment

As mentioned above, in considering any given testing policy it is fundamental to ask what the reasons for testing are and what will be done with the test results. Those advocating mandatory or compulsory testing of all prisoners have said that such testing would allow prison systems to know exactly how many prisoners are living with HIV/AIDS; provide those living with HIV/AIDS with necessary care, support, and treatment; protect staff and fellow inmates from contracting HIV in prisons; and protect third parties, such as partners and other people with whom a prisoner will likely have contact after release from prison, from contracting HIV.

### Number of Prisoners Living with HIV or AIDS

There is almost unanimous consensus in Canada that for many years we have had enough evidence that HIV is a serious problem in prisons. At least nine studies or investigations of HIV seroprevalence among incarcerated populations have been undertaken, showing HIV seroprevalence rates of between one and 7.7 percent – rates that are at least 10 times higher than in the general population.805 Prison systems do not need to know the exact number of prisoners living with HIV/AIDS in each prison: they already know of, and maintain statistics about, those prisoners who have disclosed their HIV status to medical services; seroprevalence studies have provided evidence of the extent of the problem; and there is enough evidence to indicate that the number of prisoners living with HIV and AIDS behind bars will continue to grow, particularly because of the increasing epidemic of HIV among injection drug users, many of whom spend years of their lives in prisons.806 In addition, even if more information were needed about the prevalence of HIV in Canadian prisons, properly designed UAS studies would be a less intrusive and more effective way of obtaining that information than the mandatory or compulsory testing of all inmates.

## Care, Support, and Treatment

There can be no question that prison systems have an obligation to provide prisoners who are known to be living with HIV or AIDS and who seek care, support and treatment, with health care that is equivalent to that available outside.807 At the same time, there can be no question that prisoners have the same right to refuse treatment as people living outside prison. While prisoners should be encouraged to test voluntarily and, if HIV-positive, benefit from available care and new treatments, there is no need to mandatorily test them to make that care and treatment available to them. The decision to be tested and to benefit from treatment remains their own, and the best way to encourage prisoners to make that decision is to ensure that – if HIV-positive – they will not be discriminated against and will have access to care, support and treatment equivalent to that available outside. Currently, fears about loss of confidentiality, stigmatization, and discrimination continue to be significant barriers that deter some prisoners from choosing to be tested for HIV and accessing treatments. Another concern is that a new barrier to testing for prisoners in federal institutions could be created if "specialized" care units in one or several prisons were created to address the health-care needs of people living with HIV/AIDS. As Lines has said, "[i]f prisoners know or fear that they would have to be transferred to another institution in order to receive optimal care if they tested HIV-positive, some prisoners will likely choose not to test rather than ‘choose’ transfer and segregation."808

## Protection of Staff and Fellow Inmates

Mandatory or compulsory testing of inmates alone will not protect staff or inmates from contracting HIV in prisons. Those who advocate the introduction of such testing usually argue that the results of the test should be communicated to some or all staff so that staff can better protect themselves, and – if they have been exposed to the blood or bodily fluids of an inmate who is known to be HIV-positive – take appropriate measures. Sometimes they argue that the results should also be communicated to fellow inmates, or at least to cellmates, so that inmates can better protect themselves, and take appropriate measures if they have been exposed to the blood or bodily fluids of an inmate who is known to be HIV-positive. Finally, sometimes they say that, in order to reduce the risk of HIV transmission behind bars, all prisoners testing HIV-positive should be segregated from the general population.

Communication of test results to staff and inmates, and/or segregation of HIV-positive inmates, however, are not justified. The issue of whether positive HIV test results should be communicated to staff and fellow inmates was analyzed in great detail in ECAP's Final Report. The Committee concluded:

> In federal correctional institutions, the disclosure of personal medical information absent consent of the person is seldom justifiable. In most situations, such disclosure cannot be considered to be necessary and its efficacy is questionable. Often disclosure would appear to be counterproductive or harmful, in excess of any benefits or potential benefits which might result from it. Measures that can be undertaken to prevent exposure to and infection with HIV have to be undertaken regardless of whether an inmate or staff member is or is not known, to staff, wardens, or inmates, to be infected with HIV. To educate staff and inmates about precautions that can prevent HIV transmission, and to make available to them the means necessary to prevent it, is essential if transmission of HIV infection is to be prevented in correctional institutions. Only in rare, exceptional cases will disclosure be justified, when an individual assessment shows that disclosure is necessary, likely to be effective and the least invasive and restrictive means available to prevent harms that cannot otherwise be prevented. In all other situations in which claims for disclosure may arise, other means are often already available, would be less harmful than disclosure, are likely to be necessary and more effective.809

This conclusion remains valid. In prisons, as outside, there are some situations in which disclosure of confidential medical information to a third person may be justified. However, these are exceptional situations which, as ECAP pointed out, need to be clearly defined, in collaboration with inmates and independent experts.810 They are analogous to situations that arise outside prisons. Some of the questions raised in such situations are discussed in more detail below,811 such as the question whether a person (in the prison context, a staff person or inmate) who was subject to significant exposure from another person (another staff person or inmate) needs to know that person's HIV status in order to assist in the determination of the advisability of starting or terminating chemoprophylaxis.

Segregating all prisoners who test HIV-positive in order to reduce the risk of HIV transmission behind bars is also not justified. First, testing would not allow prison systems to identify all prisoners with HIV – in any testing program some people would test negative although they carry HIV and are infectious. Therefore, segregation of those testing positive would create a false sense of security. In addition, it is not necessary because the vast majority of prisoners with HIV do not pose any danger to staff or to fellow inmates. This has been reaffirmed by a decision of the Ontario Court of Justice, which held that segregation might be warranted because of behaviour that could expose others to HIV, but that segregation because of an inmate's HIV infection alone was not warranted.812 A rational policy must discriminate among persons based on behaviours, not disease status. For example, inmates who are predatory or assaultive may need supervision, even segregation, regardless of their perceived or known HIV status.

### Protection of Third Parties

This issue is analogous to the issue addressed immediately above. In some cases, disclosure of an inmate's HIV status to a third person, such as a sexual or needle-sharing partner, may be justified or even warranted. In such cases, the *Guidelines for Practice for Partner Notification in HIV/AIDS*813 should be followed and provincial public health authorities should be involved. If notification of a partner is necessary, which should be decided according to the same rules as would apply to persons outside prisons, public health authorities rather than prison systems should undertake that notification. Generally, however, this does not warrant mandatory or compulsory testing of all inmates.

## Conclusions and Recommendations

There is no public health or security justification for compulsory or mandatory HIV testing of prisoners, or for denying inmates with HIV/AIDS access to all activities available to the rest of the population. Rather, prisoners, as all Canadians, should be encouraged to voluntarily test for HIV, with their informed, specific consent, with pre- and post-test counselling, and with assurance of the confidentiality of test results. As do people outside prison, they should have access to a variety of voluntary, high-quality, bias-free testing options, including anonymous testing or, at a minimum, flexible non-nominal testing offered by outside personnel and agencies. Offering a variety of testing options and undertaking increased efforts to ensure that HIV-related medical information remains confidential is particularly important in prisons because potential harms from testing for prisoners may be especially great because of the higher potential for stigmatization and discrimination. Although the situation in Canadian prisons has improved in that regard, much remains to be done to ensure that the benefits from testing for prisoners will be maximized, while at the same time reducing its potential harms. Clearly, those who advocate testing for the sake of testing and for the sake of being seen as "being tough on prisoners" do not assist that process. Furthermore, prison systems need to educate staff and inmates about the fact that mandatory or compulsory testing, coupled with disclosure of test results and/or segregation, is not necessary to protect them, and that application of universal precautions will protect them much better. Finally, prison systems need to make accessible to prisoners the means that will allow them to better protect themselves against contracting HIV.

**7. There is no public health or security justification for mandatory or compulsory HIV testing of all prisoners.**

**Rather, as do people outside prison, prisoners must have access to a variety of voluntary, high-quality, bias-free testing options. This should include anonymous or flexible non-nominal testing offered by outside personnel and agencies, as well as testing offered by prison health-care staff. Testing by prison health-care staff should be made more accessible and acceptable to prisoners, by offering them the option of non-nominal testing, training prison health-care staff in the delivery of pre- and post-test counselling, and better protecting the confidentiality of medical information.**

**In order to encourage prisoners to test voluntarily, prison systems must increase efforts to ensure that HIV-positive prisoners will not be wrongfully discriminated against and will have access to care, support and treatment equivalent to that available outside.**

# HIV Testing of Persons Accused and/or Convicted of Sexual Assault

The issue of whether individuals accused of (charged with) sexual assault and/or individuals convicted of sexual assault should have to undergo compulsory HIV testing is highly controversial and has been the subject of a significant amount of media attention, community discussion and political debate in Canada and elsewhere. Few subjects are as emotionally troubling as AIDS and sexual assault.814

## History

### Canada

While some have maintained that the "HIV test is proper on accused or convicted rapists"815 and that "[m]aybe the law [in Canada] needs to be changed" to allow for testing,816 most Canadian organizations and individuals who have analyzed the issues raised by testing of persons accused and/or of persons convicted of sexual assault have argued that compulsory testing would not be justified. For example, in 1987 the National Advisory Committee on AIDS discussed a proposal "that persons convicted of sexual assault likely to transmit HIV infection, be tested on a compulsory basis for the presence of HIV antibodies."817 The proposal was rejected. Instead, NAC–AIDS passed two resolutions in which it "strongly recommended" voluntary testing of persons accused or convicted of sexual assault likely to transmit HIV infection.818

On a few occasions, Canadian courts have had to decide about individual requests that persons accused or convicted of sexual assault be tested for HIV. Courts have held that persons *accused of* sexual assault cannot be forced to undergo an HIV test, but have in two cases ordered testing of persons *convicted of* sexual assault. In the first case, *R* v *Beaulieu*, Roberge J held that a man accused of sexual assault cannot be forced to undergo an HIV-antibody test.819 The accused in the case was on a day pass from Cowansville Penitentiary. The alleged sexual assault occurred in September 1992 in the presbytery of a nearby church. The victim of the assault, Margot B, had been working as a secretary at the presbytery, had been married for 25 years, and was the mother of three children between 18 and 24 years of age. As part of the preliminary inquiry on this charge, the Crown prosecutor asked the judge to order an HIV test because the woman feared she might have been infected with HIV. In her affidavit, the woman stated that:

- since there was a possibility that she might have been infected with HIV during the sexual assault and since she had to wait for at least three months before she could determine whether she had been infected, she and her family members were presently suffering from discrimination;

- her personal life and her relationship with her husband and children were disrupted as a result of the sexual assault;

- if the accused was forced to undergo HIV testing at regular intervals, she would be in a better position to establish whether she had been infected; and

- she had a right to know whether during the sexual assault the accused infected her with HIV or any other sexually transmissible disease.820

The prosecutor admitted that his request was "very unusual" ("fort inusitée") and that he was not authorized by the *Criminal Code* to formulate such a request. He based his request on a provision of the *Act respecting assistance for victims of crime*, according to which "[t]he victim of a crime has the right to be treated with courtesy, fairness, understanding, and with respect for his dignity and privacy" and "to due consideration of his views and concerns ... where his personal interests are affected."821 The judge, however, held that nothing in this provision authorized the prosecutor to intervene on behalf of the woman in the midst of a criminal case and request that the accused be tested. Therefore, the judge held that the prosecutor did not have the power to request testing of the accused. The judge continued by saying that even if the law allowed for the prosecutor to make such a request on behalf of the victim, he would have had to reject the request since the law does not authorize compulsory testing of sex offenders ("ni la Loi des victimes d'actes criminels ni quelque autre loi ne permet l'exercice d'un tel recours").822 The judge referred to the Québec Civil Code and to the Canadian and Québec charters, all of which protect the right of individuals to security of the person and the right to refuse any medical intervention. The judge cited from the Supreme Court of Canada decision in *R* v *Dyment*, in which La Forest J, for the majority, held that "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."823 La Forest J continued by saying that "the 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 who holds it subject to a duty to respect the dignity and privacy of that person."824 In another judgment, Angers JA, writing for the New Brunswick Court of Appeal, held that "the 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."825

The accused was later convicted of sexual assault causing bodily harm and sentenced to 12 years' imprisonment. The trial judge refused a second request that the accused be tested for HIV, but it appears that the accused nevertheless agreed to be tested. Ms Blackburn underwent several HIV tests herself, testing HIV-negative. She later started a national campaign and presented then Justice Minister Rock with a 50,000-signature petition calling on him to amend the law to allow judges to force persons accused or convicted of sexual assault to submit to a test for HIV.

The second case, *R* v *JPB*,826 was the first Canadian case ordering testing of a perpetrator of sexual assault. The accused was convicted of a charge of sexual assault after having had sexual intercourse with a drugged 14-year-old. At sentencing, counsel for the accused indicated that the accused was willing to undergo HIV testing. Nevertheless, post-trial, the Court issued an order that

> [t]he accused young person shall, within one month of this date, provide a sufficient sample of his blood to a medical practitioner for the purpose of analysis to determine the presence of the H.I. Virus. The results of the testing, whether positive or negative, shall be communicated forthwith to the victim in this case.

According to the Court, this was necessary in order not to hold "the victim emotionally hostage – hostage to [the accused's] good will and consistency of commitment." Bourassa J distinguished the case from *R* v *Beaulieu*, noting that none of the factors present in that case was present in the case at bar. He made an analogy with the provision for compulsory testing of blood in cases of suspected impaired drivers and, although he admitted that "the legislators may never have contemplated the use of this section in these ways," used section 20(1) of the *Young Offenders Act* to issue the testing order. Section 20(1) provides that where a Youth Court finds a young person guilty of an offence, it shall consider imposing on the young person such other reasonable and ancillary conditions as it deems advisable and in the best interest of the young person and the public. In Bourassa J's view, "a blood test will help dissipate the ongoing mental anxieties and stress the victim is undergoing." He held that "the important governmental interests served by the nonconsensual extraction of the defendant's blood for HIV testing and the subsequent disclosure of its contents to very few people plainly eclipse those of the defendant in preventing the search."

In the third case, Madam Justice Macdonald of the Ontario Court's General Division signed a court order on 23 September 1996 requiring that, at the request of six of his victims, serial rapist Paul Teale, also known as Paul Bernardo, be tested for HIV and other sexually transmitted diseases.827 No lawyers appeared for Teale to oppose the order. The plaintiffs had made a motion for an order pursuant to subsections 105(1), (2) and (3) of the *Courts of Justice Act* and Rules 33.01 and 33.06 of the *Rules of Civil Procedure* requiring Teale

> to undergo a physical examination by a health practitioner including all necessary tests to determine whether the Defendant, Paul Teale, ... is infected with the AIDS virus or other sexually transmitted diseases.828

Subsections 105(1), (2) and (3) of the *Courts of Justice Act* read:

> (1) In this section, "health practitioner" means a person licensed to practise medicine or dentistry in Ontario or any other jurisdiction, a psychologist registered under the *Psychologists Registration Act* or a person certified or registered as a psychologist by another jurisdiction. 1989, c. 55, s. 18(1).
>
> (2) Where the physical or mental condition of a party to a proceeding is in question, the court, on motion, may order the party to undergo a physical or mental examination by one or more health practitioners. 1984, c. 11, s. 118 (2); 1989, c. 55, c. 18(2).
>
> (3) Where the question of a party's physical or mental condition is first raised by another party, an order under this section shall not be made unless the allegation is relevant to a material issue in the proceedings and there is good reason to believe that there is substance to the allegation.

Rules 33.01 and 33.06 of the *Rules of Civil Procedure* read:

> 33.01 A motion by an adverse party for an order under section 105 of the *Courts of Justice Act* for the physical or mental examination of a party whose physical or mental condition is in question in a proceeding shall be made on notice to every other party. O. Reg. 560/84, r. 33.01.
>
> 33.06(1) After conducting an examination, the examining health practitioner shall prepare a written report setting out his or her observations, the results of any tests made and his or her conclusions, diagnosis and prognosis and

> shall forthwith provide the report to the party who obtained the order. O. Regs. 560/84, r. 33.06(1); 711/89, s. 21.

According to the order of 23 September, Teale's blood samples were to be taken within 45 days at Kingston Penitentiary, where he is serving an indefinite sentence.

One of the victims who was suing for damages said that the fear of contracting HIV was causing her "severe nightmares, continuing anxiety, depression, headaches, emotional instability, agoraphobia, poor concentration and an inability to work," and that this in turn has caused her "severe pain and suffering."829 She was attacked on 22 December 1989 and has tested negative for HIV but, according to her lawyer, "wishes to send out a message to whoever cares to listen that people that are assaulted this way have valid fears about these types of diseases."830 Reacting to this statement, Carey, writing for the HIV/AIDS Legal Clinic of Ontario, said:

In the case ... the woman who obtained the court order was raped by Paul Bernardo in 1989 and is currently HIV negative. As seroconversion from HIV negative to HIV positive occurs within three months of infection with the virus in well over 90% of all cases, and as the longest known "window period" for seroconversion I can find in the medical literature is twenty-four months, I am at a complete loss as to why Bernardo's HIV status is of any relevance to "D.B"'s case. Even if Bernardo is HIV positive, "D.B." will not develop HIV or AIDS as a result of being raped by him in 1989. Why then would such an order be issued?831

Because of these cases, the issue of compulsory testing of persons accused or convicted of sexual assault has received renewed interest. At the General Assembly of the Liberal Party of Québec, held in Montréal on 24-25 April 1993, the party adopted a resolution proposing that the government of Québec undertake to request that the federal government adopt a law that would allow "the competent authorities to force a sexual aggressor to undergo testing." Compulsory HIV testing of convicted sex offenders was also recommended in a report by Montréal coroner Claude Paquin. The coroner had performed the autopsy on a man who had died from AIDS-related diseases 11 weeks after he was convicted of sexually assaulting a five-year-old boy. According to the coroner, the two objectives of such testing would be "to prevent the spread of HIV within the prison system" and "to generate information in order to inform victims of sexual aggression about whether or not they may have been exposed to HIV."832

Due to the media interest generated by the cases, the federal government also came under considerable pressure to respond to the concerns of Margot B and other victims of sexual assault. As a result, a Working Group of the Interdepartmental Committee on Human Rights and AIDS833 was formed to study the issue of HIV testing of persons accused or convicted of sexual assault, and to "determine what measures were appropriate to deal with HIV in the context of sexual assault."834 In its report of 19 April 1994, the Working Group examines the status of HIV/AIDS testing and treatment and the concerns of the survivor of sexual assault;

considers the arguments against compulsory HIV-antibody testing of persons accused of sexual assault; examines whether the use of the criminal law power to mandate HIV testing is warranted; and discusses possible strategies for ensuring that survivors of sexual assault are provided with assistance in addressing their concerns about HIV.

The Report concludes that "imposing compulsory HIV antibody testing on persons accused of sexual assault is not the most effective way of dealing with the sexual assault survivor's concerns," will ultimately not help her, and is "misguided" for five reasons:835 (1) it does not provide timely or reliable information about the risks of contracting HIV infection; (2) it is a misdirected and unrealistic approach to addressing a sexual assault survivor's needs; (3) it perpetuates the dangerous misperception that information about an assailant's HIV status is critical to the sexual assault survivor's health; (4) it does not facilitate a sexual assault survivor's psychological recovery; and (5) it sets a dangerous precedent for extending mandatory testing to others, particularly pregnant women and sex workers.

According to the Report, a survivor of sexual assault, rather than knowledge of her/his assailant's HIV status, "needs reliable information about whether she [he] is HIV infected, and support and assistance in coping with uncertainty during the window period, and in living with a positive test result if it occurs." Therefore, the Working Group concluded that the focus should not be on HIV testing of persons accused and/or convicted of sexual assault, but on finding other, more practical and sensitive, ways of addressing the needs of survivors of sexual assault:

> In trying to use the criminal law to control the spread of HIV/AIDS we have to be careful not to send the wrong message to society, and divide the community between those with HIV/AIDS and those without. The focus instead should be on providing the appropriate counselling and assistance to those who may have been exposed to the disease, and ensuring that persons who commit violent sexual crimes are brought to justice for the offences defined in the *Criminal Code*.

The Working Group recommended that Health Canada, the Department of Justice, and Status of Women consider "the feasibility of developing, in consultation with involved non governmental organizations, a best practices model of the kinds of counselling, short and long term care, treatment and other services that should be made available to sexual assault survivors." According to the Working Group, the following options should be explored:

- access to anonymous HIV-antibody testing and counselling for all sexual assault survivors, provided by trained staff of sexual assault crisis centres or similar facilities;

- examination of the feasibility of making polymerase chain reaction (PCR) testing available to survivors of sexual assault to enable them to find out within a few days after the assault whether they themselves are HIV-infected, and development of an implementation plan for this proposal;

- access to prophylactic AZT and other antiviral medications for sexual assault survivors, accompanied by counselling about their uncertain utility;

- ensuring sensitivity to multiculturalism and societal diversity in the delivery of counselling, testing and support services; and

- assistance in the HIV/AIDS-related training of staff at sexual assault crisis centres and of other professionals who have contact with survivors of sexual assault.

Then Justice Minister Allan Rock accepted the conclusions reached in the Working Group's Report, saying that he was persuaded that nothing could be gained from introducing compulsory testing of perpetrators of sexual assault. He promised that concerted efforts would be undertaken to ensure that the survivors' needs are met.

Since then, Health Canada has taken "the lead on federal initiatives related to HIV and sexual violence, working in collaboration with Status of Women Canada and the Department of Justice."836 In February 1997, a needs assessment was conducted among a group of counsellors from sexual assault centres, women, and AIDS programs and AIDS service organizations across the country "to determine the extent to which HIV and sexual assault issues are addressed, and to obtain feedback on the direction of future initiatives in this area." From the findings of the needs assessment, it "was clear ... that counsellors needed and wanted more information related to HIV and sexual assault to assist them in providing adequate support to survivors of sexual assault."837 These findings were similar to those of a previous needs assessment conducted among a group of service providers from women's organizations in Ontario.838

In response to this need, Health Canada commissioned the production of *HIV and Sexual Violence Against Women. A Guide for Counsellors Working with Women Who Are Survivors of Sexual Violence*.839 The guide was prepared to: (1) "raise awareness among counsellors of the issues related to HIV and sexual violence and to provide counsellors with current information and guidance on these issues"; (2) "assist counsellors in responding to the immediate and short-term needs of survivors with regard to HIV issues, including assessment of HIV risk"; (3) "increase the probability that survivors of sexual violence will receive thorough, up-to-date information related to HIV and sexual violence upon which to base their choices and decisions"; and (4) "encourage consistency among counsellors with regard to the information and care related to HIV and sexual violence that they offer survivors."840 Among other things, the guide provides information and guidance on the risk of HIV transmission through sexual assault, HIV testing of the survivor of sexual assault, HIV testing of persons accused or convicted of sexual assault, and post-exposure prophylaxis. With regard to HIV risk associated with sexual assault, the guide points out that a few cases of HIV transmission as a result of sexual assault have been reported in the literature,841 and that in Canada some of the participants in a survey of women with HIV/AIDS reported that they felt they had become infected as a result of a sexual assault. In addition, a majority of participants in a Canadian needs assessment conducted among service providers at sexual assault centres stated that they had worked with at least one women who felt that she had contracted HIV as a result of sexual assault.842 With regard to HIV testing of persons accused or convicted of sexual assault, the guide states that

> [i]n Canada, while survivors may request that their assailant *voluntarily* undergo HIV testing, current law does not allow for the *mandatory* HIV testing of persons accused or convicted of sexual assault. Although mandatory testing of the assailant may present some advantages to survivors, there appear to be more disadvantages for survivors and society in general, in addition to some serious implications for people living with HIV/AIDS. Policies and practices that focus on meeting the medical and psychosocial needs of survivors likely will be of greater benefit to them.843

With regard to post-exposure prophylaxis for survivors of sexual assault, the guide points out that such prophylaxis has become available for survivors in a few areas of the country.844

## Developments in the US: The Working Group's Proposals

In May 1994, the Working Group on HIV Testing, Counseling, and Prophylaxis after Sexual Assault published proposals for the development of policies and principles of clinical intervention in the care of assault survivors. Among many other issues, the Group examines the ethical, public health, and legal justifications for a policy of limited compulsory testing of persons accused of sexual assault.845

### Level of Risk of Contracting HIV

The Group's paper first assesses the level of risk of contracting HIV for a survivor, concluding that it depends on the serological and clinical status of the assailant, the type of sexual assault, and the frequency of assaults. The paper points out that the seroprevalence of the population of persons who commit sexual assault is difficult to assess. It then mentions that the per-contact HIV infectivity rate from male to female via penile-vaginal intercourse was estimated at less than two per 1000 contacts in two cohort studies,846 but that others have reported higher rates.847 The presence of lesions or blood from violent assaults may significantly increase the probability of transmission. Generally, the risk of HIV transmission is highly variable, with some individuals infected after the first encounter, while others remain uninfected after hundreds of unprotected sexual contacts.848

### Physical and Psychological Burdens of Sexual Assault

The paper emphasizes that survivors frequently worry about contracting an STD from their assailant. In one study, 40 percent of the survivors said they feared contracting HIV infection as a result of the rape.849 Generally, the "fear of contracting an STD, particularly HIV infection, following rape appears to be a significant stressor adding to the incidence, prevalence, and severity of psychiatric morbidity in rape survivors."

### Counselling of Survivors

The paper stresses the importance of counselling of survivors of sexual assault, saying that, ideally, "all survivors of sexual assault would receive a medical examination and information and counseling about possible exposures to a full range of communicable diseases, the risk of pregnancy, and other possible sequelae of the assault."

### Testing of Survivors

According to the paper, survivors of sexual assaults need careful diagnosis and follow-up for a multiplicity of clinical conditions, including screening for STDs. It stresses that survivors of sexual assault should be offered voluntary HIV testing; informed about the availability and advantages of anonymous HIV testing; and fully supported in their right and ability to make autonomous decisions.

The paper points out that newer diagnostic technologies shorten the period of time after exposure in which HIV infection may not be detected. However, at the time the paper was written, these tests were not routinely available in most settings. The paper concludes that periodic testing beginning within six weeks after the assault can provide a number of potential benefits to the survivor:

It can ease the psychological burden of survivors wondering if they have contracted HIV infection. Knowledge of test results also can enable survivors to make educated decisions regarding their health, sexual or needle-sharing behavior, reproduction, breast-feeding, and parenting.

### Chemoprophylaxis for HIV Infection

At the time the paper was written, there were no clear-cut data establishing the efficacy of the prompt institution of zidovudine prophylaxis following exposure to HIV. The paper concluded:

> The decision to take zidovudine following a sexual assault should be based on a risk assessment of the exposure. The risk assessment should consider available information on the serostatus of the assailant, the type of exposure (anal, vaginal, or oral penetration and ejaculation), the nature of the physical injuries, and the

> number of assaults. The survivor will almost never have adequate information to determine the serostatus of the assailant immediately after the assault. Individual assessment of the exposed individual also would have to consider reproductive health status and ability to tolerate potential side effects.

### Testing the Accused

At the outset, the paper emphasizes that testing the accused will not be possible in most cases because of the small percentage of assailants who are arrested and convicted in a timely manner. Therefore, "meeting the needs of all survivors first requires the establishment of comprehensive systems of counseling, treatment, and anonymous or confidential testing of the survivor, which allow the survivor to come to terms with the assault and take measures to protect her or his health and the health of family and loved ones."

The paper then makes a case for limited compulsory testing, stressing that particular characteristics of sexual assault distinguish it from other situations involving potential exposure to HIV:

Survivors of sexual assault in no sense consented to the behavior that caused the potential exposure. Since the assault is, by definition, coerced, it represents a violation and a harm to the survivor. Its nonconsensual nature sharply differentiates sexual assault from many other potential exposures to HIV, including consensual sexual intercourse or needle sharing and voluntary employment in a setting where occupational exposure may occur. Because the survivor’s exposure starts with a wrong, the accused owes the survivor a duty to limit the harm caused by the assault. Sexual assault causes ongoing harm, including the continuing fear of HIV infection, which can postpone or limit recovery. It is this dynamic and ongoing nature of the harm that suggests that public policy should do everything possible to limit future harm and to preserve the health of the survivor and his or her partners and children. It is fundamentally unfair to place all the burden of limiting future harm on the survivor. In the case of sexual assault, survivors usually bear the whole burden of continuing anxiety and protecting themselves, partners, and families. If testing the accused could limit future harm to the survivor and ease the burden of unfairness, it would provide a persuasive argument for involuntary testing of the accused.

According to the paper, states that wish to permit survivors to learn the HIV status of their assailants have at least four alternatives, "all of which are imperfect": relying on counselling and testing of the survivor alone; seeking the consent of the accused to testing; testing the accused without consent (compulsory testing), but only after conviction; and testing the accused without consent, before conviction, with procedural safeguards.

The paper rejects the possibility of relying on counselling and testing of the survivor because this "does nothing to ease the unfairness inherent in requiring the survivor to bear the burden of prolonged uncertainty and possible alterations in life plans." It continues by rejecting a policy of voluntary testing of the accused: voluntary testing could provide the same benefits as compelled testing if the accused consents, but the accused controls the information and may have little motivation to benefit the survivor. Finally, the paper points out that policymakers who choose compelled testing

> face a dilemma when choosing the point in time to impose the test. The dilemma arises from the changing relationship over time between the usefulness of the information to the survivor and the strength of the privacy interests of the accused. In most cases the survivor's strongest claim to a benefit from testing the accused comes from knowing the results of the test as early as possible. Testing the accused late in the criminal process fails to assist survivors because they already have borne the burden of worry about contracting HIV infection. At the same time, the accused has the strongest claim to protection early in the criminal process. On the other hand, the problem with testing the accused before conviction is that he will sustain a significant invasion of his autonomy and privacy without a trial establishing his guilt. Therefore, any solution results in either a diminution of the usefulness of the information to the survivor or an infringement on the legitimate interests of the accused.

The paper concludes that the policy alternative that produces the greatest benefit for the largest number of survivors may be to allow pre-conviction testing of the accused at the request of the survivor. However, adequate procedural safeguards would need to be in place to reduce the likelihood of testing persons wrongly accused, to limit disclosure of the results, and to prevent punitive use of the information. A policy designed for this purpose would

- authorize pre-conviction testing, initiated at the request of the survivor;

- require the prosecution to demonstrate probable cause to believe that an assault was committed, that the accused committed the assault, and that the assault was of a type that could transmit HIV infection (eg, that semen or blood was transferred from the assailant to the survivor, or the survivor experienced traumatic injury with exposure to semen or blood);

- authorize retesting of the accused six months after the assault, if the initial test result is negative, unless the accused has already been acquitted;

- disclose the test results only to the survivor and the accused, but allow the accused to exercise a prerogative not to be informed of his serostatus;

- protect the confidentiality of the test results, except as required to inform the survivor and sexual partners or family members the survivor believes must be informed to protect their safety, with civil penalties for unauthorized disclosure to other parties; and

- limit the use of information obtained by compelled testing by making test results not admissible as evidence in the criminal or subsequent civil proceedings. In order to protect the accused from inappropriate testing and unauthorized disclosures, the procedural protections embodied in this policy, including a probable cause hearing, limited disclosure, and confidentiality protection, are particularly important and merit careful consideration by policymakers and drafters of statutory language.

## Current Situation

### Canada

As shown above, the only Canadian court decision that has specifically addressed this issue thus far held that a person *accused of* sexual assault cannot under current law be forced to undergo an HIV test.850 This raises the question of whether the law should be changed to allow for compulsory testing.

With regard to testing of persons *convicted of* sexual assault, the court order requiring Paul Bernardo to be tested for HIV does not establish a precedent because Bernardo did not oppose the issuing of the order. Therefore, the question of whether there is a legal basis for compelling a person convicted of sexual assault to undergo HIV testing remains open.

### International Developments

In the United States, federal law requires states to provide involuntary post-conviction testing of sex offenders as a condition of the receipt of 10 percent of funds allocated to a state under the Bureau of Justice Assistance Grant programs. States must also provide HIV counselling for the survivor. As of 1994, 32 states specifically authorized compulsory testing of offenders. Fifteen of these states authorized post-conviction testing only, five authorized pre-conviction testing only, and seven authorized both pre-conviction and post-conviction testing. The provisions of these statutes differed widely on a number of key variables: the stage of the criminal process at which the offender can be tested; the range of persons to whom the test results may be disclosed; and whether or not the testing must be triggered by a request from the survivor.

Four states also provided funding for testing or counselling of survivors.851

While at least some courts in the US have upheld involuntary testing, including of those merely accused of sexual assault,852 the Governor of Colorado recently vetoed a bill that would have mandated HIV testing of those accused with "a crime involving sexual behaviour."853

In one Australian state, Tasmania, HIV testing is also mandatory in a variety of circumstances, including where a person has been charged with a crime of a sexual nature, including rape and indecent assault.854

## Assessment

Compulsory testing of persons accused and/or convicted of sexual assault would be justified if its benefits outweighed its harms and potential harms, and if it was the "least restrictive, least invasive, likely to be effective, reasonably available" means available to accomplish any of the objectives of such testing.

### Potential Purposes of Compulsory Testing

#### Testing of Persons Accused of Sexual Assault

Compulsory HIV testing of persons accused of sexual assault may have different objectives. The most often cited are: to protect the health of the survivor; to protect the health of third parties; and to provide assistance to the survivor of sexual assault.

#### Testing of Persons Convicted of Sexual Assault

In addition to the objectives of testing of persons accused of sexual assault, testing of convicted sex offenders may have the following objectives: to provide information necessary to prevent the spread of HIV infection in prisons; and to collect information on the HIV status of convicted sex offenders that could be released to victims of sexual assault in cases of recidivism.

### Justification of Compulsory Testing

#### Testing of Persons Accused of Sexual Assault

In 1993, Jürgens et al concluded that testing a person accused of sexual assault was unlikely to accomplish any of the objectives mentioned above.855 At the time, testing "only provided uncertain information of limited usefulness." First, it was of little use for the purpose of protecting the health of the survivor:

> That the victim needs this information to be able to decide about whether she should begin zidovudine treatment (post-exposure prophylaxis) is ... questionable. If any benefits are to be obtained from zidovudine treatment, which is at best questionable, it has to be begun as soon after the assault as possible, and not delayed until test results are available.

Second, the authors argued that testing the accused would not provide useful information for the purpose of protecting the health of third parties:

> Because the accused’s HIV status will not tell the victim whether she has been exposed to HIV, she should not engage in unprotected sexual activities that could transmit HIV following the sexual assault, regardless of whether the accused tests positive or not.

Finally, the authors argued that testing the accused could not provide assistance to the survivors of sexual assault:

> [Testing] may accurately confirm that the accused was infected at the time of the assault, but it cannot indicate with any certainty that the accused was not infected at that time. In some cases the test result would be negative even though the accused is infected and infectious (ie, in the "window period" before antibodies to HIV are detectable). In these cases the victim would be falsely reassured that exposure has not occurred.

The authors concluded that,

> in view of the uncertainty of the information provided by testing, and considering that the only effective and reliable measures available to the victim are counselling, support, education, and possibly zidovudine treatment, it is unlikely that compulsory testing of persons charged with sexual assault would be considered as necessary.

In addition, the authors argued that compulsory testing of persons accused of sexual assault would have substantial harms and potential harms for the accused and for society:

For the accused, risks and harms from testing include breach of the accused’s rights of inviolability, self-determination, autonomy, privacy and confidentiality; offending the rule against self-incrimination; and risk of discriminatory and other harmful treatment.

> At a societal level, there is a risk that the legal system itself would be damaged by reversal of the fundamental principle of the presumption of innocence and by the wider impact of precedents set by the breach of the accused’s rights.

Most of these conclusions are still valid, but others may have to be reassessed or have been put in question. In particular, there is now more, although still limited, information about the benefits from starting post-exposure prophylaxis (PEP) after potential exposure to HIV. However, as before, the survivor will almost never have adequate information about the serostatus of the assailant immediately after the assault. PEP should be initiated "as soon as possible" after the exposure, ie, "within a few hours rather than days." Animal studies suggest that PEP probably is not effective when started later than 24 to 36 hours post-exposure, but the interval after which there is no benefit from PEP for humans is undefined. Therefore, it has been suggested that, if appropriate for the exposure, PEP should be started "even when the interval since exposure exceeds 36 hours."856 However, in the vast majority of sexual assault cases, assailants are not charged, let alone within the time frame during which PEP should be initiated. The opportunity to test assailants within this period of time would be restricted to a minimal number of cases. Therefore, in the vast majority of cases, if not all cases, the decision to *start* prophylaxis will need to be based on a risk assessment of the exposure, which should consider available information on the serostatus of the assailant, the type of exposure, the nature of the physical injuries, and the number of assaults. And even in the small number of cases where an assailant would be charged within the time frame during which PEP should be started, testing the assailant could assist the survivor in making a decision about starting prophylaxis only if the results of that test could become available to the survivor immediately. This could only be achieved by using rapid tests, which at the time of writing were not approved in Canada and, in addition, could provide only preliminary results.857

However, testing the assailant could provide useful information for the purpose of *ending* prophylaxis; if the survivor learns that the accused has tested negative, the survivor could discontinue the prophylaxis and avoid the potential side effects of continued treatment with antiviral drugs. Even though the survivor could not rely on a single negative test result to completely eliminate the risk of a false-negative result, this might provide substantial relief to survivors who experience serious side effects.

Furthermore, with regard to public health benefits of testing of the accused, Gostin et al admit that such testing is not absolutely necessary to protect the health of others: survivors have other alternatives. However, they have argued that these alternatives are more burdensome for the survivors and entail substantial behaviour changes, some risk to others (HIV transmission and pregnancy from improper use of condoms and unknown long-term effects of prenatal zidovudine treatment on children), and costs (both personal and financial), including alteration of life plans (delaying parenthood, marriage, or sexual relationships). Therefore, Gostin et al have concluded that "fairness dictates that the risks and burdens of limiting future harm should not rest solely with the survivor."858

Finally, Gostin et al have argued that, while the psychological benefits of the survivors may be limited, they nevertheless provide a strong case for imposed pre-conviction testing:

> Even given the small possibility of false-positive and false-negative test results, the news would provide substantial reassurance to the survivor. Of course, where testing reveals that the accused is infected, the survivor could experience additional psychological stress. This burden, while heavy, would fall on far fewer survivors than those who currently worry about infection. Knowledge of exposure

> might even allow survivors to begin psychological preparation for the results of their own testing. In those cases of sexual assault where the accused is apprehended relatively soon after the assault, involuntary testing, with appropriate due process and confidentiality protections for the accused, could mitigate one of the primary ongoing harms of the assault, the survivor's fear and uncertainty about the risk of contracting HIV.

Bayer agrees, saying that "[t]esting does help victims." He refers to a study published in the *Journal of the American Medical Association* that noted that the mental health of survivors of sexual assault is helped by early testing of the accused.859

For all the above reasons, Bayer and Gostin et al have argued that compulsory testing of persons accused of sexual assault is justified, provided that the harms from such testing for the accused are limited as far as possible.

### Testing of Persons Convicted of Sexual Assault

Compulsory testing of persons convicted of sexual assault is unlikely to accomplish any of its possible objectives. First, testing for the purposes of protecting the survivor and third parties or for the purpose of reassuring the survivor will in most cases not be necessary. It generally takes eight to twelve months until conviction. At that time, the survivor could be tested herself and obtain reliable information on whether s/he has contracted HIV, whereas testing the offender would not provide this information.

Second, testing for the purpose of preventing transmission of HIV in prisons is not necessary. It would not be effective in achieving this goal, and there are less intrusive measures for achieving it. There is also the risk that testing offenders and identifying those who are infected would increase their vulnerability in prison. Compulsory testing of this population of inmates would be discriminatory and stigmatize them as a potential source and threat of infection in prisons.

Finally, testing for the purpose of collecting information on the HIV status of sexual offenders to be disclosed to potential new victims would not be justified. Knowing that the offender tested negative provides no information about his HIV status at the time of a new sexual assault, because of the "window period" and time elapsed between testing and the new offence. Knowing the offender tested positive may assist the decision to start post-exposure prophylaxis, but only if that information could become available to the assailant within a very short period after the assault. Such cases would be exceedingly rare.

## Conclusion and Recommendations

> Testing, by itself, may not best serve policymakers' intent to assist victims. It may

> provide some relief to victims, but programs that include counseling, monitoring of victims' own health status, and emphasis on their own well-being may generate greater long-term benefits. States will continue to be involved in addressing this highly emotional and legally difficult issue. Legislators may want to consult with legal counsel, rape victim assistance groups, other relevant community organizations and public health personnel when considering appropriate responses.860

The issue of compulsory testing of persons accused and/or convicted of sexual assault has often been characterized as being one of choosing between accused's rights and victims' rights. However,

> to attempt to characterize the choice whether or not to require HIV antibody testing of accused persons as being either pro-woman or pro-criminal tends to obscure the real complexity of the issue and the tangible needs of the survivor. In so doing there is a danger of manipulating the survivor's understandable feelings of anger, frustration and fear in order to advance a position that ultimately will not help her.861

There can be no question that persons convicted of sexual assault have committed a serious criminal offence – if compulsory testing could further some useful objective for the survivor of the assault, it might be appropriate to regard the convicted person's claim to autonomy as appropriately of less weight.

As one respondent to the *Discussion Paper* said:

> If I were raped, I would fail absolutely to see why the perpetrator should not be required to submit himself to testing for my benefit. I would argue that this is a situation where the perpetrator's rights should be subject to mine. If HIV really is as bad and as awful as HIV/AIDS rights activists point out, then I should have rights if I am exposed to it as a result of someone else's criminal behaviour.862

Another respondent said:

> Persons accused of and/or persons convicted of sexual assault should undergo compulsory testing. Knowing the status of the accused is the right of the victim. Fear of the unknown is tremendous and delays recovery.863

However, as demonstrated above, compulsory testing and disclosure of the test result to the survivor of a sexual assault provide little if any benefit to the survivor. Testing a person *convicted of* sexual assault cannot provide the survivor with useful information. At the time of conviction, s/he can find out whether s/he her/himself is HIV-positive by undergoing testing. In contrast, testing the offender would only provide her with information about the offender's serostatus.

Similarly, compulsory testing of persons *accused of* sexual assault would only rarely further any useful objective for the survivor of the assault. It

is not the most effective way of dealing with the sexual assault survivor's concerns about possible HIV infection. She needs reliable information about whether she is HIV infected, and support and assistance in coping with uncertainty during the window period, and in living with a positive test result if this occurs. Compulsory testing also is not supportive of the public health goals of encouraging voluntary testing, counselling and prevention. Nor is it respectful of criminal law or constitutional law principles. While existing criminal law has proved to be quite effective in punishing certain kinds of conduct relating to HIV transmission, it does not appear to be the most efficacious way to address sexual survivors' concerns about HIV because so few sexual assaults actually result in criminal prosecutions.864

In addition, in contrast to persons convicted of sexual assault, persons accused of sexual assault are innocent until proven guilty. Therefore, it is not at all clear how compulsory testing could even be legally performed. Not having been convicted, testing could not be imposed as part of the punishment of the convicted person. There appear to be problems in establishing a constitutional basis for a federal regulatory scheme providing for testing of persons accused of sexual assault. If the purpose of the regulatory scheme would be to give the information to the survivor for her own purposes, but not for use in the criminal trial, it is not clear that it can be justified on the basis of the criminal law power, especially as the testing authorization would be given in a separate proceeding long before the criminal trial and any determination of guilt. The criminal law power could not be used to regulate an activity or state of affairs that is not itself a crime. This suggests that the provinces, in the exercise of their legislative powers under section 92 of the *Constitution Act, 1867*, rather than the federal government, might more appropriately create a regulatory scheme providing for testing. However, at the same time it is unlikely that provincial public health legislation could be used to require the testing of accused persons. Such public health legislation generally only permits compulsory testing or medical treatment in circumstances where there is a substantial threat to public health and safety. Merely having been accused of sexual assault is unlikely sufficient grounds to establish such a threat.

As was done by the Interdepartmental Committee, rather than focus on the issue of testing the assailant, the issues raised by sexual assault and HIV need to be examined in their full complexity: society can and must better address the needs of survivors of sexual assault. The temptation of enacting legislation requiring compulsory testing of persons accused and/or convicted of sexual assault is great. Such legislation would probably receive widespread public approval, and would suggest that the government is taking a strong stand in protecting survivors of sexual assault. In reality, however, such legislation would do little if anything to help them, and divert attention from the real, underlying problems. What is required instead is a governmental response that answers the very real concerns of survivors of sexual assault. As the Intergovernmental Committee has stated, "it is necessary to ascertain exactly what needs survivors have that are not being met and to find ways to deliver services effectively to the broadest population of survivors, not just those whose cases result in criminal prosecutions."865

**8. Compulsory testing of persons accused of sexual assault, at the request of the survivor of sexual assault, may provide some psychological reassurance to the survivor. Generally, however, it has few benefits and many potential harms.**

**Compulsory testing of persons *convicted of* sexual assault cannot provide the survivor with useful information and is therefore not justified.**

**Legislation authorizing testing of persons accused and/or convicted of sexual assault would do little to help the survivors, and divert attention from the real, underlying problems. What is required instead is a governmental response that answers the very real concerns of survivors of sexual assault and provides them with assistance.**

**Therefore, Health Canada, the Department of Justice, Status of Women, and their provincial counterparts should continue to ensure that best-practice counselling, short- and long-term care, treatment and other services are made available to sexual assault survivors. This should include**

- **access to HIV-antibody testing and counselling for all sexual assault survivors, provided by trained staff of sexual assault crisis centres or similar facilities;**

- **examination of the question whether PCR testing should be made available to survivors of sexual assault;**

- **access to post-exposure prophylaxis for sexual assault survivors, accompanied by counselling about its effects;**

- **ensuring sensitivity to multiculturalism and societal diversity in the delivery of counselling, testing and support services;**

- **assistance in the HIV/AIDS-related training of staff at sexual assault crisis centres and of other professionals who have contact with survivors of sexual assault.**

**Return to the top of this page**

**Return to Table of Contents**

---

## ENDNOTES

600 Field, supra, note 17 at 37.

601 Field, cited in S Abrams. Mandatory HIV Testing: The Search for a Quick Fix. *Harvard AIDS Letter* May/June 1995.

602 See the definition of mandatory testing in Appendix A (Glossary).

603 See the definition of compulsory testing in Appendix A (Glossary).

604 Canadian Human Rights Commission. *Policy on HIV/AIDS*. Ottawa: The Commission, 1996. See also, Canadian Human Rights Commission Releases Revised Policy on HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3 (1): 7-8.

605 Response to the *Discussion Paper* by M-W Sims, dated 17 June 1997.

606 Zeegers Paget, supra, note 175 at 97, with reference to R Roemer. The Law and Public Health – Historical and Current Perspectives. In: RF Schinazi, AJ Nahmias (eds). *AIDS in Children, Adolescents & Heterosexual Adults: An Interdisciplinary Approach to Prevention*. New York: Elsevier, 1988, at 5; L Gostin. The Resurgent Tuberculosis Epidemic in the Era of AIDS: Reflections on Public Health, Law, and Society. *Maryland Law Review* 1995; 54(1): 1-131; WF Banta. *AIDS in the Workplace: Legal Questions and Practical Answers*. Lexington, DC: Heath and Company, 1988, at 102-104.

607 Ibid, with reference to JMG Wilson, G Jungner. Principles and Practice of Screening for Disease. *WHO Public Health Paper, 34*. Geneva: World Health Organization, 1968.

608 Ibid at 98.

609 P Enel et al. Ethical Confusion: Detection of HIV Seropositives. *AIDS & Public Policy Journal* 1992; 7(1): 42–49.

610 Field, supra, note 17 at 34.

611 Ibid at 35.

612 Ibid.

613 Abrams, supra, note 601.

614 Field, supra, note 17 at 54.

615 Ibid; for more detail, see at 54-61. See also OLRC, supra, note 13 at 29-32.

616 Response to the *Discussion Paper* by J Cullingworth, supra, note 291.

617 Field, supra, note 17 at 105.

618 Ibid at 62.

619 AA Werdel. Mandatory AIDS Testing: The Legal, Ethical and Practical Issues. *Notre Dame Journal of Law, Ethics & Public Policy* 1990; 5: 155–255.

620 Field, supra, note 17 at 35.

621 L Gostin, WJ Curran. AIDS Screening, Confidentiality, and the Duty to Warn. *American Journal of Public Health* 1987; 77(3) (reprinted in *AIDS Reference Guide* July 1988, No 512).

622 S Persky. The Practical Case Against Mandatory Testing. In: J Russell (ed). *Liberties*. Vancouver: New Star Books, 1989, at 176–185.

623 WHO 1992, supra, note 53 at 3, with reference to the Forty-fifth World Health Assembly, which noted that "there is no public health rationale for any measures that limit the rights of the individual, notably measures establishing mandatory screening" (resolution WHA 45.35, 14 May 1992).

624 WHO 1992, supra, note 53 at 2-3.

625 Zeegers Paget, supra, note 175, with reference to Council of Europe. *Recommendation No. R(89) 14 of the Committee of Ministers to Member States on the Ethical Issues of HIV Infection in the Health Care and Social Settings*.

626 UNAIDS Policy, supra, note 268 at 2.

627 Ibid.

628 *HIV/AIDS and Human Rights – International Guidelines*, supra, note 162 at 12, recommendation 28(b).

629 Field, supra, note 17 at 54.

630 Somerville & Gilmore, supra, note 9 at xii.

631 Field, supra, note 17 at 64.

632 Ibid, with reference to Bayer, Levine & Wolf. HIV Antibody Screening: An Ethical Framework for Evaluating Proposed Programs. *New England Journal of Public Policy* 1988; 4: 173 at 177.

633 Ibid, with reference to Gray. The AIDS Epidemic: A Prism Distorting Social and Legal Principles. *New England Journal of Public Policy* 1988; 4: 227 at 230.

634 Somerville & Gilmore, supra, note 9.

635 NAC–AIDS, supra, note 8 at 37.

636 Sears, supra, note 274 at 158.

637 For a detailed review, see Jürgens & Palles, supra, note 2 at 124-129.

638 Somerville & Gilmore, supra, note 9 at 24.

639 Ibid at xiii.

640 CBA–Ontario, supra, note 7. The Association also recommended mandatory testing of immigrants to Canada.

641 OLRC, supra, note 13 at 57-62. This section of the Commission's report has been criticized by Sears, supra, note 274 at 159-160, who points out that it draws heavily on insurance industry–generated sources. For more information on HIV/AIDS and private insurance issues, see also L Locas. *Private Insurance Component*. Ottawa: Canadian AIDS Society (Income Security Project Phase II, Working Paper Series), 1996.

642 Royal Society, *Summary Report*, supra, note 10 at 13.

643 See MacKinnon, Cottrelle & Krever, supra, note 195 at 366-367. The Society discussed and ultimately rejected proposals for mandatory testing of hospital patients, immigrants, and students, teachers or other persons employed in schools (Royal Society, *Summary Report*, supra, note 10 at 14-15).

644 CPHA, supra, note 15 at 14-16.

645 Matiation, supra, note 19 at 21.

646 Zeegers Paget, supra, note 175 at 103.

647 Ibid.

648 S Dickman. Bavaria Begins Mandatory AIDS Tests in the Face of Criticism. *Nature* 1987; 327: 264.

649 S Dickman. Mandatory AIDS Tests on Basis 'of Slight Suspicion' in Bavaria. *Nature* 1988; 333: 585.

650 H Jager. Bavaria. A Review Symposium – Coercion or Voluntarism: An International Critical Review. Abstract WFO.20, presented at the V International Conference on AIDS, June 1989.

651 S Burris. Testing, Disclosure, and the Right to Privacy. In: S Burris, HL Dalton, JL Miller (eds). *AIDS Law Today. A New Guide for the Public*. New Haven: Yale University Press, 1993, 115-149 at 120.

652 Ibid at 121.

653 For an overview of US legislation on HIV testing, see LO Gostin. Public Health Strategies for Confronting AIDS: Legislative and Regulatory Policy in the United States. *Journal of the American Medical Association* 1989; 261(11): 1621.

654 W Curran, L Gostin, M Clark (eds). *AIDS: Legal and Regulatory Policy*. Frederick: University Publishing Group, 1988 at 294.

655 Gostin, supra, note 653 at 1625.

656 Ibid.

657 Ibid at 1625-1626.

658 LO Gostin, DW Webber. HIV Infection and AIDS in the Public Health and Health Care Systems. *Journal of the American Medical Association* 1998; 279(14): 1108-1113, at 1109.

659 Ibid, with reference to *Hill v Evans*, No 91-A-626-N, 1993 WL 595676 (MD Ala 7 October 1993).

660 Ibid.

661 J Henshaw. Wilson Signs Bill Granting Health Workers Greater HIV Protection. *Capitol Alert Online* 6 August 1998.

662 RS Magnusson, supra, note 371 at 342, with reference to Commonwealth of Australia. *National HIV/AIDS Strategy (The White Paper)*. Canberra: August 1989 at 38; Commonwealth of Australia. *National HIV/AIDS Strategy 1993-94 to 1995-96*. Canberra: October 1993 at 10.

663 Ibid at 345.

664 Ibid.

665 Ibid.

666 Communication received from F Hassan & M Heywood, dated 7 August 1998.

667 Stoltz & Shap, supra, note 210. Large sections of the following text are taken directly from that paper, with the permission of its authors.

668 Field, supra, note 17 at 95.

669 WHO 1992, supra, note 53 at 4.

670 NAC–AIDS, supra, note 8 at 39.

671 OLRC, supra, note 13 at 51.

672 RS Sperling et al. Maternal Viral Load, Zidovudine Treatment and the Risk of Transmission of Human Immunodeficiency Virus from Mother to Infant. *New England Journal of Medicine* 1996; 335: 1621.

673 LM Mofenson, ME Makhlamena. Treatment as Prevention: Mother-to-Child HIV Transmission. Plenary PL1, 12th World AIDS Conference, Geneva, 29 June 1998. See also EM Connor et al. Reduction of Maternal–Infant Transmission of Human

Immunodeficiency Virus Type 1 with Zidovudine Treatment. *New England Journal of Medicine* 1994; 331: 1173-80; N Lapointe et al. Mother to Child HIV Transmission Associated with Duration of the Second Stage of Labour. XI International Conference on AIDS, Vancouver, 1996, Abstract no Tu.C.340; for a review of PACTG 076 and its findings, a discussion of the implications of its findings for prenatal counselling and testing, and a description of future research needs, see MA Rogers, LM Mofenson, RR Moseley. Reducing the Risk of Perinatal HIV Transmission through Zidovudine Therapy: Treatment Recommendations and Implications. *Journal of the American Medical Women's Association* 1995; 50(3&4): 78-82, 93; see also Centers for Disease Prevention and Control. Recommendations of the US Public Health Service Task Force on the Use of Zidovudine to Reduce Perinatal Transmission of Human Immunodeficiency Virus. *Pediatric AIDS and HIV Infection: Fetus to Adolescent* 1994; 5(6): 387-398.

674 Reduction of HIV Transmission from Mother to Infant. *Canada Communicable Disease Report* 1994; 20(12): 100.

675 Ibid.

676 NAC-AIDS, supra, note 8 at 39.

677 National Advisory Committee on AIDS. *HIV and Human Rights in Canada*. Ottawa: The Committee, January 1992, at 19.

678 U.S. Public Health Service Recommendations for Human Immunodeficiency Virus Counselling and Voluntary Testing for Pregnant Women. *Morbidity and Mortality Weekly Report* 44(RR-7); 1 (7 July 1995).

679 Public Health Service Task Force. Recommendations for the Use of Antiretroviral Drugs in Pregnant Women Infected with HIV-1 for Maternal Health and for Reducing Perinatal HIV-1 Transmission in the United States, *Morbidity and Mortality Weekly Report* 1998; 47 (RR-2).

680 Ibid at 8-9.

681 Ibid at 3, 9.

682 Ibid at 4.

683 Mofensen & Makhlamena, supra, note 673, with references.

684 A more detailed summary of short-term and long-term effects associated with the use of antiretrovirals during pregnancy, drawn from the commentary in support of the recommendations issued by the US PHS in 1994, 1995 and 1998, can be found in Stoltz & Shap, supra, note 210.

685 1998 US PHS recommendations at 4.

686 Ibid.

687 Ibid.

688 Ibid at 4.

689 CMA 1995, supra, note 170 at 17; The Society of Obstetricians and Gynaecologists of Canada. *HIV Testing in Pregnancy. It's Best to Test!* Ottawa: The Society, 1997.

690 *NLMA Communiqué*, January/ February 1997, at 8.

691 Communication with Dr L Sweet,
1 August 1997.

692 Reproductive Care Program of Nova Scotia. *Guidelines for Antenatal Laboratory Screening and Testing*. May 1994.

693 *Reproductive Care Program of Nova Scotia Newsletter*, Spring 1998.

694 Direction de la santé publique de la Régie régionale de la santé et des services sociaux de Montréal-Centre. Montréal Prepares for the New Quebec Prenatal HIV Programme. Montréal: La direction, communiqué of 26 August 1996, at 1.

695 Government of Québec. Ministère de la Santé et des Services Sociaux. *HIV Infection and Pregnancy Intervention Program.*

696 Communication with J Tripp, Ontario AIDS Bureau, 2 October 1998.

697 College of Physicians and Surgeons of Manitoba. *Guideline: Maternal and Neonatal HIV Testing and Management*. January 1995.

698 Manitoba Advisory Committee on Infectious Diseases ("MACID"). *HIV Testing in Pregnancy: A Report of the HIV Prenatal Policy Working Committee to MACID*. Winnipeg: The Committee, December 1997.

699 Communication with N Wurtz, 6 February 1998.

700 Alberta Health. *Government Approves Routine Prenatal HIV Screening Program*. Alberta Health: Edmonton, 23 March 1998 (news release).

701 British Columbia Centre for Disease Control. Bulletin #1, HIV Transmission in Pregnancy.

702 Ibid.

703 Communication with Pat Mandal, 8 September 1997.

704 Northwest Territories Health and Social Services. *HIV Infection and AIDS Information for Health Professionals*. November 1996.

705 TM McGovern. Mandatory HIV Testing and Treating of Child-Bearing Women: An Unnatural, Illegal, and Unsound Approach. *Columbia Human Rights Law Review* 1997; 28: at
473-474, with references.

706 42 USCA para 300ff-33 *et seq.* (West Suppl 1997).

707 McGovern, supra, note 705 at 470, with reference.

708 Ibid at 471.

709 For more details see infra, the section on testing of newborns, at 151-154.

710 *Pregnancy and HIV: Recommended Code of Best Practice.* AIDS Law Project, Centre for Applied Legal Studies, University of the Witwatersrand, October 1997.

711 Ibid.

712 The International Community of Women Living with HIV/AIDS. *ICW's Position on the Key Issues Affecting Women Living with HIV/AIDS*. London, UK: ICW, 1998.

713 *Statement on Women's HIV Testing and Care*. New York, NY: The Coalition for Women's Choice in HIV Testing and Care, The HIV Law Project, no date.

714 *HIV/AIDS and Human Rights: International Guidelines*, supra, note 162 at 46, para 92.

715 Ibid at 19, para 30(j).

716 Ibid at 24, para 38(f).

717 *UNAIDS Policy on HIV Testing and Counselling*, supra, note 78 at 1.

718 CN Hudson, L Sherr. Antenatal HIV Testing in Europe. *The Lancet* 1997; 350 (13 December 1997).

719 *Winnipeg Child and Family Services (Northwest Area)* v *DFG*, [1997] 3 SCR 925.

720 Stoltz & Shap, supra, note 210, with reference to *DFG*, supra, note 719.

721 CB Britton. An Argument for Universal HIV Counselling and Voluntary Testing of Women. *Journal of the American Medical Women's Association* 1995; 50(3&4): 85-86.

722 Z Lazzarini, cited in Abrams, supra, note 601.

723 E Cooper. Mandatory HIV Testing of Pregnant/Delivering Women and Newborns: A Legal, Ethical, and Pragmatic Assessment. Abstract We.D.491, presented at the XI International Conference on AIDS, Vancouver, July 1996.

724 MB Barbacci et al. Human Immunodeficiency Virus Infection in Women Attending an Inner-City Prenatal Clinic: Ineffectiveness of Targeted Screening. *Sexually Transmitted Diseases* 1990; 00:122-126; LJ Fehrs et al. Targeted HIV Screening at a Los Angeles Prenatal/Family Planning Health Center. *American Journal of Public Health* 1991; 81: 619-622; D Gibb et al. Evaluating Antenatal HIV Testing in London, UK. Abstract Th.C.4615, presented at the XI International Conference on AIDS, 1996. (A survey of testing policies in London, England maternity units, showing that most maternity units offered HIV testing only to women considered at increased risk of infection or only on the request of the patient herself. Over a two-year period only two infected women were identified, while an estimated 154 HIV-positive women remained undiagnosed.) Meanwhile, in the state of North Carolina, a more aggressive approach was used to identify HIV-positive pregnant women and offer them treatment. By the end of the study, 90 percent of HIV-positive mothers were being identified before giving birth, whereas only 60 percent were being identified before. The rate of perinatal transmission was reduced from 21 to 9 percent (SA Fiscus et al. Perinatal HIV Infection and the Effect of Zidovudine Therapy on Transmission in Rural and Urban Communities. *Journal of the American Medical Association* 1996; 275(19): 1483).

725 McGovern, supra, note 705 at 474, with reference.

726 Ibid, with further references.

727 Ibid at 474, with references.

728 Rogers, Mofensen & Moseley, supra, note 673 at 81.

729 McGovern, supra, note 705 at 475, with references.

730 Alberta Health. *Routine Prenatal HIV Screening – Backgrounder*. Alberta Health, Edmonton: 23 March 1998, at 2.

731 Ibid.

732 See supra at 33-52.

733 MK Lindsay et al. Routine Antepartum Human Immunodeficiency Virus Infection Screening in an Inner-City Population. *Obstetrics and Gynecology* 1989; 74: 289-294; M Barbacci, JT Repke, RE Chaisson. Routine Prenatal Screening for HIV Infection. *Lancet* 1991; 337: 709-711. See also Cooper, supra, note 723, with many references.

734 E Cooper. Why Mandatory HIV Testing of Pregnant Women and Newborns Must Fail: A Legal, Historical, and Public Policy Analysis. *Cardozo Women's Law Journal* 1996; 3(1): 13-30, at 28.

735 Alberta Health, supra, note 730 at 2.

736 See Cooper, supra, note 734 at 22, for examples of successful programs.

737 Québec Program, supra, note 695
at 1.

738 Cooper, supra, note 723.

739 Ibid.

740 Bayer, supra, note 24.

741 Ibid at 121.

742 Ibid.

743 Centers for Disease Control and Prevention. *U.S. Public Health Service Recommendations for Human Immunodeficiency Virus Counseling and Voluntary Testing for Pregnant Women*. The Centers, 7 July 1995 (vol 44/no RR-7), with many references.

744 CDC. 1995 Revised Guidelines for Prophylaxis against Pneumocystis Carinii Pneumonia for Children Infected with or Perinatally Exposed to Human Immunodeficiency Virus. *Morbidity and Mortality Weekly Report* 1995; 44 (no RR-4).

745 W El-Sadr et al. Evaluation and Management of Early HIV Infection. Rockville, MD: US Department of Health and

Human Services, Public Health Service, Agency for Health Care Policy and Research, January 1994. DHHS publication no (AHCPR) 94-0572 (Clinical Practice Guideline no 7).

746 ACIP. Recommendations of the Advisory Committee on Immunization Practices (ACIP): Use of Vaccines and Immune Globulins in Persons with Altered Immunocompetence. *Morbidity and Mortality Weekly Review* 1993; 42 (no RR-4).

747 C Henderson. Prenatal HIV Screening Raises Ethical Issues. *Medical Tribune News Service* 1995.

748 Canadian Medical Association 1995, supra, note 170 at 18.

749 Cooper, supra, note 723, with reference to 42 USCA sec 300ff-34.

750 J Sternlight. Mandatory Non-Anonymous Testing of Newborns for HIV: Should it Ever Be Allowed? *John Marshall Law Review* 1994; 27: 373
at 381.

751 P Hellman. Suffer the Little Children. *New York* 21 February 1994, 27 at 30.

752 Ibid at 29.

753 Sternlight, supra, note 750 at 381.

754 See for example *Re K(R)* (1987), 79 AR 140 (Family Court).

755 *Re Eve* (1987), 31 DLR (4th) 1 at 29.

756 A Ammann. Unrestricted Prenatal HIV Testing: The Standard of Care. *Journal of the American Women's Association* 1995; 50(3&4): 83 at 84.

757 C Hanssens. *Mandatory Newborn Testing. A Policy Paper.* New York, NY: Lambda Legal Defense and Education Fund, 1996, with reference to AR Fleischman. Mandatory Newborn Screening for HIV: The Wrong Answer to the Wrong Question. *The AIDS Reader* 1994; 4: 172.

758 Fleischman, supra, note 757 at 173.

759 R Jürgens. *HIV/AIDS in Prisons: Final Report*. Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1996.

760 Newfoundland and Labrador, Department of Justice, Adult Corrections Division, Policy Directive 16.40.06, section: Special Health Care Services–HIV/AIDS, revised 1 April 1992.

761 House of Commons of Canada, 35th Parliament, 2nd session, Sub-Committee on HIV/AIDS of the Standing Committee on Health, meeting no 12, Tuesday, 26 November 1996.

762 A Noel. Guards Urge Mandatory Blood Tests to Combat AIDS in Prisons. *The* [Montréal] *Gazette* 21 September 1996, at A6; Give Inmates Needles, Study Says. *The Globe and Mail* 18 September 1996, at A7.

763 Prison Visitors Unwittingly Exposed to HIV – And Corrections Canada Knows About It. Abbotsford: Randy White

Campaign Office, press release of 30 April 1997.

764 The Progressive Conservative Caucus Committee on Family Issues. Recommendations for HIV/AIDS Testing of Federal Prison Inmates on Conditional Release Programs. Ottawa, 8 June 1993, at 2.

765 Ibid at 2.

766 See infra. For a more detailed summary, see Jürgens & Palles, supra, note 2 at 151-156.

767 Mackinnon, Cottrelle & Krever, supra, note 195 at 368.

768 OLRC, supra, note 13 at 55.

769 Ibid at 57.

770 Mackinnon, Cottrelle & Krever, supra, note 195 at 368.

771 Somerville & Gilmore, supra, note 9 at 53.

772 Correctional Service Canada. *HIV/AIDS in Prisons: Final Report of the Expert Committee on AIDS and Prisons*. Ottawa: Minister of Supplies and Services Canada, 1994, at 26. This issue is addressed in more detail in the paper on "Disclosure of Offender Medical Information: A Legal and Ethical Analysis." See Correctional Service Canada. *HIV/AIDS and Prisons: Background Materials*. Ottawa: Minister of Supplies and Services Canada, 1994, Appendix 7.

773 OLRC, supra, note 13 at 57.

774 Somerville & Gilmore, supra, note 9 at 53.

775 Ibid.

776 MacKinnon, Cottrelle & Krever, supra, note 195 at 368.

777 PASAN. HIV/AIDS in Prison Systems: A Comprehensive Strategy. A Brief from the Prisoners with HIV/AIDS Support Action Network (PASAN) to the Minister of Correctional Services and the Minister of Health. Toronto: The Network, June 1992; see also PASAN. HIV/AIDS in the Transgendered Prison Population: A Comprehensive Strategy. A Brief from the Prisoners' HIV/AIDS Support Action Network (PASAN) to the Solicitor General of Canada, the Minister of Health of Canada, the Ontario Minister of Solicitor General and Correctional Services, the Ontario Minister of Community and Social Services, and the Ontario Minister of Health. Toronto: The Network, October 1998.

778 *Final Report of the Expert Committee on AIDS and Prisons*, supra, note 772.

779 Jürgens, supra, note 759.

780 TW Harding, G Schaller. HIV/AIDS Policy for Prisons or for Prisoners? In: J Mann et al (eds). *AIDS in the World*. Cambridge, MA & London, England: Harvard University Press, 1992, 761-769 at 765.

781 State Prepares to Test Entire Prison Population for HIV. *Kaiser Daily Report* 29 July 1998.

782 See OLRC, supra, note 13 at 54-55, with references.

783 WHO. *WHO Guidelines on HIV Infection and AIDS in Prisons*. Geneva: WHO, 1993.

784 UNAIDS. *Prisons and AIDS – UNAIDS Technical Update*. Geneva: UNAIDS, 1997.

785 *HIV/AIDS and Human Rights. International Guidelines*, supra, note 162 at 15, para 29(e).

786 Communication with C Hanssens, Lambda Legal Defense and Education Fund, New York City, of 5 December 1997.

787 Magnusson, supra, note 371 at 343.

788 See The Editor. Australia – Segregation of HIV-Positive Prisoners Illegal. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 34, with reference to, WA prisons discriminate against HIV positive prisoners. [Australian] *HIV/AIDS Legal Link* 1996; 7(4): 5.

789 WA prison segregation ends. [Australian] *HIV/AIDS Legal Link* 1996; 7(4): 3.

790 Harding & Schaller, supra, note 780 at 765.

791 See, eg, The United Nations Joint Programme on HIV/AIDS. *Prisons and AIDS. UNAIDS Point of View*. UNAIDS: Geneva, April 1997.

792 *HIV/AIDS and Human Rights. International Guidelines*, supra, note 162 at 15, para 29(e).

793 Supra, note 791 at 7.

794 Response to the *Discussion Paper* dated 6 June 1997.

795 J Beauchemin, JF Labadie. *Évaluation de l'utilité et de l'accessibilité des services de counselling et de dépistage du VIH en milieu carcéral – Services offerts par le CLSC Ahuntsic à la Maison Tanguay et à l'Établissement de détention de Montréal. Rapport final: août 1997.* Montréal: Direction de la santé publique de Montréal-Centre and CLSC Ahuntsic, 1997.

796 Ibid at 6.

797 Correctional Service of Canada. Backgrounder: CSC Response to the Expert Committee on AIDS and Prisons (ECAP). Ottawa: CSC, Health Care Services Branch, 24 March 1994.

798 Ibid.

799 See R Jürgens. Bleach and Anonymous HIV Testing in Federal Prisons. *Canadian HIV/AIDS Policy & Law Newsletter* 1995; 1(4): 1, 15-16.

800 For more details, see Jürgens, *Final Report*, supra, note 759 at 13-15.

801 Correctional Service Canada. News Release: Correctional Service of Canada to Introduce Methadone Maintenance Treatment. Ottawa: The Service, 1 December 1997.

802 Ibid.

803 Jürgens, *Final Report*, supra, note 759 at 101.

804 Ibid; R Jürgens. Methadone, But No Needle Exchange Pilot in Federal Prisons. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4) and 4(1): 26-27; R Jürgens. Promoting the Rights of Prisoners: Condoms, Bleach, Needles, Methadone and Care in Prisons. 12th World AIDS Conference, Geneva, 1998, abstract no 44191.

805 See, eg, C Hankins et al. HIV-1 Infection in a Medium Security Prison for Women – Quebec. *Canada Diseases Weekly Report* 1989; 15(33): 168-170; P Ford et al. Seroprevalence in a Male Medium Security Penitentiary – Ontario. *Canada Communicable Disease Report* 1994; 20(6): 45-47; D Rothon et al. Prevalence of HIV Infection in Provincial Prisons in British Columbia. *Canadian Medical Association Journal* 1994; 151(6): 781-787; L Calzavara. Preliminary Results from an Anonymous Unlinked HIV Seroprevalence Study of Inmates in Ontario. In: CSC, *Background Materials*, supra, note 772; LY Lior et al. Behind Bars: An Epidemiological Investigation of HIV, HBV and HCV Inside a Federal Penitentiary. Seventh Annual Canadian Conference on HIV/AIDS Research, Québec, 1998, abstract no 262P.

806 Jürgens, *Final Report*, supra, note 759 at 32.

807 See, eg, CSC, *Final Report*, supra, note 772 at 90-97; Jürgens, *Final Report*, supra, note 759 at 84-90 and 112-113.

808 R Lines. The Case against Segregation in "Specialized" Care Units. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4) & 4(1): 30-32.

809 Disclosure of Offender Medical Information: A Legal and Ethical Analysis. In: CSC, *Background Materials*, supra, note 772 at 145. For more details, see there.

810 CSC, *Final Report*, supra, note 772 at 36-37 (Recommendation 3.(5)); the recommendation was repeated in Jürgens, *Final Report*, supra, note 759 at 101-102 (Recommendation 3.3).

811 See the section on testing of persons accused or convicted of sexual assault.

812 *Ratte* v *Kingston Penitentiary (Warden)*, Ontario Judgments: [1991] OJ No 1745 (Ontario Court of Justice – General Division). For more details, see CSC, *Background Materials*, supra, note 772, Appendix 4: Canadian Case Law and Precedents.

813 Supra, note 350.

814 PH MacDonald. Note. AIDS, Rape, and the Fourth Amendment: Schemes for Mandatory AIDS Testing of Sex Offenders. *Vanderbilt Law Review* 1990; 43: 1607-1636 at 1607.

815 Nightmares of Uncertainty: HIV Test is Proper on Accused or Convicted Rapists. *The* [Montréal] *Gazette* 10 January 1993.

816 B Friedman. AIDS and Rape. *The* [Montréal] *Gazette* 7 November 1992, at B6.

817 Reported in C Hankins. AIDS and the Correctional System. *SIECCAN Journal* 1988; 3(4): 43-46 at 45.

818 NAC–AIDS, supra, note 8 at 42-43.

819 *R* v *Beaulieu*. CQ Bedford (Cowansville) 455-01-000963-920, 1992-11-03. Decision no 92-1769 (Court of Québec), Roberge J.

820 Ibid at 3.

821 RSQ, c A-13.2, ss 2 and 3.

822 *R* v *Beaulieu*, supra, note 819 at 8.

823 *R* v *Dyment*, [1988] 2 SCR 417 at 431-432.

824 Ibid at 432.

825 *R* v *Legere*, [1988] 43 CCC (3d) 502 at 513.

826 *R* v *JPB*, [1992] NWTJ No 207 (Northwest Territories Youth Court).

827 *DC* v *Paul Bernardo et al*, Court File No 93-CQ-46124, unreported decision of 23 September 1996, Ontario Court (General Division), MacDonald J.

828 *DC* v *Paul Bernardo et al*, Court File No 93-CQ-46124, Notice of Motion of 8 September 1996, at 1-2.

829 D Downey. Bernardo to Take AIDS Test after Victims Make Request. *The Globe and Mail* 24 September 1996, at A7.

830 Ibid.

831 Letter by R Carey to The Editor, *The Toronto Star*, dated 22 October 1996.

832 Government of Québec, Coroner's Office. Rapport d'investigation, Claude Paquin, Coroner investigateur, Montréal, 24 November 1992.

833 For more information about the Interdepartmental Committee, see the *Canadian HIV/AIDS Policy & Law Newsletter* 1994; 1(1): 11.

834 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. Unless otherwise indicated, all citations in the next paragraphs are from this report.

835 Center for Women Policy Studies. More Harm than Help: The Ramifications for Rape Survivors of Mandatory HIV Testing of Rapists (reprinted in *AIDS Reference Guide*. Atlantic Information Services Inc, December 1992, ¶505, and cited in the Working Group's Report).

836 C Neron. *HIV and Sexual Violence Against Women. A Guide for Counsellors Working with Women Who Are Survivors of Sexual Violence.* Ottawa: Health Canada, March 1998, at 1. The following description of Health Canada initiatives is taken from that guide.

837 Ibid, with reference to C Neron. *HIV and Sexual Assault Project Report*. (Unpublished report). Ottawa: Health Canada, 1997.

838 Ibid, with reference to AIDS Committee of Toronto. *Sexual Assault and AIDS Needs Assessment Survey Highlights*. (Unpublished report). Toronto: ACT, 1991.

839 Supra, note 836.

840 Ibid at 3.

841 Ibid at 10, with reference to J Albert et al. Analysis of a Rape Case by Direct Sequencing of the Human Immunodeficiency Virus Type 1 Pol and Gag Genes. *Journal of Virology* 1994; 68: 5918-5924; S Murphy et al. Rape and Subsequent Seroconversion to HIV. *British Medical Journal* 1989; 299: 718; S Murphy et al. Rape and HIV. *International Journal of STD and AIDS* 1991; 2(3): 200-201.

842 Ibid, with reference to D Lobb & S Smith. B.C. Positive Women's Study. *Hospice Update. Vancouver Hospice Program* February 1995, 6-8; Neron, supra, note 837.

843 Ibid at 32, with references.

844 Ibid at 37, with reference to British Columbia Women's Hospital, Sexual Assault Service. *Protocol for PEP with Sexual Assault Survivors*. Vancouver, BC: The Hospital, 1997.

845 LO Gostin et al. HIV Testing, Counseling, and Prophylaxis after Sexual Assault. *Journal of the American Medical Association* 1994; 271(18): 1436-1444. Unless otherwise indicated, all citations in the following text are from this document.

846 Ibid, with reference to TA Peterman et al. Risk of Human Immunodeficiency Virus Transmission from Heterosexual Adults with Transfusion-Associated Infections. *Journal of the American Medical Association* 1988; 259: 55-58; N Padian. Heterosexual Transmission: Infectivity and Risks. In: NJ Alexander et al (eds). *Heterosexual Transmission of AIDS*. New York, NY: Wiley-Liss, 1990, at 25-34. However, in his response to the *Discussion Paper*, dated 24 June 1997, Peterman says that his paper has been misinterpreted and emphasizes that the risk of HIV transmission is not simply a function of the number of sexual contacts with an HIV-positive person.

847 NH Steigbigel et al. Heterosexual Transmission of HIV Infection. In: Program and Abstracts of the Fourth International Conference on AIDS. 12-16 June 1988, Stockholm, Sweden. Abstract 4057; N Padian et al. Clinical and Immunological Correlates of the Heterosexual Transmission of HIV. In: Program and Abstracts of the 28th Interscience Conference on Antimicrobial Agents and Chemotherapy. 23-26 October 1988, Washington, DC. Abstract 344.

848SD Holmberg et al. Biologic Factors in Sexual Transmission of Human Immunodeficiency Virus. *Journal of Infectious Diseases* 1989; 160: 116-125. For a recent overview, see A Rachel et al. Sexual Transmission of HIV. *The New England Journal of Medicine* 1997; 336(15): 1072-1078.

849 National Victim Center, Crime Victims Research and Treatment Center. National Women's Study, reported in: Rape in America: A Report to the Nation. Arlington, VA: National Victim Center, Crime Victims Research and Treatment Center, Dept of Psychiatry and Behavioral Sciences, Medical University of South Carolina, Charleston, 23 April 1992.

850 See supra, note 819.

851 Gostin et al, supra, note 845.

852 S Anderson. Individual Privacy Interests and the "Special Needs" Analysis for Involuntary Drug and HIV Tests. *California Law Review* 1998; 86: 119-177 at 144, with reference to *Virgin Islands v Roberts*, 756 F Supp 898 (D.V.I. 1991); NJ Court Rules on AIDS Testing. [Newark] *Star-Ledger*, October 1997.

853 Governor Cites Confidentiality Concerns in His Veto. Health Policy Tracking Service, National Conference of State Legislatures, 8 June 1998 (available at http://stateserv.hpts.org).

854 Magnusson, supra, note 371 at 345.

855 See R Jürgens et al. Are Compulsory HIV Testing and Disclosure of HIV Status Ever Justifiable? Ethical and Legal Analysis Using Sex Offenders, Health Care Providers, Patients as Examples. Poster presentation at the Third Annual Conference on HIV/AIDS Research, Montréal, 13-15 May 1993. Unless otherwise indicated, all citations in the following paragraphs are from this presentation.

856 Centers for Disease Control and Prevention. Public Health Service Guidelines for the Management of Health-Care Worker Exposures to HIV and Recommendations for Postexposure Prophylaxis. *Morbidity and Mortality Weekly Review* 1998; 47(No RR-7): 1-34 at 18. See also Health Canada. An Integrated Protocol to Manage Health Care Workers Exposed to Bloodborne Pathogens. *Canada Communicable Disease Report* 1997; 23(Suppl 2), where it says that, if "PEP is to be implemented, it should be started as soon as possible, preferably within 1 to 2 hours after exposure. It is thought to be less effective if delayed, but there are no data to indicate if there is a specific time after which it is ineffective."

857 See above, the section on rapid tests in the chapter on new testing technologies.

858 Supra, note 845 at 1439.

859 R Bayer. Assault Victims Have Right to Know Attacker's H.I.V. Status. Medical Tribune News Service, 1996.

860 L Bryant, TA Hooker. Testing Sex Offenders for HIV. *State Legislative Report* 1991; 17(7): 1-7 at 5 (Denver: National Conference of State Legislatures).

861 Interdepartmental Committee, supra, note 834.

862 Response to the *Discussion Paper* by RS Magnusson, dated 29 July 1997.

863 Response to the *Discussion Paper* by D Neary, dated 20 August 1997.

864 Interdepartmental Committee, supra, note 834 at 19.

865 Ibid., at 20.

**Return to the top of this page**

**Return to Table of Contents**

# HIV Testing and Confidentiality: Final Report

**Prepared by Ralf Jürgens**

ISBN 1-896735-16-9

---

# MANDATORY OR COMPULSORY HIV TESTING (Part 2)

Link to Part 1 of this chapter

## HIV Testing of Sex Workers

> The history of public health and disease control is marked by the assumption that certain women carry disease, overshadowing the fact that they suffer from diseases as well.866

Legal, moral and social censure of sex workers has increased dramatically since the advent of HIV/AIDS. Women and men working in the sex trade have been considered as vectors of transmission rather than people who for many reasons, including legal reasons, are vulnerable to contracting HIV. Female sex workers in particular have been perceived as the bridge between an HIV-infected "underworld" and the "general population": "All over the world, prostitutes are being made the scapegoats for heterosexual AIDS."867

This scapegoating is taking place "in the context of a general viewing of women as vectors for transmission of the disease to their male sex partners ... and their babies."868 In some countries, laws have been "introduced to protect the interests of prostitutes' clients, considered to be potentially innocent victims of AIDS, at the expense of prostitutes, on whose side guilt is deemed to lie."869 The media have also responded with hysteria, blaming sex workers for the transmission of HIV among the heterosexual population. As stated by Brock, by blaming sex workers, "we forget that they are working women and men who attempt to maintain as much control over their working conditions, including hygiene, as possible."870

However, according to some policymakers and the media, the protection of public health justifies draconian legal measures and moral intolerance.871 Few if any of the measures proposed reduce a sex worker's own risk of contracting HIV.872

## History

### Canada

Only a few Canadian organizations have specifically addressed the issue of whether sex workers should be mandatorily or compulsorily tested for HIV. Those who have, such as the National Advisory Committee on AIDS, have concluded that mandatory or compulsory HIV testing is unwarranted "because harms from such testing would outweigh any benefits for them."873

According to the Ontario Law Reform Commission, it is not clear that mandatory testing of sex workers can deter high-risk activity: "The effect of these laws has been to drive prostitution underground and limit the areas in which it is practised."874 Similarly, the Commission continued, "it is not clear that a female sex worker's clients are at a significantly increased risk of infection": "A large percentage of female prostitutes report using condoms with their clients, which reduces the risk of infection." Finally, the Commission pointed out that the risk of female-to-male transmission is lower than the risk of male-to-male transmission:

> This might explain why the rate of infection among male clients of female prostitutes is low. It also suggests that female prostitution, by itself, is not a significant factor in the transmission of HIV.875

The Commission concluded that in the absence of a cure for AIDS, "it is not clear how involuntary testing could be useful in preventing HIV transmission in the sex industry."876

While proposals for mandatory or compulsory testing of sex workers have been rejected, in a few cases Canadian courts have required testing from a particular sex worker. In 1987, in the case of *R* v *GDM*,877 the British Columbia Provincial Court imposed as a condition of probation that a young offender be required to furnish to his youth worker, at least once a month, a medical certificate that he had been examined for HIV and other venereal diseases within the previous month. The Court held that this was a "reasonable and ancillary condition" and in the best interest of the young person and the public, within the meaning of s 20(1)(e) of the *Young Offenders Act*. The youth had pleaded guilty to a charge of soliciting for the purpose of prostitution and was a 17-year-old homosexual sex worker who had no prior convictions for similar offences and had spent one day in custody.

In another case, *R* v *Cornier*, a British Columbia sex worker was convicted of solicitation and then sentenced to monthly mandatory HIV and other STD testing. The sex worker appealed the sentence, arguing that it violated his right to be free from unreasonable search and seizure (s 8 of the *Canadian Charter of Rights and Freedoms*). On appeal, the BC Court of Appeal held that, although monthly examinations were excessive, one examination was reasonable and would promote "good conduct."878

## International Developments

Internationally, there have been two main governmental responses to the issue of sex workers and AIDS: mandatory testing backed up with quarantine, or nothing at all.879 However, in some countries, HIV prevention efforts aimed at sex workers have gone further and addressed structural and policy and legal considerations. Examples of this are the Thai 100 percent condom-use program880 and the sex industry law reform process in Australia that has led to the adoption of laws such as the *Prostitution Act* 1992 (in the Australian National Capital), which prohibits discrimination against someone "due to their trade, occupation or calling.881

In the literature, much attention is devoted to the issue of whether sex workers should be mandatorily tested for HIV.882 Most articles reject mandatory testing and other compulsory measures directed at "controlling" sex workers, and suggest alternative ways of reducing the spread of HIV among sex workers and to their clients. The policy of the AIDS and Civil Liberties Project of the American Civil Liberties Union (ACLU) points out that, as a purely practical matter, compulsory testing of sex workers won’t work: "[i]f there is any group which will be driven underground by such a policy, it is prostitutes."883 Research has indicated that punitive measures to control the sex trade – such as increased criminal penalties, mandatory testing, and electronic monitoring – further erode sex workers’ ability to negotiate safe sex and further alienate them from public health initiatives. As a result, HIV risks are increased rather than reduced.884

Generally, the rationale behind compulsory measures, which focus exclusively on sex workers and not on clients, is criticized. Alexander suggests that "governments are more interested in blaming prostitutes, and thereby appearing to do something to control the spread of AIDS, than they are in actually developing workable programs to help people protect themselves."885

In response, the Asia-Pacific Sex Workers Network recently developed a policy statement on the rights of HIV-positive sex workers. The Network encourages other regional organizations and networks to adopt the statement, and plans to "encourage the adoption of these philosophies through international organizations such as the UN."886 In the statement, the Network undertakes to advocate for and work to:

> ENSURE that HIV status alone does not prevent a person from choosing and undertaking sex work as an occupation;
>
> ENSURE that testing for HIV is not a mandatory requirement for work;
>
> ENSURE that an individual's right of freedom to travel within and between countries is guaranteed irrespective of occupation and/or HIV status;
>
> ENSURE all sex workers are entitled to safe and confidential access to safer sex products, health care and medication, irrespective of HIV status. This includes equitable access to AIDS therapies for all HIV positive people;
>
> ENSURE an individual's right to privacy and confidentiality is championed and upheld, irrespective of occupation and/or HIV status;
>
> ENSURE that education programs and campaigns foster an environment of understanding, acceptance and support for all sex workers, and in particular HIV positive sex workers;
>
> ENSURE that all sex workers are guaranteed equitable access to legal support services irrespective of their HIV status;
>
> ENSURE that governments and law makers are lobbied (and urged) to decriminalize homosexuality and prostitution;
>
> ENSURE that political targeting of HIV positive sex workers is strongly condemned and eradicated wherever and whenever it occurs.887

The International Guidelines on HIV/AIDS and Human Rights also oppose mandatory testing of sex workers and recommend a broader prevention approach:

> With regard to adult sex work that involves no victimization, criminal law should be reviewed with the aim of decriminalizing, then legally regulating occupational health and safety conditions to protect sex workers and their clients, including support for safe sex during sex work. Criminal law should not impede provision of HIV/AIDS prevention and care services to sex workers and their clients.888

## Current Situation

## Canada

Canada does not have legislation requiring mandatory or compulsory testing of sex workers, nor is it currently planned to introduce such legislation. However, particularly in Toronto, the media have portrayed sex workers as vectors of transmission, contributing to a climate favouring coercive measures against sex workers.

Generally, Canadian policymakers want to make prostitution laws tougher. In 1992, a Working Group on Prostitution was established by the Federal/ Provincial/Territorial Deputy Ministers Responsible for Justice. The Working Group released "Dealing with Prostitution in Canada – A Consultation Paper" in March 1995. The paper discusses a number of options that have been proposed by various parties to deal with prostitution in Canada. It is mainly concerned with two issues: "youths in prostitution and street prostitution."889 The majority of the options discussed involve changes to sections 212 and 213 of the *Criminal Code*. Section 212 contains various offences known collectively as "procuring" or "living on the avails," which are not aimed at prostitutes but are designed to "prevent persons from being forced into a life of prostitution"; under s 213, it is an offence on the part of the customer, as well as the prostitute, to communicate in public for the purpose of engaging in prostitution. The options for change of these sections include:

- increased and/or mandatory jail sentences for pimps and customers of youths;
- making s 213 a dual procedure or hybrid offence to allow for the fingerprinting and photographing of sex workers and customers charged under s 213;
- electronic surveillance and interception of communications between sex workers, pimps and customers;
- mandatory and/or increased sentences for customers; and
- allowing provinces/territories and/or municipalities to license and operate prostitution establishments or formal zones of tolerance for street prostitution.

The paper also contains a list of "social intervention options." For youth, options are explored to:

- divert young offenders to child welfare services; and
- develop informational and educational materials to warn youth about the dangers of prostitution.

Another option discusses the development of outreach services, with health, training, and rehabilitation programs located in bus terminals, restaurants, and storefronts, and the creation of safehouses with counselling programs.

On 6 November 1995, *The Globe and Mail* reported that then Justice Minister Rock was planning "tougher penalties – not legalization of the sex trade – to tackle problems associated with street prostitution."890

### United States

As of 1994, 14 US states had passed legislation requiring mandatory or compulsory HIV testing of sex workers convicted of, or in at least two cases charged with, prostitution.891 For example, under a California law requiring mandatory testing, if a sex worker tests positive, subsequent prostitution convictions carry three-year sentences, whether the sex worker practised safe sex or not.892 As Bastow has said, the law "has spawned appalling forms of state oppression of HIV-positive prostitutes: for example, two women prostitutes who tested positive for HIV were released from custody only on condition that they agree to be `electronically monitored'."893 Courts in California and Illinois have upheld the constitutionality of testing of convicted sex workers, "characterizing the government interest in promoting public health and slowing the spread of AIDS as compelling," and minimizing the intrusion upon sex workers' privacy interests.894 Both courts undertook no real inquiry into whether the HIV tests were truly necessary to serve the government interest in promoting public health, or whether other, less restrictive means were available.895

## Assessment

As the Ontario Law Reform Commission has emphasized, it is not clear how mandatory or compulsory testing of sex workers could be useful in preventing HIV transmission:

> Unless Canadians were willing to consider isolating indefinitely or otherwise restricting all infected sex workers – measures that would encourage prostitutes and others at risk to avoid HIV-related testing and other help-seeking alternatives – little could be done with the information. In short, for both the client and the sex worker the Commission believes the risk of transmission is best addressed by targeted education efforts and programs designed to encourage risk-reducing behaviour, including information about the use of condoms and clean needles. No exception to a general rule requiring voluntary, specific, and informed consent for all HIV-related testing is justified with respect to male or female sex workers.896

Rather than coercive measures, interventions are necessary that would give sex workers the means to protect themselves against HIV transmission and would empower them to use them. A variety of such measures has been proposed. For example, Cohen et al advocate the development of educational strategies for reaching sex workers, giving them accurate information about the ways of preventing transmission, and supporting them in their efforts to utilize these measures consistently.897 Leigh recommends disability payments to sex workers who may be HIV-positive, and provision of income and job-training alternatives for those who wish stop working in the sex business.898 The English Collective of Prostitutes has issued a list of "demands," including provision of "money and other resources, including raising Child Benefit, Supplementary Benefit and other welfare payments, so that women aren't forced into prostitution by economic need, and for women who want to get off the game."899 Decarlo, Alexander and Hsu have recommended that:

Increased funding is needed for prevention programs that address the full range of problems sex workers face, both on and off the streets, especially programs staffed and managed by peers. Drug treatment, housing, child care and skills training for prostitutes are essential. Better health care services are needed for prostitutes, including diagnosis and treatment for STDs/HIV, care for injuries due to violence, and mental health care. A comprehensive HIV prevention strategy uses a variety of elements to protect as many people at risk as possible. Sex workers require a broad range of protective services, including HIV prevention.900

In addition, it needs to be acknowledged that current prostitution laws affect the spread of HIV among sex workers:

> The criminalization of sex for money means that [q]hookers who are subject to abuse from their customers are less able to report their abusers. It also makes it difficult for them to insist on condom use with their customers, and thus increases their chances of becoming infected. In conversations I had with a number of women who were raped by their customers, without condoms, they said that because their work is illegal they are not willing to prosecute these men. Instead, they maintain a "bad date" list and disseminate it to other hookers. In contrast, it has been found that decriminalization of prostitution enables those in the sex trade to practise safe sex, and will ultimately result in lower infection rates.
>
> The intention behind increasing penalties in prostitution laws may be to discourage participation in the sex trade and thereby reduce health risks. In reality, however, few prostitutes are discouraged by tougher laws. Instead, such laws make them even more vulnerable. For example, increased penalties will result in an increased seriousness of a prostitute's criminal record, and this will reduce the employment opportunities for those who choose to leave the sex-trade industry.
>
> Evidentiary issues also affect prostitutes' ability to protect themselves from contracting HIV from their customers. For example, possession of condoms is sometimes used as evidence of prostitution. As a result, prostitutes are less likely

> to carry condoms.901

Recognizing the impact of existing laws on the spread of HIV, the World Health Organization recommended that a meeting be organized to address issues such as "laws which impinge on social, economic, and legal rights of prostitutes and therefore impede HIV prevention efforts."902

A comprehensive analysis of legal issues pertaining to sex workers and HIV/AIDS – in particular the impact of laws regulating and/or penalizing prostitution on efforts to prevent HIV infection – has already been undertaken by the Australian Intergovernmental Committee on AIDS' Legal Working Party.903 The Working Party's report proposes the following public health objectives that should guide a reform of prostitution laws:

- removing provisions that make it difficult for sex workers and their clients to take steps to protect themselves against infection;
- encouraging responsible behaviour by workers and clients;
- alleviating the stigma associated with the industry;
- promoting conditions within the culture of the sex industry to permit and encourage safer sex activities; and
- improving working conditions within the industry.

In addition, the report recommends decriminalization of prostitution and state regulation of working conditions. While many authors support decriminalization, they emphasize that soliciting for the purpose of prostitution should not be legalized (legalization is defined as the legal recognition of prostitution with full government control). One Canadian lawyer stated:

> I'd like to see women being able to work out of their own homes. That would be the ideal situation, both for safety and for dignity. But I don't want to see prostitution legalized.

In her view, in every jurisdiction where prostitution has been legalized, "control has been taken away from the women and they experience oppressive working conditions."904

## Conclusion and Recommendations

> Laws under which prostitutes may be required to refrain from specific conduct, undergo specified treatment or counselling, submit to supervision, undergo

> treatment while detained, or, if infected with HIV, be detained during the operation of the order, may be counterproductive: "Prostitutes will not come forward for public testing for HIV infection. Clients are absolved of any responsibility for using safe sex methods because the effect of the legislation leads them to assume that working prostitutes will be `clean'."905

Mandatory or compulsory testing of sex workers or other coercive measures directed at them will do little to prevent the spread of HIV among sex workers and to clients. As has been said,

[p]lacing the major burden for HIV prevention on prostitutes themselves may not be [the] most effective tactic. Economic dependence and gender power imbalances can make it nearly impossible for prostitutes to demand safer sex.906

Rather than such measures, interventions are necessary that would give sex workers the means to protect themselves against HIV transmission and would empower them to use them. This will also necessitate an analysis of the impact of laws regulating and/or penalizing prostitution on efforts to prevent HIV infection.907

> **9.1 Mandatory or compulsory testing of sex workers and other coercive measures directed at them will do little to prevent the spread of HIV among sex workers and to clients. Rather than undertake such measures, policymakers must consult with sex workers to develop policies that will truly prevent and reduce the spread of HIV.**
>
> **9.2An analysis of the impact of municipal, provincial and federal policies and laws regulating and/or penalizing prostitution on efforts to prevent HIV infection should be undertaken, and alternatives to current regulation recommended.**

## HIV Testing of Health-Care Workers

> The issue of HIV infected HCWs [health-care workers] has attracted widespread publicity. As a political issue, it cannot be ignored, and while it also impacts upon individual rights and livelihoods as well as public confidence in the health care system, it is also largely irrelevant to the public health goal of minimising HIV transmission. If all HIV infected HCWs were excluded from practice, this would have, in numerical terms, virtually no impact upon the epidemic.908 While the issue deserves attention, therefore, one hopes that it does not overshadow the continuing and difficult issue of achieving behavioural change in sexual and drug-taking practices, because this is what will really make a change to the profile of the epidemic in Australia [and Canada].909

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. In July 1990, the American Centers for Disease Control (CDC) reported the first such case. Transmission appeared to occur during an invasive procedure performed by a dentist in Florida.910 In 1991, CDC reported that four other patients may possibly have been infected by the dentist. Experts have remained puzzled by the case.911 In one patient, the period from first dental visit to AIDS was less than two years, which would be an exceptionally short latency period, and has raised the question of possible earlier acquisition of HIV by the patient from an unidentified source outside the dental practice.912 It also seems that some of the patients who allegedly contracted HIV from the dentist had risk factors for HIV infection other than being patients in his dental practice, that the dentist did not use universal precautions or standard methods of sterilizing equipment, and that the dentist was known to have had sex with at least one of his patients.913 But it was this case and, in particular, the near-death testimony before Congress of one patient, Kimberly Bergalis, in which she denounced those who had failed to protect her, "that forced the issue of infected doctors on to the agenda of AIDS policy."914 As Mauth has stated,

> no explanation could reduce the hysteria that followed Kimberly's death. The public demanded government action and in many jurisdictions, they got it.915

In January 1997, the French health ministry announced that a French surgeon had "almost certainly" infected a patient during an operation at a hospital near Paris. After the surgeon informed the French authorities that he was HIV-positive, the authorities contacted 5000 people he had operated on since 1983, when the surgeon is believed to have become infected. Of 986 people who responded and have been tested, one woman was HIV-positive.916

These cases (and other cases of HIV-positive surgeons or dentists where no transmission to patients has been documented) have provoked considerable public anxiety. It seems to matter little that the estimates of the risk of HIV transmission are "vanishingly small":917 1/40,000 to 1/400,000 from HIV-positive surgeons and 1/200,000 to 1/2,000,000 from HIV-positive dentists.918

The cases raise the following issues and questions:

> Given that there is some risk, however small, of transmission of HIV from a health

care worker to a patient during the practice of invasive procedures:

- Is it appropriate to require that HIV-infected health care workers refrain from performing invasive procedures? Or certain specific invasive procedures where the risk is believed to be greater?

- Should HIV-infected health care workers be required to inform their patients of their status before performing invasive procedures?

- Is it appropriate to require mandatory testing of health care workers who perform invasive procedures in order to ensure (a) that they refrain from engaging in such procedures; and/or (b) that they inform their patients of their status before engaging in such procedures?919

The related issue of transmission of HIV from patients to health-care workers will not be addressed in this report, although there are a number of documented cases where health-care workers have contracted HIV as a result of occupational exposure.920 As a result, there have been repeated calls for the mandatory testing of patients, particularly hospital or surgery patients, in the hope that such testing might reduce the risk of transmission to health-care workers. On the whole, however, such calls have been rejected, on the grounds that the most effective means to prevent HIV transmission in the health-care setting is the use of universal precautions, not the testing of patients. Repeatedly, it has been established that identifying HIV-infected patients will do little if anything to reduce the risk of infection. In fact, the vast majority of cases of occupational exposure and infection have occurred when the health-care worker in question was treating a person for an AIDS-related condition, and the patient’s HIV status was already known by the health-care worker.921

## History

### Canada

Canadian organizations that have expressed themselves on the issue of whether health-care workers should be mandatorily tested for HIV have all rejected such an approach. However, most recently, extremely controversial recommendations have been published by the Laboratory Centre for Disease Control (LCDC) of Health Canada, including recommendations that

- immunization for hepatitis B should be mandatory for health-care workers "who perform or will perform exposure-prone procedures";922

- all health-care workers who perform exposure-prone procedures have an ethical obligation to know their serologic status with reference to HIV and hepatitis B and C; and

- health-care workers who perform exposure-prone procedures and who learn that they are infected with a bloodborne pathogen are "ethically obligated to report the fact to their profession's regulatory body, e.g. the College of Physicians and Surgeons of Canada or the College of Nurses in accordance with provincial regulations, or to the local public health agency or occupational health service if their profession does not have a regulatory body."923

In one of the first statements on the issue, the National Advisory Committee on AIDS said in 1988 that there was no evidence to indicate that patients might be at risk of HIV infection from HIV-positive health-care workers and concluded that "compulsory or mandatory HIV antibody testing to prevent HIV transmission from personnel to patients is unwarranted for health care personnel."924 In April 1991, the Canadian Dental Association announced a preliminary policy stating that infected dentists need not refrain from performing invasive procedures and need not inform their patients of their HIV status. The CDA concluded that the risk of an infected dentist transmitting HIV to a patient "is so small that it becomes irrelevant."925 In August 1991, the policy was endorsed by the CDA's Board of Governors. In December 1992, national recommendations were published from a national "Consensus Conference" and a series of meetings organized by LCDC on issues relating to the transmission of hepatitis B and HIV from health-care workers to patients in the health-care setting. In 1995 and 1996, these recommendations were extended to hepatitis C.926 The recommendations included the following key points:927

- Mandatory testing of health care workers is not justified.

- Health-care workers who have had a previous significant exposure or who have personal risk factors should be encouraged to voluntarily seek HBV and HIV testing.

- Following a significant exposure to a patient's blood or other high-risk body fluid, voluntary testing of health-care workers is recommended if (1) the source patient is known to be infected; (2) epidemiological evidence suggests possible infection; (3) the source patient is unknown, is unable to consent to testing, or refuses testing.

- Health-care workers have a moral and ethical obligation to be tested following a significant exposure by a patient to a health-care worker's blood or high-risk body fluid if the health-care worker's serological status is unknown.

- Any health-care worker with an infectious disease that could put a patient at risk is encouraged to voluntarily seek medical evaluation with respect to the potential for transmission of the infection to patients.

- Medical evaluation of an infected health-care worker should be the responsibility of the

> health-care worker’s primary care physician. Primary care physicians who care for HBV- or HIV-infected health-care workers are encouraged to seek advice on assessment of risk for transmission of infection in the health-care setting through an established consultation mechanism.
>
> • A consultation mechanism that can be easily accessed by a primary care physician should be established, ideally in each province. This mechanism should ensure confidentiality and allow for input from public health, licensing bodies and/or professional associations, experts in infectious diseases and infection control, and others as judged appropriate in the situation. Participants in this process need not know the health-care worker’s identity.
>
> • Criteria used to assess seropositive health-care workers should include a medical evaluation, knowledge, application of infection control practices, and risk for injuries from sharp objects in the context of the individual’s occupation.
>
> • Supportive nonthreatening programs should be developed to assist seropositive health-care workers whose practices are modified because of their infection status.
>
> • Routine disclosure of an infected health-care worker’s serological status is not justified.
>
> • The patient should be notified when a significant exposure to an infected health-care worker has occurred. There is no need to disclose the identity of the source of the exposure.

In addition, at the meetings, "[i]t was accepted that similar recommendations would apply to the testing, disclosure and management of patients."928

Since 1992, these recommendations have been widely accepted and endorsed by other organizations that have analyzed the issues raised by health-care workers with HIV and other bloodborne pathogens, including the Canadian AIDS Society, the Ontario Law Reform Commission, the Canadian Public Health Association,929 the Canadian Medical Association, and the Canadian Human Rights Commission.930 These organizations have all concluded that

> no exception to a general rule requiring voluntary, specific, and informed consent is justified respecting health care workers. The prevention of transmission in the health care setting is best furthered by strict adherence to universal precautions and the promotion of appropriate infection control procedures.931

The Canadian Medical Association’s "principles and recommendations on HIV in the general and health-care workplace" emphasize that

> [h]ealth care workers must act as competent professionals and take reasonable care not to transmit HIV or other pathogens to patients. At the same time, the rights of health care workers must be protected against wrongful discrimination on the basis of HIV or AIDS status, or perceived status.932

While they state that the routine testing of health-care workers for HIV is not justified, they recognize that "patients and health care workers have the right to be protected with the use of reasonable infection-control procedures." Therefore, the CMA supports the application of universal precautions that enhance the protection of health-care workers against potential infection from patients and vice versa. Finally, the principles and recommendations emphasize that health-care workers living with HIV or AIDS "should be afforded the opportunity to compete for jobs and to continue to work at their usual occupation as long as they meet acceptable performance standards and are mentally and physically able to perform the essential components of work safely, efficiently and reliably."

Despite this broad consensus, in May 1994 the College of Physicians and Surgeons of Ontario adopted a new policy that, while it did not require compulsory HIV testing of physicians, required mandatory reporting of the identity of infected physicians by their treating physician.933 As a result of a challenge brought by a Toronto physician, the policy was suspended in May 1994.934 In an article published in the *Canadian Medical Association Journal* in 1995, the physician who brought the challenge argued that "mandatory reporting of HIV-infected physicians would not protect the public from undiagnosed HIV infection," and that "the best way to protect the public from the spread of HIV in the health care setting is by strict adherence to universal precautions and the voluntary use of an expert advisory panel on an anonymous basis":

This is because the risk of acquiring HIV infection from a health care professional is very low. Mandatory reporting of infected physicians and reliance on expert panels that could ban doctors from performing certain procedures does not address the problem of undiagnosed HIV infection and would only lead to fewer HIV-infected physicians getting treated and to repeated mandatory HIV testing of all patients. There are also many dangers involved in setting up panels empowered to restrict physicians’ practices. In addition, it would be impossible to develop a list of "exposure-prone" procedures from which to ban doctors who are infected.935

Finally, an article on the Charter implications of compelling dentists to reveal their HIV status concluded that a policy requiring HIV-positive dentists to disclose their status to their governing body would be discriminatory, violating section 15 of the Charter, and could not be justified under section 1 of the Charter as a reasonable limit in a free and democratic society.936

## International Developments

In the United States, CDC guidelines issued in 1991 rejected mandatory testing, advocated universal precautions, yet provided that health-care workers who perform exposure-prone procedures should know their HIV/HBV status, and that those infected with HIV/HBV should not perform exposure-prone procedures except under the guidance of and in accordance with any restrictions laid down by an expert review panel.937 These guidelines were opposed by a number of professional medical organizations on the basis that the low risk of transmission did not justify restricting the practices of HIV-positive health-care workers.938 No professional body agreed to draw up a list of "exposure prone invasive procedures," and the CDC revised its guidelines, recommending that health-care workers performing "invasive surgical, dental or obstetric procedures" should know their HIV status. The new guidelines recommend that expert review panels should decide on an individual basis which invasive procedures an HIV-positive health-care worker may perform.939 US federal legislation requires each state to adopt the CDC guidelines or their "equivalent" as a condition of receiving federal Medicaid and Medicare funds.940 In addition, several courts have held that health-care professionals have a duty to disclose their HIV status to patients or health authorities, assuming that their professional activities pose a risk of transmission to patients.941

In Australia, as of 1995, the NSW Health Department’s draft guidelines on HIV/HBV-infected health-care workers did not recommend disclosure to patients but prohibited infected health-care workers from performing exposure-prone procedures. At the time, there were no relevant restrictions in any other state.942

In the United Kingdom, health-care workers who test positive for HIV, HBV and HCV infection are required to stop performing invasive procedures.943

## Current Situation

As mentioned above, new recommendations on infected health-care workers were published in July 1998 by LCDC. The recommendations were accepted by a majority of participants at a so-called consensus conference on infected health-care workers that was held in Ottawa on 19 and 20 November 1996.944 The goals of the conference were to increase the understanding of the epidemiology of the transmission of bloodborne pathogens from infected health-care workers to patients, and to update and/or create a set of guidelines, principles or models to prevent and manage the transmission of bloodborne pathogens from infected health-care workers to patients.

The following specific issues were addressed:

- risk analysis of the modes and means of transmission of bloodborne pathogens from health-care worker to patient, from a Canadian perspective;
- assessment of active and passive measures to prevent transmission from health-

care worker to patient;

- confidentiality and issues of disclosure;
- methodologies for the surveillance of transmission from infected health-care worker to patient;
- effective and appropriate practice modifications; and
- retraining and support of the health-care worker infected with bloodborne pathogens.

The new guidelines do not recommend that health-care workers be mandatorily tested for HIV. However, as mentioned above, they otherwise differ significantly from the 1992 guidelines. The recommendations in the guidelines were supported by a majority of participants in the "consensus conference," but serious concerns about them have been raised by both the Canadian Medical Association and the Canadian Dental Association, which requested that the guidelines not be published. In the end, after consulting with conference participants, LCDC decided to go ahead with the publication of the guidelines, but to provide CMA and CDA with an opportunity to respond. Thirty-seven percent of conference participants who responded to LCDC's request had said that they did not want the recommendations published until CMA's and CDA's concerns had been addressed, 33 percent wanted the recommendations published with an acknowledgment of CMA's and CDA's concerns, 8 percent wanted the recommendations published and gave direction to seek added input from CMA and CDA, and 22 percent wanted the recommendations published as they are.945

In its response to the recommendations, CMA states that it "believes that the claim to consensus coming out of the conference is misleading."946 It continues by saying:

> The recommendations in these proceedings supersede the ones published in 1992 and diverge from them in important respects. CMA does not support the new recommendations. In the move from a voluntary system of immunization and screening to a mandatory one in the case of hepatitis B, and by the introduction of a new system of management for all health care workers known to be infected with hepatitis B virus (HBV), hepatitis C virus or human immunodeficiency virus, important rights of privacy, confidentiality and autonomy will be infringed upon, and new burdens and responsibilities imposed. The revised recommendations are not explicit about why it is thought that these changes are necessary or justified. CMA does not believe they are.947

In addition,

> CMA considers that health-care workers have a responsibility to know their

> serologic status if they put patients at significant risk. This responsibility is grounded in the principle of medical ethics, "do no harm". The health care system does and must rely to a considerable extent upon the moral integrity of health care workers. A voluntary approach incorporating an explicit appeal to professional responsibility would draw on the individual moral integrity of every health care worker.948

Finally, CMA stresses that "further gains in risk reduction could be made if an intensive voluntary approach were coupled with improved use of universal precautions or the use of other prophylactic measures."949

In addition to the concerns raised by CMA, the CDA notes that "the recommendations for mandatory testing of practitioners and related requirements for practitioners to show proof of seroconversion are impractical because of potential legal challenges and other serious difficulties that would follow implementation."950 The Association points out that it has obtained a preliminary legal opinion suggesting that provisions for mandatory testing or proof of seroconversion could be challenged under the Charter: "Professional regulatory authorities will accordingly be faced with the LCDC report's recommendations on the one hand, and on the other the possibility of legal challenges if they choose to follow them."951 It emphasizes that there have been no reported cases of transmission of hepatitis B from dentist to patient since 1986 and comments that "[i]t is difficult to justify mandatory immunization of dentists when it is apparent that voluntary approaches are practical and can work."952 The Association concludes by saying that, despite the concerns noted, it views the proceedings of the "Consensus" Conference as "an indication of a *need for re-emphasis upon voluntary approaches, directed by professional regulatory authorities, to the prevention of transmission of disease from practitioner to patient*." [emphasis in the original]

In a submission to the College of Physicians and Surgeons of Ontario, which initially supported the recommendations coming out of the "Consensus" Conference, and was "soliciting feedback on ideas for implementation,"953 the AIDS Committee of Toronto and AIDS ACTION NOW! also expressed their opposition to the recommendations, saying that, if implemented, they would be "destructive to public AIDS education, public confidence in their health care providers, the livelihood and dignity of physicians and the care of patients with blood borne infections."954 The organizations said:

> The recommendations are correct to take a stand against mandatory testing for HIV/AIDS. ... It is also reassuring to see the recommendations not move in the direction of notifying patient of their health care worker's status. ... However, the ethical obligation to "report" to an expert panel is equivalent to mandatory reporting and this is unwarranted and counterproductive. The recommendations do not provide any justification for this. There is no epidemiological evidence provided in the LCDC report that comes close to justifying a "continuous and comprehensive monitoring program". To develop and implement such a punitive

> policy, the College should at least be on firm scientific, medical ground."955

They concluded by emphasizing that health-care workers with HIV "do not want to place the public at risk," and that they "and their health care providers should be more fully engaged in developing solutions, real solutions that relate to the real size of the problem."

## Assessment

### "Hotel" Functions in the Health-Care Workplace

As Gilmore has stated,

> [f]or many health care providers, their work does not represent a risk to them from infected patients nor a risk to the public when they are infected. So called "hotel" functions in the health care workplace do not differ from other, general workplace situations. This work is not associated with a risk of being exposed to HIV or of exposing others to HIV.956

Therefore, HIV testing of these health-care workers and imposing restrictions on those testing HIV-positive is not justified. As Magnusson has stated, "[i]n view of the fact that procedures which are not exposure prone ... are not considered to pose any risk of HIV transmission, no one seriously suggests that healthy, HIV infected HCWs should be excluded from practising their profession."957

### Invasive Procedures

> The risk of HIV transmission in the health care workplace arises from performing invasive procedures. However, it is not invasive procedures, themselves, which create this risk but accidents during such procedures which result in parenteral exposure. Fear of being exposed to HIV, workplace education, and stringent application of universal precautions has undoubtedly reduced the incidence of exposures to blood and infectious materials and the risk of HIV transmission. Nevertheless, this has not eradicated risk entirely.958

Those who argue against mandatory testing of health-care workers who perform invasive procedures have emphasized that the risk of transmission from an HIV-positive health-care worker to a patient is extremely low, even in the case of invasive procedures.959 As stated by the chairman of the ethics committee of the CDA, the risk is "infinitesimal."960 In contrast, proponents of testing argue that although the risk of transmission is very low, it is within such a range that public health should urge that certain precautions be taken; and that the consequences of HIV infection are uniformly serious, if not fatal, thereby justifying coercive and costly measures to prevent transmission.961

However, an effective public health response need not necessarily involve mandatory testing and exclusion. As stated in the 1992 LCDC guidelines,

> a mandatory testing program for health care workers would not materially change the already extremely low risk for patients to acquire HBV or HIV infection in health care settings. In view of the risk, mandatory testing would be an unjustified measure that would violate the rights of individual privacy, and could result in acts of discrimination. The existence of such a testing program would likely have a major negative influence on the delivery of service and the training of health care workers in proper infection control practices because it would use scarce resources currently devoted to these high priority activities. There is also no scientific consensus on how often testing should be repeated if such a program were initiated.962

While LCDC has since changed its recommendation with regard to hepatitis B – an extremely controversial move, as shown above –the above statement remains valid. For all the reasons mentioned in it, mandatory HIV testing is impractical and unjustified. Instead, 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. However, this does not necessitate the introduction of a new system of management for all health-care workers known to be infected with HBV, HCV or HIV. As CMA and CDA have convincingly argued, such a system is neither necessary nor justified. As Roy has emphasized,

> [t]here seems to be no justification for drastic, radical approaches ... The general idea is: let the decision match the risk.963

According to Roy, three "essential considerations" need to be taken into account:

- HIV-positive physicians and surgeons, and their patients, can be best helped by creating a nondraconian, confidential, and sympathetic environment that encourages them to seek help;

- HIV-positive physicians, particularly those whose specialty requires that they perform invasive procedures, should seek specialist advice on the extent to which they should limit their professional practice in order to protect their patients. HIV-positive physicians and surgeons should not continue their practice solely on the basis of their own assessment of the risk they pose to patients.

- Restricting HIV-positive surgeons only from practising certain particularly high-risk

> procedures, not from practising surgery altogether, may offer patients sufficient protection.964

Newspaper reports have suggested that in adopting the 1998 policy "the government, apparently trying to learn from the mistakes of the tainted-blood scandal, has adopted an aggressive stance in favour of public health."965 While it is not surprising that governments would use such arguments to justify the proposed change in policy, the situation here is not at all comparable to the situation that led to the Krever Inquiry. Recommendations about how best to protect the public from infected health-care workers have existed since the early 1990s, and no evidence has been provided to justify changes to those recommendations. In contrast, in the mid 1980s, the blood system failed to act or to act quickly enough despite overwhelming evidence that changes were required. In addition, it would seem that the argument that the government must learn from the mistakes of the past and adopt an aggressive stance in favour of public health is being used selectively. Talking about the situation in the US, Bayer has pointed out that "those who had opposed simple measures like needle exchange for injecting drug users – a policy that might have prevented thousands of infections – suddenly argued that any measure that might prevent even one infection (such as testing all doctors and debarring all those who were seropositive) was morally imperative."966 In Canada, governments that argue that we must learn from the mistakes of the past and adopt an aggressive stance in favour of public health, rather than adopting recommendations for which there is little or no justification, such as some of the 1998 recommendations on infected health-care workers, should be prepared to adopt policies that have been proven to prevent infections and would have a much bigger impact on public health, but are politically more controversial. However, in those contexts, the argument has not been used.

### Conclusion and Recommendations

As Silverman has said, "if we get into testing, patients will suffer, health care workers are going to suffer, and health care is going to suffer – and for all that we will not have reduced the risk at all."967

> **10. Mandatory testing of health-care workers is not justified. Instead, all health-care workers who practice invasive procedures should regularly monitor their HIV status. If infected, they should seek advice about whether they need to limit their professional practice in order to protect their patients. 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.**

## HIV Testing of Immigrants

**(For more information and an update on this section, see the Legal Network's 2001 report, *HIV/AIDS and Immigration: Final Report*, available at http://www.aidslaw.ca/Maincontent/issues/immigration.htm).**

The issue of whether all immigrants to Canada should be tested for HIV and, if HIV-positive, automatically or only under certain circumstances be barred from immigrating to Canada, remains controversial. Opinion is widely divergent. Some, such as Reform MP Art Hanger, have issued a call for mandatory testing of all candidates for permanent residence in Canada, and denial of status to all candidates who test HIV-positive, including refugees. In addition, Hanger has demanded that temporary visitors living with HIV be barred from entering Canada.968 A motion introduced by Hanger, proposing the HIV testing of all applicants for residence in Canada, was however defeated in the House of Commons in September 1994.969 Then Immigration Minister Sergio Marchi stated that barring HIV-positive visitors was "going too far," but announced that he was reviewing the issue of whether immigrants should be tested.970 Others, such as many working in the area of HIV/AIDS and/or in the fields of human rights and disability rights, urge that would-be immigrants to Canada not be rejected on the basis of their HIV status.971

## History

### Canada

In Canada, some of the individuals and organizations who have expressed themselves on the issue have supported compulsory or mandatory testing of would-be immigrants and exclusion of those testing positive. For example, the Canadian Bar Association –Ontario stated that there are "very good arguments" in favour of requiring testing of potential immigrants, "given that the opportunity to immigrate to Canada is a privilege and not a right, given that it is a legitimate criterion for immigration that the individual be reasonably expected to contribute to Canadian society," and given that there is a high chance that HIV-positive individuals will impose significant costs on Canada's health-care systems.972

Most other individuals and organizations have, however, rejected compulsory or mandatory testing and automatic exclusion of HIV-positive would-be immigrants. According to the National Advisory Committee on AIDS, compulsory or mandatory testing is unwarranted, particularly for persons entering Canada for short periods of time, but also for those entering Canada for longer periods who are or may be eligible for health-care benefits.973 The Committee acknowledged that entry into Canada of HIV-positive persons who are or will become eligible for Canadian health-care benefits could represent a potentially major burden for Canadian health and welfare systems, and that exclusion of such persons would diminish the additional cost of HIV disease in Canada attributable to these persons. However, it held that, in assessing the issue of HIV testing of persons seeking permanent residence in Canada, serious deficiencies in relevant and necessary knowledge were apparent, including lack of information on the potential number of persons who might be excluded on the basis of their HIV status, and on the potential health-care burden that may result for Canada if HIV-positive persons were not excluded; and uncertainty in determining who among HIV-positive persons might become ill or die, or when this might be likely to occur.

Furthermore, the Committee expressed concern about the potential harm to applicants that could result from being tested outside Canada, "including the suffering, disadvantage and discrimination that testing can produce and the potential difficulty in verifying the accuracy of HIV antibody testing outside Canada."974 The Committee concluded that there was an urgent need for more information on HIV infection and its outcomes among persons who apply to immigrate to Canada, and on its economic impact upon Canadian health and welfare systems.

The results of a study assessing the economic impact of HIV testing of all potential immigrants on Canada’s health-care system was published by Zowall et al in 1990. The authors estimated the costs and benefits that testing of the 160,135 immigrants who entered Canada in 1988 would have had. They concluded that testing would have saved $1.7 to $13.7 million over the ten years after immigration. However, they did not advocate testing on the basis of economic analysis alone and acknowledged that any policy regarding testing "must also incorporate social, legal and ethical considerations."975 Such considerations led others who have analyzed the issue – in particular, the Royal Society of Canada and Margaret Somerville, then Director of the McGill Centre for Medicine, Ethics and Law –to reject proposals calling for testing of all persons seeking permanent residence in Canada. The Royal Society stressed that testing of immigrants would not be likely to prevent the spread of HIV, and concluded that a "legitimate concern about an increased burden on the taxpayer to fund the health-care system should not justify a denial of entry to a seropositive but healthy individual":

> An asymptomatic seropositive individual may not be suffering a present health impairment and ... it is unlikely that the individual will be known to be a danger to public health; nor can it be known that any individual will develop AIDS or create any demand on health or social services. We believe that only the current health of an immigrant should be considered.976

Somerville first pointed out that it would be totally irrational to exclude HIV-positive immigrants on the grounds that they constitute a danger to public health and safety. She then focused on the second ground in the *Immigration Act* for excluding immigrants who are HIV-positive – that they would or might reasonably be expected to place excessive demands on Canadian health or social services. Somerville emphasized that it is difficult to determine what excessive means:

> [A]ll of us, including immigrants, will at one time or another probably place some demand on the Canadian health care system. Whether the cost of that demand is excessive, assuming the cost of the demand is the relevant criterion, is a value judgment.977

She pointed out that an "immigrant who may be more productive than the average person, could contribute more in 5 years of work within Canada than that person could cost, even if he or she were to become ill and die of HIV-related disease." She posed two questions: "Would this net benefit to the Canadian economy mean that such a person should not be considered an excessive cost to the health care system? Therefore, should people with at least a 5-year life expectancy not be regarded as inadmissible as immigrants on medical grounds?" In the end, Somerville provided four major arguments against mandatory testing of immigrants978 and concluded by saying that "Canada could provide an important, indeed critical, example to the rest of the world if it is prepared to state that the potential costs, in economic terms, to care for people admitted as immigrants who later develop HIV-related illness are more than compensated for by the values – humaneness, humanitarian concern and respect for human rights – that we wish to uphold in *choosing* not to test asymptomatic prospective immigrants for HIV antibodies."

## International Developments

Restrictions on the travel and immigration of HIV-positive people have become a "significant feature in the response to the AIDS epidemic by a growing number of countries around the world."979

Travel restrictions in particular have been heavily criticized. According to Gilmore et al, the possible harmful or adverse consequences of exclusionary policies include: labeling and exclusion of "false positives"; fostering of a black market in counterfeit certificates of HIV-antibody seronegativity; disruption of commerce, labour migration, educational exchange, tourism and other travel-related activities that are essential to the economies of some countries; costs of administering these policies or laws, including those of testing itself; disruption of family reunification; abrogation of the rights of refugees; disregard for the International Health Regulations and national and international human rights law; wrongful discrimination on the basis of national origin, sickness or disability, or sexual orientation; stigmatization of persons with HIV infection or AIDS rather than of risk-producing activities; creation of a false sense of security among nationals that their country is or will become "HIV-free" because positive travelers are being excluded; and diversion of resources from effective national prevention efforts.980

According to the International Guidelines on HIV/AIDS and Human Rights,

> [t]here is no public health rationale for restricting liberty of movement or choice of residence on the grounds of HIV status. According to the current international health regulations, the only disease which requires a certificate for international travel is yellow fever [reference omitted]. Therefore, any restrictions on these rights based on suspected or real HIV-status alone, including HIV-screening of international travellers, are discriminatory and cannot be justified by public health

> concerns.
>
> 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, as opposed to comparable conditions, 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.981

## Current Situation

Canada

### 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 the country: 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/AIDS represented a danger to public health. It was government policy that they should not be allowed to visit Canada. An exception was made for the V International Conference on AIDS in Montréal in 1989; people with HIV/AIDS were allowed to enter the country to attend the conference.

In April 1991, the Ministers of Health and Welfare and Employment and Immigration jointly announced a new policy for short-term visitors. The policy stated that a person with HIV/AIDS did not constitute a threat to public health during short-term travel to Canada, and henceforth would be treated like any other visitor to Canada. Those who "posed a risk of becoming a significant burden on the health care system while in Canada would still be generally inadmissible, or at least subject to a medical assessment, but the new policy effectively means that asymptomatic HIV-positive people entering Canada for a short term visit (less than six months) should not be denied entry or encounter trouble at the border because of their HIV status."982

However, even after the new policy was announced, there were a few instances of people with HIV/AIDS being denied entry to Canada:

The new policy got off to a rocky start when an American man, Craig Rowe, alleged that he was denied entry for a three-day visit to Montreal on 29 December 1991. He is suing the government, alleging that an immigration officer told him that he posed a risk of becoming a burden on the health care system because he was HIV-positive. This was despite Mr Rowe's being in good health, having private medical coverage, and possessing a return ticket indicating that his intended visit was very brief.983

Immigration officials later acknowledged that more training of border personnel was necessary to ensure uniform application of the short-term visitor policy.984

On 3 August 1994, then Minister of Immigration Sergio Marchi wrote to CAS clarifying the government's policy. According to Minister Marchi:

- a diagnosis of HIV/AIDS is not in itself a barrier to visiting Canada;
- persons living with HIV/AIDS do not generally represent a danger to the public under s 19 of the *Immigration Act*;
- the issue is therefore whether visitors living with HIV/AIDS would place excessive demand on the Canadian health-care system;
- it is not normally expected that visitors with HIV would place any demand on the health-care system;
- therefore, for the vast majority of short-term visits by persons living with HIV/AIDS, the excessive demand criterion would likely not be invoked;
- the excessive demand criterion will only be invoked if there is reason to believe a person would need medical treatment while in Canada, although even in this case a person may still be able to enter the country if he or she had made arrangements for treatment and payment;
- the carrying of HIV/AIDS medication is not a ground for refusing admission; and
- the government will provide immigration officers with thorough information on the travel policy and implement a training program on HIV/AIDS for immigration officers.

This policy is still in place and is unlikely to change in the near future.985 Implementation of the training program referred to in the Minister's letter was completed before the XI International Conference on AIDS in Vancouver in July 1996.986

### Canada's Immigration Policy

People 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 their admission must not place excessive demand on Canada's health and social service systems.

Currently, 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. Therefore, immigration applicants who are found to be HIV-positive are assessed as "medically inadmissible" and will not normally be allowed to immigrate to Canada.

*Testing*

At the present time, however, some asymptomatic HIV-positive immigrants may not be detected because "a screening test for HIV is not required as a routine"987 during the medical examination that applicants for immigration to Canada have to undergo to determine their health status.988 The examining physician may require an immigration candidate to take an HIV test.

As part of a pilot project, examining physicians in Canada were given instructions that "[c] ountry of origin, race, gender, and sexual orientation, by itself, is NOT a sufficient reason to warrant a screening test for HIV" (emphasis in original). HIV testing (after counselling) is required only "when clinically indicated." The instructions continued by saying that the "age of the applicant should be taken into account when assessing these indications for an HIV test – common sense and a realistic estimation of risk should prevail." They contained the following "partial list of possible indications" for requiring an HIV test:

> (1) The applicant has a history of receiving unscreened blood transfusions or blood products or the equipment used was reusable with inadequate sterilization
>
> (2) The applicant has unexplained significant weight loss
>
> (3) The applicant has used intravenous drugs at some point in the past – especially if the needles were shared
>
> (4) The applicant's history/physical examination is consistent with an AIDS defining condition
>
> (5) The applicant has X-ray evidence of a prior TB infection and is at risk of having acquired the human immunodeficiency virus (e.g. unprotected sexual intercourse with prostitutes)

> (6) The applicant's biologic mother is HIV positive
>
> (7) The applicant has taken part in unsafe sexual practices where the HIV status of the sexual partner was known to be positive (or where it was reasonable to assume that the partner was HIV positive)
>
> (8) The applicant has reason to believe that he may be HIV positive989

In addition, according to the instructions, any child for adoption should be tested "where there is a significant likelihood that the HIV status of the biologic mother was positive at the time of the child's birth." In contrast, applicants for a "short term temporary visa to Canada should be asked to undergo HIV testing only if signs of the acquired immunodeficiency syndrome are present."990

However, these instructions have not become official policy. In practice, although "a screening test for HIV is not required as a routine" during the medical examination that applicants for immigration to Canada have to undergo to determine their health status, there are reports that at least some physicians test all applicants for immigration.991

In addition, it is expected that the policy according to which HIV testing is not routinely required during the medical examination may be reviewed in the near future. A report released by the Minister of Citizenship and Immigration, the Honourable Lucienne Robillard, on 6 January 1998, recommends, among other things, that

[r]outine medical tests to be taken by visitor and immigration applicants should be determined by the Minister of Health in consultation with the Minister of Citizenship and Immigration and provincial health ministers. The Immigration and Citizenship Act should direct the Minister of Health to table an annual report in Parliament establishing the testing regime for the coming year and stating the statistical outcomes of the previous year's medical examinations.992

The report, which contains 172 recommendations of an Immigration Legislative Review Advisory Group, a panel of independent consultants appointed by the government that began work in November 1996, points out that the tests required during the routine medical examination have been in place for over 40 years and that "it is generally agreed that the time has come to design a new set of tests which better reflect current realities and the state of technology."993 According to the report, establishing these new tests should be "a matter for the Minister of Citizenship and Immigration, the Minister of Health and the provincial ministers responsible for health."994 The report continues by saying that,

> [w]hile Citizenship and Immigration Canada must remain in control of the operational aspects of medical screening for the purposes of immigration, the Minister of Health should assume a central role in defining medical testing criteria.

> The Minister of Health should work with colleagues in provincial governments and with the Minister of Citizenship and Immigration to establish, on an annual basis, which tests are necessary for immigrants and visitors.995

The National Consensus Conference on Tuberculosis, held from 3 to 5 December 1997, after stating that it "must be acknowledged that tuberculosis in immigrants, refugees, visitors, students and those returning from countries where tuberculosis is endemic is the major issue for tuberculosis control and elimination,"996 also made a reference to HIV testing of immigrants, refugees, and visitors, saying that "[t]he control of tuberculosis in these groups must consider ... HIV screening ..."997

### *"Excessive Demand"*

Long before the Immigration Legislative Review Advisory Group started its work, development of new regulations regarding medical inadmissibility started. If adopted, they could affect the current situation whereby people known to be HIV-positive or to have AIDS are prohibited from immigrating to Canada. A first draft of the new regulations, published in August 1993, provided for a five-year "window of comparison" in assessing excessive demand:

applicants for immigration would be medically admissible where, over five years, they would not cost the Canadian health care system more than the average Canadian citizen or permanent resident. Thus "early" cases of HIV would be admissible to Canada.998

A revised draft of the regulations was expected to be published by the end of June 1995.999 However, the determination of medical inadmissibility is ongoing and it now seems "unlikely" that the five-year "window of comparison" suggested in the first draft of the regulations will be maintained.1000 At the same time, there is some indication that some people with HIV, although technically medically inadmissible, have been allowed into Canada on compassionate humanitarian grounds.1001

### Canada’s Policy with Respect to 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 self-declared person with HIV/AIDS has been allowed into Canada as a refugee.1002 In that case, the Immigration and Refugee Board granted refugee status to a Polish man persecuted because of his sexual orientation and HIV-positive status.1003 The decision was criticized by Reform MP Grant Hill, who claimed that Canada would become a magnet for people with serious medical conditions. Then Immigration Minister Marchi responded by pointing out that each claim for refugee status is considered individually.1004

## Outside Canada

Surveys have revealed that at least fifty countries restrict the entry of people with HIV or AIDS.1005 A January 1998 list of HIV Testing Requirements for Entry into Foreign Countries, compiled by the US Department of Foreign Affairs, lists 57 such countries.1006 A very limited number of countries, including the United States, go so far as to bar HIV-positive people from entering their country, even for short periods of time. Other countries require testing of all applicants for longer-term residence and provide for the exclusion of those testing HIV-positive. Still other countries provide for the testing of all applicants, but do not automatically exclude all those testing HIV-positive. The following text reviews the situation in Australia, the country that is best comparable with Canada in terms of its general immigration policies.

### Australia

In Australia, until 1994 no people with HIV had been granted permanent residence. However, in 1994 pressure from community organizations led to the introduction of a new system for considering applications from people with HIV. Australia now has a system that allows people with HIV permanent residence, in certain circumstances.1007

In 1989, the Australian government issued the first *National HIV/AIDS Strategy*, which contained the following statement:

> HIV testing will be required for applicants for permanent residence. This is not intended to have a significant impact on the spread of HIV infection, but HIV infection status, as with other medical conditions, is a factor to be considered when assessing applications on the ground that there are considerable potential costs to the Australian community. A positive result will not automatically exclude applicants from permanent residency; scope will be retained to approve applications where justified by compassionate or other circumstances.

However, between 1989 and 1993 no HIV-positive applicants were approved for residence, and a number of people were rejected solely on the basis of their HIV-positive status. It was only after a meeting of the Australian Federation of AIDS Organisations (AFAO) with the Australian Minister for Immigration and Ethnic Affairs that the policy guidelines on the assessment of HIV/AIDS were reviewed to ensure alignment with the government’s policy as announced in 1989. Since early 1994, quite a number of people with HIV have been granted permanent residence.

In contrast to Canada, in Australia all people aged 15 and over who apply for permanent residence, or for temporary residence of 12 months or more, are required to undergo an HIV test. Children under 15 are tested if they are adopted by an Australian resident and have a history of blood transfusions or have clinical signs of illness. The HIV test is part of the medical examination undertaken by all applicants for permanent residence.

As a matter of practice, a person who tests positive for antibodies to HIV will not meet the health requirements that apply to all classes of immigrants except refugee applicants applying within Australia. However, the health requirements may be waived in certain circumstances. Waivers are limited in scope and are available only for those applying under the following classes:

- spouse, including de facto spouse, of Australian citizen or permanent resident;
- interdependency, which includes a gay or lesbian partner of an Australian citizen or permanent resident;
- child of Australian citizen or permanent resident; and
- refugee and humanitarian applications.

If an applicant in any of these classes does not meet the usual health requirements, the Department of Immigration and Ethnic Affairs (DIEA) has an obligation to consider the question of whether to waive the health requirements.

The main issue in the waiver process is whether the granting of a visa to a person with HIV will likely result in undue cost to the community. In each case, the DIEA will obtain from the Department of Human Services and Health an estimate of the overall lifetime cost to public funds of treatment, care, social security, and housing. The figure used in 1995 was in the region of Can$240,000, but possibly less depending on the stage of disease progression.

In their decision-making process, DIEA officers are advised to take the following matters into account:

- the extent of social welfare, medical, hospital or other institutional care likely to be required in Australia;
- the educational and occupational needs of, and prospects for, the applicant in Australia;
- the availability of, and local demand for, the appropriate health, welfare, educational and employment services in the area of intended residence in Australia;
- the willingness and ability of a sponsor, other family member or other person or body to provide any special services and care at no public cost;
- the potential for deterioration in the applicant’s state of health, taking into account not only the known medical factors but influences such as the strains of adjustment to a new

environment, lifestyle, occupation, etc;

- the overall lifetime charge to Australian public funds.

The decision must weigh the estimated cost (a "negative factor") against the positive factors identified in the application. If the positive factors are stronger, the decision-maker may waive the health requirements and grant the visa.

According to the Australian Federation of AIDS Organisations (AFAO), the policy appears to be working satisfactorily. The Federation is not aware of any applicant since early 1994 who has been refused permanent residence solely on the basis of having HIV. Applications have been approved in the following circumstances: husbands and wives of Australian citizens and permanent residents; gay partners of Australian citizens and permanent residents; children of Australian citizens and permanent residents; and refugees.

Applicants with HIV are considered in the same way as applicants with other disabilities, such as heart disease. However, there are still many people with HIV – otherwise qualified to migrate –who cannot possibly qualify for residence under the present law.

## Assessment

> Canada has a strong commitment to human rights, but for most of us this is a commitment in theory rather than one that is regularly tested in practice. HIV transmission and AIDS present a test in practice of our real commitment to human rights; and how we meet the challenge in relation to immigration will provide a particular and important example in this respect.1008

## Canada’s Travel Policy

As CAS has stated, the current travel policy for persons living with HIV or AIDS

> is the best that we will be able to obtain. The government will not provide an absolute guarantee that every person living with HIV/AIDS will be allowed to visit Canada. It insists that all visitors, including persons living with HIV/AIDS, meet the two medically-related criteria in the *Immigration Act* and that each visitor be assessed against these criteria.1009

In particular, then Minister Marchi’s letter to CAS of 3 August 1994 provided clarification of Canada’s policy, including a clear statement that people will not be excluded on the basis of their HIV status and that the vast majority of people with HIV/AIDS will be able to visit Canada; a commitment to communicate the policy to immigration officials; and a commitment to undertake HIV/AIDS training for immigration officials.

## Canada's Immigration Policy

Canada needs to be congratulated for not having mandated HIV testing of all prospective immigrants. However, the blanket exclusion of all immigrants *known* to be living with HIV or AIDS is inappropriate.

### Testing

For many reasons, Canada should continue its current policy of not automatically requiring HIV testing of all prospective immigrants. Somerville well set out these reasons:

> - [J]ust because a test is available does not mean that its use is acceptable or even more so that it should be used. Many tests that will become available probably should not be used for screening immigrants, or people in many other circumstances, because the harm involved, whether to those tested or to the values of our society, is not outweighed by compensating benefits.
>
> - Second, to institute such testing could appeal to and confirm the deepest prejudices of people who are opposed to anyone they perceive as unlike themselves, of whom immigrants are often considered to be a prime example.
>
> - Third, in an era when many countries are closing their borders to both immigrants and visitors on the basis of their HIV antibody status, Canada could stand out as an enlightened example to the contrary.
>
> - Fourth, there are technical-humanitarian concerns that support the argument against mandatory HIV testing of asymptomatic prospective immigrants. ... [An important] issue would be the effect on people identified as being HIV antibody positive who lived in countries with coercive legislation ...

Somerville concluded by saying that "[e]ven if it costs Canada some money for additional health care because some HIV-infected immigrants are admitted, what Canada could achieve by not requiring mandatory testing for HIV antibodies among asymptomatic prospective immigrants would far outweigh any losses that such testing involves."1010

It is acknowledged that the opportunity to immigrate to Canada is a privilege and not a right, and that it is a legitimate criterion for immigration that a prospective immigrant be reasonably expected to contribute to Canadian society. It is further admitted that HIV-positive people will impose costs on Canada's health-care systems. Nevertheless, as shown by Somerville, mandatory testing is unwarranted. Immigrants would be the first and – because of constitutional guarantees applying to Canadian residents that disallow involuntary testing except in very limited circumstances – 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, who would be perceived as a group at high risk of HIV when there is no evidence that HIV is in fact overrepresented among immigrants to Canada. In addition, while mandatory testing of all immigrants would be the only way to identify *all* prospective immigrants living with HIV, immigrants are already being screened for HIV and many are asked to undergo HIV testing. Therefore, it is likely that a majority of immigrants living with HIV are already being identified, without mandatory testing of *all* immigrants. Finally, more and more tests are becoming available, particularly genetic screening tools, that "enable us, if we wish to use them, to predict with greater or lesser accuracy when and from which disease a given person will likely die."1011 The question is whether, if we mandate HIV testing, we should also use such tests on immigrants.

### "Excessive Demand"

As mentioned above, Canada has been undertaking a review of its medical inadmissibility regulations. The language of a set of recommendations proposed in June 1992 by Employment and Immigration Canada1012 appeared to move away from the current blanket exclusionary policy with regard to people living with HIV/AIDS, but was vague and subject to much interpretation. Currently, the determination of medical inadmissibility is ongoing. In some ways, the outcome of the review is even more important than Canada’s decision about whether or not to change its current policy about HIV testing of prospective immigrants. This is because, in practice, it is likely that the vast majority of prospective immigrants with HIV today either self-disclose their HIV status or are tested for HIV on the discretion of the examining physician, even in the absence of a policy of routine testing. As mentioned above, those who are HIV-positive are automatically excluded from immigration, with very limited exceptions: in some cases, HIV-positive immigrants may receive a Minister’s Permit, which gives them a legal right to be present in Canada but otherwise provides fewer rights than regular immigration status. Clearly, Canada needs a system that does not automatically exclude people with HIV/AIDS or other similar conditions from immigrating, but takes the individual circumstances of each case into account. While it is important that Canada adopt such a system now, it would be even more important should HIV testing become routine.

With regard to HIV, the situation is changing rapidly: because of new treatments, people with HIV lead longer and potentially very productive lives during which they can contribute a lot to Canadian society. At the same time, the costs of the new treatments are high. Assessing the potential costs and potential benefits from 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. Australia’s system of assessing eligibility, while not perfect, is certainly better than Canada’s current system and could serve as an example. In any system it must also be ensured that HIV and AIDS are not treated differently from other diseases or situations with potentially high costs for Canadian taxpayers. Any rules about medical admissibility must be applied equally and fairly to all potential immigrants, including people with HIV.

Finally, as a society, we also 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 and continue to contribute significantly to Canadian society. Recognizing this, the medical inadmissibility review process should allow for taking humanitarian concerns into account.

## Recommendations

> **11.1 Canada should not introduce mandatory HIV testing of prospective immigrants.**
>
> **11.2 The current system according to which immigration applicants who are found to be HIV-positive are assessed as "medically inadmissible" should be changed so that people with HIV/AIDS or other similar conditions will not automatically be excluded from immigrating. A new system should be developed in consultation with all those concerned, in particular people with HIV/AIDS and organizations representing their interests. It should take the individual circumstances of each case into account, weigh the costs against the benefits of allowing a particular person to immigrate, and take humanitarian concerns into account.**

**Return to the top of this page**

**Return to Table of Contents**

---

ENDNOTES

866 C Pies. AIDS, Ethics, Reproductive Rights: No Easy Answers. In: B Schneider and N Stoller (eds). *Women Resisting AIDS: Feminist Strategies of Empowerment*. Philadelphia, Temple University Press, 1995, 322-334 at 323, with reference to

J Terry. The Body Invaded: Medical Surveillance of Women as Reproducers. *Socialist Review* 1989; 19: 13-43.

867 P Alexander. Response to AIDS: Scapegoating of Prostitutes. San Francisco, CA: National Task Force on Prostitution, 1988.

868 Ibid.

869 AE Wills. Public Health, AIDS and Sex Workers in New South Wales. [Australian] *National AIDS Bulletin* November 1991: 39-43.

870 D Brock. Prostitutes are Scapegoats in the AIDS Panic. *RFR/DFR* 1989; 18(2): 13-16.

871 D Brock. Scapegoating Prostitutes in the AIDS Epidemic. *Broadside*; 10(4): 6.

872 M Plant. Conclusions and Strategies. In M Plant (ed): *AIDS, Drugs and Prostitution*. London and New York: Tavistock/ Routledge 1990, at 198.

873 NAC–AIDS, supra, note 8 at 40.

874 OLRC, supra, note 13 at 53.

875 Ibid at 54.

876 Ibid.

877 *R* v *GDM* (1987), 2 WCB (2d) (BC Prov Ct).

878 *R* v *Cornier*, unreported, 1991 CA 12803 BCCA.

879 Alexander 1988, supra, note 867.

880 World Health Organization. *Effective Approaches to AIDS Prevention*. Report of a Meeting. Geneva: WHO, Global Programme on AIDS, May 1992.

881 S Pinwall. Sex Industry Law Reform Across Australia. *HIV/AIDS Legal Link* 1998; 9(2): 8-9. See also B Reuter. Sex Work Law Reform, Transmission Offences, & Regional Issues. *HIV/AIDS Legal Link* 1998; 9(3): 14-15.

882 See, eg, P Alexander. Mandatory Testing of Prostitutes Will Not Prevent AIDS. In: CC Abt, KM Hardy (eds). *AIDS and the Courts*. Cambridge, MA: Abt Books Inc, 1990, at 132-139; L Bowleg. Unjust Punishments: Mandatory HIV Testing of Women Sex Workers and Pregnant Women. Washington, DC: Center for Women Policy Studies, National Resource Center on Women and AIDS, 1992; J Cohen, P Alexander, C Wofsky. Prostitutes and AIDS: Public Policy Issues. *AIDS & Public Policy Journal* 1988; 3(2): 16-22; C Leigh. No Mandatory Testing! A Feminist Prostitute Speaks Out. *On the Issues* 1988; 10: 10, 24.

883 AIDS and Civil Liberties Project, American Civil Liberties Union Foundation. Mandatory HIV Testing of Female Prostitutes: Policy Statement of the American Civil Liberties Union. In: M Blumberg (ed). *AIDS. The Impact on the Criminal Justice System*. Columbus, OH: Merrill Publishing Company, 1990.

884 Policy Paper on the Forced Testing and Quarantining of Prostitutes. Prostitutes Safe Sex Project (Maggies). Toronto: The Project, 1993; English Collective of Prostitutes. Prostitute Women and AIDS: Resisting the Virus of Repression. San Francisco, CA: PROstitutes Collective, 1988 (US edition). See also Sex Industry and the AIDS Debate '88. Report and Conference Papers from the First National Sex Industry Conference, Melbourne, Australia, 25-27 October 1988. St Kilda, Victoria: Prostitutes Collective of Victoria, 1988.

885 Alexander 1988, supra note 867.

886 C Ward. Interview: HIV Positive Sex Workers. *HIV/AIDS Legal Link* 1998; 9(2): 12-13, at 12.

887 Policy Statement on the Rights of HIV Positive Sex Workers for the Asia-Pacific Network of Sex Worker Projects. *HIV/AIDS Legal Link* 1998; 9(2): 13.

888 *HIV/AIDS and Human Rights. International Guidelines*, supra, note 162 at 14, para 29(c).

889 The following summary is a shortened version of R Achilles. The Regulation of Prostitution. Unpublished background paper written for the Department of Public Health of the City of Toronto (updated 14 April 1995), on file with editor.

890 Tougher Sex Trade Penalties Planned – Rock to Propose Changes in Code. *The Globe and Mail* 6 November 1995, at A4.

891 JG Snell. Note. Mandatory HIV Testing and Prostitution: The World's Oldest Profession and the World's Newest Deadly Disease. *Hastings Law Journal* 1994; 45: 1565, 1569 note 24.

892 Awful New Prostitution Laws. COYOTE (Call off your old tired ethics) Howls, January 1989, at 1-2.

893 K Bastow. Prostitution and HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(2): 12-14 at 12, with reference to *Stiletto* 1991; 1(3): 6.

894 See Anderson, supra, note 852, at 143.

895 *Love v Superior Court*, 276 Cal Rptr 660 (Ct App 1990); *People v Adams*, 597 N.E.2d 574 (Ill 1992).

896 OLRC, supra, note 13 at 53.

897 Cohen et al, supra, note 882.

898 Leigh, supra, note 882.

899 English Collective of Prostitutes, supra, note 884.

900 What Are Sex Workers' HIV Prevention Needs? A publication of *HIV Prevention: Looking Back, Looking Ahead*, a project of the Center for AIDS Prevention Studies, University of California, San Francisco, April 1996.

901 Bastow, supra, note 893, with reference to R Perkins. AIDS Preventative Practices among Prostitutes in New South Wales. [Australian] *National AIDS Bulletin* September 1991, at 28; see also CA Campbell. Women and AIDS. *Social Sciences in Medicine*; 30(4): 411.

902 Global Programme on AIDS and Programme of STD. Consensus Statement from the Consultation on HIV Epidemiology and Prostitution (Geneva, 3-6 July 1989). Geneva: World Health Organization, 1989.

903 Intergovernmental Committee on AIDS, Legal Working Party. *Legal Issues Relating to HIV/AIDS, Sex Workers and Their Clients*. Canberra: Department of Health, Housing and Community Services, 1991.

904 A Derrick, cited in S Fraser. Defending the Right to Do the Work They Do. *Atlantic Insight* June 1988: 14-19.

905 R Jürgens. Prostitution and HIV/AIDS: A Literature Review. *Canadian HIV/AIDS Policy & Law Newsletter* 1995; 2(1): 3-5 at 3, with reference to Wills, supra, note 869.

906 Supra, note 900.

907 See E Maticka-Tyndale. Working in the Sex Trades: Policies to Decrease Vulnerability to HIV. Seventh Annual Canadian Conference on HIV/AIDS Research, Québec, 1998, abstract no 123.

908 L Glantz et al. Risky Business: Setting Public Policy for HIV-Infected Health Care Professional. *The Milbank Quarterly* 1992; 70: 48-53 at 46.

909 RS Magnusson. A Decade of HIV Testing in Australia, Part 2: A Review of Some Current Debates. *University of New South Wales Law Journal* 1995; 18(2): 364-408 at 381.

910 Centers for Disease Control and Prevention. Possible Transmission of HIV to a Patient During an Invasive Dental Procedure. *Morbidity and Mortality Weekly Review* 1990; 39: 489-493.

911 Centers for Disease Control and Prevention. Transmission of HIV Infection During an Invasive Procedure, Florida. *Morbidity and Mortality Weekly Review* 1991; 40: 21-27, 33; Centers for Disease Control and Prevention. Update: Investigations of Persons Treated by HIV-Infected Health Care Workers – United States. *Morbidity and Mortality Weekly Review* 1993; 42: 329-331. See also OLRC, supra, note 14 at 64-65, with many references.

912 SH Weiss. Occupational Exposures and Risks Related to the HIV Epidemic. In: GP Wormser (ed). *AIDS and Other Manifestations of HIV Infection, Third Edition*. Philadelphia: Lippincott-Raven Publishers, 1998, 699-716 at 708, with reference to S Barr. The 1990 Florida Dental Investigation: Is the Case Really Closed? *Annals of Internal Medicine* 1996; 124: 250-254.

913 AIG Karrel. HIV-Infected Physicians: How Best to Protect the Public? *Canadian Medical Association Journal* 1995; 152 (7): 1059-1062 at 1059-1060, with many references.

914 R Bayer. Discrimination, Informed Consent, and the HIV Infected Clinician. *British Medical Journal* 1997; 314: 915-916, at 915.

915 T Mauth. Charter Implications of Compelling Dentists to Reveal Their HIV Status. *Health Law in Canada* 1996: 97-106 at 97, with references.

916 Weiss, supra, note 912 at 708. See also: Surgeon Blamed in HIV Case. *The Globe and Mail* 17 January 1997, at A8; Le médecin transmet le sida. *Le Devoir* 16 January 1997, at A2.

917 Bayer, supra, note 914 at 915.

918 Ibid, with reference to Centers for Disease Control and Prevention. *Estimates of the Risk of Transmission of Hepatitis B Virus and Human Immunodeficiency Virus to Patients by the Percutaneous Route During Invasive Surgical and Dental Procedures.* Atlanta: CDC, 1991.

919 Canadian AIDS Society. The Right of Health Care Workers with HIV to Practice Their Profession without Restrictions. A Position Paper. Ottawa: The Society, 11 September 1992, at 4.

920 For more details, see Weiss, supra, note 912 at 701ff; Magnusson, supra, note 909 at 375-381; W Flanagan. HIV Testing in the Health Care Setting. *Queen's Law Journal* 1993; 18: 71.

921 Flanagan, ibid.

922 Health Canada. Proceedings of the Consensus Conference on Infected Health Care Workers: Risk for Transmission of Bloodborne Pathogens. *Canada Communicable Disease Report* 1998; 24(Suppl 4): at 9.

923 Ibid at 10.

924 NAC–AIDS, supra, note 8 at 40.

925 Dr J Brookfield, chairman of the CDA's ethics committee, cited in CAS 1992, supra, note 919 at 2.

926 Consensus Conference, supra, note 922 at 1.

927 Bloodborne Pathogens in the Health Care Setting: Risk for Transmission. *Canadian Medical Association Journal* 1993; 148(10): 1747-1752 at 1748-1752 (reprinted from *Canada Communicable Disease Report* 1992; 18: 177-184).

928 Ibid at 1747.

929 CPHA, supra, note 15 at 15.

930 Canadian Human Rights Commission. Canadian Human Rights Commission Policy on HIV/AIDS. Ottawa: The Commission, June 1996. Reprinted in *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 7-8.

931 OLRC, supra, note 13 at 71.

932 Canadian Medical Association. CMA Policy Summary. HIV Infection in the Workplace. *Canadian Medical Association Journal* 1993; 148(10): 1800A-1800H (reprinted in *Health Law Review* 1994; 3(2): 27-30).

933 Karrel, supra, note 913 at 1059.

934 Ibid.

935 Ibid at 1061.

936 Mauth, supra, note 915 at 97.

937 Magnusson, supra, note 909 at 371, with reference to CDC. Recommendations for Preventing Transmission of Human

Immunodeficiency Virus and Hepatitis B Virus to Patients During Exposure-Prone Invasive Procedures. *Morbidity and Mortality Weekly Review* 1991; 40(No RR-8): 1 at 5.

938 Ibid, with reference to B Lo, R Steinbrook. Health Care Workers Infected with the Human Immunodeficiency Virus. *Journal of the American Medical Association* 1992: 267, 1100 at 1101-1102.

939 Ibid, with reference to Lo & Steinbrook, ibid.

940 Ibid.

941 Gostin & Webber, supra, note 658 at 1110.

942 Magnusson, supra, note 909 at 382.

943 Consensus Conference, supra, note 922 at 3.

944 Ibid; the author would like to thank Paul Muirhead of Williams, McEnery & Davis, Ottawa, for information about the conference, provided on 10 January 1997.

945 Ibid at 2.

946 Ibid at 19.

947 Ibid.

948 Ibid at 20.

949 Ibid.

950 Ibid at 21.

951 Ibid.

952 Ibid.

953 Written communication by C Fooks, Director, Policy and Research, The College of Physicians and Surgeons of Ontario, to C Roy, Executive Director, AIDS Committee of Toronto, dated 16 March 1998.

954 Response by the AIDS Committee of Toronto and AIDS ACTION NOW! to The College of Physicians and Surgeons of Ontario, dated 24 April 1998.

955 Ibid.

956 N Gilmore. HIV in the Workplace: Legal and Ethical Issues. Text of a presentation at the 6th Annual British Columbia AIDS Conference on 1 November 1993.

957 Magnusson, supra, note 909 at 381.

958 Gilmore, supra, note 956.

959 See OLRC, supra, note 13 at 65-66, with reference to Barnes et al. The HIV-Infected Health Care Professional: Employment Policies and Public Health. *Law, Medicine & Health Care* 1990; 18: 311.

960 Dr J Brookfield, cited in CAS 1992, supra, note 919 at 2.

961 OLRC, supra, note 13 at 66.

962 Supra, note 927 at 1748.

963 Roy, supra, note 184 at 53.

964 A distinction is made between "exposure-prone" invasive procedures and invasive procedures that are not "exposure-prone." With respect to the latter, it is generally said that health-care professionals with HIV need not be restricted in their practice.

965 M Kennedy. Doctors Oppose Testing for Hepatitis B. *The* [Montréal] *Gazette* 17 July 1998, A1-A2, at A2.

966 Bayer, supra, note 914 at 916.

967 Dr Mervyn Silverman, President, American Foundation for AIDS Research, cited in CAS 1992, supra, note 919.

968 J Bryden. Marchi Considers AIDS Tests for Immigrants. *The* [Montréal] *Gazette* 26 April 1994, at B4.

969 See House of Commons Debates, Official Report (Hansard), vol 133, no 96, 23 September 1994.

970 Bryden, supra, note 968.

971 WC Bartlett. *AIDS: Legal Issues*. Ottawa: Library of Parliament Research Branch, Current Issue Review 93-7E, 14 April 1994 (revised 19 April 1995), at 5.

972 CBA–Ontario, supra, note 7 at 37-39.

973 Somerville & Gilmore, supra, note 9 at 61.

974 Ibid at 63.

975 H Zowall et al. HIV Antibody Screening among Immigrants: A Cost-Benefit Analysis. *Canadian Medical Association Journal* 1990; 143(2): 101-107 at 101.

976 Mackinnon, Cottrelle & Krever, supra, note 195 at 368.

977 MA Somerville. The Case against HIV Antibody Testing of Refugees and Immigrants. *Canadian Medical Association Journal* 1989; 141: 889-894, at 891.

978 See infra, under "Canada's Immigration Policy."

979 M Duckett, AJ Orkin. AIDS-Related Migration and Travel Policies and Restrictions: A Global Survey. *AIDS* 1989; 3 (Suppl 1): S231-S252 at S231.

980 N Gilmore et al. International Travel and AIDS. *AIDS* 1989; 3(Suppl 1): S225-S230 at S228-S229, with many references.

981 Supra, note 162 at 50, para 105–106.

982 Bartlett, supra, note 971 at 6-7.

983 Ibid.

984 Ibid.

985 Communication with GA Giovinazzo, Director, Immigration Health Services, Ottawa, on 13 February 1997; and with N Heywood, Director, Immigration Health Policy Division, Citizenship and Immigration Canada, on 2 October 1998.

986 The Editor. Policy for Persons Living with HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(2): 14-15, with reference to Canadian AIDS Society. Report on Canada's Travel and Immigration Policies for People Living with AIDS. Ottawa: The Society, 25 September 1995.

987 Correspondence received from Dr GA Giovinazzo, Director, Immigration Health Services, Ottawa, on 13 February 1997.

988 This examination is a screen. Its purpose is to determine medical and psychiatric conditions that may create an excessive demand on Canadian health or social services or that might reasonably pose a threat to public health or safety.

989 Supra, note 987.

990 Ibid.

991 Comment made by Ruth Carey, HIV/AIDS Legal Clinic of Ontario, on 25 July 1998.

992 Immigration Legislative Review. *Not Just Numbers. A Canadian Framework for Future Immigration*. Ottawa: Minister of Public Works and Government Services Canada, 1997, at 112, recommendation 134.

993 Ibid.

994 Ibid.

995 Ibid.

996 Recommendations from the National Consensus Conference on Tuberculosis, December 3–5, 1997 (recommendation 4.1).

997 Ibid, recommendation 4.5.

998 Bartlett, supra, note 971 at 6. For more details, see S Wilson. Recent Developments in Immigration Law. *Canadian HIV/AIDS Policy & Law Newsletter* 1994; 1(1): 9-10.

999 Bartlett, ibid.

1000 Communication with Dr Giovinazzo, supra, note 985; communication with N Heywood, supra, note 985.

1001 Communication with Dr Giovinazzo, supra, note 985; see also R Carey. Challenging Ontario's Denial of Medical Care to HIV-Positive Immigrants. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 18-19.

1002 See S Wilson. HIV-Positive Refugee Admitted to Canada. *Canadian HIV/AIDS Policy & Law Newsletter* 1995; 1(3): 5. For an Australian case, see P Blair. Refugee Status Granted on Grounds of HIV. *HIV/AIDS Legal Link* 1994; 5(4): 3. For a US case, see The Editor. US – Asylum Granted to Person Living with HIV. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 19.

1003 [1994] DSSR No 92 (QL).

1004 Wilson, supra, note 1002.

1005 See, eg, Duckett & Orkin, supra, note 979.

1006 Human Immunodeficiency Virus (HIV) Testing Requirements for Entry into Foreign Countries. Washington, DC: US Department of Foreign Affairs (available at http://travel.state.gov/ HIVtestingreqs.html).

1007 See The Editor. Australia: Allowing People with HIV Permanent Residence. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(3): 16-17, with reference to M Alexander. HIV and Permanent Residence. [Australian] *HIV/AIDS Legal Link* 1995; 6(2): 8-10. Parts of the following text are taken from Alexander's article. See also Magnusson, supra, note 371 at 342-343; J Godwin et al. *Australian HIV/AIDS Legal Guide*. Annandale, NSW: The Federation Press, 2nd ed 1993, at 341-358.

1008 Somerville, supra, note 977 at 893.

1009 Supra, note 986.

1010 Supra, note 977 at 893-894.

1011 Ibid at 892.

1012 Medical Inadmissibility Review. Recommendations prepared by Employment and Immigration Canada in consultation with Health and Welfare Canada, June 1992.

**Return to the top of this page**

**Return to Table of Contents**

# HIV Testing and Confidentiality: Final Report

**Prepared by Ralf Jürgens**

**ISBN 1-896735-16-9**

---

# CONFIDENTIALITY

> The issue of medical confidentiality is so important in the HIV testing and reporting context because it has been widely recognized as a central element in the effective response to AIDS. Not only does the principle rest upon ethical norms of autonomy and respect for privacy, but it has been viewed as crucial to encouraging those most at risk to come forward for HIV testing and for clinical attention.
>
> But as important as the principle of confidentiality is, it has its limits. When competing social concerns are of sufficient magnitude, physicians and ethicists have acknowledged that exceptions may be made. The definition of when the concerns reach the standard of sufficient magnitude, however, has always been a matter of grave dispute.1013

As stated by the OLRC,

> [t]he appropriate collection, use, and disclosure of HIV-related personal information can benefit society. But the unauthorized disclosure of an individual's serological status may lead to social opprobrium, estrangement of family and

> friends, and to loss of employment, housing, and insurance.1014

The majority of people with HIV/AIDS in Canada are members of groups that have been subject to discrimination. This is particularly important because "the chief weapon for combatting the spread of this disease relies upon influencing behaviour." As a result, public health officials, professional medical associations, and AIDS support groups, among others, have called for a strengthening of confidentiality protections for HIV-related personal information. Where is the line, however, between

> the need for patient confidentiality and the protection of public health? Should there be a requirement to maintain patient confidentiality if an unsuspecting partner is at significant risk of infection? Should the line be extended to include the groups in society that assert a "right to know" the serological status of HIV-infected individuals?1015

These questions, raised by the OLRC in 1992, are still controversial. Indeed, they have become more controversial as a result of the new developments discussed in this Report.

This chapter first reviews the recommendations made by organizations in Canada and internationally since 1986 regarding confidentiality and the "need to know" HIV/AIDS-related information (History). The chapter then briefly examines the current situation in Canada and, to a lesser extent, internationally (Current Situation). The chapter then

- discusses the reasons why confidentiality is generally important in medicine and is particularly important with respect to HIV/AIDS;

- points out that, for many reasons, protecting confidentiality is often extremely difficult and may be unrealistic. As a result, some have called confidentiality a "decrepit concept";

- in addition to being difficult to protect, there are limits to the principle of confidentiality. This chapter addresses claims that certain people have a "need to know" the HIV status of other people, while the next two chapters address two other contentious areas: reporting of HIV and AIDS and partner notification or contact tracing programs; and

- suggests ways in which confidentiality could be better protected (Assessment).

The chapter concludes that, the new developments notwithstanding, confidentiality continues to be particularly important with respect to HIV/AIDS because HIV/AIDS continues to be a disease that is different from most other diseases, leading to stigmatization of and discrimination against those infected or affected.

With regard to disclosure of HIV/AIDS-related information to third parties, the chapter argues that in the vast majority of cases there is no "need to know" a third party's HIV status.

Finally, the chapter concludes that, while efforts to better protect confidentiality are important, efforts to protect people with HIV or AIDS from discrimination may be equally important because of the limits of confidentiality and the difficulties of protecting it in practice.

# History

## Canada

Organizations and individuals in Canada who have analyzed the issues raised by confidentiality of HIV/AIDS-related information, including the Canadian Bar Association – Ontario, the National Advisory Committee on AIDS,1016 the Royal Society of Canada, the Federal/Provincial/Territorial Advisory Committee on AIDS,1017 the Privacy Commissioner of Canada, the Information and Privacy Commissioner of Ontario,1018 the Access to Information Commission of Québec,1019 the Ontario Law Reform Commission1020 and others have generally stressed the importance of respecting the confidentiality of such information, but have acknowledged the limits of confidentiality. With respect to certain people's "need to know" the HIV status of other people, they have generally agreed that such a "need to know" only exists in exceptional circumstances, and that the claim that one needs to know someone else's HIV status in order to protect oneself is most often based on ignorance or misconceptions. The following is a short summary of the main issues raised.1021

The Canadian Bar Association – Ontario emphasized that "much of the success of the physician/patient relationship and indeed, the successful provision of health care within the existing system, is premised upon a mutual respect for the confidentiality of the patient care information that flows between the patient and the health care provider." It pointed out that the physician cannot accurately diagnose and treat the patient without being provided with all of the relevant information by the patient and that, in turn, "the patient will not be inclined to provide such full and complete disclosure of information unless he or she has absolute trust and confidence that all such information will remain confidential." In light of this, the Association concluded, the physician has both an ethical and legal duty to respect the confidentiality of information provided by the patient.1022

The Royal Society of Canada also stressed that "[c]onfidentiality of all health information is of paramount importance," and stated that a "breach of confidentiality about an individual's test for HIV may well have devastating effects."1023 However, citing from Mr Justice Krever's Report of the Commission of Inquiry into the Confidentiality of Health Information, the Society pointed out that

[n]ot only have breaches been occurring for a long time, but the disregard for privacy and for the interests protected by the concept of confidentiality has ... not been confined to a single

group. It has been universal.1024

The Society concluded that, because "breaches continue to occur and may well increase with the incentives that exist and with the growing use of computers to store medical information," a statutory deterrent may now be justified. It therefore recommended

> that the provinces enact legislation imposing liability for breaches of confidentiality without proof of actual damage. Liability should be for a predetermined amount sufficiently large to act as a significant deterrent to such breaches.1025

In its report, the Parliamentary Ad Hoc Committee on AIDS endorsed the importance of protecting information about HIV test results and HIV status, and agreed that legislation should be reviewed, and amended where necessary, to ensure this. In addition, it urged that more attention be given to the enforcement of existing legislation.1026 While agreeing that there is a need to improve the effectiveness of existing means of protection of confidentiality, Glenn et al stressed that legislation is in itself an inadequate means of improving protection of HIV/AIDS-related personal information.1027 According to them, there is need for "widespread development at the level of individual communities and institutions of soft law (written procedures, policies, guidelines, protocols) which enhance the protection of the privacy of persons with HIV/AIDS." Legislation, if it is to be enacted, should "therefore call for the local creation of soft law, and not address the range of issues which the soft law itself must address."1028

In their paper, Glenn et al also addressed the issues of collection and disclosure of HIV/AIDS-related personal information. With regard to the former, they suggested that it should occur "only in conformity with a test of proportionality which permits the benefits of collection of such information to be measured against attendant risks to personal privacy." The paper stressed that, in principle, collection of such information without the consent of the subject of the information is unjustifiable; and that collection required as a prerequisite to contract or benefit is acceptable "only in very limited circumstances."1029 With regard to disclosure of HIV/AIDS-related personal information, the paper noted that it is "in principle violative of personal privacy absent consent of the subject of the information."1030 The paper suggested greater use of anonymous treatment of HIV/AIDS-related personal information, notably with respect to reporting of HIV/AIDS status and with respect to medical records, "which would have to be modified to accommodate anonymous information."1031 This approach is consistent with that taken by the Privacy Commissioner of Canada who, in his 1989 report on *AIDS and the Privacy Act*,1032 urged caution in the collection of AIDS-related personal information by federal institutions, as well in its use and its disclosure.

While stressing the importance of respecting the confidentiality of HIV/AIDS-related information, individuals and organizations have recognized that the duty of confidentiality is not absolute. As the Royal Society of Canada stated,

> [a] strong ethical case can be made in support of a physician's breaking confidence with a seropositive person when such a person persistently refuses to stop endangering the health and life of a sexual partner, when the physician knows the person in danger, and when the physician is the only one with that knowledge. The case is even stronger if the endangered person is the physician's patient as well.1033

In the same vein, Glenn et al have said that disclosure may be justifiable because of the need to protect human life and to prevent transmission of disease:

> Even given the sensitive nature of HIV/AIDS-related personal information, it is unlikely that disclosure for purposes of protection of the life of individual persons will be regarded as wrongful according to traditional standards of civil fault. Nor should it be regarded as morally reprehensible. Precise and justifiable exceptions to medical confidentiality are more tolerable than widespread disrespect for it. ... Those concerned with confidentiality of HIV/AIDS-related personal information should ... be careful not to defend what may be malevolent conduct through arguments of rights to confidentiality, because this will harm rather than advance their cause. Rather, attention should be concentrated on the too frequent cases of unjustifiable disclosure.1034

Consequently, the Information and Privacy Commissioner/Ontario recommended that, if necessary, legislation should be amended to include the concept of a physician's "duty to warn," enabling physicians to warn those at risk of transmission. According to the report, such a duty to warn "should only be exercised if an individual infected with a communicable disease such as HIV, refuses to inform his/her partner of this fact and also refuses to give the physician permission to do so on his/her behalf."1035

Similarly, the Royal Society recommended that

> provincial regulatory legislation provide that, where a health-care provider has reasonable cause to believe that an HIV-infected person is in such mental, physical or emotional condition as to be dangerous to others, and that disclosure of information about the patient is necessary to prevent the threatened danger, the health-care provider may disclose such information to the person or persons in danger without the consent of the patient. Disclosure made under that reasonable belief shall not amount to professional misconduct.1036

## International Developments

As in Canada, the importance of protecting the confidentiality of medical information and, in particular, HIV/AIDS-related information, has been emphasized in other countries.1037 In particular, the International Guidelines on HIV/AIDS and Human Rights recommend that "[p]ublic health legislation should ensure that information relative to the HIV status of an individual be protected from unauthorized collection, use or disclosure in the health-care and other settings and that the use of HIV-related information requires informed consent."1038

# Current Situation

## Provisions in Public Health Acts or Regulations

In Prince Edward Island, Québec, Ontario, Manitoba, Alberta, and British Columbia, provisions in public health acts or regulations impose a duty of confidentiality on public health officials with respect to information they receive either in the course of their duties generally, or in relation specifically to a person infected with a notifiable or communicable disease.1039 However, in Prince Edward Island, Ontario, Manitoba, Saskatchewan, and Alberta specific statutory exceptions permit the confidential information to be divulged in certain limited circumstances, such as when it is necessary "in the public interest"1040 or for any reason "in the interest of protecting the public health."1041

In the other provinces and territories, there are no provisions in public health legislation containing specific protection of confidentiality.

## Physician’s Duty of Confidentiality1042

### The Law

The law establishes that physicians have a duty of confidentiality to their patients.1043 All information generated in the course of a medical relationship must be kept confidential, and the patient has a right to, and the physician has a duty of, confidentiality.1044 This duty is recognized at common law.1045 In particular, in *Re Inquiry into the Confidentiality of Health Records in Ontario*, Dubin JA, writing for the majority of the Court, held that "[m]embers of the medical profession have a duty of confidentiality with respect to their patients," and that "[t]hey are under restraint not to volunteer information respecting the condition of their patients or any professional services performed by them."1046 In addition, the duty is often reiterated in statutes.1047 Moreover, the Supreme Court of Canada, in *McInerney* v *MacDonald*, characterized the physician–patient relationship as "fiduciary" and held that from the special relationship of trust and confidence between doctor and patient arise certain special duties:

> Among these are the duty of the doctor to act with the utmost good faith and loyalty, and to hold information received from or about the patient in confidence. When a patient releases personal information in the context of the doctor–patient relationship, he or she does so with the legitimate expectation that these duties

> will be respected.1048

The Supreme Court continued by saying that, while the physician is the owner of the actual medical record, the information contained in it is to be used by the physician for the benefit of the patient, and that the "confiding of the information to the physician for medical purposes gives rise to an expectation that the patient's interest in and control of the information will continue."1049

In *Hay* v *University of Alberta Hospital*,1050 the status of the right of confidentiality was described by Picard J as follows:

The physician–patient relationship is clothed with confidentiality, a right which may be waived by the patient. Confidentiality is an important attribute of the physician– patient relationship, essential in promoting open communication between physician and patient. The patient may expressly waive this right or, by his actions, be found to have impliedly waived it. Alternatively, an overriding public interest or a statutory direction may justify a physician disclosing information about the patient. In the absence of such circumstances, the right remains and a physician who divulges confidential information could face an action for breach of confidentiality, a possibility which obviously causes physicians some concern.1051

As stated by the Supreme Court of Canada, the duty of confidentiality that arises from the doctor–patient relationship is meant to encourage disclosure of information by the patient to the physician and communication between them.1052 Patients must be encouraged to seek treatment without fear that their ailment, condition or treatment will be disclosed. In addition, "[e]ncouraging patients to come forward and seek treatment benefits not only patients themselves but also others who may be at risk of infection; that is, maintaining the patient's confidence is not only in his or her interest but also in the public interest."1053

The duty of confidentiality may even be constitutionally guaranteed.1054 In addition, in most provinces and territories, physicians are expressly required by statute to keep confidential patient information concerning communicable diseases, including AIDS.1055

At the federal level, the *Privacy Act*1056 seeks to protect Canadians from the collection and dissemination, without sufficient cause, of personal information about them by federal institutions and agents. Other deterrents to disclosure of personal information, applicable to this situation, include liability resulting from unauthorized or unjustifiable disclosure and abuse of such information following disclosure, and remedies for abuses resulting from such disclosure, such as protection against discrimination.

## Ethical Obligations

Physicians also have an ethical obligation to maintain the confidentiality of the information that is given to them by their patients. This duty has roots that date back to the Hippocratic oath written during the fourth century BCE, which contains the vow:

> Whatever, in connection with my professional practice, or not in connection with it, I see or hear, in the life of men, which ought not to be spoken abroad, I will not divulge, as reckoning that all such should be kept secret.1057

With regard to HIV/AIDS, it has been said that "[a]s a general principle of medical ethics, a physician who has knowledge of positive test results or even a confirmed diagnosis of AIDS must protect confidentiality and avoid disclosure of this information."1058

## Exceptions to the Duty of Confidentiality

While the "prima facie presumption governing confidentiality of medical information, including confidentiality in the AIDS situation, is that everyone is entitled to respect for their rights of privacy and confidentiality and that these can only be infringed upon for the most serious reasons and with adequate justification being shown,"1059 privacy sometimes must give way to other social goods.1060

### The Law

There are situations in which confidential medical information may be disclosed without breach of the duty of confidentiality, and there are exceptions to the duty of confidentiality that permit or even require a breach of confidentiality.

A physician may disclose patient information with the informed consent of the patient (when informed consent is given, confidentiality is not breached), or where legislation requires that confidentiality be breached. As will be shown in the following chapters, all Canadian jurisdictions have legislation requiring physicians to report cases of AIDS, and sometimes also cases of HIV infection, either nominally or non-nominally, to medical officers of health. On the other hand, there is no HIV/AIDS-specific legislation requiring or authorizing disclosure by a physician of such information to a sexual or drug-using partner of the patient. There is, however, legislation in some provinces and territories requiring or authorizing disclosure by a physician of patient information if such disclosure is necessary to protect a third party. Partner notification is required or authorized by some public health acts.

Absent the patient’s informed consent and absent legislation requiring or authorizing disclosure, disclosure of patient information may still be justified under general law doctrines that operate to provide exceptions to the duty of confidentiality.

First, a defence of necessity may apply to justify breaching confidentiality when "the harm inflicted by the breach is clearly outweighed by the harm it avoids; the harm avoided cannot be avoided in any other less invasive way; and the harm avoided is sufficiently serious to merit avoiding it through a breach of confidentiality."1061

Second, in rare situations, there is a "duty to warn" or "duty to protect" others. In general, such a duty applies "only to identified or readily identifiable persons, for example, those whom an HIV-seropositive person is clearly putting at risk and who have no other means of knowing about, and so avoiding, that risk, or who, because of their lack of knowledge, might place others at risk."1062

The Supreme Court of Canada, in *McInerney*, held that the patient's right to require that professional secrets acquired by the practitioner not be divulged is absolute unless there is some paramount reason that overrides it:

> [T]here may be cases in which reasons connected with the safety of individuals or the public ... would be sufficiently cogent to supersede or qualify the obligations *prima facie* imposed by the confidential relation.1063

In another case the Supreme Court dealt with disclosure of confidential medical information in court proceedings. However, the Court also commented on disclosure in the extrajudicial context.1064 It held that, in an extrajudicial context, the main principle underlying the duty of a professional or a hospital to keep their medical records secret is that of the privacy of the individual:

It is, therefore legitimate for a court to give a broad interpretation to the general duty of non-disclosure imposed on hospitals and medical professionals in these circumstances and to interpret restrictively any violation of the right to confidentiality.1065

Courts in the United States have repeatedly held that "a physician's duty of nondisclosure is outweighed in certain circumstances by a need for public safety."1066 Courts in some states have found physicians liable to the patient's family members for failure to disclose that the patient had a contagious disease. Belitzky and Solomon have concluded that "a physician with knowledge of a diagnosis of AIDS who fails to disclose the information to a foreseeable victim could be found liable."1067 In *Tarasoff v Regents of the University of California*,1068 the California Supreme Court imposed a duty on psychotherapists to protect third parties from the potentially dangerous acts of their patients. The Court held that when a therapist determines, or should have determined, "that a patient presents a serious danger of violence to another, he or she incurs an obligation to use reasonable care to protect the intended victim against such danger."1069 The Court concluded that "the public policy favoring protection of the confidential character of patient ... communications must yield to the extent to which disclosure is essential to avert dangers to others." *Tarasoff* was positively referred to and accepted as relevant to Canadian law in two Alberta decisions.1070 However, the question whether other Canadian jurisdictions would accept its reasoning remains open.1071 One case that has often been misinterpreted as supportive of a physician's duty to warn third parties is *Pittman v Bain*.1072 The case concerned a physician who, when informed that his patient had been transfused with a potentially HIV-contaminated blood component, decided to withhold that information from his patient. The court found the physician's conduct negligent, holding that his decision to withhold information "fell below the standard of care of a reasonable and prudent family physician." However, the court did not decide on the issue of whether the physician had an independent duty to the patient's wife, explicitly saying that it was unnecessary to decide on this issue because had the physician "told the husband the latter would have told his wife."1073

### Ethical Obligations

The ethical obligation to maintain the confidentiality of the information given to physicians by their patients is not absolute. This is recognized in the Canadian Medical Association's Code of Ethics, approved in August 1996, according to which physicians shall

> [r]espect the patient's right to confidentiality except when this right conflicts with your responsibility to the law, or when the maintenance of confidentiality would result in a significant risk of substantial harm to others or to the patient if the patient is incompetent; in such cases, take all reasonable steps to inform the patient that confidentiality will be breached.1074

## Assessment

> [N]ew policies and procedures must be developed to better address the sensitive balance between the need to control the spread of HIV infection and the need to secure individual privacy. There should be an explicit recognition of the need to maximize the confidentiality of HIV/AIDS-related personal information.

These policies and procedures should contain a recognition that maximum confidentiality of personal information related to HIV/AIDS is an essential public health measure. In order to retain the full trust and confidence of persons at risk, the government has an interest both in ensuring that HIV/AIDS-related personal information is not improperly disclosed and in having clear rules for the appropriate disclosure of such information.1075

> To a certain extent, respecting confidences and promoting public health are consistent goals; public health campaigns often depend upon the community's trust and cooperation and include substantive and procedural protections for information obtained in the course of public health work. However, a basic tension exists between the need for information and the need for privacy. Realistically, significant levels of privacy cannot exist within the government's wide and complex web of data collection. Therefore, as a society, we face a vexing issue: What is the proper balance between public health information collection and

> privacy protection, and how might we realize it?1076

## Importance of Confidentiality

There is consensus that, because of the stigmatization of and discrimination against persons living with or otherwise affected by HIV/AIDS, confidentiality is particularly important with respect to HIV/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.1077

While many countries, including Canada, have taken measures to decrease discrimination that arises from people's fear of HIV infection, these measures have done little to affect the roots of the discrimination, fear, prejudice, and misunderstanding of the risk of HIV, nor have they reversed the underlying discrimination that many people vulnerable to contracting HIV already face:

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. In the United States [and in Canada], HIV and AIDS disproportionally 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.1078

As Doughty has said,

> [t]he importance of confidentiality in fighting AIDS remains as strong as it ever was in the 1980s – and for many of the same reasons. Individuals with AIDS and HIV still face discrimination and ostracism based on their medical condition. Improper disclosures of HIV-related information still occur. Moreover, the trust and cooperation of people at risk of infection or in need of medical treatment for HIV-related conditions still depends on the airtight quality of confidentiality. In the unique context of fear, discrimination, and ostracism which surrounds the AIDS/HIV epidemic, the perceptions of individuals affected by HIV matter as much as the reality of confidentiality protections. There people must trust that the health care system will zealously guard their interests. Loss of that trust will lead people to avoid contact with the system entirely, with serious ramifications both for those individuals' health and for the public health in general [references deleted].1079

For the safety, security, and peace of mind of people with HIV/AIDS, it remains essential that they "have control over the disclosure of their HIV status, that they are assured of the confidentiality of their medical records, and that they do not experience discrimination in health-care settings.1080

In addition to being particularly important with respect to HIV/AIDS, confidentiality is generally important in medicine. There are two main reasons for this.1081 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 candor, and in the absence of candor, 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 doctors with information of a personal nature."1082 Conversely, as Hendriks observes, "non-observance of the principle of confidentiality endangers the enjoyment and exercise of health rights.1083

## Limits and Underlying Problems

While there is general acceptance of the need for confidentiality, particularly in dealing with HIV/AIDS-related personal information, this acceptance appears to have relatively little practical effect in the circumstances of contemporary medical care. It has been said that the law's protection of medical confidence is frequently illusory: "Too much in the law itself compels, justifies, and excuses disclosure of information."1084 Some have even argued that

[m]edical confidentiality, as it has traditionally been understood by patients and doctors, no longer exists. This ancient medical principle, which has been included in every physician's oath and code of ethics since Hippocratic times, has become old, worn-out, and useless; it is a decrepit concept. Efforts to preserve it appear doomed to failure and often give rise to more problems than solutions.1085

In this context, HIV/AIDS presents a major challenge to the contemporary drift toward medical non-confidentiality:

> Disclosure of HIV/AIDS-related personal information may ruin a life not threatened by illness; it may render meaningless efforts to alleviate an existing infection. In the most deliberate, reasoned and protected cases of disclosure there remain serious problems of justification; too frequently, however, disclosure is simply a result of negligence, malice or simple ignorance.1086

According to Glenn et al, all of this suggests that both the language and the practice of medical confidentiality must be rethought in the light of HIV/AIDS. Attempting to do this will be fundamental if medical confidentiality in general and specifically of HIV/AIDS-related information is to survive. At the moment, problems are numerous.1087 A first problem consists in defining possible exceptions to the principle of confidentiality. A second problem is that medical care today has become extended: many people are involved in the provision of care and its administration. Therefore, to say that medical information is confidential "is to say nothing of consequence with respect to information circulated within a self-defining group of people entitled to access to such confidential information."1088 A third problem is the apparent ineffectiveness of formal statements of law as a means of reinforcement of medical confidentiality. At the moment, legal protections are "inconsistent or inadequate."1089 Even where specific legislation relating to HIV/AIDS and confidentiality has been created, such as in the United States, some commentators have felt that "there are no effective guarantees as to the confidentiality of test results or the purposes to which results may be put."1090 A fourth problem is that the increasing use of computer systems for health information has led to heightened concern about security: "More people are authorized to use a person’s health information, unauthorized access can be difficult or impossible to detect, and a much greater amount of information can be accessed or copied in a single instance."1091

Many have suggested ways to address these problems. However, as emphasized by Gostin, Lazzarini and Flaherty, the "growing collection of health-related data and the potential for improper disclosure, secondary use, and security breaches within computerized systems, suggests ... that the resolution of the conflict between the need for information and the privacy of patients will not be simple."1092 The law at present neither adequately protects privacy, nor does it ensure fair information practices. The following statement well summarizes the current situation in Canada:

> As patients, we all remain both concerned and skeptical about the ability of governments, insurance companies, health care facilities, providers and others who collect, compile, create and hold information about our health to keep this information secure.
>
> While we often have difficulty in gaining access to our own health care information, we sometimes fear that others may have greater success in obtaining it without our knowledge and permission. These concerns are particularly germane now that technology permits our data to be linked in ways never contemplated when much of it was being compiled and stored.
>
> On the other hand, those planning new methods of delivering health care that stress integration, greater effectiveness and efficiencies with less duplication and waste and ultimately better protect and care for us emphasize the need to be able to share our information using the developing technologies as the pivotal methodology to achieving these goals.

> Our confidentiality laws, where they exist, are usually rules relating to the compilation and disclosure of our medical records. Very little exists to regulate our health care information from its initial creation to all aspects of its storage and disclosure.
>
> While reports and commissions have addressed these matters, very little comprehensive law has resulted.1093

In addition, information and privacy legislation, such as that of Manitoba1094 and the proposed Ontario *Personal Health Information Protection Act*,1095 has been criticized, among other things, for concentrating "on how private health information can be used and disclosed," rather than focusing on the protection of the privacy of personal health information.1096

Such problems, however, go well beyond the scope of this Report, and the reader is referred to the reports and papers that have addressed them in detail, suggesting ways to overcome them.1097 This Report focuses on three areas that have been particularly controversial in the HIV/AIDS context: reporting and partner notification, which will be addressed in the following chapters, and the "need to know."

However, it does agree with the International Guidelines on HIV/AIDS and Human Rights and recommends that confidentiality laws be enacted or amended to conform to them. The Guidelines state:

> General confidentiality and privacy laws should be enacted. HIV-related information on individuals should be included within definitions of personal/medical data subject to protection and should prohibit the unauthorized use and/or publication of HIV-related information on individuals. Privacy legislation should enable an individual to see his or her own records and to request amendments to ensure that such information is accurate, relevant, complete and up to date. An independent agency should be established to redress breaches of confidentiality. Provision should be made for professional bodies to discipline cases of breaches of confidentiality as professional misconduct under codes of conduct discussed below.1098 Unreasonable invasion of privacy by the media could also be included as a component of professional codes governing journalists. People living with HIV/AIDS should be authorized to demand that their identity and privacy be protected in legal proceedings in which information on these matters will be raised.1099

## Confidentiality and the Need to Know

> [D]iscussions of medical confidentiality usually have focused on the tension

> between a physician's responsibility to keep information divulged by patients secret and a physician's legal and moral duty, on occasion, to reveal such confidences to third parties, such as families, employers, public-health authorities, or police authorities. In all these instances, the central question relates to the stringency of the physician's obligation to maintain patient confidentiality when the health, well-being, and safety of identifiable others or of society in general would be threatened by a failure to reveal information about the patient. The tension in such cases is between the good of the patient and the good of others.1100

Many groups have claimed that in some situations they need to know the serostatus of HIV-positive persons: among these are correctional officers, health-care providers, patients, and survivors of sexual assault. In evaluating the merit of such claims, it is important to consider what purpose the disclosure would serve. In addition, it needs to be established whether disclosure is necessary or whether other, less intrusive means could achieve its goals.

## The Objective of Disclosure

There are two situations in which claims for disclosure of medical information may arise: disclosure preceding exposure to HIV in order to prevent HIV transmission, and disclosure following exposure to HIV.

### Disclosure Preceding Exposure to HIV

The objective of disclosure in this situation is to avoid or minimize exposure to HIV. Disclosure would lead to an intervention aimed at preventing the exposure. Staff in federal penitentiaries, for example, have often claimed that they need to know the HIV status of positive inmates in order to take adequate precautions to protect themselves and their families. In particular, some staff have maintained that the use of universal precautions is not practical and that it is unrealistic to believe that protective measures that can prevent HIV transmission in penitentiaries can be applied universally. They have also argued that knowing a particular inmate is HIV-positive would protect them because they would then handle the known positive offender with increased caution.

Given the limited opportunities for the transmission of HIV outside of sex or needle-sharing, the cases where a need to know might arise are very limited. There is consensus that a better way of preventing exposure is the adoption of universal precautions. Those who favour taking "extra" precautions only where they are in the presence of someone who is known to be HIV-positive may be pursuing an unwise policy. For example, were prison staff to be routinely informed about inmates known to be HIV-positive, it could create a false sense of security. Staff would know of only some of the HIV-positive inmates because not all inmates would be tested and because inmates would not be tested repeatedly. There is also concern that if the HIV status of seropositive inmates were disclosed to staff, fewer inmates would come forward for testing or self-disclose their positive HIV status, thereby further reducing the number of inmates known to be positive.

### Disclosure After Exposure to HIV

Exposure to HIV almost always elicits intense fear and distress, and it is often claimed that the person who was potentially exposed has a right to know the HIV status of the person who is the source of the exposure.

Claims that people who have potentially been exposed to HIV have a need to know the HIV status of the person at the source of the exposure have been analyzed above, in the context of survivors of sexual assault. It has been shown that, while voluntary disclosure of the HIV status of the person who is the source of the exposure should be encouraged, forced testing and disclosure of HIV status can seldom be justified.

## Conclusions and Recommendations

In 1989, the report of the Privacy Commissioner of Canada – because of the possible negative consequences of disclosure of someone's positive HIV status for that person – urged "caution in the collection of AIDS–related personal information, caution in its use and caution in its disclosure." The report pointed out that the situation calling for this extreme caution may change:

Disclosure of AIDS–related personal information may one day not threaten the physical and psychological well–being of those affected by the disclosure ... nor drastically alter the conditions of their membership in Canadian society. But for now, the strong possibility exists that public, and even government, opinion and actions could harm those individuals whose personal information is disclosed – without providing any measurable benefit to society.1101

Unfortunately, in 1998 disclosure of HIV/AIDS-related information still threatens the physical and psychological well–being of those affected by such disclosure. Therefore, the need for caution continues. While most agree that there are situations in which breaching confidentiality would be justified, such breaches 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 candor about their behaviour? ... Will the public health suffer as a consequence?1102

According to Bayer, 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 same vein, Gillon concludes by saying:

> 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.1103

Kain is concerned that people with HIV/AIDS would not speak freely about either their antibody status or sexual activities after being informed that such disclosure could result in a breach of confidentiality and the resulting increased opportunity for discrimination. He concludes by saying that the question of whether to breach confidentiality seems to overshadow a more crucial question:

> If a client is not telling his or her sexual partner about his or her seropositivity, *why not*? Prevention of the spread of AIDS lies not in police–like reporting practices but rather in the working through of deep-rooted issues of rejection, abandonment, loneliness, homophobia, and infidelity. Clients come to counsellors for help with troubling issues, not to be turned over to health officials.1104

This leads to another important issue: While it is important to increase efforts to protect confidentiality of medical information in general and HIV/AIDS-related information in particular, protecting people from discrimination may be even more important, and efforts may be better devoted not simply to protecting confidentiality but also to minimizing discrimination against people with HIV/AIDS.1105 One of the main reasons why protecting the confidentiality of HIV/AIDS-related information is so important is that the revelation of a person’s HIV status (and, often, of a person’s sexual orientation or drug use) exposes people to stigmatization, discrimination, and rejection. People with HIV or AIDS would have less reason to fear disclosure of their HIV status if that disclosure did not expose them to such negative reactions and if they were better protected against discrimination. Confidentiality would still remain important for all the reasons for which it is generally important, but would be less important. Because confidentiality is often breached, because it is so difficult to effectively protect information from disclosure, and because people with HIV or AIDS often have an interest in being able to be open about their HIV status, efforts to protect people with HIV or AIDS from discrimination need to be strengthened.1106

> **12.1 Confidentiality laws in Canada should conform to the recommendations in the International Guidelines on HIV/AIDS and Human Rights, which read as follows: "General confidentiality and privacy laws should be enacted. HIV-related information on individuals should be included within definitions of personal/medical data subject to protection and should prohibit the unauthorized use and/or publication of HIV-related**

**information on individuals. Privacy legislation should enable an individual to see his or her own records and to request amendments to ensure that such information is accurate, relevant, complete and up to date. An independent agency should be established to redress breaches of confidentiality. Provision should be made for professional bodies to discipline cases of breaches of confidentiality as professional misconduct under codes of conduct ..."1107**

**12.2 The disclosure of HIV/AIDS-related medical information to persons claiming that they have a need or right to know the serological status of HIV-positive individuals is seldom justifiable. In most situations, disclosure is unnecessary and its efficacy is questionable. In addition, disclosure is often counterproductive or harmful, in excess of any benefits or potential benefits that might result from it. Measures that can be undertaken to prevent exposure to and infection with HIV have to be undertaken regardless of whether a person is or is not known to be seropositive. To educate people about precautions that can prevent HIV transmission, and to make available to them the means necessary to prevent it, is essential if transmission of HIV infection is to be prevented. Only in rare, exceptional cases will disclosure be justified, when an individual assessment shows that disclosure is necessary, likely to be effective, and the least invasive and restrictive means available to prevent harms that cannot otherwise be prevented. In all other situations in which claims for disclosure may arise, other means are often already available, would be less harmful than disclosure, and are likely to be necessary and more effective.**

**12.3 Because of the limits of confidentiality and the difficulties of protecting it in practice, efforts to protect people living with or affected by HIV/AIDS from discrimination need to be strengthened. To this end, the recommendations in *HIV/AIDS and Discrimination: A Discussion Paper*1108 should be implemented.**

[Return to the top of this page](#)

[Return to Table of Contents](#)

---

ENDNOTES

1013 R Bayer. HIV Testing and Reporting. *AIDS Ethics and Policy Updates*. At the *Journal of the American Medical Association* website.

1014 Supra, note 13 with reference to L Gostin. A Decade of a Maturing Epidemic: An Assessment and Directions for Future Public Policy. *Notre Dame Journal of Law, Ethics & Public Policy* 1990; 5: 7 at 27.

1015 OLRC, supra, note 13, with many references.

1016 Somerville & Gilmore, supra, note 9
at 6.

1017 Supra, note 11 at 46.

1018 Information and Privacy Commissioner/Ontario. *HIV/AIDS: A Need for Privacy*, October 1990, at 3.

1019 Commission d'accès à l'information du Québec. Renseignements personnels relatifs au sida: une confidentialité à respecter. Québec: The Commission, March 1991.

1020 OLRC, supra, note 13 at 78.

1021For more details, see Jürgens & Palles, supra, note 2 at 229-251.

1022 CBA-Ontario, supra, note 7 at 54.

1023 Supra, note 10, *Summary Report* at 10.

1024 Ibid.

1025 Ibid at 11.

1026 Supra, note 12 at 41.

1027 P Glenn et al. *HIV Infection, AIDS and Privacy*. Montréal: McGill Centre for Medicine, Ethics and Law, 1990, at 5.

1028 Ibid.

1029 Ibid at 5-6.

1030 Ibid.

1031 Ibid at 7.

1032 The Privacy Commissioner of Canada. *AIDS and the Privacy Act*. Ottawa: Minister of Supply and Services Canada, 1989.

1033 Royal Society, Summary Report, supra, note 10 at 11.

1034 Glenn et al, supra, note 1027 at 76-77.

1035 Supra, note 1018 at 3.

1036 Summary Report, supra, note 10 at 11.

1037 See, for information on (1) Australia: RS Magnusson et al. HIV and Confidentiality. *Medical Journal of Australia* 1996; 165: 90-91; RS Magnusson. Australian HIV/AIDS Legislation: A Review for Doctors. *Australian and New Zealand Journal of Medicine* 1996; 26: 396-406; RS Magnusson. Privacy, Confidentiality and HIV/AIDS Health Care. *Australian Journal of Public Health* 1994; 18(1): 51-58; (2) South Africa: F Hassan. Confidentiality: Tool of the Trade. *The AIDS Legal Quarterly* February 1998, at 11; (3) US: Gostin & Webber, supra, note 658; (4) different countries: Zeegers Paget, supra, note 175 at 63-69.

1038 Supra, note 162 at 13, para 28(f).

1039 Hamblin & Somerville, supra, note 346 at 239; communication with Dr Patrick, Associate Director of HIV/AIDS, British Columbia Centre for Disease Control, on 29 January 1997, with reference to s 6(1) *Communicable Diseases Regulation*.

1040 *Alberta Public Health Act, SA 1984, c P-27.1, s 63(5)(b).*

1041 Ibid, s 63(2).

1042 The following section is a slightly revised version of R Jürgens, N Gilmore. Disclosure of Offender Medical Information: A Legal and Ethical Analysis. In: Correctional Service Canada. *HIV/AIDS in Prisons: Background Materials*. Ottawa: Minister of Supply and Services Canada, 1994, Appendix 7, 127-145.

1043 DG Casswell. Disclosure by a Physician of AIDS-Related Patient Information: An Ethical and Legal Dilemma. *Canadian Bar Review* 1989; 68: 225-258 at 228, with further references.

1044 N Gilmore, MA Somerville. *Physicians, Ethics and AIDS*. Ottawa: Canadian Medical Association, 1989, at 21.

1045 Casswell, supra, note 1043 at 228 n12, with reference to *AB* v *CD* (1851), 14 Sess. Cas. (Second Series) 177 (Scot Ct Sess). See also J Sestito. The Duty to Warn Third Parties and AIDS in Canada. *Health Law in Canada* 1996; 16(3): 83-97 at 85.

1046 (1979), 98 DLR (3d) 704 at 714; 24 OR (2d) 545 at 555 (Ont CA).

1047 For a list of provincial legislation recognizing the duty of confidentiality, see Casswell, supra, note 1043 at 228 n13: the *Health Disciplines Act Medicine Regulation*, RRO 1980, Reg 448, s 27.22; the *Charter of Human Rights and Freedoms*, RSQ 1977, c C-12, s 9; the *Medical Act*, RSQ 1977, c M-9, s 42; and the Code of Ethics of Physicians, RRQ 1981, c M-9, r 4, s 3.01. See also the Supreme Court of Canada decision in *Frenette* v *Metropolitan Life Insurance Company*, [1992] 1 SCR 647-696 at 666: "Hospital records in Quebec are statutorily protected by a veil of confidentiality (s. 7 of *An Act Respecting Health Services and Social Services*), as are confidences given to physicians by reason of their profession (s. 9, para 2 of the Charter and s. 42 of the *Medical Act*). The right to non-disclosure of confidential information generally is also provided for in the first paragraph of s. 9 of the Charter." See also ibid at 673.

1048 *McInerney* v *MacDonald*, [1992] 2 SCR 138 at 149, with many references.

1049 Ibid at 151.

1050 (1990), 69 DLR (4th) 755 (Alta QB), quoted in *Frenette*, supra, note 1047 at 688.

1051 *Hay*, ibid at 757-758.

1052 *McInerney*, supra, note 1048 at 153.

1053 Casswell, supra, note 1043 at 229.

1054 Ibid at 228, n14, with reference to EI Picard. *Legal Liability of Doctors and Hospitals in Canada*. 2nd ed, 1984, p 8, n 51, referring to the *Canadian Charter of Rights and Freedoms*, Constitution Act, 1982, Part I, s 7.

1055 For an overview of statutes and regulations requiring patient information about communicable/reportable/ infectious/ contagious diseases to be kept confidential, see Casswell, ibid at 255 (Table A).

1056 RSC 1985, c P-21.

1057 Hippocratic Oath, as translated by BM Dickens. Confidentiality and the Duty to Warn. In: LO Gostin (ed). *AIDS and the Health Care System*. New Haven: Yale University Press, 1990, 98-112 at 98.

1058 R Belitzky, RA Solomon. Doctors and Patients: Responsibilities in a Confidential Relationship. In: LH Dalton, S Burris (eds). *AIDS and the Law: A Guide for the Public*. New Haven: Yale University Press, 1987, 201-209 at 202.

1059 MA Somerville. AIDS: A Challenge to Health Care, Law, and Ethics. In: D Snowden, DF Cassidy (eds). *AIDS: A Handbook for Professionals*. 1989, 200-220 at 211.

1060 The Privacy Commissioner of Canada, supra, note 1032 at 1.

1061 Gilmore & Somerville, supra, note 1044 at 21; Somerville, supra, note 1059 at 211-212.

1062 Gilmore & Somerville, ibid at 21.

1063 *McInerney*, supra, note 1048 at 154, citing *Halls* v *Mitchell*, [1928] SCR 125 at 136.

1064 The extrajudicial context must be distinguished from the judicial context. In the latter the issue is whether patient-physician communications are privileged when sought in court proceedings.

1065 *Frenette*, supra, note 1047 at 675.

1066 Belitzky & Solomon, supra, note 1058 at 203 n24, with reference to *Edwards v Lamb*, 69 NH 599, 45 A. 480 (1899); *Earle v Kuklo*, 26 NJ Super 471, 98 A.2d 107 (1953) (landlord exposing tenants to tuberculosis); *Kliegel v Aitken*, 94 Wis 432, 60 NW67 (1896) (employer exposing employees to typhoid fever); *Davis v Rodman*, 147 Ark 385, 227 SW 612 (1921) (typhoid fever); *Skillings v Allen*, 143 Minn 323, 173 NW 663 (1919) (scarlet fever); *Edwards*, 69 NH 599, 45 A.480

(infectious sore); *Fosgate v Corona*, 66 NJ 268, 330 A.2d 355 (1974) (tuberculosis); *Wojick v Aluminium Company of America*, 18 Misc 2d 740, 183 NYS 2d 351 (Sup Ct 1959) (employer who administers regular x-rays to employee liable for failure to disclose tuberculosis).

1067 Belitzky & Solomon, supra, note 1058 at 203.

1068 17 Cal 3d 425, 551 P 2d 334, 131 Cal Rptr 14 (1976).

1069 Belitzky & Solomon, supra, note 1058 at 203-204, with reference to *Tarasoff*.

1070 Sestito, supra, note 1045 at 87, with reference to *Tanner v Norys*, [1980] 4 WWR 33 (Alta C.A.); *Wendon v Trikha et al* (1991), 116 AR 81 (Q.B.).

1071 Ibid at 88.

1072 (1994), 112 DLR (4th) 257. For a summary, see B Guillot-Hurtubise. First Canadian Ruling in a Tainted-Blood Case. *Canadian HIV/AIDS Policy & Law Newsletter* 1994; 1(1): 8-9.

1073 Ibid at 261.

1074 Canadian Medical Association. Code of Ethics of the Canadian Medical Association. *Canadian Medical Association Journal* 1996; 155(8): 1176A-B at 1176B. In 1989, the CMA had stressed the need to respect the confidentiality of patients with HIV infection and consequently recommended that legal and regulatory safeguards be put in place to protect such confidentiality (A CMA Position: Acquired Immunodeficiency Syndrome. *Canadian Medical Association Journal* 1989; 140: 64A at 64B).

1075 Information and Privacy Commissioner/Ontario, supra, note 1035 at 4.

1076 LO Gostin, Z Lazzarini, KM Flaherty. Legislative Survey of State Confidentiality Laws, with Specific Emphasis on HIV and Immunization. Final Report Presented to: The U.S. Centers for Disease Control and Prevention, The Council of State and Territorial Epidemiologists, The Task Force for Child Survival and Development. Carter Presidential Center. 2 July 1996, at 32, with reference to LO Gostin. Health Information Privacy. *Cornell Law Review* 1995; 80: 101-184.

1077 Ibid at 62, with reference to The Panos Institute. *The Third Epidemic: Repercussions of the Fear of AIDS*. London: Norwegian Red Cross, 1990. See also *HIV/AIDS and Human Rights: International Guidelines*, supra, note 162 at 48, para 98.

1078 Ibid at 63.

1079 R Doughty. The Confidentiality of HIV-Related Information: Responding to the Resurgence of Aggressive Public Health Interventions in the AIDS Epidemic. *California Law Review* 1994; 82: 111-184 at 133, with many references.

1080 *HIV/AIDS and Discrimination: A Discussion Paper*, supra, note 6 at 30, with reference to M Shaw et al. Survey of Patients' Views on Confidentiality and Non-Discrimination Policies in General Practice. *British Medical Journal* 1996; 312 (7044): 1463-1464.

1081 See, eg, R Bayer. Confidentiality and Its Limits. In: H Fuenzalida–Puelma et al (eds). *Ethics and Law in the Study of AIDS*. Pan American Health Organization Scientific Publication No 530; P Wilson. Medical Confidentiality – A Decrepit

Concept? Paper presented at the Law and Society Association Meeting, Toronto, 2 June 1995; M Siegler. Confidentiality in Medicine – A Decrepit Concept. *The New England Journal of Medicine* 1982; 307(24): 1518-1521 at 1519.

1082 A Hendriks. Confidentiality, Testimonial Privilege and Patients' Right to Secrecy Under the ECHR. *European Journal of Health Law* 1997; 4.

1083 Ibid.

1084 BM Dickens. Legal Limits of AIDS Confidentiality. *Journal of the American Medical Association* 1988; 259: 3449-3451 at 3449, 3551.

1085 Siegler, supra, note 1081 at 1518.

1086 Glenn et al, supra, note 1027 at 55.

1087 See ibid at 30-32.

1088 Ibid at 31.

1089 A Legal Framework for Health Information – Consultation Paper. Toronto: Ontario Ministry of Health, June 1996, at 5.

1090 M Closen et al. AIDS in America: Death, Privacy and the Law. *Human Rights* 1987; 14: 27 at 48.

1091 A Legal Framework for Health Information, supra, note 1089 at 9.

1092 Supra, note 1076 at 154.

1093 Editorial. Focus on Confidentiality of Health Care Information. *Health Law in Canada* 1997; 17(3): 67.

1094 D Roberts. Manitoba Bill Still Flawed, Critics Say. *The Globe and Mail* 25 June 1997, at A6.

1095 Personal Health Information Protection Act, 1997. Draft for Consultation. Queen's Printer for Ontario, November 1997.

1096 The HIV/AIDS Community Ad Hoc Committee on the *Personal Health Information Protection Act, 1997*. *Position Statement*. Toronto: The Committee, 1998.

1097 See, eg, A Legal Framework, supra, note 1089; Glenn et al, supra, note 1027; Gostin, Lazzarini & Flaherty, supra, note 1076; the articles in *Health Law in Canada* 1997; 17(3), which all concern confidentiality of health-care information.

1098 According to strategy 10 of the Guidelines (see supra, note 162),

States should ensure that the government and the private sector develop codes of practice regarding HIV/AIDS issues that translate human rights principles into codes of professional responsibility and practice, with accompanying mechanisms to implement and enforce these codes.

1099 Supra, note 162 at 16, para 30(c).

1100 Siegler, supra, note 1081 at 1519.

1101 Supra, note 1032 at 2.

1102 Bayer, supra, note 1081.

1103 R Gillon. AIDS and Medical Confidentiality. *British Medical Journal* 1987; 294: 1675–1677.

1104 CD Kain. To Breach or Not To Breach: Is that the Question? A Response to Gray and Harding. *Journal of Counselling and Development* 1988; 66: 224–225.

1105 Dickens, supra, note 1084.

1106 Similarly, Spencer suggests that legislatures devote their attention to the social discrimination against AIDS that hampers voluntary HIV testing programs and control of HIV. See ETH Spencer. The Sexually Active, HIV-Infected Patient: Confidentiality Versus the Duty to Protect. *Psychiatric Annals* 1988; 18(10): 571-576.

1107 Supra, note 162 at 16, para 30(c).

1108 Supra, note 6 at 109-119.

**Return to the top of this page**

**Return to Table of Contents**

# HIV Testing and Confidentiality: Final Report

**Prepared by Ralf Jürgens**

**ISBN 1-896735-16-9**

---

# REPORTING

As Zeegers Paget has said,

> [t]he surveillance of an infectious disease has been defined as the continuous scrutiny of all aspects of its spread. ... The reporting of an infectious disease is often seen as a first step in controlling its further spread. Reporting allows determination of the presence of the disease in the population.1109

In relation to AIDS, the Canadian Bar Association-Ontario has indicated three aims of reporting, namely to permit education and counselling to be directed to those groups where HIV infection or AIDS is more frequent, to facilitate the tracing of contacts, and to gather epidemiological data on AIDS and HIV infection.1110

In the debate on reporting, two questions are prominent: the first concerns the scope of reporting, and the second the type of reporting to be used.1111 The scope of reporting concerns what it is that has to be reported: AIDS, HIV infection and/or other symptoms of HIV/AIDS. Some jurisdictions require reporting only of AIDS, while others require reporting of AIDS and HIV and some require reporting of other symptoms of HIV/AIDS.

The second question in the debate regarding the type of reporting concerns whether it is nominal or non-nominal. In nominal reporting, the name or other identifying information of the patient is reported to public health authorities. In non-nominal reporting, the name or other identifying data is not reported.

In Canada, AIDS was treated as notifiable in British Columbia beginning in 1983 under a provincial regulation requiring physicians to report a communicable disease "which becomes epidemic or shows unusual features."1112 AIDS and sometimes HIV was subsequently made notifiable or reportable by legislative amendment in all provinces and territories. Some provinces and territories require nominal reporting of AIDS and sometimes even HIV, while in the others reporting is non-nominal. Recently, some provinces have revised their HIV reporting requirements or, like Québec, are in the process of doing so. In the United States, debate about HIV reporting has been raging for the last twelve months. While there is consensus that there is a need for accurate monitoring of HIV infection and that AIDS surveillance "can no longer provide as timely, complete, representative, and accurate a reflection of the epidemic as we need,"1113 many oppose proposals for *nominal* reporting of HIV, fearing that it inhibits rather than supports public health goals such as protecting the confidentiality of those living with HIV and encouraging people to seek HIV testing.

This chapter first reviews the recommendations made by organizations in Canada – and, to a lesser extent, internationally – since 1986 regarding reporting of HIV and AIDS (History). The chapter then briefly examines the current situation in Canada, pointing out that with respect to reporting there are wide divergencies in legislation and practice between and within Canadian provinces and territories. Internationally, the situation is similar, with wide divergencies in legislation and practice between and sometimes within different countries (Current Situation). The chapter then examines how reporting of HIV and AIDS should be undertaken in Canada (Assessment). It supports reporting of HIV cases, but only if such reporting is non-nominal, using unique identifiers or coded identifiers that ensure privacy and confidentiality of the individual (Conclusions and Recommendations).

The chapter does not address questions raised by setting up a national system for HIV surveillance in Canada.1114 Such questions are beyond the scope of this Report.

# History

## Canada

Most people and organizations in Canada that have addressed the issue of reporting have recommended that both HIV and AIDS be reportable.1115 For example, the Royal Society of Canada stated that, "whether the purpose of reporting is surveillance for epidemiological purposes or reduction of the spread of the disease, if reporting is justified, it would seem preferable to include both HIV infection and AIDS."1116 Only rarely has it been questioned whether HIV-antibody positivity should be reportable at all.1117

Individuals and organizations have, however, stressed that reporting should be non-nominal. The Canadian Bar Association –Ontario suggested that the uses of personal identifiers such as the patient's initials, present address, and exact date of birth should be omitted from the reporting procedures and from the notification forms sent to the medical officers of health. According to the Association's report, personal identifiers are not required to serve the reporting objective of collecting epidemiological data. In addition, in light of the report's recommendation that it be the physician, and not the medical officer of health, who is initially responsible for partner notification, "it is unnecessary for the medical officer of health to obtain this personal identifying information for contact tracing purposes."1118 Similarly, the Royal Society of Canada recommended that reporting laws be amended to provide that the reporting of HIV seropositivity and AIDS not identify the person,1119 and the Information and Privacy Commissioner/Ontario suggested that "any obligation imposed by legislation to report nominal HIV/AIDS-related personal information ... be removed."1120 In particular, the Royal Society held that reporting by number, age, sex and municipality provides sufficient information for epidemiological purposes:

Personal identification is not required for an incurable disease for which isolation or segregation is not recommended as a public health measure. ... We do not support ... nominal reporting.1121

Hamblin and Somerville questioned whether many of the existing HIV infection and AIDS case-reporting requirements would be able to withstand a challenge under the *Charter of Rights and Freedoms*.1122 With regard to the epidemiological objective of existing systems of surveillance of HIV and AIDS, they agreed that the need is for consistent and accurate data in a form that enables the spread of HIV to be monitored, but pointed out that personal identifying information is not relevant for epidemiological purposes.1123 Therefore, they concluded that "compulsory case reporting requirements in Canada are not designed to achieve the epidemiological objective in the most effective and least harmful way."1124 With regard to the objective of facilitating public health measures such as partner notification, the authors pointed out that "the majority of reporting provisions in Canada go further than is needed for contact tracing to take place."1125 The authors concluded by pointing out that "the diversity to be found in surveillance of HIV infection and AIDS in Canada has resulted in a lack of coherence in the way that information about these conditions is collected." In their view, inconsistencies among approaches to case reporting in the different Canadian jurisdictions present real obstacles to effective surveillance of HIV and AIDS.1126 To overcome those obstacles, the Canadian Public Health Association recommended that Health Canada, in collaboration with the provincial and territorial ministries of health, compare and report on the experiences of provinces with mandatory HIV reporting and on those without mandatory reporting; develop a standard, non-duplicative reporting mechanism for HIV and AIDS across Canada; and develop a protocol for reporting to the province or territory and to Health Canada.1127

Finally, in 1997, at its Annual General Meeting, the Canadian Public Health Association called on the ministers of health of British Columbia, Alberta, and Québec "to make HIV reportable in their jurisdictions and provide such data to Health Canada so that the full extent of and changes in the HIV epidemics in Canada can be determined and monitored."1128

## International Developments

Internationally, as in Canada, reporting of AIDS cases has until recently formed the cornerstone of efforts to monitor and characterize the epidemic of HIV infection. While AIDS surveillance was, and still is, broadly accepted, requirements of HIV reporting have long been controversial. In particular, it remains controversial whether cases of HIV should be reported by name or whether HIV surveillance by unique identifier or other non-name based surveillance systems should be adopted.

In the United States,

> AIDS first emerged in the early 1980s as a health crisis among gay men, who began experiencing an onset of severe and unexplained health problems that quickly turned fatal. At the time there was no medical understanding of the emerging epidemic, and there was widespread societal fear about possible contagion. AIDS became a marker for gay men, and since many in the population held strong biases against gay people, a social stigma attached to AIDS that set the syndrome apart from other contagious diseases. Gay men with AIDS were fired from their jobs, lost their health insurance and their homes, were turned away by health care providers, and were ostracized by their families, either because of their mysterious health condition, their sexual orientation, or both.1129

Surveillance of AIDS cases, including reporting the names of people diagnosed with AIDS to public health authorities, began almost immediately and "with little fanfare."1130 There were several reasons for this:

First, name reporting was a public health response which had been used with some other sexually transmitted diseases. Second, individuals who were diagnosed with AIDS were already in the late stages of what we now know to be HIV disease, and were for the most part already participating in the health care system. Thus in a real sense they had already been "identified" as persons with AIDS. And finally, although an AIDS diagnosis and public dissemination of that information often triggered a hostile societal response, the harsh reality was that persons diagnosed with AIDS usually died quickly, and the struggle for survival overwhelmed any attempt of leading a "normal life."1131

HIV was not discovered until 1983, and HIV testing became available only in the mid 1980s. At that time, surveillance of cases of HIV infection, as opposed to AIDS diagnosis, was opposed by advocacy groups and by public health authorities. There were several reasons for this opposition:

> First, because AIDS initially appeared in populations which have traditionally been discriminated against ... and because of the stigma which quickly surrounded the disease, there was concern about reporting HIV cases and suspicion about what would be done with the information collected. This concern was justified, in light of the fact that few confidentiality protections existed in law, and that proposed policies were often driven by fear and misunderstanding. Historically, proposals for HIV surveillance almost always called for mandatory name reporting.
>
> Second, there was no cure or even effective treatment to offer to those infected with HIV and no medical way to make an infected person uninfectious, reasons given under traditional public health practice for reporting cases of a disease...
>
> Finally, there was fear that reporting HIV cases would drive people away from testing and the health care system generally – especially those who might be likely to test positive for HIV – and therefore would undermine public health efforts. In short, the harm that could potentially have come from HIV surveillance outweighed the benefits that it could provide.1132

Thus, the first requirement for HIV reporting, in Colorado, and the early public health proposals for HIV surveillance in the mid 1980s "ignited a firestorm of community protest."1133

In recent years, however, in the United States as elsewhere in the developed world, a number of factors have shifted the focus of epidemiological surveillance to the "front end" of the AIDS epidemic, HIV infection. As medical treatments prolong the lives of many people with HIV and significantly delay the amount of lapsed time from infection to AIDS diagnosis, surveillance of AIDS cases tells us less and less about how HIV infection is developing and spreading. For the United States, Gostin et al have argued that "[w]e are at a defining moment in the epidemic of HIV infection and AIDS," and that "[u]nless we revise our surveillance system, health authorities will not have reliable information about the prevalence, incidence, and future directions of HIV infection, the kinds of behavior that currently increase the risk of HIV transmission, or the heightened impact on specific subpopulations, such as racial and ethnic minorities and women."1134 The authors have therefore proposed that all states in the US require HIV case reporting. This proposal has received wide support, including from those who have traditionally opposed HIV case reporting, such as the American Civil Liberties Union and the New York-based group Gay Men’s Health Crisis, which in January 1998 called for a new system for tracking HIV infection in New York State, saying "that the old hospital-based AIDS reporting system is obsolete."1135 However, heated debate continues about whether reporting should be nominal or non-nominal. In particular, the debate centres around whether HIV case surveillance through the use of non-name unique identifiers, such as undertaken in some states, is effective.1136

In October 1997, the National Association of Persons with HIV/AIDS (NAPWA) adopted a policy position paper on the monitoring of the HIV epidemic. The following 14 criteria define NAPWA's position "on the responsible and ethical approach to monitoring the HIV/AIDS epidemic in the United States":1137

> 1. Under no circumstance does NAPWA support HIV named reporting, the CDC's promotion of a national standard in support of HIV named reporting or the creation of a federal name-based registry of people living with HIV/AIDS. The CDC should in no way encourage or require states to do HIV named reporting.
>
> 2. NAPWA guardedly supports the expansion of our national HIV/AIDS surveillance system to include HIV infection case reporting; however, only using unique or coded identifiers that insure privacy and confidentiality of the individual.
>
> 3. The CDC must aggressively promote, expand and improve anonymous HIV testing in the United States. The availability of readily accessible anonymous testing is a necessary condition/prerequisite for any maintenance and/or expansion of HIV surveillance in the United States. CDC must mandate readily accessible anonymous testing in all HIV Prevention Cooperative Agreement jurisdictions as a condition of establishing HIV surveillance tools nationally.
>
> 4. CDC-funded research has shown that certain individuals and/or communities will only use anonymous testing sites. Therefore, access to primary care (after testing positive) is predicated upon the availability of anonymous testing.
>
> 5. CDC's HIV/AIDS surveillance's primary goal is to collect useful data in a timely fashion to provide an accurate estimate of the prevalence of HIV/AIDS in the United States. Accordingly, HIV/AIDS surveillance has to provide reliable data. As such, while it is a goal of anonymous and confidential counseling and testing to link individuals into services, this is not necessarily either a goal or an outcome of surveillance.
>
> 6. The applied uses of reliable, accurate and timely surveillance data include informing: resource allocation; health planning; and evaluation of both programmatic as well as system-wide activities (i.e. access to care,

survival/death rates, seroincidence rates, etc.).

7. As a guiding principle, unless a name is uniquely essential for the protection and promotion of an individual's health and well-being or a community's health and well-being, the name of the person whose information is being reported to the state or local health department should not be taken.

8. Surveillance is an adaptive science. As such, surveillance systems should be constantly re-evaluated to determine if the goal of applying surveillance data to meaningful education, programs, planning and resource allocation is happening. If not, these systems should be discontinued.

9. Surveillance systems consist of several different types of activities in addition to case counting (number of individuals living or deceased who have said disease): sentinel studies; incidence and prevalence studies (density of disease and breadth of disease); and even behavioral (risk-taking) surveillance. The more varied the surveillance system, the more relevant the data sets that result.

10. Decisions regarding what type of HIV/AIDS surveillance to implement in a given jurisdiction are best made by each jurisdiction based on resources, community acceptance, confidentiality/privacy protections, the severity of the epidemic, and other local considerations.

11. Data from HIV case reporting must be appropriately disseminated to the community planning bodies within jurisdictions for use in both prevention and care planning.

12. Categorical funding for HIV/AIDS surveillance must be maintained and augmented. However, resources for HIV/AIDS surveillance must not come at the expense of resources for HIV-related research, care and prevention (both primary and secondary) programs.

13. National HIV/AIDS public health policy should reinforce that the data collected under this system must remain decoupled from partner notification and contact tracing processes. These processes' relationship to surveillance must be made only as a component of and only with the explicit concurrence from the jurisdiction's HIV Prevention Community Planning group.

> 14. Federal law must establish an individual's enforceable right to privacy with respect to individually identifiable health information, and must protect each person from discrimination based on real or perceived health and/or genetic status. Such laws must include strong and enforceable repercussions for those individuals and systems that breach an individual's confidentiality and/or privacy.1138

In Australia, the Legal Working Party of the Intergovernmental Committee on AIDS recommended that uniform notification requirements be adopted throughout the country, requiring coded reporting of confirmed HIV positive test results by laboratories, and of clinical AIDS diagnosis by doctors.1139

Internationally, the Guidelines on HIV/AIDS and Human Rights state that "[p]ublic health legislation should ensure that HIV and AIDS cases reported to public health authorities for epidemiological purposes are subject to strict rules of data protection and confidentiality."1140

# Current Situation

## Canada

In Canada, matters of public health typically fall under provincial jurisdiction as a "local or private" matter pursuant to s 92(16) of the *Constitution Act, 1867*.1141 There are therefore wide divergences in legislation and practice between and within the provinces and territories.

### Reporting of AIDS

In all Canadian provinces and territories, either public health legislation or regulations passed pursuant to such legislation, have been amended to make cases of AIDS notifiable to public health authorities.1142

#### Nominal/Non-Nominal Reporting

Newfoundland, Nova Scotia, New Brunswick, Ontario and Manitoba require nominal reporting of AIDS.

Saskatchewan requires nominal reporting of AIDS to the level of the Medical Health Officer and non-nominal reporting to the CDC, Saskatchewan Health.1143

In British Columbia, reporting may take place using non-nominal records, but some clinicians do submit the full name of the patient.1144

In Prince Edward Island, reporting is done "in such manner as the Chief Health Officer may direct."1145 In February 1991, "[n]otification for AIDS and 'HIV antibodies' ... became dependent ... upon risk assessment."1146 The reporting physician may choose to report nominally "where there is reason to believe that someone who tests HIV+ will not cooperate in contact tracing or that the person must be reported by name in order to protect the health of the public."

Québec, Alberta, and Yukon do not require nominal reporting of AIDS.

## Reporting of HIV Seropositivity

Cases of HIV seropositivity must be reported in all provinces and territories with the exception of Québec, British Columbia, and Yukon. In Alberta, HIV became a notifiable disease on 1 May 1998. In Québec, an Ad Hoc Committee was struck in March 1998 with the mandate to "review HIV infection surveillance strategies in Québec, including obligatory reporting of HIV, and to propose recommendations for putting into place or improving the means of obtaining the information necessary to monitor the epidemic and to better help those living with HIV."1147 The Committee released a draft report in August 1998 recommending that HIV become non-nominally reportable in the province.1148 In British Columbia, HIV is not reportable by physicians, but non-nominal collection of data does occur at the level of the testing laboratories. As of August 1998, it was not planned to make any changes to the BC reporting system.1149 In 2001, however, it was expected that British Columbia would make HIV reportable.

In Yukon, all HIV-antibody testing is carried out under the direction of the Territory's Communicable Disease Officer, who keeps a record of all persons who test positive.

### Nominal/Non-Nominal Reporting

Newfoundland, New Brunswick, Ontario, and the Northwest Territories require nominal reporting of HIV infection. However, in Ontario, physicians who provide professional services to a patient in certain specified clinics have been exempted from reporting the patient's name and address. In Prince Edward Island, reporting is done "in such manner as the Chief Health Officer may direct."1150 According to correspondence received from Dr Sweet, Chief Medical Officer of Prince Edward Island, this allows 80% of reporting to be non-nominal. However, in the other 20% of cases nominal reporting is required in order to ensure that adequate partner notification or contact tracing/testing can be carried out.1151

In Alberta, reporting could be nominal or non-nominal. In the other provinces, reporting of HIV is non-nominal.

### Duty to Report

The classes of people on whom reporting of HIV infection and/or AIDS is imposed varies from province to province. In Québec, only physicians and directors of laboratories have a duty to report. In Manitoba, physicians and laboratory operators have a duty to report. In Newfoundland, Nova Scotia, Ontario, and Alberta a duty to report is imposed on additional classes of people, typically teachers (Alberta and Newfoundland), school principals (Ontario), persons in charge of certain specified institutions, such as, eg, hospitals, prisons, or boarding schools (Alberta, Newfoundland, Nova Scotia, and Ontario), and hotel-keepers and keepers of boarding houses (Newfoundland).

## International Developments

As in Canada, legislation and practice concerning reporting varies greatly from one jurisdiction to another. In Australia, the mandatory reporting of HIV and AIDS to the Health Department is required by public health legislation in all jurisdictions.1152 In addition to reporting HIV and AIDS to State Health Departments, HIV laboratories and sexual health clinics also report new cases of HIV infection and AIDS and deaths from AIDS to the National Centre in HIV Epidemiology and Clinical Research located at St Vincent’s Hospital, Sydney. Reporting of both HIV and AIDS is usually coded. For example, in New South Wales and Victoria, medical practitioners are required to report diagnosed cases of AIDS to the Health Department using a name code constructed from the first two letters of the patient’s surname and given name. In some states, exceptions from coded reporting are possible and nominal reporting may be undertaken in order to protect the public against an "outbreak" of HIV.1153 Additional demographic data are also collected. The mode of infection of a patient diagnosed with HIV or AIDS is notifiable by the laboratory or doctor concerned in accordance with reporting forms prescribed in all States and Territories. Ethnic origin is notifiable in Queensland, racial origin is notifiable in South Australia, one’s "language spoken at home" and country of birth are notifiable in Tasmania, and aboriginality is notifiable in New South Wales, Queensland, Western Australia, and Tasmania.1154

In the United States, all states require that AIDS cases be reported by name. An increasing number of states (30 as of July 1998) also mandate nominal HIV reporting, while some states rely on a coded unique identifier to track HIV cases and a small number of states has not yet required reporting of HIV cases. The issue gained a lot of attention in 1998 because a number of states enacted reporting-related legislation, most notably New York State, where legislation to implement name-based reporting was enacted in July. In Texas, the state was considering shifting from a unique-identifier system to a name-based reporting system,1155 while California adopted legislation requiring HIV reporting using coded identifiers in August.1156 Federal guidelines for HIV case surveillance, expected to be released in early 1998, have been delayed and had not been issued at the time of writing. However, it has been reported that the guidelines will not recommend that states rely on names to track the epidemic and that they will focus on performance standards for conducting surveillance, rather than urging states to record HIV infection using the person’s name.1157

In Europe as elsewhere, AIDS case reporting has long been the principal means for monitoring the HIV epidemic. More recently, however, HIV surveillance strategies have been the focus of attention. Information from a study conducted in September 1997 to explore the feasibility of setting up an HIV case-reporting system at the European level showed that

HIV case reporting systems exist since the late 1980s in most European countries. Their organization is different according to the country. Laboratories and clinicians are frequently both involved as a source of reporting to obtain both a high reporting rate and sufficient clinical and epidemiological information. A minority of countries have adopted nominative reporting, which allows precise identification of cases but may increase the risk of discrimination if confidentiality is breached. In most other countries, reporting through an identifying code still allows the elimination of most duplicate reports and the linkage between HIV and AIDS reporting.1158

The study reports that changes in HIV case reporting are planned in several European countries1159 and that a preliminary consensus was reached in February 1998 to set up a European HIV case-report database to complement the existing European databases on AIDS cases and on HIV prevalence studies.1160

## Assessment

> Public health authorities must substantiate the need for a named identifier when collecting information. If they could achieve the public health goal as well, or better without personal identifiers, the collection of non-identifiable or aggregate data is preferable. These data collection principles recognize that government authority to acquire sensitive personal information ought to be justified by substantial public health goals that cannot be achieved by means that are less invasive of individual privacy.1161

As shown above, all Canadian provinces and territories require reporting of cases of AIDS to public health authorities, and most, but not all, also require reporting of cases of HIV seropositivity. Some provinces require nominal reporting, while others don’t. The wide divergencies in legislation and practice between the provinces and territories has made surveillance of the epidemic in Canada more difficult, leading to calls for development of a standard, non-duplicative reporting mechanism for HIV and AIDS across Canada. Because matters of public health fall under provincial jurisdiction, development of such a reporting mechanism would require that all provinces and territories agree on one reporting mechanism and amend their public health acts accordingly. It seems unlikely that, more than 15 years into the HIV and AIDS epidemic, a consensus will be reached across Canada on how to best achieve the goals of reporting.

However, it does seem that provinces that have thus far not required the reporting of cases of HIV seropositivity are moving toward changing their laws and regulations to require such reporting. Indeed, as reported above, since the publication of the *Discussion Paper* in March 1997, Alberta has changed its legislation to require reporting of HIV and in Québec an Ad Hoc Committee has recommended that HIV become reportable. This may soon lead to a situation where all provinces and territories will require reporting of cases of both AIDS and HIV seropositivity. As long as reporting is non-nominal, this is not a cause for concern. To achieve the epidemiological objective of reporting, there are good reasons at this point in the epidemic to require reporting of cases of HIV seropositivity. HIV surveillance can allow us to develop a more accurate picture of the current epidemic and craft a more finely-tuned response. As the US Centers for Disease Control and Prevention have stated, HIV surveillance can "provide a more timely measure of emerging patterns of HIV transmission, a more complete estimate of the number of persons with HIV infection and disease, and a better mechanism to evaluate access to HIV testing and medical and prevention services than AIDS surveillance alone.1162

However, neither the epidemiological objective of reporting nor the objective of facilitating public health measures such as partner notification, require *nominal* reporting. With regard to the epidemiological objective, the need is for consistent and accurate data in a form that enables the spread of HIV to be monitored, including demographic information about the age, sex, and geographic location of an HIV-positive person, information about how that person is thought to have been exposed to HIV and about the person’s previous testing history, in order to prevent duplication of reporting. Personal identifying information is not relevant.

With regard to the objective of facilitating public health measures such as partner notification, personal identifying information is also not necessary: people can identify partners without identifying themselves. As has been said, "the name of the person testing HIV positive ... is not what is important in partner notification, rather, it is the names of the sexual or needle-sharing partners of the source patient."1163

Therefore, it can be concluded that nominal reporting requirements are not designed to achieve their objectives in the most effective and least harmful way. The desire for HIV surveillance can be accommodated without nominal reporting.

In addition, Nash Colfax and Bindham have recently pointed out that

[a]lthough reporting individuals by name may appear to be a logical control measure for most diseases, there is little evidence as to whether reporting actually improves individual or public health outcomes. Despite nearly a century of requirements to report patients with sexually transmitted diseases by name, the impact of these policies has not been systematically evaluated. The impact of reporting AIDS cases by name has also never been quantified; there

is no evidence that name reporting has helped significant numbers of individuals gain entry into care.1164

The authors continued by saying that there are two main risks to reporting people by name: the information could be misused to harm infected people, and fear of being reported may deter infected individuals from being tested, potentially delaying their receipt of appropriate counselling and medical care. Talking about the situation in the United States, the authors referred to concerns that

> HIV-related legislation might allow legal disclosure of HIV test results, superseding efforts to keep name reporting information restricted and confidential. For example, in Illinois, an amendment to the Sexually Transmissible Disease Control Act gave the state health department, under certain conditions, authority to reveal previously confidential information about HIV-positive health-care workers.1165

In addition, the authors pointed to the 1996 breach of the Florida Health Department's AIDS computer database, which resulted in a list of names of 4000 people with AIDS being leaked to the media, reinforcing the fact that confidential name reporting systems are not foolproof.1166 Even if public health departments have very good records of keeping confidential the information they have collected, concern about *the potential* for such transgressions may be sufficient to reduce or delay HIV testing. In many ways, confidentiality concerns regarding an HIV surveillance system are even greater than those for an AIDS surveillance system, due to "the fact that many persons with HIV infection are not ill and/or receiving health care, that HIV surveillance reports must be maintained for longer periods of time ... and that the negative consequences of unauthorized disclosure of HIV infection status are potentially greater than for AIDS."1167 When asked, people have generally claimed that reporting of HIV test results by name would deter them from being tested.1168 A study published in 1997 found that 20 percent of people with high-risk behaviours surveyed for HIV listed the fear of name reporting as a reason for avoiding HIV testing.1169 However, other studies have shown no clear association between reporting policies and testing behaviour.1170 Most recently, a US Centers for Disease Control and Prevention study indicated that HIV reporting by name did not significantly affect the level of HIV testing in publicly funded anonymous and confidential test sites. The study showed no significant declines in testing following the implementation of HIV reporting. However, to help ensure that reporting policies do not deter even a small number of people from seeking testing, CDC recommended in the study that states make anonymous testing available.1171 This is consistent with the recommendation in the report by the AIDS Action Committee of Massachusetts and the AIDS Action Council of Washington DC. The two organizations emphasized that states that still choose to use name reporting as an HIV surveillance tool despite the many concerns raised

> should, at a minimum, maintain the option of anonymous testing for those individuals who will not test for HIV without assurance of their anonymity. Such

> states also must enact privacy protections which provide for penalties severe enough to underscore the importance of confidentiality and deter breaches."1172

However, in many ways, this would simply shift the deterrence problem away from testing and instead deter people from entering treatment. In a 1996 survey of individuals testing for HIV in Los Angeles County, over 20 percent of survey participants said that they would delay treatment if their doctor were required to report their name to public health authorities.1173

## Conclusions and Recommendations

There may come a time "when HIV is so unremarkable a part of our 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." On the contrary, "the best evidence we have suggests that those who most need HIV testing are afraid of name reporting because they fear discrimination. Moreover, we know those fears are not groundless."1174 In addition, neither the epidemiological objective of reporting, nor the objective of facilitating public health measures such as partner notification, require nominal reporting. Therefore, provinces and territories that currently require nominal reporting of HIV seropositivity and/or AIDS should review their reporting requirements by forming working groups including people with HIV/AIDS, test providers, ethicists, public health professionals, technical experts and others, and develop a system that collects only the information necessary, using unique or coded identifiers that ensure privacy and confidentiality of the individual.

> **13. Reporting of both HIV and AIDS should be non-nominal: nominal reporting is not warranted either for surveillance or for partner notification purposes. Provinces and territories that currently require nominal reporting should review their reporting requirements by forming working groups including people with HIV/AIDS, test providers, ethicists, public health professionals, technical experts and others, and develop a system that collects only the information necessary, using unique or coded identifiers that ensure privacy and confidentiality of the individual.**

**Return to the top of this page**

**Return to Table of Contents**

---

ENDNOTES

1109 Zeegers Paget, supra, note 175 at 109, with reference to AS Benenson (ed). *Control of Communicable Diseases in Man: An Official Report of the American Public Health Association*. 14th edition. Washington, DC: American Public Health Association, 1985.

1110 Zeegers Paget, supra, note 175 at 13, with reference to CBA-Ontario, supra, note 7.

1111 Ibid at 109.

1112 Commission of Inquiry on the Blood System in Canada, volume 2, supra, note 4 at 575.

1113 AIDS Action Committee of Massachusetts and AIDS Action Council of Washington DC. *Creating an Effective Public Health Response to the Changing Epidemic: Moving to HIV Surveillance by Unique Identifier and Other Non-Name Based Surveillance Systems.* Boston & Washington DC: AIDS Action Committee and AIDS Action Council, October 1997, at 4.

1114 See JD Farley et al. HIV/AIDS Surveillance in Canada, Change in Strategy. Presentation at the Seventh Annual Canadian Conference on HIV/AIDS Research, Québec, abstract 241P.

1115 For a detailed review, see Jürgens & Palles, supra, note 2 at 229-251.

1116 MacKinnon, Cottrelle & Krever, supra, note 195 at 358.

1117 Glenn et al, supra, note 1027 at 4.

1118 CBA–Ontario, supra, note 7 at 50.

1119 MacKinnon, Cottrelle & Krever, supra, note 195 at 359; see also supra, note 10, *Background Papers* at 6.

1120 Information and Privacy Commissioner/Ontario, supra, note 1018 at 4.

1121 Royal Society. *Summary Report*, supra, note 10 at 11.

1122 Hamblin & Somerville, supra, note 346.

1123 Ibid at 236.

1124 Ibid.

1125 Ibid at 237.

1126 Ibid at 245.

1127 CPHA, supra, note 15 at 17.

1128 Canadian Public Health Association. *1997 Resolutions and Motions*. Ottawa: The Association, 1997 (resolution no 8).

1129 Supra, note 85.

1130 Ibid.

1131 Ibid.

1132 AIDS Action Committee and AIDS Action Council, supra, note 1113 at 1-2.

1133 LO Gostin, JW Ward, AC Baker. National HIV Case Reporting for the United States. A Defining Moment in the History of the Epidemic. *The New England Journal of Medicine* 1997; 337(16): 1162-1166 at 1162, with reference to R Bayer. *Private Acts, Social Consequences: AIDS and the Politics of Public Health*. New York: Free Press, 1989.

1134 Gostin, Ward & Baker, supra, note 1133 at 1163.

1135 Gay Men's Health Crisis. Gay Men's Health Crisis Calls for Monitoring of HIV Infections. New York, NY: Gay Men's Health Crisis News Release, 13 January 1998.

1136 See, eg, American Civil Liberties Union. The Maryland Lesson. Conducting Effective HIV Surveillance with Unique Identifiers. The American Civil Liberties Union, December 1997 (available at www.aclu.org), arguing that "in light of Maryland's increasingly successful experiment with Unique Identifiers, UI's must be considered as a viable alternative to names-based reporting as we expand HIV surveillance in response to the changing nature of the epidemic"; Evaluation of HIV Case Surveillance Through the Use of Non-Name Unique Identifiers – Maryland and Texas, 1994-1996. *Morbidity and Mortality Weekly Review* 1998; 46(52&53): 1254-1272; L Solomon. Experience [with the Maryland HIV reporting system]. *NASTAD HIV Prevention Community Planning Bulletin*, April 1998; Texas Department of Health. Recommendations on HIV Infection Reporting. Austin: The Department, Bureau of HIV and STD Prevention, 21 March 1998.

1137 National Association of Persons with HIV/AIDS. NAPWA Position Statement on HIV Surveillance, 3 October 1997.

1138 Ibid.

1139 Magnusson, supra, note 371 at 348, with reference to Intergovernmental Committee on AIDS, Legal Working Party. *Final Report*. The Committee, November 1992, Recommendation 2.1.

1140 *HIV/AIDS and Human Rights – International Guidelines*, supra, note 162 at 13, para 28(e).

1141 See generally *Schneider* v *R*, [1982] 2 SCR 112.

1142 The following survey was compiled by asking selected individuals in the health ministry of each province and territory to update information contained in previously published lists, such as those in MacKinnon, Cottrelle & Krever, supra, note 195 at 359; J Hamblin et al. *Responding to HIV/AIDS in Canada*. Toronto: Carswell, 1990, and updates by R Jürgens, N Gilmore, M Somerville; Hamblin & Somerville, supra, note 346; The Privacy Commissioner of Canada, supra, note 1032.

1143 Communication with Nida Wurtz, AIDS Coordinator (Saskatchewan), on 28 January 1997.

1144 Communication with Dr David Patrick, Associate Director of HIV/AIDS, British Columbia Centre for Disease Control, on 29 January 1997.

1145 EC 409/87, s 17.

1146 Correspondence received from Dr Lamont Sweet, Chief Health Officer, Department of Health and Social Services, Charlottetown, Prince Edward Island, dated 14 May 1991.

1147 Rapport du comité ad hoc sur la surveillance épidémiologique de l'infection par le VIH au Québec. Déposé à la Direction générale de la santé publique, Ministère de la Santé et des Services sociaux. Draft, Montréal, August 1998, at 5.

1148 Ibid at 39.

1149 Communication with Dr D Patrick, 20 August 1998.

1150 See supra, note 1146.

1151 Response to the *Discussion Paper*, dated 22 May 1997.

1152 Magnusson, supra, note 371 at 348.

1153 Ibid at 350.

1154 Ibid at 352.

1155 National Conference of State Legislatures. Fact Sheet: HIV Reporting. 1998 Health Policy Tracking Service, dated 10 July 1998 (available at http://stateserv.hpts.org/HPTS98/NFTS)

1156 California Lawmakers Approve HIV Reporting Using Coded IDs. *AIDS Policy & Law* 1998; 13(17): 1, 6.

1157 Under Pressure, CDC Ends Push for Name Reporting. *AIDS Policy & Law* 1998; 13(17): 6.

1158 See supra, note 320, at 43.

1159 See also, for France, La déclaration obligatoire de la séropositivité. *Le Journ' ALS*, Spring 1998, at 5; for an overview focusing on France and the United Kingdom, Rapport du comité ad hoc sur la surveillance épidémiologique de l'infection par le VIH au Québec, supra, note 1147, Appendix 6.

1160 Supra, note 320 at 43.

1161 Gostin, Lazzarini & Flaherty, supra, note 1076 at 164.

1162 AIDS Action Committee & AIDS Action Council, supra, note 1113 at 3, with reference to Centers for Disease Control and Prevention. *Morbidity and Mortality Weekly Report* 1997; 46(37).

1163 AIDS Action Committee & AIDS Action Council, supra, note 1113 at 6.

1164 G Nash Colfax, AB Bindham. Health Benefits and Risks of Reporting HIV-Infected Individuals by Name. *American Journal of Public Health* 1998; 88(6): 876-879 at 877.

1165 Ibid at 878, with reference to C Levine, GL Stein. What's In A Name? The Policy Implications of the CDC Definition of AIDS. *Law Med Health Care* 1991; 19: 278-290.

1166 Ibid, with reference to: Florida Investigates Breach of Confidentiality in HIV Records. *AIDS Policy & Law* 1996; 11(18): 1.

1167 Council of State and Territorial Epidemiologists and Centers for Disease Control and Prevention. *Consultation on the Future of HIV/AIDS Surveillance*. The Carter Center, 21-22 May 1997.

1168 Ibid, with reference to SM Kegeles et al. Mandatory Reporting of HIV Testing Would Deter Men from Being Tested. *Journal of the American Medical Association* 1989; 261: 1275-1276; EJ Fordyce et al. Mandatory Reporting of Human Immunodeficiency Virus Testing Would Deter Blacks and Hispanics from Being Tested. *Journal of the American Medical Association* 1989; 262: 349.

1169 A Forbes. Myths and Facts About HIV Case Reporting by Name Versus by Unique Identifier. September 1997.

1170 Nash Colfax & Bindham, supra, note 1164 at 878, with references.

1171 AK Nakashima et al. Effect of HIV Reporting by Name on Use of HIV Testing in Publicly Funded Counseling and Testing Programs. *Journal of the American Medical Association* 1998; 280(16): 1421.

1172 Supra, note 1113 at 9.

1173 American Civil Liberties Union, HIV Surveillance and Name Reporting, supra, note 85, with reference to GM Reed et al. An Assessment of the Impact of Mandatory Name Reporting on HIV Testing and Treatment. XI International Conference on AIDS, Vancouver, 1996, abstract Th.D.4958.

1174 American Civil Liberties Union, supra, note 85.

**Return to the top of this page**

**Return to Table of Contents**

# HIV Testing and Confidentiality: Final Report

**Prepared by Ralf Jürgens**

**ISBN 1-896735-16-9**

---

# PARTNER NOTIFICATION

"Contact tracing" or "partner notification" has been defined as "the spectrum of public health activities in which sexual and injection equipment–sharing partners of individuals with HIV infection are notified, counselled about their exposure and offered services."1175 Contact tracing developed earlier in the 20th century for control of sexually transmitted diseases. It was called contact tracing because public health workers would, and still do, conduct analyses to determine which sex partners were most likely to be infected or at risk of developing infection and then make confidential efforts to locate them and provide treatment.1176 Because syphilis has a 10- to 90-day incubation period, leads to distinctive symptoms in many infected persons, and can be cured with antibiotics, it is particularly susceptible to a strategy such as contact tracing.1177 If a client can be diagnosed during the primary, secondary, or early latent stages of tertiary syphilis, it is feasible to reach, and treat at least some of his/her sex partners before they develop symptoms and spread the infection to others. As Thomas Parran, surgeon general of the US in the 1930s, asserted: "We can break the chain of infection promptly by treatment; we can find the source and the exposed contacts, get them under treatment, and prevent new chains of infection."1178 There is evidence that contact tracing can help reduce reported syphilis prevalence in at least some populations.1179 Contact tracing has also been widely implemented in attempts to control other STDs such as gonorrhea.

Despite four decades of experience with contact tracing, efforts to undertake such public health interventions in the context of AIDS met with fierce resistance in the first years of the epidemic.1180 Today, however, it is almost universally recognized that "partner notification can make a positive contribution to a successful HIV/AIDS public health and prevention program."1181 The controversial question that remains to be addressed is *not about whether* sex partners or needle-sharing partners should be informed that they may be HIV-infected, *but about how* this notification should be achieved."1182

This chapter first clarifies the terms "contact tracing" and "partner notification" (Terminology). It then reviews the recommendations made by organizations in Canada and, to a lesser extent, internationally, since 1986 regarding partner notification (History). The chapter then briefly examines the current situation in Canada, pointing out that with respect to partner notification there are wide divergencies in legislation and practice among and within Canadian provinces and territories (Current Situation). The chapter then examines how partner notification efforts should be undertaken in Canada (Assessment). It supports voluntary, non-coercive, and non-prejudicial partner notification that respects the principles developed in the 1997 *Guidelines for Practice for Partner Notification in HIV/AIDS*, and stresses the importance of community involvement in the development, implementation, and evaluation of partner notification programs. Finally, while recognizing the utility of partner notification and recommending that partner notification services be available to people who test positive for HIV, the chapter cautions against overemphasizing the importance of partner notification efforts. For the populations most vulnerable to contracting HIV, targeted education and support through community-based programs remain essential, and the public health benefit gained from partner notification "must be measured by considering how money spent for partner notification might otherwise have been spent"1183 (Conclusions and Recommendations).

The impact of the Supreme Court of Canada decision in *R v Cuerrier*1184 — released while this report was undergoing final editing — in the area of partner notification could not be analyzed. It will be discussed in a forthcoming Legal Network report on the decision’s impact, due to be published in the Spring of 1999.

## Terminology

Contact tracing has been defined1185 as a "standard public health strategy in which current and past sexual partners of individuals infected with sexually transmitted diseases (STDs) are notified, counselled about their exposure and offered services."

Partner notification has been defined as the "spectrum of public health activities in which current and past partners of individuals with HIV infection are notified, counselled about their exposure and offered services." Partner notification involves two general approaches: patient referral and provider referral. Patient referral is a strategy

> by which HIV-infected persons are encouraged to notify partners of their possible exposure to HIV, without the direct involvement of health care providers. In this approach, the health care provider counsels the infected person with regard to the information to be passed on to their partners and the techniques for providing it.

In contrast, provider referral is a strategy

> by which health care providers or other health workers notify an HIV-infected person’s partner. In this approach, HIV-infected persons give their partner’s name to health care providers or other health workers, who then confidentially notify the partners directly, maintaining the anonymity of the index person. This notification can be undertaken in the context of primary health care and can involve the index person as well as the health care provider or other health worker.

A third, intermediate strategy has been called "conditional referral." It refers to an approach

> by which the health care provider or other health worker and the index person agree that the index person will notify the partner(s) within a reasonable period of time – often 48–72 hours. It is further agreed that the health worker will complete the notification process for partners not reached within the set period. The names of partners are usually given to the health worker at the initial interview.

Partner notification and contact tracing are comparable and, in fact, these terms are often used interchangeably. Partner notification, however, is a more recent term that is usually used in the context of HIV/AIDS. It is "meant to encompass injection equipment-sharing partners and to emphasize preventive education."

# History

## Canada

A detailed account of early partner notification efforts in Canada can be found in Justice Krever’s report of the Commission of Inquiry on the Blood System in Canada.1186 The report notes that no provincial department or ministry of health took measures to establish a program of contact tracing for HIV/AIDS until the summer of 1985, and that most provinces did not implement such a program until 1987 or 1988. Public health officials at the Inquiry testified that "a contact tracing program for AIDS would have required significant financial resources, which might be used more effectively for other activities."1187 They added that among gay men, the hardest hit community at that time, there "were some who had anonymous sexual relations with many partners," and that they "did not believe that the funds that would be required to train and pay employees to trace contacts, especially in such cases, would be a worthwhile expenditure of public funds."1188 The National Advisory Committee on AIDS also discouraged provincial public health officials and physicians from tracing contacts. In a document published in April 1984, the Committee said:

> Contact tracing is not necessary nor is it appropriate, and, in fact, is discouraged. In the instance where a sexual contact presents himself/herself to a MOH [medical officer of health]/ physician, assurances are all that can be offered.1189

Once the HIV test became available and provinces moved to implement some sort of partner notification programs, the National Advisory Committee on AIDS and other organizations and individuals who analyzed the issues raised by partner notification programs between 1986 and 1993 recognized that partner notification has a role in HIV prevention. They pointed out that, even for a contagious disease that has no cure, it may decrease risks for society generally. However, they emphasized the limits of partner notification programs and stated that such programs may be useful only in limited circumstances, for several reasons: lack of a drug therapy to cure HIV or prevent transmission, a long incubation period that makes it difficult for patients to name and locate past partners, and serious concerns about confidentiality and social stigma. Most recently, national guidelines for practice for partner notification in HIV/AIDS were released. The guidelines state that "partner notification can make a positive contribution to a successful HIV/AIDS public health and prevention program," and that "[s]ome form of partner notification should be implemented in every jurisdiction in Canada."1190

In a statement published in 1987,1191 the National Advisory Committee on AIDS adopted a "least invasive, least restrictive, likely to be effective means, readily available" approach to contact tracing.1192 According to the Committee, in order for contact tracing to be effective, every effort should be made to protect the rights of privacy and confidentiality of the person being tested; encourage cooperation of persons who are found to be HIV-positive to inform their partners of the possibility that they have been exposed to, or have exposed others to, HIV; and enable physicians to legally request the assistance of public health authorities, "whenever contact tracing might not be done voluntarily, and third party contact tracing is ethically justified."1193 The Committee emphasized that contact tracing by a third party without the express consent of the person being tested is "an invasion of that person’s right of privacy and a breach of confidentiality, and places that person at risk for disadvantage or discrimination." Consequently, it held that "such contact tracing must be justified in each case in which the person being tested refuses to contact trace or to consent to the physician doing this."1194

Similarly, Roy rejected any model of partner notification that would jeopardize the goals of a voluntarist public health care policy in the matter of HIV infection: "Systematic active contact tracing models that pressure infected persons to reveal the names of their partners, that send third persons into the spheres of personal and sexual privacy, and that publicly store nominal and highly sensitive and potentially damaging information do not merit serious consideration and should be rejected as inconsistent with the ethos of our society."1195 However, Roy continued by saying that,

> though we cannot realistically hope to eradicate HIV infection totally, we do have a public moral obligation to control the spread of HIV infection, and to protect unsuspecting exposed persons from avoidable damage, by every means that are practicable and consistent with human rights and dignity. Voluntary contact tracing and partner notification offer such a means.1196

Therefore, the author recommended that research be undertaken to ascertain how voluntary contact tracing and partner notification can be most efficiently and respectfully accomplished.

The Canadian Bar Association – Ontario also expressed the view that, in certain circumstances, "contact tracing can serve the goals of education and counselling, thereby contributing to the prevention of the spread of the disease."1197 However, the Association said that tracing contacts in so-called "high-risk groups" may be both impossible and unnecessary in most cases:

]If persons in high-risk groups act as if they were infected, whether or not they know what their actual antibody status is, then they would not necessarily benefit from the education and counselling. Moreover ... it may simply prove impractical to trace contacts within certain high-risk groups, at least where the patient has been very promiscuous.1198

In contrast, the Association held that in cases where contacts may not be aware of the risks to which they have been exposed, contact tracing is a "necessary and justifiable initiative in the effort to protect public health."1199 According to the Royal Society of Canada, the feasibility of contact tracing would be influenced "by the number of partners per person, their degree of anonymity, and the time period during which the individuals are thought to have been infectious."1200 The Society also felt that to attempt tracing of all partners of all HIV-positive persons would not be feasible, and suggested that emphasis should be placed on tracing contacts who have no reason to expect that they have been exposed; and contacts who would be most likely to benefit from knowing their HIV-antibody status.1201

With regard to how and by whom partner notification should be carried out, the Royal Society and many others1202 have said that the prime responsibility for contact tracing remains with the HIV-positive index patient, who would undertake to inform his/her sexual contacts that they may have been exposed to HIV. However,

> there will likely be instances where the patient recognizes the importance of notifying sexual contacts but is unable or unwilling to carry out this responsibility directly. In such cases, with the patient’s consent and help in identifying the individuals concerned, the treating physician may undertake partner notification and referral.1203

Recognizing that "certain members of the medical profession are unable or unwilling to engage in such activity," the Canadian Bar Association-Ontario held that physicians should have a choice: either to engage in partner notification directly or, alternatively, to refer the matter to the medical officer of health. Importantly, the Association recognized that, if physicians are expected to be effective participants in the contact-tracing process, they must be adequately compensated for their involvement. Finally, the Association recommended that changes be made to the rules concerning confidentiality so that physicians can undertake partner notification without any fear that they have breached their duty to their patient. This is consistent with the principles for partner notification developed by the Ontario Law Reform Commission, according to which:

> (a) patients should be encouraged to notify partners voluntarily, or to cooperate with their personal physician’s attempt to do so, within a physician-centred program of partner notification;
>
> (b) physicians should be able to directly notify identifiable, unsuspecting partners of HIV-infected patients who are at risk, under clearly defined guidelines governing the disclosure of HIV-related information;
>
> (c) the option to seek the assistance of public health authorities in the notification process should be available to both physicians and patients;
>
> (d) physicians who notify partners should be protected against the potential for liability resulting from responsibilities relating to partner notification.1204

The strongest support for partner notification efforts came from the Federal/Provincial/Territorial Advisory Committee on AIDS, which held that it is "desirable" that contact identification and tracing be undertaken and added that "testing can be non-nominal" only as long as contact tracing will occur by means of one of the following mechanisms:

> i) The physician who initiated the test requisition ensures that contact tracing is being done, and reports non-nominal data regarding all HIV-positive persons.
>
> ii) The physician obtains from the HIV-positive patient a list of contacts which is given to the public health authority for contact tracing.
>
> iii) Where (i) or (ii) are not possible, the physician should report nominally the HIV-positive individual to public health authorities for contact tracing.1205

The Committee recommended that physicians "be empowered to legally request the assistance of public health authorities for the purposes of contact tracing, when this is ethically justified," and that all provinces have legislation empowering the public health authority to "initiate proceedings to confine or to otherwise restrain persons from irresponsible conduct which constitutes a [danger] to others."1206

Finally, in 1993 the Canadian Public Health Association endorsed two "fundamental principles" regarding partner notification: (1) "Sex or drug-sharing partners have a right to know if they may have been exposed to HIV"; and (2) "High-quality standards of practice and confidentiality must be maintained in all partner notification efforts."1207 In addition, the Association recommended that a standard but flexible protocol for partner notification be developed, in collaboration with physicians and persons affected by HIV/AIDS. This recommendation led to the establishment of a working group of the Federal/ Provincial/ Territorial Advisory Committee on AIDS with the mandate of drafting guidelines for partner notification in HIV/AIDS. The guidelines were released in 1997 and provide "a framework that provinces and territories in Canada can use to shape their partner notification programs."1208 The partner notification working group agreed on three statements: (1) "Partner notification can make a positive contribution to a successful HIV/AIDS public health and prevention program"; (2) "Partners of HIV-infected persons should be notified of HIV exposure if at all possible"; and (3) "Some form of partner notification should be implemented in every jurisdiction in Canada." However, the group also agreed that partner notification as part of a comprehensive HIV/AIDS public health and prevention program "is acceptable only if it adheres to the following principles."1209

> Partner notification should:
>
> > (a) respect the human rights and dignity of the index person and the partners.
> >
> > (b) be voluntary, non-coercive and non-prejudicial; index persons and their partners should have full access to available services independent of their willingness to cooperate with partner notification activities.
> >
> > (c) maintain strict confidentiality for all information of 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.
> >
> > (d) ensure that during the notification process, when partners are told of the possibility of HIV exposure, no additional information is given which may identify the index person.
> >
> > (e) be a balanced part of a comprehensive HIV/AIDS public health and

> prevention program which includes education, testing and counselling, prevention, screening, diagnosis and treatment.
>
> (f) be coordinated in the context of primary health care and other public health activities including STD control, family planning, maternal and child health, tuberculosis control and substance abuse prevention and treatment.
>
> (g) be undertaken only when appropriate support services are available to index persons and partners; the minimum requirements are counselling on the implications of having been exposed to HIV infection, voluntary and confidential HIV testing with pre- and post-test counselling, access to HIV/ AIDS clinical management and basic health and social services. The quality of all of these services should be assured and regularly monitored.
>
> (h) attempt to ensure that index persons and partners have adequate social support systems, such as family, friends, community, psychologists and counsellors. Emergency support services may need to be directed to individuals in remote areas and this should be possible.
>
> (i) ensure that notification, education and counselling be delivered in a language and form that is understandable and culturally sensitive.
>
> (j) keep in mind the importance of the rights of the individual infected with HIV and try to balance these with the welfare of the community.1210

The Guidelines further emphasize that "[a]ny partner notification strategy must be effective, appropriate and sensitive to the needs of index person and partners."1211 They point to the advantages and disadvantages of each type of partner notification, without expressing a preference for one over another type.1212 Recognizing that "a single system of partner notification is unlikely to be suitable for all jurisdictions,"1213 the type of notification may depend on a variety of factors, including the level of resources available, the community environment, and the socio-political climate.1214 Ultimately, a program must be developed that recognizes that "the involved communities must participate from the outset in the discussions and the decision-making process around partner notification":

> This should include persons living with HIV/AIDS, community-based AIDS organizations, medical practitioners, public health and specific affected communities such as the gay community, blood and blood product recipients, injection drug users, sex workers, youth, First Nations and Inuit, immigrants from endemic areas and culturally diverse populations. Once a program is decided upon through consultation and consensus, this program and its elements should

> be made public.1215

The Guidelines have been widely disseminated and it was planned that the Federal/Provincial/Territorial Advisory Committee on AIDS would reassess the status of partner notification in Canada in 1999.1216

## International Developments

Internationally, the debate about partner notification has followed a pattern similar to that observed in Canada, moving from opposition to widespread partner notification programs to cautious embracing of such programs. For example, in the US, opposition by gay leaders and civil liberties groups in the mid 1980s had a profound impact on the response of public health officials, particularly in states with large numbers of AIDS cases. As Bayer and Toomey report, a proposal in San Francisco that health department staff offer partner notification services to bisexual men whose female partners might unknowingly have been placed at risk was denounced as Orwellian because of the prospect of creating lists of bisexual men and their partners.1217 Even greater antagonism greeted the possibility of creating lists of the homosexual contacts of gay men, because of the fear of discrimination:

> Homesexual behavior, it was argued in the early and mid 1980s, was still a crime in 24 states, and the Supreme Court had declared in *Bowers v Hartwick* that sodomy laws represented a constitutional exercise of state authority. Thus, in the course of an especially bitter controversy sparked by the Minnesota Department of Health's effort to launch an aggressive contact tracing program in 1986, one opponent declared that "the road to the gas chamber began with lists in Weimar Germany."1218

Although by 1988 all 50 states in the United States were establishing the capacity to offer contact tracing services at the request of the index patient, only 22 states emphasized such an approach – with the exception of Florida, all states with relatively low numbers of AIDS cases. As Bayer and Toomey say, "[d]oubts about effectiveness and about the costs of so labor-intensive an approach to AIDS prevention partially explain the resistance to emphasizing contact tracing, but more important was the political opposition to such efforts, opposition that was most visible and effective in the states that had borne the brunt of the epidemic."1219

In the following years, CDC encouraged states to make available some form of partner notification, by asking grant recipients to, "where appropriate, offer health department assistance in confidentially notifying partners."1220 By the late 1980s, the debate over partner notification had shifted "from one centered on the ethical issues of privacy to one focused on efficacy."1221

In New Zealand and Australia, proposals made are similar to those made by Canadian organizations and described above. For example, the New Zealand Medical Association adopted a partner notification protocol authorizing a doctor to inform and counsel the sexual or injection drug sharing partner(s) of an HIV-positive patient if the following criteria are met:

- there is a clear risk of HIV transmission to an acknowledged partner;
- the patient has been provided with education, counselling and support to encourage him/her to disclose his/her status voluntarily; but
- the patient has failed to do so;
- the doctor has sought advice from colleagues, or an institutional ethics committee;
- the matter has been discussed with the doctor’s medical protection or defence adviser;
- the patient has been advised in writing of the doctor’s intention to disclose the information to the patient’s partner; and
- the patient still refuses to inform the party at risk.1222

In Australia, the Legal Working Party of the Intergovernmental Committee on AIDS has recommended that professional caregivers be protected by legislation from actions for breach of confidence or for breach of duty of care for *failure* to warn a third party when acting in accordance with partner notification protocols containing the criteria listed above.1223

Statements by international organizations have also all endorsed patient referral, but allowed for limited exceptions when the patient refuses to cooperate. For example, the World Health Organization Consensus Statement on Partner Notification states that "patient-referral is the natural starting point for partner-notification; however, this approach may not be feasible for selected index persons and partners."1224 Similarly, the Council of Europe asks its member states to "ensure that as a general rule there is no partner notification without the consent of the patient, and consider procedures of consultation in accordance with national codes of medical ethics and regulations for the extreme case where a patient refuses to co-operate in the notification of an unsuspecting third party known to the health care worker."1225 Finally, the International Guidelines on HIV/AIDS and Human Rights state that "[p]ublic health legislation should authorize, but not require, that health-care professionals decide, on the basis of each individual case and ethical considerations, whether to inform their patients’ sexual partners of the HIV status of their patient."1226 According to the Guidelines, such a decision should be made in accordance with the following criteria:

- the HIV-positive person in question has been thoroughly counselled;

- counselling has failed to achieve appropriate behavioural changes;
- the person has refused to notify, or consent to the notification of his/her partner;
- a real risk of HIV transmission to the partner(s) exists;
- the HIV-positive person is given reasonable advance notice;
- the identity of the HIV-positive person is concealed from the partner(s), if this is possible in practice;
- follow-up is provided to ensure support to those involved, as necessary.1227

# Current Situation

## Canada

As mentioned above, in Canada, matters of public health typically fall under provincial jurisdiction as a "local or private" matter within s 92(16) of the *Constitution Act, 1867*. Therefore, there are wide divergences in legislation and practice among and within the provinces and territories.

The following is a brief survey of provincial and territorial statutes and regulations that allow for or require partner notification. Legislation differs substantially from province to province, but these differences are often not reflected in the provinces' partner notification practices. Most provinces have adopted "largely informal contact tracing procedures, usually focussing on voluntary contact tracing and, in some circumstances, a limited contact tracing program confined to the populations who may unknowingly be at risk for HIV infection."1228

### Legislation Requiring Partner Notification

Only Ontario, Saskatchewan, the Northwest Territories, and Yukon have legislation requiring partner notification.

In Ontario, partner notification is required under the Mandatory Health Programs and Services Guidelines, pursuant to s 7 of the HPPA. The guidelines are currently under review and may be revised by the Ministry.1229

In Saskatchewan, a designated public health officer who receives a list of contacts shall promptly notify the persons named in the list that they have been exposed to a communicable disease without naming the source of the exposure.1230

In the Northwest Territories, a duty is imposed upon medical practitioners and nurses who have a patient with HIV or AIDS to carry out "contact tracing and surveillance of those aspects of the occurrence and spread of the communicable disease that are pertinent to the effective control of the disease." Alternatively, the physician or nurse may request the Chief Medical Health Officer to carry out the contact tracing or surveillance.1231

In Yukon, Regulations under the *Public Health Act* impose a positive obligation on physicians to carry out contact tracing with respect to a person with AIDS. This provision states that "[e] very medical practitioner who has reason to believe or suspect that one of his patients is infected with a communicable disease shall advise such patient, any persons attending him and any known contacts or carriers, to adopt the specific control measures for such disease and shall give them the necessary instructions therefor."1232 Because AIDS, but not HIV infection, has been designated as a communicable disease in Yukon, a physician is not expressly required to trace the contacts of a patient who is HIV-positive. However, the legislation uses the words "suspect" and "infected," and it has been suggested that these words encompass HIV seropositivity in addition to AIDS.1233

## Legislation Authorizing Partner Notification

In many provinces, provisions of the public health acts or regulations under them, while not explicitly requiring or authorizing contact tracing, would seem to be broad enough to allow contact tracing.

In Prince Edward Island, regulations under the *Public Health Act* authorize, but do not require, a physician or the Chief Health Officer or his delegate to give information concerning the condition to the person’s family "for the protection of their health."1234 Also relevant in this context is a provision that authorizes the Chief Health Officer to conduct a physical examination of any person suspected of being infected with a regulated disease, "including a suspected carrier or contact."1235 AIDS, but not HIV seropositivity, has been designated as a regulated disease. The Regulations also impose a duty on any persons who suspect themselves of being infected with a regulated disease, or who have been so informed by a physician or health officer, to identify any contact or provide such other relevant information as may be required by the physician or the Chief Health Officer.1236

In New Brunswick, a medical officer may take any measures "which have proven practical in public health administration and which have been accepted by public health authorities" to control and prevent the spread of HIV.1237 In practice, the Department of Health and Community Services encourages doctors to perform this function in cooperation with the HIV-positive person. If doctors are unwilling, however, the Department will consider undertaking contact tracing.

In Alberta, all medical officers of health have been sent a copy of the *Guidelines for Practice for Partner Notification in HIV/AIDS*1238 by the Provincial Health Officer and have been advised that physicians

> should be reminded of the need for ... contact follow-up. The assistance of public health for counselling and/or contact follow-up should be offered. In every case, the MOH is required to contact the individual's physician before initiating public health follow-up of any kind. As well, individuals with HIV infection should be informed by their physician when referrals are made to "public health."1239

## Absence of Legislation Expressly Authorizing or Requiring Partner Notification

In Newfoundland, Nova Scotia, Québec, and British Columbia there is no legislation that would expressly require or authorize a physician or medical health officer to undertake partner notification. However, in practice, partner notification efforts are undertaken.

In Nova Scotia, Medical Guidelines for HIV Antibody Screening issued by the Nova Scotia Department of Health in November 1987 assert that the Department has a "legal right to identifying information on the contacts and to ensure that contact-tracing occurs." In addition, the Guidelines assert that physicians have a "legal and ethical obligation" to ensure that "every reasonable attempt" has been made to notify contacts, as a means of preventing the spread of HIV.

In Québec, the *Code of Ethics of Physicians* provides that, generally, a physician must not disclose the information obtained in the practice of his or her profession.1240 The physician may, however, "reveal facts which have come to his personal attention ... if there should be a just and imperative motive related to the health of the patient or the welfare of others."1241 In recent years, a variety of partner notification programs or services have been piloted. In particular, an HIV partner notification demonstration project started in Montréal in August 1996, based on the experience of an STD partner notification program that started as a pilot project in 1995 and, since January 1997, has become a regular program of the Régies régionales de la santé et des services sociaux of Montréal-Centre and Laval. Partner notification is undertaken by public health if requested by a physician, who does not need to provide the name of the index case, only relevant information about him or her and a list of the contacts. Identifying information regarding the contacts is deleted from the files after notification is undertaken. In another, informal partner notification program in the Laurentians north of Montréal, a community-based AIDS-service organization undertakes partner notification on request of physicians in the region.1242

In Manitoba, regulations made under the *Public Health Act* impose a duty on physicians to report the contacts of a person infected with a sexually transmitted disease where it can reasonably be expected that the disease has been transmitted to another person. HIV seropositivity and AIDS, however, are specifically excluded from this provision.1243 Therefore, there is currently no requirement to trace or report the contacts of persons living with HIV or AIDS. Nevertheless, partner notification is offered on a voluntary basis. In addition, the regulations were expected to be changed, making HIV reportable by physicians (non-nominally) and requiring partner notification.1244 In British Columbia, partner notification guidelines exist and voluntary partner notification is strongly recommended. Clinicians and clients have always been advised to notify partners.1245

## International Developments

As in Canada, legislation and practice concerning contact tracing vary greatly from one legislation to another. In Australia, according to information provided by Magnusson, in some states contact tracing is essentially a voluntary activity undertaken by doctors; in other states the Health Department supervises the contact-tracing process. In Victoria, where there is no obligation to perform contact tracing or to "come up with names," the Health Department employs two community nurses "who have come to be highly respected by doctors and the HIV/gay communities." Doctors who regularly see HIV clients refer patients to these nurses.1246

In the US, at least 33 states have enacted HIV/AIDS-specific partner notification laws. Some states impose a legal obligation on people with HIV/AIDS to notify their partners. For example, in Indiana, HIV-positive individuals who fail to notify present and past partners may be subject to a penalty of 180 days in jail and/or a fine of $1000.1247 Some states, like Texas, require health-care providers to notify partners of all HIV-positive patients regardless of whether the patient has done the notification. Other states authorize, but do not require, physicians and/or public health officials to notify partners of individuals who have tested positive for HIV, even without the consent of the patient.1248 While some of these laws were enacted years ago, there has recently been an increase in legislative activity. This is due, at least in part, to the "national debate on HIV reporting laws, which some policy makers feel should be linked to partner notification requirements"1249 and to the 1997 Ryan White reauthorization law requiring states to make a concerted effort to institute partner notification programs. Probably the best-known of the new laws is the New York State legislation mandating HIV partner notification. According to it, doctors are required to report to the health department the names of people with HIV or AIDS, as well as the names, if available, of their contacts who may have been exposed to HIV under circumstances that present a risk of transmission. Health officers must then notify these contacts about their potential exposure.1250

In the fall of 1998, four years after developing the first partner notification guidelines, the Centers for Disease Control and Prevention completed a draft document concerning partner notification that some critics say is too late because many states have already passed their own laws, many of which do not embrace positions similar to the policies of the CDC.1251 The CDC has stated that the guidelines are aimed at helping service providers develop partner notification services that go beyond one-time contact and address controversial issues, such as violation of confidentiality. Unlike "simple" partner notification, a term that has been replaced with "partner counselling and referral services," the guidelines recommend developing a comprehensive program that offers both sex and needle-sharing partners long-term counselling and support, including client-centered counselling, support for clients who choose to notify their own partners, and help in seeking medical evaluation and treatment.1252

## Assessment

Early in the epidemic, there was vigorous discussion about whether, and in what form, partner notification should be undertaken. Those in favour of partner notification called for the extension of STD partner notification programs to partners of individuals with HIV infection.1253 In support of their position, they cited the long history of partner notification within STD control programs, the good record of STD programs for maintaining confidentiality, and the relatively high percentage of HIV-positive people who appear to be unaware of having been exposed to infection.

Those opposed to partner notification argued that it "has little proven value for its relatively high cost," that "[t]he long asymptomatic incubation period makes location of all partners difficult at best," and that anonymous and many casual contacts cannot be traced. In addition, it has been suggested that the efficacy of partner notification activities in reducing HIV transmission is unproven, that such activities may violate civil liberties and lead to discrimination, and may ultimately dissuade individuals most at risk for HIV infection from seeking counselling and testing.1254 Finally, critics have noted that when domestic violence is present, informing a male partner may expose an HIV-positive woman to abuse, injury and even death from her abusive spouse.1255 It was broadly recognized that

> among communities or populations at a higher risk, such as gay men and intravenous drug users, contact tracing 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. Moreover, the nature of sexual contact between men, or transmission through the re-use of needles, made it very difficult, if not impossible, to conduct effectively any contact tracing program. The various contacts might simply be impossible to identify. Finally, the threat of contact tracing, particularly a scheme that closely involved the state and public health officials, was regarded as seriously threatening by most persons at a higher risk of HIV infection. Contact tracing might lead to public disclosure and even more coercive acts by the state, and the mere threat of mandatory reporting of HIV status to public health officials, and contact tracing, operated as a substantial chill on prevention efforts in populations at risk.1256

According to Flanagan, it remains true that contact tracing serves no particular function among those populations most severely hit by HIV. However, Flanagan conceded that

> 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 practice risk-reducing behaviour, contact tracing may play an important role. Again, with the availability of new treatments, it is essential that all persons at risk determine their HIV status as soon as possible, and seek immediate intervention if necessary.1257

Flanagan concluded by saying that

the time may have come to reevaluate the long-standing opposition among many AIDS activists to any form of contact tracing in the context of HIV infection. Among persons who may reasonably but incorrectly believe that they are at no particular risk, most commonly women, contact tracing might be useful in encouraging these persons to seek HIV testing and if necessary HIV-related treatments. ... The availability of helpful interventions makes a much stronger case for a specifically targeted contact tracing program than was the case in the past, when there were no particularly helpful interventions available.1258

For this reason, in 1998 there can be no doubt that the case for partner notification programs has become stronger.1259 In addition, knowledge about the effectiveness of partner notification has increased. A review of literature undertaken by West and Stark 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 client 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 of, misunderstand, discount, or deny their HIV risks; and

- sex and needle-sharing partners of HIV-positive clients have high rates of HIV seropositivity, ranging from 5 to 56 percent.1260

As Roy has said, the controversial 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 effected. The 1997 *Guidelines for Practice for Partner Notification* should be used to answer the latter question. As detailed above, they reject any model of partner notification that would jeopardize the goals of a voluntarist public health-care policy in the matter of HIV infection, and instead favour partner notification programs that respect the human rights and dignity of the index person and the partners and are voluntary, non-coercive, and non-prejudicial.1261 Thus, they recognize that partner notification cannot be successful without the cooperation of the HIV-positive person. Without this cooperation, the HIV-positive person may not inform his/her partners or provide their names for notification by others, particularly if there may be a threat of criminal prosecution. Compulsory or coercive approaches may drive people underground, alienate them, and impede partner notification and the practice of safe behaviour. Therefore, as a general principle, and as with HIV-antibody testing, partner notification should be voluntary, that is, only undertaken with the informed consent of the HIV-positive person. Further, it should preferably be carried out by the HIV-positive person him/herself.

However, in certain circumstances, compulsory partner notification should be considered: if an HIV-positive person has been thoroughly counselled, counselling has failed to result in the appropriate behavioural changes, the person refuses to inform or to consent to the notification of his/her partner(s), a real risk of HIV transmission to the partner(s) exists, the partners have little or no reason to suspect they are at risk, and the HIV-positive person is given reasonable advance notice. Such notification can be undertaken by the person’s physician or, if the physician requests it or the patient prefers it, can be performed by public health authorities.

As the *Guidelines* emphasize, the involved communities must participate from the outset in the discussions and the decision-making process around partner notification, and once a program is decided upon through consultation and consensus, the program and its elements should be made public.1262

Finally, partner notification programs must be a balanced part of a comprehensive HIV/AIDS public health and prevention program. Indeed, the major prevention and control efforts must continue to be directed to education aimed at personal risk reduction through behavioural change. Because of the prevalence rates among men who have sex with men and among injection drug users, and/or the impracticability of follow-up, targeted risk-reduction programs aimed at these communities likely continue to be more cost-effective than partner notification programs aimed at individuals in these groups.1263

# Recommendations

> **14.1 Partner notification programs should be implemented in every jurisdiction in Canada. These programs must respect the human rights and dignity of the index person and the partners, must be voluntary, non-**

**coercive, and non-prejudicial, and must be consistent with the principles set out in the 1997 *Guidelines for Practice for Partner Notification in HIV/AIDS*.1264**

**14.2 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. This should include people with HIV/AIDS, community-based AIDS organizations, medical practitioners, public health, and specific affected communities such as the gay community, blood and blood-product recipients, injection drug users, sex workers, youth, First Nations and Inuit, immigrants from areas where HIV is endemic, and culturally diverse populations. Once a program is decided upon through consultation and consensus, the program and its elements should be made public.**

**14.3 Each person who requests HIV testing and counselling must be made aware of and understand the partner notification program in his/her jurisdiction and its implications before testing proceeds.**

**14.4 Partner notification programs must be a balanced part of a comprehensive HIV/AIDS public health and prevention program. For the populations most vulnerable to contracting HIV, targeted education and support through community-based programs remain essential. It would be dangerous to allocate increasing resources to partner notification programs without at least maintaining current funding levels for education and for support programs.**

Return to the top of this page

Return to Table of Contents

---

## ENDNOTES

1175 World Health Organization. Consensus Statement Consultation on Partner Notification for Preventing HIV Transmission. *Venereology* 1990; 3(1): 17.

1176 GR West, KA Stark. Partner Notification for HIV Prevention: A Critical Reexamination. *AIDS Education and Prevention* 1997; 9(Suppl B): 68-78 at 69, with reference to R Bayer, K Toomey. HIV Prevention and the Two Faces of Partner Notification. *American Journal of Public Health* 1992; 82: 1158-1164; W Cates, K Toomey. Sexually Transmitted Diseases:

Overview of the Situation. *Primary Care* 1990; 17: 1-27.

1177 Ibid.

1178 Ibid, with reference to T Parran. *Shadow on the Land*. New York: Waverly Press, 1937.

1179 Ibid, with many references.

1180 Bayer & Toomey, supra, note 1176 at 1159, with reference to R Bayer. *Private Acts, Social Consequences: AIDS and the Politics of Public Health*. New Brunswick, NJ: Rutgers University Press, 1990.

1181 Supra, note 350 at 4.

1182 Roy, supra, note 184 at 56.

1183 *HIV Partner Notification: Why Coercion Won't Work*. An American Civil Liberties Union Report. New York, NY: ACLU, March 1998.

1184 Supra, note 5.

1185 All definitions are taken from the *Guidelines for Practice for Partner Notification in HIV/AIDS*, supra, note 350 at 3-4.

1186 Supra, note 4, vol 2 at 573-590.

1187 Ibid at 575.

1188 Ibid at 575-576.

1189 Ibid at 576.

1190 *Guidelines for Practice for Partner Notification,* supra, note 350 at 4.

1191 *Canadian Diseases Weekly Report* 1987; 13: 13-14.

1192 This approach was later endorsed by Somerville and Gilmore, supra, note 9 at xi.

1193 Ibid.

1194 Ibid at 17. See also the Committee's 1992 report on *HIV and Human Rights in Canada*. Ottawa: Health and Welfare Canada, 1992. It contains a section on partner notification.

1195 See supra, note 184 at 57.

1196 Ibid.

1197 CBA-Ontario, supra, note 7 at 51.

1198 Ibid.

1199 Ibid at 52.

1200 Fraser et al, supra, note 266 at 136.

1201 Ibid.

1202 See, eg, Glenn et al, supra, note 1027 at 78-79; Information and Privacy Commissioner/Ontario, supra, note 1018.

1203 Fraser et al, supra, note 266 at 137.

1204 Ontario Law Reform Commission, supra, note 13 at 114.

1205 F/P/T Working Group, supra, note 11 at 45.

1206 Ibid at 45.

1207 CPHA, supra, note 15 at 19.

1208 *Guidelines for Practice for Partner Notification in HIV/AIDS*, supra, note 350 at 2.

1209 Ibid at 6.

1210 Ibid, at 6-7.

1211 Ibid at 8.

1212 Ibid at 5.

1213 Ibid at 2.

1214 Ibid at 6.

1215 Ibid at 8.

1216 Ibid at 13.

1217 Bayer & Toomey, supra, note 1176 at 1159.

1218 Ibid, with reference to *Newsday* 16 November 1985, at 7.

1219 Ibid at 1160.

1220 Ibid, with reference to *Human Immunodeficiency Virus (HIV)/Acquired Immunodeficiency Syndrome (AIDS)*

*Prevention and Surveillance Cooperative Agreements*. Atlanta, Ga: Centers for Disease Control, Division of STD/HIV Prevention, 1990. Announcement No 002, FY 1990.

1221 Ibid.

1222 Magnusson, A Decade of HIV Testing, Part 2, supra, note 909 at 393, with reference to New Zealand Medical Association. *Policy Relating to HIV/AIDS*, 1990.

1223 Ibid, with reference to Intergovernmental Committee on AIDS, Legal Working Party. *Final Report*. The Committee, 1992 (recommendation 2.2).

1224 World Health Organization. *Consensus Statement from Consultation on Partner Notification for Preventing HIV Transmission, Geneva, 11-13 January 1989*. Geneva: WHO, Global Programme on AIDS, 1989, Doc No: WHO/GPA/INF/89.3, at 3.

1225 Zeegers Paget, supra, note 175 at 119, with reference to Council of Europe, Committee of Ministers. *Recommendation No. R(89)14 of the Committee of Ministers to Member States on the Ethical Issues of HIV Infection in the Health Care and Social Settings*. Adopted on 24 October 1989, Appendix I, at 4.

1226 *HIV/AIDS and Human Rights – International Guidelines*, supra, note 162 at 13, para 28(g).

1227 Ibid.

1228 Flanagan, supra, note 361 at 551.

1229 Communication from F McGee, AIDS Coordinator (Ontario), 3 March 1997.

1230 Section 35 of the *Public Health Act.*

1231 *Communicable Diseases Regulations*, RRNWT 1980, Reg 212, as amended NWT Reg R 013-88, s 5.

1232 *Communicable Diseases Regulations*, YT OIC 1961/48, s s(1).

1233 DG Casswell. *AIDS, Ethics and Law*. Victoria, BC: University of Victoria, Division of University Extension, 1990, at 32.

1234 *Notifiable and Communicable Diseases Regulations*, EC 330/85, s 14.

1235 Ibid, s 2(g).

1236 Ibid, s 4.

1237 *General Regulation – Health Act*, NB Reg 84-283, s 98.

1238 See supra, note 350.

1239 Letter of Dr JR Waters, Provincial Health Officer, to Medical Officers of Health, Regional Health Authorities, dated 16 March 1998.

1240 *Code of Ethics of Physicians*, RRQ 1980, c M-9, r 4, s 3.01.

1241 *Code of Ethics*, s 3.04.

1242 Communication with Nicole Turcotte, Régie régionale de la santé et des services sociaux, Montréal-Centre, on 27 February 1997.

1243 *The Public Health Act Diseases and Dead Bodies Regulation*, Man Reg P210-338/88R, ss 6 and 43(1)(b).

1244 Communication with Pat Matusko on 4 February 1997.

1245 Communication with Dr Patrick, supra, note 1144.

1246 Response to the *Discussion Paper* by RS Magnusson, supra, note 862.

1247 ACLU, HIV Partner Notification, supra, note 1183.

1248 Ibid.

1249 S Wasserman. Notifying People Exposed to HIV. Issue Brief. Health Policy Tracking Service, National Conference of State Legislatures, 1998 (available at http://stateserv.hpts.org)

1250 Ibid.

1251 Notification Guidelines Finally Being Published. *AIDS Alert* 1998; 13(8): 89.

1252 Ibid.

1253 KE Toomey, W Cates. Partner Notification for the Prevention of HIV Infection. *AIDS* 1989; 3(suppl 1): S57-S62 at S57-S58.

1254 Ibid at S58.

1255 RL North, KH Rothenberg. Partner Notification and the Threat of Domestic Violence Against Women with HIV Infection. *New England Journal of Medicine* 1993; 329: 1194-1196.

1256 Flanagan, comment, supra, note 27 at 15.

1257 Ibid.

1258 Ibid.

1259 See also Gostin, Lazzarini & Flaherty, supra, note 1076 at 83.

1260 GR West, KA Stark. Partner Notification for HIV Prevention: A Critical Reexamination. *AIDS Education and Prevention*

1997; 9(Suppl B): 68-78, at 71, with many references.

1261 Supra, note 350 at 6.

1262 Ibid at 8.

1263 See also NAC–AIDS, supra, note 1191 at 13.

1264 Supra, note 350.

**Return to the top of this page**

**Return to Table of Contents**

# HIV Testing and Confidentiality: Final Report

**Prepared by Ralf Jürgens**

**ISBN 1-896735-16-9**

---

# SUMMARY OF CONCLUSIONS AND RECOMMENDATIONS

> We know that the HIV test is an enormously effective public health tool, but it's only effective when deployed in ways that are socially, politically, and medically appropriate. If it's not, it can actually be a detriment to public health.1265
>
> Although we know a lot about preventing HIV disease, we tend to focus our hopes on technological fixes. Many of these hopes have been disappointed and have

> prevented us from taking a look at the kind of social, behavioral, and preventive programs that could have a very positive effect right now.1266

> [A]lthough circumstances of treatment and ongoing assessment may be changing, the circumstances necessary to ensure ethical observance of testing procedures have not. Physicians are ethically required to offer testing as an option for those who are concerned about their lifestyle history or state of health; the patient can and must still choose whether or not to be tested in the light of available information and their own situation.1267

Early in the HIV/AIDS epidemic, a concerted effort was made to address the issues surrounding HIV-antibody testing and confidentiality in a way that would respect the human rights of individuals, yet at the same time promote the goals of protecting public health. In particular, in Canada a broad consensus emerged that, except in a few well-defined circumstances, people should be tested only with their informed, voluntary and specific consent; when counselling and education before and following testing are available and offered; and when confidentiality of results or anonymity of testing can be guaranteed. This consensus was expressed in recommendations such as those prepared by NAC–AIDS,1268 which provided an ethical framework for evaluating testing policy based on a careful consideration of the inherent costs and benefits of testing to the individual and to society.

In the past few years, the broad consensus has shown signs of breaking down. New testing technologies, in particular the availability of home testing kits and rapid testing, new treatments, and changing patterns of HIV infection, force us to reconsider approaches to HIV testing and confidentiality. We need to be open to the challenges posed by the new developments and test our deeply held beliefs. However, we must do so without forgetting the lessons learned over the last fifteen years and without forgetting that, because HIV/AIDS continues to disproportionately impact on marginalized populations, leading to discrimination against those infected and affected, it remains different from other diseases. In particular, the new treatments constitute a huge step forward, but do not represent a solution to all problems faced by people with HIV or AIDS – problems that stem from the underlying issues of poverty and discrimination that are both a result and a cause of HIV infection. Therefore, while early detection of HIV infection has indeed become a pressing priority, a trend toward making HIV testing a routine or even mandated test needs to be treated with great caution. It would be a great mistake to dismiss the importance of respecting people’s rights and the risk of discrimination, and it would be imprudent to rush the implementation of coercive measures when treatments are not accessible for many of those living with HIV, their long-term benefits remain unproven, and the efficacy of coercive strategies is at best questionable. As Bayer has stated,

> [w]ere the end of HIV exceptionalism to mean a reflexive return to the practices of the past, it would represent the loss of a great opportunity to revitalize the tradition of public health so that it might best be adapted to face the inevitable

> challenges posed not only by the continuing threat of AIDS but also by threats to the communal health that will inevitably present themselves in the future.1269

Testing policy will continue to require constant reevaluation as treatments and technology evolve, but 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, must remain the basis of any legal and ethical approach to the threat posed by HIV.

# Conclusions and Recommendations

## 1. Consent

> **1.1 Recent developments notwithstanding, the arguments for specific informed consent remain as pertinent as they ever were. As a general rule, HIV testing in Canada should only be undertaken with the specific informed consent of the person being tested.**
>
> **1.2 Hospitals and colleges of physicians should adopt policies on HIV testing specifying that HIV testing should only be undertaken with the specific informed consent of the person being tested.**
>
> **1.3 Physicians should routinely offer information about HIV-antibody testing to all patients, but never test without specific informed consent, for two reasons: potential harms from testing, and respect for the autonomy of patients.**
>
> **1.4 The general rule that HIV testing in Canada should only be undertaken with the specific informed consent of the person being tested does not apply to the testing of donors of blood, organs, semen, or similar bodily products. In all cases of donations, prospective donors should be informed before the performance of the test that an HIV-related test will be conducted, and given adequate information about the nature and purpose of the test.**
>
> **1.5 The general rule that HIV testing in Canada should only be undertaken with the specific informed consent of the person being tested does not apply to testing performed as part of an anonymous (unlinked) HIV screening program for epidemiological or research purposes, provided the Guidelines on Ethical and Legal Considerations in Anonymous Unlinked HIV Seroprevalence Research are followed.**

**However, increased efforts must be made to reduce the potential for discrimination against groups or populations targeted by this research. In particular, before an anonymous (unlinked) HIV screening program is undertaken in a particular population, community consent should be secured. Researchers and community leaders and members must undertake all necessary steps to ensure that communities understand the advantages and disadvantages of this type of research and take ownership of the research process and outcome so that the results can be usefully applied to programming and policy with respect to HIV/AIDS.**

**Anonymous unlinked HIV-seroprevalence research involving Aboriginal people should be based on the principle of Aboriginal control over and ownership of research and data. Aboriginal AIDS organizations and others in the Aboriginal community, particularly those with HIV/AIDS expertise, should direct the design of guidelines for the conduct of HIV-seroprevalence research involving Aboriginal people. Such guidelines should seek to avoid stigmatization and discrimination of specific groups involved in blind studies.**

## 2. Access to HIV Testing

**2.1 The availability of new treatments for HIV infection underscores the importance of making all Canadians aware of, and providing them with access to, a variety of voluntary, high-quality, bias-free testing options, including anonymous testing or, at a minimum, flexible non-nominal testing.**

**2.2 The availability of anonymous testing – at anonymous testing facilities and/or at facilities offering flexible non-nominal testing – needs to be widely advertised, waiting periods at such facilities need to be reduced, and ongoing evaluation should be undertaken.**

**2.3 Barriers to testing, in particular for women, need to be removed. There is a need for a more sensitive approach to the assessment of a woman’s risk of HIV infection, and for education and training directed at increasing doctors’ awareness of the potential vulnerability of women to HIV infection. In addition, the broader problems of abuse and economic dependence of women need to be addressed in order to create a climate where women will be less fearful of the potential consequences of testing. Finally, rather than focusing efforts to increase access to testing for women nearly exclusively on pregnant women – which makes it seem as if there is less concern about the welfare of women than for that of their children or potential children – it**

**will be necessary to ensure that efforts encompass all women and take their needs, knowledge, and various life situations into consideration.**

**2.4 Barriers to HIV testing for Aboriginal people need to be removed. Provincial, territorial, federal, 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, including anonymous or, at a minimum, flexible non-nominal testing.**

**HIV/AIDS education for Aboriginal communities should continue to be emphasized in order to help reduce stigmatization related to HIV testing.**

**Mobile testing units should be examined for their potential to overcome some of the problems related to HIV testing and Aboriginal communities.**

## 3. Counselling

**3.1 While the availability of new treatments for HIV infection underscores the importance of removing barriers to access to HIV testing, pre- and post-test counselling should not be seen as barriers to HIV testing. Rather, they maximize the benefits from testing for the persons being tested and for society, while reducing potential harms. Therefore, as a general rule, testing should be undertaken only with quality pre- and post-test counselling, consistent with existing counselling guidelines.**

**3.2 Counselling should be culturally competent, sensitive to issues of sexual identity, developmentally appropriate, and linguistically specific.**

**3.3 The CMA and other existing counselling guidelines should be updated to reflect the many new developments that have occurred in recent years, and should be made widely available.**

**3.4 Health-care professionals need to be educated about the importance of providing counselling, and about the recommended counselling process, in basic and continuing education.**

**3.5 The expertise available at dedicated testing clinics should be acknowledged, and testing and counselling services available there should receive increased support and be widely promoted.**

**3.6 Counselling services available to HIV-negative and HIV-positive people outside the testing context need to be supported, to offer both care and**

**support as well as prevention advice.**

**3.7 When testing individuals for insurance purposes, insurance companies should adhere to the same principles as public health, hospitals and physicians in private practice, including provision of pre- and post-test counselling.**

## 4. New Testing Technologies

**4.1 Home test kits are devices with potential benefits for individuals, unproven benefits for society, and commercial interests behind them. Their introduction – particularly that of true home testing – carries risks that need to be better assessed before they are made widely available in Canada. Decisions about their introduction should not be based on the availability of the technology, but on sound scientific data and consultation with consumers, including people with HIV and AIDS.**

**4.2 Home test kits that meet a set of criteria designed to minimize their potential harmful effects should be allowed for sale in Canada. In particular, manufacturers need to be able to demonstrate that their kits meet the technical standards set by existing approved tests and that counselling provided over the phone is adequate.**

**In addition, measures should be implemented that would reduce the potential harms from making home test kits available, such as (1) addressing the risk of abuse by reemphasizing the need for specific informed consent to HIV testing, by providing for support for those who are the victims of misuse of such tests by others, and by establishing severe penalties and quick complaint mechanisms in cases of violations; (2) renewing the commitment to the provision of free testing and counselling at a variety of state-sponsored testing clinics, advertising their services, and decreasing, as far as possible, delays at such clinics; and (3) renewing the commitment to prevention efforts that have proven successful, such as counselling, education, provision of wide access to preventive means such as condoms and sterile needles, and, generally, community-based efforts to prevent the further spread of HIV.**

**4.3 Serious consideration should be given to first offering home test kits on a limited trial basis and to requiring, as a precondition of approval, that post-marketing studies be carried out by independent researchers.**

**4.4 A national workshop on issues raised by the new testing technologies,**

**that includes people providing counselling, those who have tested positive, those caring for and working with them, representatives of Aboriginal communities, representatives of the federal and provincial and territorial health ministries, researchers, HIV test manufacturers, and others concerned, should be held to further discuss the issues addressed in this Report and to attempt to reach a consensus and develop a research agenda on the various new testing technologies.**

## 5. Testing of Pregnant Women

**5.1 In all Canadian provinces and territories, programs should be implemented under which all pregnant women – and not only those considered at risk of HIV – are routinely counselled about the advantages and disadvantages of HIV testing and offered voluntary HIV testing. These programs should be designed so as to maximize the uptake rate (including the regular evaluation of strategies for effectiveness), professionals responsible for implementing the policy should be provided with supportive education and training, and the colleges of physicians and surgeons should take an active role in ensuring that physicians offer HIV testing to all pregnant women and provide appropriate counselling. To ensure that women provide informed consent and receive counselling, prenatal testing requisition forms should require the physician to declare that counselling was provided and be accompanied by an informed consent form signed by the woman receiving testing.**

**5.2 Increased efforts need to be made at all levels to pursue effective strategies to prevent HIV transmission to women.**

## 6. Testing of Newborns

**Routine or compulsory testing of newborns is unwarranted. Rather, all pregnant women should be offered voluntary testing and counselling and, if HIV-positive, be encouraged to consider taking treatment that will benefit them and reduce the risk of transmission to their infants (see Recommendation 5.1).**

## 7. Testing of Prisoners

**There is no public health or security justification for mandatory or compulsory HIV testing of all prisoners.**

**Rather, as do people outside prison, prisoners must have access to a**

**variety of voluntary, high-quality, bias-free testing options. This should include anonymous or flexible non-nominal testing offered by outside personnel and agencies, as well as testing offered by prison health-care staff. Testing by prison health-care staff should be made more accessible and acceptable to prisoners, by offering them the option of non-nominal testing, training prison health-care staff in the delivery of pre- and post-test counselling, and better protecting the confidentiality of medical information.**

**In order to encourage prisoners to test voluntarily, prison systems must increase efforts to ensure that HIV-positive prisoners will not be wrongfully discriminated against and will have access to care, support and treatment equivalent to that available outside.**

## 8. Testing of Persons Accused of and/or Convicted of Sexual Assault

**Compulsory testing of persons accused of sexual assault, at the request of the survivor of sexual assault, may provide some psychological reassurance to the survivor. Generally, however, it has few benefits and many potential harms.**

**Compulsory testing of persons *convicted of* sexual assault cannot provide the survivor with useful information and is therefore not justified.**

**Legislation authorizing testing of persons accused and/or convicted of sexual assault would do little to help the survivors, and divert attention from the real, underlying problems. What is required instead is a governmental response that answers the very real concerns of survivors of sexual assault and provides them with assistance.**

**Therefore, Health Canada, the Department of Justice, Status of Women, and their provincial counterparts should continue to ensure that best-practice counselling, short- and long-term care, treatment and other services are made available to sexual assault survivors. This should include**

**• access to HIV-antibody testing and counselling for all sexual assault survivors, provided by trained staff of sexual assault crisis centres or similar facilities;**

**• examination of the question whether PCR testing should be made available to survivors of sexual assault;**

**• access to post-exposure prophylaxis for sexual assault survivors,**

**accompanied by counselling about its effects;**

- **ensuring sensitivity to multiculturalism and societal diversity in the delivery of counselling, testing and support services;**

- **assistance in the HIV/AIDS-related training of staff at sexual assault crisis centres and of other professionals who have contact with survivors of sexual assault.**

## 9. Testing of Sex Workers

**9.1 Mandatory or compulsory testing of sex workers and other coercive measures directed at them will do little to prevent the spread of HIV among sex workers and to clients. Rather than undertake such measures, policymakers must consult with sex workers to develop policies that will truly prevent and reduce the spread of HIV.**

**9.2 An analysis of the impact of municipal, provincial and federal policies and laws regulating and/or penalizing prostitution on efforts to prevent HIV infection should be undertaken, and alternatives to current regulation recommended.**

## 10. Testing of Health-Care Workers

**Mandatory testing of health-care workers is not justified. Instead, all health-care workers who practice invasive procedures should regularly monitor their HIV status. If infected, they should seek advice about whether they need to limit their professional practice in order to protect their patients. 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.**

## 11. Testing of Immigrants

**11.1 Canada should not introduce mandatory HIV testing of prospective immigrants.**

**11.2 The current system according to which immigration applicants who are found to be HIV-positive are assessed as "medically inadmissible" should be changed so that people with HIV/AIDS or other similar conditions will not**

**automatically be excluded from immigrating. A new system should be developed in consultation with all those concerned, in particular people with HIV/AIDS and organizations representing their interests. It should take the individual circumstances of each case into account, weigh the costs against the benefits of allowing a particular person to immigrate, and take humanitarian concerns into account.**

## 12. Confidentiality

**12.1 Confidentiality laws in Canada should conform to the recommendations in the International Guidelines on HIV/AIDS and Human Rights, which read as follows: "General confidentiality and privacy laws should be enacted. HIV-related information on individuals should be included within definitions of personal/medical data subject to protection and should prohibit the unauthorized use and/or publication of HIV-related information on individuals. Privacy legislation should enable an individual to see his or her own records and to request amendments to ensure that such information is accurate, relevant, complete and up to date. An independent agency should be established to redress breaches of confidentiality. Provision should be made for professional bodies to discipline cases of breaches of confidentiality as professional misconduct under codes of conduct ..."1270**

**12.2 The disclosure of HIV/AIDS-related medical information to persons claiming that they have a need or right to know the serological status of HIV-positive individuals is seldom justifiable. In most situations, disclosure is unnecessary and its efficacy is questionable. In addition, disclosure is often counterproductive or harmful, in excess of any benefits or potential benefits that might result from it. Measures that can be undertaken to prevent exposure to and infection with HIV have to be undertaken regardless of whether a person is or is not known to be seropositive. To educate people about precautions that can prevent HIV transmission, and to make available to them the means necessary to prevent it, is essential if transmission of HIV infection is to be prevented. Only in rare, exceptional cases will disclosure be justified, when an individual assessment shows that disclosure is necessary, likely to be effective, and the least invasive and restrictive means available to prevent harms that cannot otherwise be prevented. In all other situations in which claims for disclosure may arise, other means are often already available, would be less harmful than disclosure, and are likely to be necessary and more effective.**

**12.3 Because of the limits of confidentiality and the difficulties of protecting**

**it in practice, efforts to protect people living with or affected by HIV/AIDS from discrimination need to be strengthened. To this end, the recommendations in *HIV/AIDS and Discrimination: A Discussion Paper*1271 should be implemented.**

## 13. Reporting

**Reporting of both HIV and AIDS should be non-nominal: nominal reporting is not warranted either for surveillance or for partner notification purposes. Provinces and territories that currently require nominal reporting should review their reporting requirements by forming working groups including people with HIV/AIDS, test providers, ethicists, public health professionals, technical experts and others, and develop a system that collects only the information necessary, using unique or coded identifiers that ensure privacy and confidentiality of the individual.**

## 14. Partner Notification

**14.1 Partner notification programs should be implemented in every jurisdiction in Canada. These programs must respect the human rights and dignity of the index person and the partners, must be voluntary, non-coercive, and non-prejudicial, and must be consistent with the principles set out in the 1997 *Guidelines for Practice for Partner Notification in HIV/AIDS*.**

**14.2 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. This should include people with HIV/AIDS, community-based AIDS organizations, medical practitioners, public health, and specific affected communities such as the gay community, blood and blood-product recipients, injection drug users, sex workers, youth, First Nations and Inuit, immigrants from areas where HIV is endemic, and culturally diverse populations. Once a program is decided upon through consultation and consensus, the program and its elements should be made public.**

**14.3 Each person who requests HIV testing and counselling must be made aware of and understand the partner notification program in his/her jurisdiction and its implications before testing proceeds.**

**14.4 Partner notification programs must be a balanced part of a comprehensive HIV/AIDS public health and prevention program. For the**

**populations most vulnerable to contracting HIV, targeted education and support through community-based programs remain essential. It would be dangerous to allocate increasing resources to partner notification programs without at least maintaining current funding levels for education and for support programs.**

**Return to the top of this page**

**Return to Table of Contents**

---

ENDNOTES

1265 A Brandt, Professor of the History of Medicine at Harvard Medical School, cited in Abrams, supra, note 601.

1266 Ibid.

1267 Miller & Pinching, supra, note 204 at S191.

1268 Supra, note 8.

1269 Bayer, supra, note 1081 at 1504.

1270 Supra, note 162 at 16, para 30(c).

1271 Supra, note 6 at 109-119.

**Return to the top of this page**

**Return to Table of Contents**

# HIV Testing and Confidentiality: Final Report

**Prepared by Ralf Jürgens**

**ISBN 1-896735-16-9**

---

# BIBLIOGRAPHY

A Legal Framework for Health Information – Consultation Paper. Toronto: Ontario Ministry of Health, June 1996.

Aboriginal Nurses Association of Canada. *HIV/AIDS and Its Impact on Aboriginal Women in Canada*. Ottawa: Minister of Health Canada, March 1996.

Aboriginal Working Group on HIV/AIDS Surveillance and Research. Ethical Review Checklist for Support or Approval of Research Proposals on Aboriginal People. Draft. Ottawa: LCDC, 1998.

Abrams S. Mandatory HIV Testing: The Search for a Quick Fix. *Harvard AIDS Letter* May/June 1995.

Achilles R. The Regulation of Prostitution. Unpublished background paper written for the Department of Public Health of the City of Toronto (updated 14 April 1995).

ACIP. Recommendations of the Advisory Committee on Immunization Practices (ACIP): Use of Vaccines and Immune Globulins in Persons with Altered Immunocompetence. *Morbidity and Mortality Weekly Review* 1993; 42 (no RR-4).

Additional Recommendations to Reduce Sexual and Drug Abuse-Related Transmission of Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus. *Morbidity and Mortality Weekly Report* 1986; 35: 152-155.

Adhere Say. *POZ* March 1998, 79.

Advances in HIV Testing Technology. *The Association of State and Territorial Health Officials HIV/AIDS Update* 1997; 1(4):
section 2.

Advocate Poll Results. *The Advocate*, 23 July 1996.

AIDS Action Committee of Massachusetts and AIDS Action Council of Washington DC. *Creating an Effective Public Health Response to the Changing Epidemic: Moving to HIV Surveillance by Unique Identifier and Other Non-Name Based Surveillance Systems.* Boston & Washington DC: The Committee and the Council, October 1997.

AIDS and Civil Liberties Project, American Civil Liberties Union Foundation. Mandatory HIV Testing of Female Prostitutes: Policy Statement of the American Civil Liberties Union. In: M Blumberg (ed). *AIDS. The Impact on the Criminal Justice System*. Columbus, OH: Merrill Publishing Company, 1990.

AIDS Project Los Angeles. *HIV Surveillance: Proposals for the New Era of the HIV Epidemic*, Summer 1997.

AIDS Committee of Ottawa. Submission to the Ontario Law Reform Commission Project on HIV/AIDS Testing. Ottawa: The Committee, no date.

AIDS Committee of Toronto. *Sexual Assault and AIDS Needs Assessment Survey Highlights*. (Unpublished report). Toronto: ACT, 1991.

Albert J et al. Analysis of a Rape Case by Direct Sequencing of the Human Immunodeficiency Virus Type 1 Pol and Gag Genes. *Journal of Virology* 1994; 68: 5918-5924.

Alberta Health. *Routine Prenatal HIV Screening – Backgrounder*. Alberta Health, Edmonton: 23 March 1998.

Alberta Health. *Government Approves Routine Prenatal HIV Screening Program*. Alberta Health: Edmonton, 23 March 1998 (news release).

Alexander M. HIV and Permanent Residence. [Australian] *HIV/AIDS Legal Link* 1995; 6(2): 8-10.

Alexander P. Mandatory Testing of Prostitutes Will Not Prevent AIDS. In: CC Abt, KM Hardy (eds). *AIDS and the Courts*. Cambridge, MA: Abt Books Inc, 1990.

Alexander P. Response to AIDS: Scapegoating of Prostitutes. San Francisco, CA: National Task Force on Prostitution, 1988.

American Civil Liberties Union. The Maryland Lesson. Conducting Effective HIV Surveillance with Unique Identifiers. ACLU, December 1997.

American Civil Liberties Union. HIV Surveillance and Name Reporting. A Public Health Case for Protecting Civil Liberties. ACLU, October 1997.

American Civil Liberties Union. *HIV Partner Notification: Why Coercion Won't Work*. An American Civil Liberties Union Report. New York, NY: ACLU, March 1998.

Ammann A. Unrestricted Prenatal HIV Testing: The Standard of Care. *Journal of the American Women's Association* 1995; 50(3&4): 83.

Anderson S. Individual Privacy Interests and the "Special Needs" Analysis for Involuntary Drug and HIV Tests. *California Law Review* 1998; 86: 119-177.

Antalek J. The Lazarus Effect – Protease Inhibitors: A Return to Health? *Q San Francisco* March/April 1997, 30-33.

Association of State and Territorial Health Officials. *Recommended Actions Resulting from the Workshop: "HIV Home Sample Collection Kits: Maximizing the Public Health Benefits."* Washington, DC: The Association, March 1997.

Association of State and Territorial Health Officials. *Advances in HIV Testing Technology*. Washington, DC: The Association, 1997.

Austin J et al. A Study of Antiretroviral Drug Taking Behaviour in Persons Living with HIV/AIDS. 7th Annual Canadian Conference on HIV/AIDS Research, April/May 1998. Abstract no 438P.

Awful New Prostitution Laws. COYOTE (Call off your old tired ethics) Howls, January 1989.

Banta WF. *AIDS in the Workplace: Legal Questions and Practical Answers*. Lexington, DC: Heath and Company, 1988.

Barbacci M, JT Repke, RE Chaisson. Routine Prenatal Screening for HIV Infection. *Lancet* 1991; 337: 709-711.

Barbacci MB et al. Human Immunodeficiency Virus Infection in Women Attending an Inner-City

Prenatal Clinic: Ineffectiveness of Targeted Screening. *Sexually Transmitted Diseases* 1990; 00:122-126.

Barlow K et al. Involving Aboriginal Communities in HIV/AIDS Surveillance and Research. 7th Annual Canadian Conference on HIV/AIDS Research, April/May 1998, abstract no 150P.

Barnes et al. The HIV-Infected Health Care Professional: Employment Policies and Public Health. *Law, Medicine & Health Care* 1990; 18: 311.

Barr S. The 1990 Florida Dental Investigation: Is the Case Really Closed? *Annals of Internal Medicine* 1996; 124: 250-254.

Bartlett WC. *AIDS: Legal Issues*. Ottawa: Library of Parliament Research Branch, Current Issue Review 93-7E, 14 April 1994 (revised 19 April 1995).

Bastow K. Prostitution and HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(2): 12-14.

Bayer R. The Ethical Dimensions of HIV Testing. In: J Mann et al (eds). *AIDS in the World. A Global Report*. Cambridge, MA & London, UK: Harvard University Press, 1992, 747-759.

Bayer R. *Private Acts, Social Consequences: AIDS and the Politics of Public Health*. New Brunswick, NJ: Rutgers University Press, 1990.

Bayer R. Editorial Review – Ethical and Social Policy Issues Raised by HIV Screening: The Epidemic Evolves and So Do the Challenges. *AIDS* 1989; 3: 119-124.

Bayer R. Discrimination, Informed Consent, and the HIV Infected Clinician. *British Medical Journal* 1997; 314: 915-916.

Bayer R et al. Testing for HIV Infection at Home. *New England Journal of Medicine* 1995; 332: 1296–1299.

Bayer R. Confidentiality and Its Limits. In: H Fuenzalida–Puelma et al (eds). *Ethics and Law in the Study of AIDS*. Pan American Health Organization Scientific Publication No 530.

Bayer R et al. The American, British, and Dutch Responses to Unlinked Anonymous HIV Seroprevalence Studies: An International Comparison. *AIDS* 1990; 4: 286.

Bayer R. Assault Victims Have Right to Know Attacker’s H.I.V. Status. Medical Tribune News Service, 1996.

Bayer R. HIV Testing and Reporting. *AIDS Ethics and Policy Updates*. At the *Journal of the American Medical Association* website.

Bayer R. Public Health Policy and the AIDS Epidemic. An End to HIV Exceptionalism? *New England Journal of Medicine* 1991; 324(21): 1500-1504.

Bayer R. AIDS: Human Rights and Responsibilities. *Hospital Practice* 1994; 29(2): 155-164.

Bayer R. HIV Exceptionalism Revisited. *AIDS & Public Policy Journal* 1994; 9(1): 16-18.

Beauchemin J, JF Labadie. *Évaluation de l'utilité et de l'accessibilité des services de counselling et de dépistage du VIH en milieu carcéral – Services offerts par le CLSC Ahuntsic à la Maison Tanguay et à l'Établissement de détention de Montréal. Rapport final: août 1997.* Montréal: Direction de la santé publique de Montréal-Centre and CLSC Ahuntsic, 1997.

Belitzky R, RA Solomon. Doctors and Patients: Responsibilities in Confidential Relationship. In: LH Dalton, S Burris (eds). *AIDS and the Law: A Guide for the Public*. New Haven: Yale University Press, 1987, 201-209.

Benenson AS (ed). *Control of Communicable Diseases in Man: An Official Report of the American Public Health Association*. 14th edition. Washington, DC: American Public Health Association, 1985.

Benko LB. No Needles. *Investor's Business Daily* 2 March 1997.

Berberian E, A Richardson-Moore. New York State's Oral Fluid Testing in the Anonymous Counseling and Testing Program. The Implementation and Preference Pilot Study. *NASTAD HIV Prevention Community Planning Bulletin* April 1998.

Bernasconi E et al. Metabolic Changes in HIV-Infected Patients Treated with Protease Inhibitors. 12th World AIDS Conference, Geneva, abstract no 12375.

Berrios DG et al. HIV Antibody Testing Among Those at Risk for Infection: The National AIDS Behavioral Surveys. *Journal of the American Medical Association* 1993; 270(13): 1576-1580.

Black WW. *B.C. Human Rights Review. Report on Human Rights in British Columbia.* Vancouver: Ministry Responsible for Multiculturalism and Human Rights, 1994.

Blair P. Refugee Status Granted on Grounds of HIV. *HIV/AIDS Legal Link* 1994; 5(4): 3.

Blankenship EM et al. HIV Partner Notification with an Anonymous Testing System. In: *V*

*International Conference on AIDS*. June 1989, Montréal, Canada. Abstract WDP1.

Bloodborne Pathogens in the Health Care Setting: Risk for Transmission. *Canadian Medical Association Journal* 1993; 148(10): 1747-1752 (reprinted from *Canada Communicable Disease Report* 1992; 18: 177-184).

Borra J. Faith Test. *Hour* [Montréal], 30 March 1996.

Bowleg L. Unjust Punishments: Mandatory HIV Testing of Women Sex Workers and Pregnant Women. Washington, DC: Center for Women Policy Studies, National Resource Center on Women and AIDS, 1992.

Branson B. Update: HIV Home Collection Kits. *NASTAD HIV Prevention Community Planning Bulletin* April 1998.

Branson BM, HD Gayle. Home Testing for HIV – It's Coming. Are You Ready? *International AIDS Society Newsletter* no 4, March 1996.

British Columbia Centre for Disease Control. Bulletin #1, HIV Transmission in Pregnancy.

British Columbia Civil Liberties Association. *AIDS Discrimination in Canada: A Study of the Scope and Extent of Unfair Discrimination in Canada against Persons with AIDS, and Those Known or Feared to Be HIV Positive.* Vancouver: The Association, 1989.

British Columbia Women's Hospital, Sexual Assault Service. *Protocol for PEP with Sexual Assault Survivors*. Vancouver, BC: The Hospital, 1997.

Britton CB. An Argument for Universal HIV Counselling and Voluntary Testing of Women. *Journal of the American Medical Women's Association* 1995; 50(3&4): 85-86.

Brock D. Prostitutes are Scapegoats in the AIDS Panic. *RFR/DFR* 1989; 18(2): 13-16.

Brock D. Scapegoating Prostitutes in the AIDS Epidemic. *Broadside*; 10(4): 6.

Browne J et al. HIV Anonymous Testing – Does It Make a Difference? In: *IX International Conference on AIDS/IV STD World Congress*. June 1993, Berlin, Germany. Abstract PO-C28-3249.

Bryant L, TA Hooker. Testing Sex Offenders for HIV. *State Legislative Report* 1991; 17(7): 1-7.

Bryden J. Marchi Considers AIDS Tests for Immigrants. *The* [Montréal] *Gazette* 26 April 1994, B4.

Burr C. The AIDS Exception: Privacy vs. Public Health. *The Atlantic Monthly* June 1997, 57-67.

Burris S. Driving the Epidemic Underground? A New Look at Law and the Social Risk of HIV Testing. *AIDS & Public Policy Journal* 1997; 12(2): 66-78.

Burris S. Testing, Disclosure, and the Right to Privacy. In: S Burris et al (eds). *AIDS Law Today: A New Guide for the Public*. New Haven: Yale University Press, 1993, 115-149.

California Lawmakers Approve HIV Reporting Using Coded IDs. *AIDS Policy & Law* 1998; 13 (17): 1, 6.

Calypte. *Food and Drug Administration Summary Basis for Approval*. Bethesda, MD: US Department of Health and Human Services, 1996.

Calzavara L. Preliminary Results from an Anonymous Unlinked HIV Seroprevalence Study of Inmates in Ontario. In: Correctional Service Canada. *HIV/AIDS and Prisons: Background Materials*. Ottawa: Minister of Supplies and Services Canada, 1994, Appendix 7.

Campbell CA. Women and AIDS. *Social Sciences in Medicine*; 30(4): 411.

Canadian AIDS Society. Report on Canada’s Travel and Immigration Policies for People Living with AIDS. Ottawa: The Society, 25 September 1995.

Canadian AIDS Society. The Right of Health Care Workers with HIV to Practice Their Profession without Restrictions. A Position Paper. Ottawa: The Society, 11 September 1992.

Canadian HIV/AIDS Legal Network. *HIV, Injection Drug Use, and Care, Treatment and Support: Legal and Ethical Issues. Report on the Consultation*. Montréal: The Network, 1998.

*Canadian Diseases Weekly Report* 1987; 13: 13-14.

Canadian Human Rights Commission. Canadian Human Rights Commission Policy on HIV/AIDS. Ottawa:
The Commission, June 1996. Reprinted in *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 7-8.

Canadian Public Health Association. *1997 Resolutions and Motions*. Ottawa: CPHA, 1997.

Canadian Public Health Association. *HIV & AIDS: A Public Health Perspective*. Ottawa: The

Association, 1993.

Canadian Medical Association. *Counselling Guidelines for HIV Testing*. Ottawa: The Association, 1995.

Canadian Medical Association. A CMA Position: Acquired Immunodeficiency Syndrome. *Canadian Medical Association Journal* 1989; 140: 64A.

Canadian Medical Association. Code of Ethics of the Canadian Medical Association. *Canadian Medical Association Journal* 1996; 155(8): 1176A-B.

Canadian Medical Association. CMA Policy Summary. HIV Infection in the Workplace. *Canadian Medical Association Journal* 1993; 148(10): 1800A-1800H (reprinted in *Health Law Review* 1994; 3(2): 27-30).

Canedy D. Seeking Assurance from a $40 Kit. *New York Times* 21 November 1996.

Carey R. Challenging Ontario's Denial of Medical Care to HIV-Positive Immigrants. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 18-19.

Carpenter CC et al. Antiretroviral therapy for HIV infection in 1997: updated recommendations of the International AIDS Society–USA panel. *Journal of the American Medical Association* 1997; 277: 1962-1969.

Carson R et al. Drug Compliance in Patients Starting Saquinavir. 7th Annual Canadian Conference on HIV/AIDS Research, April/May 1998. Abstract no 435P.

Casswell DG. *AIDS, Ethics and Law*. Victoria, BC: University of Victoria, Division of University Extension, 1990.

Casswell DG. Disclosure by a Physician of AIDS-Related Patient Information: An Ethical and Legal Dilemma. *Canadian Bar Review* 1989; 68: 225-258.

Casswell DG. *Lesbians, Gay Men, and Canadian Law*. Edmond Montgomery Publications Ltd, 1996.

Cates W, K Toomey. Sexually Transmitted Diseases: Overview of the Situation. *Primary Care* 1990; 17: 1-27.

Celentano DD et al. Self-Reported Antiretroviral Therapy in Injection Drug Users. *Journal of the American Medical Association* 1998; 280(6): 544.

Centers for Disease Control and Prevention. 1995 Revised Guidelines for Prophylaxis against Pneumocystis Carinii Pneumonia for Children Infected with or Perinatally Exposed to Human Immunodeficiency Virus. *Morbidity and Mortality Weekly Report* 1995; 44 (no RR-4).

Centers for Disease Control and Prevention. Public Health Service Task Force Recommendations for the Use of Antiretroviral Drugs in Pregnant Women Infected with HIV-1 for Maternal Health and for Reducing Perinatal HIV-1 Transmission in the United States. *Morbidity and Mortality Weekly Review* 1998; 47(RR-2): 1-31.

Centers for Disease Control and Prevention. Recommendations for Preventing Transmission of Human Immunodeficiency Virus and Hepatitis B Virus to Patients During Exposure-Prone Invasive Procedures. *Morbidity and Mortality Weekly Review* 1991; 40(No RR-8): 1.

Centers for Disease Control and Prevention. Update: Investigations of Persons Treated by HIV-Infected Health Care Workers – United States. *Morbidity and Mortality Weekly Review* 1993; 42: 329-331.

Centers for Disease Control and Prevention. Rapid HIV Test Enables Same-Day Test Results. *HIV/AIDS Prevention* June 1998, 11, 18.

Centers for Disease Control and Prevention. *U.S. Public Health Service Recommendations for Human Immunodeficiency Virus Counseling and Voluntary Testing for Pregnant Women*. The Centers, 7 July 1995 (vol 44/no RR-7).

Centers for Disease Control and Prevention. Update: HIV Counseling and Testing Using Rapid Tests – United States, 1995. *Morbidity and Mortality Weekly Report* 27 March 1998.

Centers for Disease Control. Interpretation and Use of the Western Blot Assay for Serodiagnosis of Human Immunodeficiency Virus Type 1 Infections. *Morbidity and Mortality Weekly Review* 1998; 38(Suppl 7): S4-S6.

Centers for Disease Control and Prevention. *Estimates of the Risk of Transmission of Hepatitis B Virus and Human Immunodeficiency Virus to Patients by the Percutaneous Route During Invasive Surgical and Dental Procedures.* Atlanta: CDC, 1991.

Centers for Disease Control. Technical Guidance on HIV Counseling. *Morbidity and Mortality Weekly Report* 1993; 42(RR-2): 8-17.

Centers for Disease Control and Prevention. Transmission of HIV Infection During an Invasive Procedure, Florida. *Morbidity and Mortality Weekly Review* 1991; 40: 21-27, 33.

Centers for Disease Control and Prevention. Possible Transmission of HIV to a Patient During an Invasive Dental Procedure. *Morbidity and Mortality Weekly Review* 1990; 39: 489-493.

Centers for Disease Control and Prevention. Public Health Service Guidelines for the Management of Health-Care Worker Exposures to HIV and Recommendations for Postexposure Prophylaxis. *Morbidity and Mortality Weekly Review* 1998; 47(No RR-7): 1-34.

Centers for Disease Control and Prevention. *Rapid HIV Tests: Questions/Answers*. Atlanta, GA: March 1998.

Centers for Disease Control and Prevention, National AIDS Clearinghouse. HIV Oral Fluid Tests. In: *Guide to Information and Resources on HIV Testing*, 1997.

Centers for Disease Control and Prevention. Comparison of Anonymous and Confidential Registrants for HIV Testing. *Morbidity and Mortality Weekly Report* 1993; 29 January: 53-56.

Centers for Disease Control. HIV Counseling and Testing Services from Public and Private Providers-United States, 1990. *Morbidity and Mortality Weekly Report* 1992; 41(40): 743, 749-752.

Centers for Disease Control. *External Review of CDC's HIV Prevention Strategies by the CDC Advisory Committee on the Prevention of HIV Infection*. Atlanta: The Centers, June 1994.

Centers for Disease Prevention and Control. Recommendations of the US Public Health Service Task Force on the Use of Zidovudine to Reduce Perinatal Transmission of Human Immunodeficiency Virus. *Pediatric AIDS and HIV Infection: Fetus to Adolescent* 1994; 5(6): 387-398.

Centers for Disease Control. *HIV Counseling, Testing, and Referral: Standards and Guidelines*. Atlanta: US Department of Health and Human Services, May 1994.

Center for Women Policy Studies. More Harm than Help: The Ramifications for Rape Survivors of Mandatory HIV Testing of Rapists (reprinted in *AIDS Reference Guide*. Atlantic Information Services Inc, December 1992, ¶505.

Centre for Human Rights, Geneva. *Report of an International Consultation on AIDS and Human Rights* (Geneva, 26-28 July 1989). New York: United Nations, 1991 (HR/PUB/90/2).

Cheng TL et al. Confidentiality in Health Care: A Survey of Knowledge, Perceptions and Attitudes Among High School Students. *Journal of the American Medical Association* 1993; 269: 1404-1407.

Closen M et al. AIDS in America: Death, Privacy and the Law. *Human Rights* 1987; 14: 27.

Coburn D. Individual and Community Rights in Anonymous Unlinked HIV Seroprevalence Research: A Response to Dr Emson. *Health Law in Canada* 1992; 12(4): 97.

Cohen J, P Alexander, C Wofsky. Prostitutes and AIDS: Public Policy Issues. *AIDS & Public Policy Journal* 1988; 3(2): 16-22.

Cohen R, LS Wiseberg. *Double Jeopardy – Threat to Life and Human Rights. Discrimination against Persons with AIDS*. Cambridge, MA: Human Rights Internet, 1990.

College of Physicians and Surgeons of Manitoba. *Guideline: Maternal and Neonatal HIV Testing and Management*. January 1995.

*Commission of Inquiry on the Blood System in Canada: Final Report*. Volumes 1-3. Ottawa: Minister of Public Works and Government Services Canada, 1997.

Commission d'accès à l'information du Québec. Renseignements personnels relatifs au sida: une confidentialité à respecter. Québec: The Commission, March 1991.

Commonwealth of Australia. *National HIV/AIDS Strategy (The White Paper)*. Canberra: August 1989.

Commonwealth of Australia. *National HIV/AIDS Strategy 1993-94 to 1995-96*. Canberra: October 1993.

Community Prescription Service. HIV Patients in Better Health Least Likely to Adhere to Treatment Regimens. New York, NY, Press release of 8 June 1998.

Community AIDS Treatment Information Exchange (CATIE). 12th World AIDS Conference. Interim Report. Toronto: CATIE, (also available at www.catie.ca).

Confide Results Are Demonstrating Ease of Use and Public Health Benefits. Confide HIV Testing Service, Johnson & Johnson, press release of 16 January 1997.

Confidentiality in Relation to HIV Seropositivity. Report of the Federal/Provincial/ Territorial Advisory Committee on AIDS. *Canada Diseases Weekly Report* 1989; 15(8): 43-47.

Connor EM et al. Reduction of Maternal–Infant Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment. *New England Journal of Medicine* 1994; 331: 1173-80.

Cook S. Go-Ahead for Mass AIDS Tests. *The Guardian* 24 November 1988.

Cooper E. Why Mandatory HIV Testing of Pregnant Women and Newborns Must Fail: A Legal, Historical, and Public Policy Analysis. *Cardozo Women's Law Journal* 1996; 3(1): 13-30.

Cooper E. Mandatory HIV Testing of Pregnant/Delivering Women and Newborns: A Legal, Ethical, and Pragmatic Assessment. Abstract We.D.491, presented at the XI International Conference on AIDS, Vancouver, July 1996.

Correctional Service Canada. *HIV/AIDS and Prisons: Background Materials*. Ottawa: Minister of Supplies and Services Canada, 1994.

Correctional Service of Canada. Backgrounder: CSC Response to the Expert Committee on AIDS and Prisons (ECAP). Ottawa: CSC, Health Care Services Branch, 24 March 1994.

Correctional Service Canada. *HIV/AIDS in Prisons: Final Report of the Expert Committee on AIDS and Prisons*. Ottawa: Minister of Supplies and Services Canada, 1994.

Correctional Service Canada. News Release: Correctional Service of Canada to Introduce Methadone Maintenance Treatment. Ottawa: The Service, 1 December 1997.

Council of Europe. *Recommendation No. R(89) 14 of the Committee of Ministers to Member States on the Ethical Issues of HIV Infection in the Health Care and Social Settings*.

Council of State and Territorial Epidemiologists and Centers for Disease Control and Prevention. *Consultation on the Future of HIV/AIDS Surveillance*. The Carter Center, 21-22 May 1997.

Curran W, L Gostin, M Clark (eds). *AIDS: Legal and Regulatory Policy*. Frederick: University Publishing Group, 1988.

d'Eca C. Medico-Legal Aspects of AIDS. In: D Harris, R Haigh (eds). *AIDS: A Guide to the Law*. London: Routledge, 1990, 8-10.

de Bruyn T. *HIV/AIDS and Discrimination: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998.

DeJong W, L O'Donnell, AD San Doval et al. The Status of Clinic-Based STD Patient Education: The Need for a Commitment to Innovation in Health Communication. *Journal of Health Communication* 1996; 1: 51-63.

Department of Community Services and Health. *Consultation paper No 5: report of the working panel on testing for HIV/AIDS*. Canberra: Commonwealth of Australia, 1989.

Department of Health, Housing and Community Services. *The Final Report of the Legal Working Party of the Intergovernmental Committee on AIDS*. November 1992.

Deutsch G, A-M Robert, C Tsoukas. Impact of HAART in a Major AIDS Treatment Facility. 7th Annual Canadian Conference on HIV/AIDS Research, April/May 1998. Abstract no 458P.

Dickens BM. Legal Limits of AIDS Confidentiality. *Journal of the American Medical Association* 1988; 259: 3449-3451.

Dickens BM. Confidentiality and the Duty to Warn. In: LO Gostin (ed). *AIDS and the Health Care System*. New Haven: Yale University Press, 1990, 98-112.

Dickman S. Mandatory AIDS Tests on Basis 'of Slight Suspicion' in Bavaria. *Nature* 1988; 333: 585.

Dickman S. Bavaria Begins Mandatory AIDS Tests in the Face of Criticism. *Nature* 1987; 327: 264.

Direct Access Diagnostics. The Confide HIV Home Testing and Counselling Service. Publicity distributed at the HIV & Telemedicine Symposium, Vancouver, 9 July 1996.

Direction de la santé publique de la Régie régionale de la santé et des services sociaux de Montréal-Centre. Montréal Prepares for the New Quebec Prenatal HIV Programme. Montréal: La direction, communiqué of 26 August 1996.

Doganci L. Home-Use HIV Test Kits in Turkey. *The Lancet* 1997; 349(9062): 1401.

Doll L, M Kennedy. HIV Counseling and Testing: What Is It and How Well Does It Work? In: G Schochetman, JR George (eds). *AIDS Testing*. New York: Springer-Verlag, 1994, 301-319.

Doll R. A Proposal for Doing Prevalence Studies of AIDS. *British Medical Journal* 1987; 294: 244.

Don't keep AIDS victims in the dark. *USA Today* 21 January 1987.

Dong K et al. Changes in Body Habitus in HIV+ Women After Initiation of Protease Inhibitor Therapy. 12th World AIDS Conference, Geneva, 1998, abstract no 12373.

Doughty R. The Confidentiality of HIV-Related Information: Responding to the Resurgence of Aggressive Public Health Interventions in the AIDS Epidemic. *California Law Review* 1994; 82: 111-184.

Downey D. Bernardo to Take AIDS Test after Victims Make Request. *The Globe and Mail* 24 September 1996.

Duckett M, AJ Orkin. AIDS-Related Migration and Travel Policies and Restrictions: A Global Survey. *AIDS* 1989; 3(Suppl 1): S231-S252.

Duffy J. *The Sanitarians: A History of American Public Health*. Urbana: University of Illinois Press, 1990.

Dwyer J. Legislating AIDS Away: The Limited Role of Legal Persuasion in Minimizing the Spread of HIV. *Journal of Contemporary Health Law and Policy* 1993; 9: 167.

Editorial. Focus on Confidentiality of Health Care Information. *Health Law in Canada* 1997; 17 (3): 67.

El-Sadr W et al. Evaluation and Management of Early HIV Infection. Rockville, MD: US Department of Health and Human Services, Public Health Service, Agency for Health Care Policy and Research, January 1994. DHHS publication no (AHCPR) 94-0572 (Clinical Practice Guideline no 7).

Elliott R. *Criminal Law and HIV/AIDS: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997.

Emson HE. The Ethics and Legality of HIV Prevalence Studies: A Contrary View. *Health Law in Canada* 1992; 12(4): 95.

Enel P et al. Ethical Confusion: Detection of HIV Seropositives. *AIDS & Public Policy Journal* 1992; 7(1): 42–49.

English Collective of Prostitutes. Prostitute Women and AIDS: Resisting the Virus of Repression. San Francisco, CA: PROstitutes Collective, 1988 (US edition).

European Working Group on HIV Infection in Female Prostitutes. HIV Infection in European Female Sex Workers: Epidemiological Link with the Use of Petroleum-Based Lubricants. *AIDS* 1993; 7: 401.

European Centre for the Epidemiological Monitoring of AIDS. *HIV/AIDS Surveillance in Europe*. Saint-Maurice, France: The Centre, Quarterly Report no 56, 1997/4.

Evaluation of HIV Case Surveillance Through the Use of Non-Name Unique Identifiers – Maryland and Texas, 1994-1996. *Morbidity and Mortality Weekly Review* 1998; 46(52&53): 1254-1272.

Farley JD et al. HIV/AIDS Surveillance in Canada, Change in Strategy. Presentation at the Seventh Annual Canadian Conference on HIV/AIDS Research, April/May 1998, abstract 241P.

Farnham PG et al. Counseling and Testing for HIV Prevention: Costs, Effects, and Cost-Effectiveness of More Rapid Screening Tests. *Public Health Reports* 1996; 111: 44-53.

FDA Approves First Urine-Based HIV Test System. *The Association of State and Territorial Health Officials HIV/AIDS Update* 1998; 1(8): section 6.

Federal/Provincial/Territorial Advisory Committee on AIDS Working Group on Partner Notification. *Guidelines for Practice for Partner Notification in HIV/AIDS*. Ottawa: Minister of Health, 1997.

Federal Centre for AIDS Working Group on Anonymous Unlinked HIV Seroprevalence. Guidelines on Ethical and Legal Considerations in Anonymous Unlinked HIV Seroprevalence Research. *Canadian Medical Association Journal* 1990; 143(7): 625-627.

Federal/Provincial/Territorial Working Group on Confidentiality in Relation to HIV Seropositivity. *Report*. Ottawa: The Working Group, 1988.

Fee E. Sin Versus Science: Venereal Disease in Twentieth-Century Baltimore. In: E Fee, DM Fox (eds). *AIDS: The Burdens of History*. Berkeley: University of California Press, 1988, 121-146.

Fehrs LJ et al. Targeted HIV Screening at a Los Angeles Prenatal/Family Planning Health Center. *American Journal of Public Health* 1991; 81: 619-622.

Fehrs LJ et al. Trial of Anonymous Versus Confidential Human Immunodeficiency Virus Testing. *Lancet* 1988; ii:
379-382.

Field MA. Testing for AIDS: Uses and Abuses. *American Journal of Law & Medicine* 1990; 16: 33-106.

*Fighting the Other Epidemic*. Report of the New South Wales Attorney-General's Committee on the Monitoring and Implementation of the Anti-Discrimination Board Report on HIV and

AIDS Related Discrimination. 1993.

Fiscus SA et al. Perinatal HIV Infection and the Effect of Zidovudine Therapy on Transmission in Rural and Urban Communities. *Journal of the American Medical Association* 1996; 275(19): 1483-1488.

Fisher J et al. *Gay and Lesbian Legal Issues: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998.

Flanagan W. HIV Testing in the Health Care Setting. *Queen's Law Journal* 1993; 18: 71.

Flanagan W. Equality Rights for People With AIDS: Mandatory Reporting of HIV Infection and Contact Tracing. *McGill Law Journal* 1989; 34: 531-602.

Fleischman AR. Mandatory Newborn Screening for HIV: The Wrong Answer to the Wrong Question. *The AIDS Reader* 1994; 4: 172.

Florida Investigates Breach of Confidentiality in HIV Records. *AIDS Policy & Law* 1996; 11(18): 1.

For a Testing Controversy, Press 1. *Bridges* 1997; 3(1): 3-6. Reprinted in the *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 8-10.

Forbes A. Myths and Facts About HIV Case Reporting by Name Versus by Unique Identifier. September 1997.

Ford P et al. Seroprevalence in a Male Medium Security Penitentiary – Ontario. *Canada Communicable Disease Report* 1994; 20(6): 45-47.

Fordyce EJ et al. Mandatory Reporting of Human Immunodeficiency Virus Testing Would Deter Blacks and Hispanics from Being Tested. *Journal of the American Medical Association* 1989; 262: 349.

Frank AP et al. Anonymous HIV Testing Using Home Collection and Telemedicine Counseling. *Archives of Internal Medicine* 1997; 157: 309-314.

Fraser S. Defending the Right to Do the Work They Do. *Atlantic Insight* June 1988: 14-19.

Fraser R et al. Public Health Imperatives of HIV Infection and AIDS in Canada. In: Royal Society of Canada. *AIDS: A Perspective for Canadians – Background Papers*. Ottawa: The Society, 1988.

Frerichs R. Personal Screening for HIV in Developing Countries. *Lancet* 1994; 343: 960-962.

Freundlich N. The Trials of a Home HIV Test. *Business Week* 18 March 1996.

Friedman B. AIDS and Rape. *The* [Montréal] *Gazette* 7 November 1992.

Gallo D et al. Evaluation of a System Using Oral Mucosal Transudate for HIV-1 Antibody Screening and Confirmatory Testing. *Journal of the American Medical Association* 1997; 277 (3): 254.

Gardner L, R Trow. Anonymous Testing Considered Essential, Good Follow-up Results. In: *VI International Conference on AIDS*; June 1990; San Francisco, Calif. Abstract Th.D.831.

Gay Men's Health Crisis. Gay Men's Health Crisis Calls for Monitoring of HIV Infections. New York, NY: Gay Men's Health Crisis News Release, 13 January 1998.

Gibb D et al. Evaluating Antenatal HIV Testing in London, UK. Abstract Th.C.4615, presented at the XI International Conference on AIDS, 1996.

Gillon R. AIDS and Medical Confidentiality. *British Medical Journal* 1987; 294: 1675–1677.

Gilmore N, MA Somerville. *Physicians, Ethics and AIDS*. Ottawa: Canadian Medical Association, 1989.

Gilmore N. HIV in the Workplace: Legal and Ethical Issues. Text of a presentation at the 6th Annual British Columbia AIDS Conference on 1 November 1993.

Gilmore N et al. International Travel and AIDS. *AIDS* 1989; 3(Suppl 1): S225-S230.

Give Inmates Needles, Study Says. *The Globe and Mail* 18 September 1996.

Glantz L et al. Risky Business: Setting Public Policy for HIV-Infected Health Care Professional. *The Milbank Quarterly* 1992; 70: 48-53.

Glenn P et al. *HIV Infection, AIDS and Privacy*. Montréal: McGill Centre for Medicine, Ethics and Law, 1990.

Global Programme on AIDS and Programme of STD. Consensus Statement from the Consultation on HIV Epidemiology and Prostitution (Geneva, 3-6 July 1989). Geneva: World Health Organization, 1989.

Godin G et al. Understanding the Intention of Gay Men to Take the HIV Antibody Test. In: *IX International Conference on AIDS/IV STD World Congress*. June 1993, Berlin, Germany. Abstract PO-C25-3223.

Godwin J et al. *Australian HIV/AIDS Legal Guide*. Annandale, NSW: The Federation Press, 2nd ed 1993.

Goldstein A. Whitman Walker Adopts Oral HIV Test Before Other Big AIDS Clinics. *Washington Post* 16 January 1997.

Goltz J, J Noble. New Brunswick Needs Anonymous HIV Testing. Fredericton: AIDS New Brunswick, 1996.

Gore SM, AG Bird. Letter to the Editor. *The Lancet* 1994; 343: 1295.

Gorman C. The Disease Detective. *Time* 30 December 1996/6 January 1997, 24-31.

Gostin LO, DW Webber. HIV Infection and AIDS in the Public Health and Health Care Systems. *Journal of the American Medical Association* 1998; 279(14): 1108-1113.

Gostin LO. Health Information Privacy. *Cornell Law Review* 1995; 80: 101-184.

Gostin LO. Public Health Strategies for Confronting AIDS: Legislative and Regulatory Policy in the United States. *Journal of the American Medical Association* 1989; 261(11): 1621.

Gostin L, WJ Curran. AIDS Screening, Confidentiality, and the Duty to Warn. *American Journal of Public Health* 1987; 77(3) (reprinted in *AIDS Reference Guide* July 1988, No 512).

Gostin L. The Resurgent Tuberculosis Epidemic in the Era of AIDS: Reflections on Public Health, Law, and Society. *Maryland Law Review* 1995; 54(1): 1-131.

Gostin LO et al. HIV Testing, Counseling, and Prophylaxis after Sexual Assault. *Journal of the American Medical Association* 1994; 271(18): 1436-1444.

Gostin L. A Decade of a Maturing Epidemic: An Assessment and Directions for Future Public Policy. *Notre Dame Journal of Law, Ethics & Public Policy* 1990; 5: 7.

Gostin LO. The AIDS Litigation Project. A National Review of Court and Human Rights Commission Decisions, Part II: Discrimination. *Journal of the American Medical Association* 1990; 263(15): 2086-2093.

Gostin LO, Z Lazzarini, KM Flaherty. Legislative Survey of State Confidentiality Laws, with Specific Emphasis on HIV and Immunization. Final Report Presented to: The U.S. Centers for Disease Control and Prevention, The Council of State and Territorial Epidemiologists, The Task Force for Child Survival and Development. Carter Presidential Center. 2 July 1996.

Gostin LO, JW Ward, AC Baker. National HIV Case Reporting for the United States. A Defining Moment in the History of the Epidemic. *The New England Journal of Medicine* 1997; 337(16): 1162-1166.

Government of Québec, Coroner's Office. Rapport d'investigation, Claude Paquin, Coroner investigateur, Montréal, 24 November 1992.

Grant I. Consensus on HIV Testing. *British Medical Journal* 1988; 297: 356.

Gray J et al. Incomplete Care Experiences of Gay Men as Young Adults (Ages 28 to 40) Can Influence Adherence to Antiretroviral Therapy. 7th Annual Canadian Conference on HIV/AIDS Research, April/May 1998. Abstract no 165P.

Graydon M. Report on the Health Canada (Health Protection Branch) Home HIV Self-Test Kit Workshop, 16 July 1993. Ottawa: Canadian AIDS Society, 23 July 1993.

Green A et al. Physician Perceptions of HIV(+) IDUs as Barriers to Treatment. 7th Annual Canadian Conference on HIV/AIDS Research, April/May 1998. Abstract no 125.

Grimshaw J et al. *"I Feel Like I've Got a Future." The Social and Economic Impact of Anti HIV Drugs on People with HIV*. London, UK: The Terrence Higgins Trust, 1998.

Grinstead OA. HIV Counseling for Behavior Change. *AIDS Education and Prevention* 1997; 9 (2): 125-132.

Grove DI, JB Mulligan. Consent, Compulsion and Confidentiality in Relation to Testing for HIV Infection: the Views of WA Doctors. *Medical Journal of Australia* 1990; 152: 174.

Grubb A, D Pearl. *Blood Testing, AIDS and DNA Profiling: Law and Policy*. Bristol: Family Law, 1990, 3-27.

Guillot-Hurtubise B. First Canadian Ruling in a Tainted-Blood Case. *Canadian HIV/AIDS Policy & Law Newsletter* 1994; 1(1): 8-9.

Guillot-Hurtubise B. Dentist Found Guilty of Discrimination. *Canadian HIV/AIDS Policy & Law Newsletter* 1995; 1(4): 1,
14-15.

Gulick RM et al. Treatment with indinavir, zidovudine, and lamivudine in adults with human immunodeficiency virus infection and prior antiretroviral therapy. *New England Journal of Medicine* 1997; 337: 734-739.

Hamblin J et al. *Responding to HIV/AIDS in Canada*. Toronto: Carswell, 1990.

Hamblin J, M Somerville. Surveillance and Reporting of HIV Infection and AIDS in Canada: Ethics and Law. *University of Toronto Law Journal* 1991; 41; 224-246.

Hamblin J. Health Care: Rights and Responsibilities. *Law Society Journal* 1992 (May): 66.

Hammer SM et al. A trial comparing nucleoside monotherapy with combination therapy in HIV-infected adults with CD4 cell counts between 200 to 500 per cubic millimeter. *New England Journal of Medicine* 1996; 335: 1081-1090.

Hammer SM et al. A controlled trial of two nucleoside analogues plus indinavir in persons with human immunodeficiency virus infection and CD4 cell counts of 200 per cubic millimeter or less. *New England Journal of Medicine* 1997; 337: 725-733.

Hankins C. HIV Counselling and Testing Issues for Women – Testing Experiences of HIV+ Women, Montréal. In: *Women and HIV National Workshop. A National Workshop to Enhance Networking and Collaboration between the Affected Community, Educators, Health and Social Service Professionals, and Researchers*. Montréal: Group for Action-Research, McGill AIDS Centre, 1995, 17.

Hankins C. AIDS and the Correctional System. *SIECCAN Journal* 1988; 3(4): 43-46.

Hankins C et al. HIV Testing Experience of Women Living with HIV. Abstract presented at the Second International Conference on the Biopsychosocial Aspects of HIV Infection, Brighton, England, July 1994.

Hankins C et al. HIV-1 Infection in a Medium Security Prison for Women – Quebec. *Canada Diseases Weekly Report* 1989; 15(33): 168-170.

Hanssens C. *Mandatory Newborn Testing. A Policy Paper.* New York, NY: Lambda Legal Defense and Education Fund, 1996.

Hanssens C. Inventing "AIDS Exceptionalism." New York, NY: Lambda Legal Defense AIDS Project News & Views, 28 February 1998.

Harding TW, G Schaller. HIV/AIDS Policy for Prisons or for Prisoners? In: J Mann et al (eds). *AIDS in the World*. Cambridge, MA & London, England: Harvard University Press, 1992, 761-769.

Hassan F. Confidentiality: Tool of the Trade. *The AIDS Legal Quarterly* February 1998.

Health Canada. Proceedings of the Consensus Conference on Infected Health Care Workers: Risk for Transmission of Bloodborne Pathogens. *Canada Communicable Disease Report* 1998; 24(Suppl 4).

Health Canada. An Integrated Protocol to Manage Health Care Workers Exposed to Bloodborne Pathogens. *Canada Communicable Disease Report* 1997; 23(Suppl 2).

Health Notes. Home Testing for HIV Infection. *United Press International* 15 May 1996.

Health Canada. *HIV/AIDS Epi Update: HIV Testing among Canadians: An Estimated 11,000–17,000 Current HIV Infections May Not Be Diagnosed*. Ottawa, May 1998.

Health Canada. *HIV/AIDS Epi Update. HIV/AIDS Among Injection Drug Users in Canada*. Ottawa, May 1998.

Health Canada. *Inventory of HIV Incidence/Prevalence Studies in Canada*. Ottawa, April 1998.

Health Canada. *HIV/AIDS Epi Update: HIV and AIDS among Women in Canada.* Ottawa, May 1998.

Hellman P. Suffer the Little Children. *New York* 21 February 1994, 27.

Henderson C. Prenatal HIV Screening Raises Ethical Issues. *Medical Tribune News Service* 1995.

Hendriks A. Confidentiality, Testimonial Privilege and Patients' Right to Secrecy Under the ECHR. *European Journal of Health Law* 1997; 4.

Henshaw J. Wilson Signs Bill Granting Health Workers Greater HIV Protection. *Capitol Alert Online* 6 August 1998.

Herek G, JP Capitanio. AIDS Stigma and HIV-related Beliefs in the United States: Results from a National Telephone Survey. 12th World AIDS Conference, Geneva, 1998, abstract no 44173.

Herek GM, JP Capitanio. Public Reactions to AIDS in the United States: A Second Decade of

Stigma. *American Journal of Public Health* 1993; 83(4): 574-577.

Hertz-Picciotto I, J Goltz, J Noble. HIV Test-Seeking Before and After the Restriction of Anonymous Testing in North Carolina. *American Journal of Public Health* 1996; 86(10): 1446-1450.

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.

*HIV/AIDS: International Perspectives on Legal Issues and Human Rights*. Washington: National Council for International Health, 1995, 29-33.

HIV Testing Action Coalition. *Statement of the National HIV Testing Action Coalition on the Necessity for Maintaining Anonymous HIV Testing Sites in All States*. The Coalition, 21 May 1997.

HIV in Women Conference: Women Seek Greater Influence in Research, Prevention Policies. *AIDS Policy & Law* 1995; 10(4): 9.

HIV Home Test Could Aid Prevention, Awareness. *The Nation’s Health*, July 1996.

Ho DD. Time to Hit HIV, Early and Hard [Editorial]. *New England Journal of Medicine* 1995; 333: 450-451.

Hoffman RE et al. Comparison of Partner Notification at Anonymous and Confidential Test Sites: HIV Test Sites in Colorado. *Journal of Acquired Immune Deficiency Syndrome and Human Retrovirology* 1995; 8: 406-410.

Hogg RS et al. Improved Survival Among Men and Women on Triple Antiretroviral Therapy. 7th Annual Canadian Conference on HIV/AIDS Research, April/May 1998. Abstract no 443P.

Holmberg SD et al. Biologic Factors in Sexual Transmission of Human Immunodeficiency Virus. *Journal of Infectious Diseases* 1989; 160: 116-125.

Holtgrave DR et al. The Evaluation of HIV Counseling-and-Testing Services: Making the Most of Limited Resources. *AIDS Education and Prevention* 1997; 9(Suppl B): 105-118.

Home HIV Test Is Found to Be Reliable and Effective. *AIDS Weekly Plus*, 2 October 1995.

*Home Access HIV Counseling and Testing Report*. Home Access Health Corporation, 1 December 1997 (available at www.homeaccess.com/hicctrpt.html).

Hoxworth T et al. Anonymous HIV Testing: Does It Attract Clients Who Would not Seek Confidential Testing? *AIDS Public Policy Journal* 1994; 9: 182-189.

Hudson CN, L Sherr. Antenatal HIV Testing in Europe. *The Lancet* 1997; 350 (13 December 1997).

Huijer M. Ethical Implications of the Medical and Existential Uncertainty Related to New Antiretroviral Therapies. Abstract no 44129, 12th World AIDS Conference, Geneva, 1998.

Huisman MJ. Mistrust and Consequences – Telling Antiretroviral Fact from Fiction is no Game Show. *POZ* July 1998.

Hull HF et al. Comparison of HIV-antibody Prevalence in Patients Consenting to and Declining HIV-antibody Testing in an STD Clinic. *Journal of the Americal Medical Association* 1988; 260: 935-938.

Human Immunodeficiency Virus (HIV) Antibody Testing. *British Medical Journal* 1987; 295: 911.

Human Immunodeficiency Virus (HIV) Testing Requirements for Entry into Foreign Countries. Washington, DC:
US Department of Foreign Affairs (available at http://travel.state.gov/HIVtestingreqs.html).

Human Immunodeficiency Virus Antibody Testing in Canada. Recommendations of the National Advisory Committee on AIDS. *Canada Diseases Weekly Report* 1989; 15(8): 37-43.

Hutchcraft C. AIDS Tests Join At-Home Diagnostics. *Chicago Tribune*, 7 October 1996.

Immen W. AIDS Drugs Show Surprising Success. *The Globe and Mail*, 8 May 1997, A1 and A8.

Immen W. Mail-Order HIV Saliva Test Raises Concerns. *The Globe and Mail* 13 May 1996.

Immigration Legislative Review. *Not Just Numbers. A Canadian Framework for Future Immigration*. Ottawa: Minister of Public Works and Government Services Canada, 1997.

Information and Privacy Commissioner/Ontario. *HIV/AIDS: A Need for Privacy*, October 1990.

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.

Intergovernmental Committee on AIDS, Legal Working Party. *Final Report*. The Committee, 1992.

Intergovernmental Committee on AIDS, Legal Working Party. *Legal Issues Relating to HIV/AIDS, Sex Workers and Their Clients*. Canberra: Department of Health, Housing and Community Services, 1991.

Irwin K et al. Performance Characteristics of a Rapid HIV Antibody Assay in a Hospital with a High Prevalence of HIV Infection. *Annals of Internal Medicine* 1996; 125; 471-475.

Isbell MT. AIDS and Public Health: The Enduring Relevance of a Communitarian Approach to Disease Prevention. *AIDS & Public Policy Journal* 1993; 8(4): 157-176.

Jackson LA, P Millson, L Calzavara 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.

Jager H. Bavaria. A Review Symposium – Coercion or Voluntarism: An International Critical Review. Abstract WFO.20, presented at the V International Conference on AIDS, June 1989.

Jalbert Y. Triple-Drug Therapy and Return to Work: Results of a Québec Survey. *Canadian HIV/AIDS Policy & Law Newsletter* 1998; 3(4)/4(1): 13-15.

Johnson WD, FS Sy, KL Jackson. The Impact of Mandatory Reporting of HIV Positive Persons in South Carolina. In: *IV International Conference on AIDS*; June 1988; Stockholm, Sweden. Abstract 6020.

Joint United Nations Programme on HIV/AIDS. UNAIDS Policy on HIV Testing and Counselling. Geneva: UNAIDS, August 1997.

Joint United Nations Programme on HIV/AIDS. *Counselling and HIV/AIDS: UNAIDS Best Practice Collection: Technical Update*. Geneva: UNAIDS, November 1997.

Joint United Nations Programme on HIV/AIDS. *Prisons and AIDS. UNAIDS Point of View*. UNAIDS: Geneva, April 1997.

Joint United Nations Programme on HIV/AIDS. *Prisons and AIDS – UNAIDS Technical Update*. Geneva: UNAIDS, 1997.

Joint National Committee on Aboriginal AIDS Education and Prevention. *Recommendations for a National Strategy on Aboriginal AIDS Education and Prevention*. Ottawa: Health and Welfare Canada, 1990.

Jürgens R. Promoting the Rights of Prisoners: Condoms, Bleach, Needles, Methadone and Care in Prisons. 12th World AIDS Conference, Geneva, 1998, abstract no 44191.

Jürgens R, N Gilmore. Disclosure of Offender Medical Information: A Legal and Ethical Analysis. In: Correctional Service Canada. *HIV/AIDS in Prisons: Background Materials*. Ottawa: Minister of Supply and Services Canada, 1994, Appendix 7, 127-145.

Jürgens R. Bleach and Anonymous HIV Testing in Federal Prisons. *Canadian HIV/AIDS Policy & Law Newsletter* 1995; 1(4): 1, 15-16.

Jürgens R et al. Are Compulsory HIV Testing and Disclosure of HIV Status Ever Justifiable? Ethical and Legal Analysis Using Sex Offenders, Health Care Providers, Patients as Examples. Poster presentation at the Third Annual Conference on HIV/AIDS Research, Montréal, 13-15 May 1993.

Jürgens R. HIV/AIDS and Discrimination: A Brief to the Sub-Committee on HIV/AIDS of the House of Commons by the Canadian HIV/AIDS Legal Network. Montréal: Canadian HIV/AIDS Legal Network, 15 May 1996.

Jürgens R, M Palles. *HIV Testing and Confidentiality: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997.

Jürgens R. Methadone, But No Needle Exchange Pilot in Federal Prisons. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4) and 4(1): 26-27.

Jürgens R. *HIV/AIDS in Prisons: Final Report*. Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1996.

Jürgens R. New York Policy on HIV Testing of Newborns. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(2): 15.

Jürgens R. *Legal and Ethical Issues Raised by HIV/AIDS: Literature Review and Annotated Bibliography*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1995.

Jürgens R. Prostitution and HIV/AIDS: A Literature Review. *Canadian HIV/AIDS Policy & Law Newsletter* 1995; 2(1): 3-5.

Kain CD. To Breach or Not To Breach: Is that the Question? A Response to Gray and Harding.

*Journal of Counselling and Development* 1988; 66: 224–225.

Kamb ML et al. A Multi-Center, Randomized, Controlled Trial Evaluating HIV Prevention Counseling (Project RESPECT): Preliminary Results. 11th International Conference on AIDS, Vancouver, 1996, abstract no Th.C.4380.

Karrel AIG. HIV-Infected Physicians: How Best to Protect the Public? *Canadian Medical Association Journal* 1995; 152(7): 1059-1062.

Kassler WJ. Advances in HIV Technology and Their Potential Impact on Prevention. *AIDS Education and Prevention* 1997; 9(Suppl B): 27-40.

Kassler WJ et al. Performance of a Rapid, On-site Human Immunodeficiency Virus Antibody Assay in a Public Health Setting. *Journal of Clinical Microbiology* 1995; 33: 2899-2902.

Kassler WJ et al. Anonymous vs Confidential HIV Testing in North Carolina. In: *VIII International Conference on AIDS/III STD World Congress*. July 1992, Amsterdam, The Netherlands. Abstract PoC 4818.

Kassler WJ et al. The Performance of a Rapid On-site HIV Assay in Uganda: Results of a Field Trial. XI International Conference on AIDS, Vancouver, 1996, abstract no Th.C.4845.

Kassler WJ et al. Eliminating Access to Anonymous HIV Antibody Testing in North Carolina: Effects on HIV Testing and Partner Notification. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1997; 14: 281-289.

Kassler WJ et al. On-Site, Rapid HIV Testing with Same-Day Results and Counseling. *AIDS* 1997; 11(8): 1045-1051.

Kegeles SM et al. Mandatory Reporting of HIV Testing Would Deter Men from Being Tested. *Journal of the American Medical Association* 1989; 261: 1275-1276.

Kegeless SM et al. Many People Who Seek Anonymous HIV-Antibody Testing Would Avoid It under Other Circumstances. *AIDS* 1990; 4: 585-588.

Kennedy M. Doctors Oppose Testing for Hepatitis B. *The* [Montréal] *Gazette* 17 July 1998, A1-A2.

Keown K. The Ashes of AIDS and the Phoenix of Informed Consent. *Modern Law Review* 1989; 52: 790.

Kirby M. Human Rights and the HIV Paradox. *The Lancet* 1996; 348: 1217-1218. Reprinted in *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 50-52.

Kruzel KE. Comparison of a Home HIV Test System to Public Health HIV Test Services. 12th World AIDS Conference Geneva, 1998, abstract no 43143.

La déclaration obligatoire de la séropositivité. *Le Journ' ALS*, Spring 1998.

Laframboise S et al. The Health Care Experiences of HIV-Positive Transgendered Persons Can Influence Adherence to HIV Therapies. 7th Annual Canadian Conference on HIV/AIDS Research, April/May 1998. Abstract no 180P.

Landis et al. Results of a Randomized Trial of Partner Notification in Cases of HIV Infection in North Carolina. *New England Journal of Medicine* 1992; 326: 101-106.

Lapointe N et al. Mother to Child HIV Transmission Associated with Duration of the Second Stage of Labour. XI International Conference on AIDS, Vancouver, 1996, Abstract no Tu.C.340.

Lawless S et al. Dirty, Diseased and Undeserving: The Positioning of HIV Positive Women. *Social Science and Medicine* 1996; 43(9): 1371-1377.

Le médecin transmet le sida. *Le Devoir* 16 January 1997, A2.

Leigh C. No Mandatory Testing! A Feminist Prostitute Speaks Out. *On the Issues* 1988; 10: 10, 24.

Lenz M. Länger leben heißt nicht besser leben. *Süddeutsche Zeitung*, 28 August 1997.

Levine C. AIDS and the Ethics of Human Subjects Research. In F Reamer (ed). *AIDS and Ethics*. New York: Columbia University Press, 1991, 77-105.

Levine C, GL Stein. What's In A Name? The Policy Implications of the CDC Definition of AIDS. *Law Med Health Care* 1991; 19: 278-290.

Leviton LC. For Whom Do We Test? What Do We Say? Rapid HIV Screening. *Public Health Reports* 1996; 111(1): 54.

Lewis CE, K Montgomery. The HIV-Testing Policies of US Hospitals. *Journal of the American Medical Association* 1990; 264(21): 2764.

Lin-In Tseng A. Anonymous HIV Testing in the Canadian Aboriginal Population. *Canadian*

*Family Physician* 1996; 42: 1734-1740.

Lindsay MK et al. Routine Antepartum Human Immunodeficiency Virus Infection Screening in an Inner-City Population. *Obstetrics and Gynecology* 1989; 74: 289-294.

Lines R. The Case against Segregation in "Specialized" Care Units. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4) & 4(1): 30-32.

Lior LY et al. Behind Bars: An Epidemiological Investigation of HIV, HBV and HCV Inside a Federal Penitentiary. Seventh Annual Canadian Conference on HIV/AIDS Research, April/May 1998, abstract no 262P.

Lo B, R Steinbrook. Health Care Workers Infected with the Human Immunodeficiency Virus. *Journal of the American Medical Association* 1992: 267, 1100.

Lobb D & S Smith. B.C. Positive Women’s Study. *Hospice Update. Vancouver Hospice Program* February 1995.

Locas L. *Private Insurance Component*. Ottawa: Canadian AIDS Society (Income Security Project Phase II, Working Paper Series), 1996.

Lorezi P et al. Safety of Combined Therapies in Pregnancy. 12th World AIDS Conference Geneva, 1998, abstract no 32453.

MacDonald PH. Note. AIDS, Rape, and the Fourth Amendment: Schemes for Mandatory AIDS Testing of Sex Offenders. *Vanderbilt Law Review* 1990; 43: 1607-1636.

MacKinnon M, K Cottrelle, H Krever. Legal and Social Aspects of AIDS in Canada. In Royal Society of Canada. *AIDS: A Perspective for Canadians – Background Papers*. Ottawa: The Society, 1988, 347-373.

Magnusson RS et al. HIV and Confidentiality. *Medical Journal of Australia* 1996; 165: 90-91.

Magnusson RS. Australian HIV/AIDS Legislation: A Review for Doctors. *Australian and New Zealand Journal of Medicine* 1996; 26: 396-406.

Magnusson RS. Privacy, Confidentiality and HIV/AIDS Health Care. *Australian Journal of Public Health* 1994; 18(1): 51-58.

Magnusson RS. A Decade of HIV Testing in Australia, Part 2: A Review of Some Current Debates. *University of New South Wales Law Journal* 1995; 18(2): 364-408.

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.

Magnusson RS. Testing for HIV without Specific Consent: A Short Review. *Australian and New Zealand Journal of Public Health* 1996; 20(1): 57-60.

Magnusson RS. Specific Consent, Fiduciary Standards and the Use of Human Tissue for Sensitive Diagnostic Tests and in Research. *Journal of Law and Medicine* 1995; 2: 206-232.

Major CJ et al. Comparison of Saliva and Blood for Human Immunodeficiency Virus Prevalence Testing. In: British Columbia Centre for Excellence in HIV/AIDS. *HIV/AIDS Research in British Columbia. A Ten Year Retrospective*. Vancouver: The Centre, 1996.

Manitoba Advisory Committee on Infectious Diseases ("MACID"). *HIV Testing in Pregnancy: A Report of the HIV Prenatal Policy Working Committee to MACID*. Winnipeg: The Committee, December 1997.

Marwick C. Home Testing Kits for HIV Apt to Get FDA Approval. *Journal of the American Medical Association* 1995; 273(12): 908-909.

Matiation S. *HIV Testing and Confidentiality: Issues for the Aboriginal Community: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network, 1998.

Matiation S. *Discrimination, HIV/AIDS and Aboriginal People*. Montréal: Canadian HIV/AIDS Legal Network, 1998.

Maticka-Tyndale E. Working in the Sex Trades: Policies to Decrease Vulnerability to HIV. Seventh Annual Canadian Conference on HIV/AIDS Research, April/May 1998, abstract no 123.

Mauth T. Charter Implications of Compelling Dentists to Reveal Their HIV Status. *Health Law in Canada* 1996: 97-106.

Maxwell J et al. The Need for Anonymous Genetic Counseling and Testing. *American Journal of Human Genetics* 1996; 58: 393-397.

McAmmond D. *Care, Treatment and Support for Injection Drug Users Living with HIV/AIDS. A Consultation Report*. Health Canada, March 1997.

McGovern TM. Mandatory HIV Testing and Treating of Child-Bearing Women: An Unnatural, Illegal, and Unsound Approach. *Columbia Human Rights Law Review* 1997; 28: 499-499. 42

USCA para 300ff-33 *et seq.* (West Suppl 1997).

McMurchy D, R Palmer, R Throop. Who Pays for Antiretroviral Therapy in Ontario? 7th Annual Canadian Conference on HIV/AIDS Research, April/May 1998. Abstract no 174P.

Medical Services Branch. *Guidelines for the Delivery of HIV/AIDS Programs and Services*. Ottawa: Health Canada, March 1995.

Medical Inadmissibility Review. Recommendations prepared by Employment and Immigration Canada in consultation with Health and Welfare Canada, June 1992.

MedMira Laboratories Inc, Halifax. Health Canada Authorizes MedMira's Rapid HIV-1 & HIV-2 Screen Test for Sale in Canada, 27 May 1998 (press release).

Merson MH et al. Rapid Self Testing for HIV Infection. *The Lancet* 1997; 349: 352-353.

Miller C. HIV Kits Target Untested Market. *Marketing News* 1997; 31(2): 1.

Miller D, AJ Pinching. HIV Tests and Counselling: Current Issues. *AIDS* 1989; 3(Suppl 1): S187-S192.

Millson P et al. Prevalence of Human Immunodeficiency Virus and Associated Risk Behaviour in Injection Drug Users in Toronto. *Canadian Journal of Public Health* 1995; 86(3): 176-180.

Ministerium Verbietet AIDS-Heimtest. *Süddeutsche Zeitung* 28 August 1997.

Minkoff H, MJ O'Sullivan. The Case for Rapid HIV Testing During Labor. *Journal of the American Medical Association* 1998; 279: 21, 1743-1744.

Mofenson LM, ME Makhlamena. Treatment as Prevention: Mother-to-Child HIV Transmission. Plenary PL1, 12th World AIDS Conference, Geneva, 29 June 1998.

Montessori V et al. Aggressive Therapy of Intravenous Drug Users with Primary HIV Infection. 7th Annual Canadian Conference on HIV/AIDS Research, April/May 1998. Abstract no 442P.

Moser M. Anonymous HIV Testing (letter to the editor). *American Journal of Public Health* 1998; 88(4): 683.

MSSS, Centre québécois de coordination sur le sida (Direction générale de la Santé publique) et Direction de la recherche et de l'évaluation (Direction générale de la Planification et de l'Évaluation). «Dépistage», *Rapport de la consultation réalisé pour le bilan de la phase 3 et* *l'élaboration de la phase 4 de la Stratégie québécoise de lutte contre le sida*, November 1996, 45-49.

Murphy S et al. Rape and HIV. *International Journal of STD and AIDS* 1991; 2(3): 200-201.

Murphy S et al. Rape and Subsequent Seroconversion to HIV. *British Medical Journal* 1989; 299: 718.

Myers T et al. Factors Affecting Gay and Bisexual Men's Decisions and Intentions to Seek HIV Testing. *American Journal of Public Health* 1993; 83: 701-704.

Nakashima AK et al. Effect of HIV Reporting by Name on Use of HIV Testing in Publicly Funded Counseling and Testing Programs. *Journal of the American Medical Association* 1998; 280(16): 1421.

Nash Colfax G, AB Bindham. Health Benefits and Risks of Reporting HIV-Infected Individuals by Name. *American Journal of Public Health* 1998; 88(6): 876-879.

National Advisory Committee on AIDS. *HIV and Human Rights in Canada*. Ottawa: Health and Welfare Canada, January 1992.

National AIDS Fund to Distribute Home Access HIV Home Tests. National AIDS Fund and Home Access Health, press release of 14 January 1998.

National Association of Persons with HIV/AIDS. NAPWA Position Statement on HIV Surveillance, 3 October 1997.

National Conference of State Legislatures. Fact Sheet: HIV Reporting. 1998 Health Policy Tracking Service, dated 10 July 1998 (available at http://stateserv.hpts.org/HPTS98/NFTS).

National Victim Center, Crime Victims Research and Treatment Center. National Women's Study, reported in: Rape in America: A Report to the Nation. Arlington, VA: National Victim Center, Crime Victims Research and Treatment Center, Dept of Psychiatry and Behavioral Sciences, Medical University of South Carolina, Charleston, 23 April 1992.

Neergaard L. AIDS Patients Developing Fat Deposits on Face, Bodies. *The Globe and Mail* 22 June 1998.

Neergard L. Activists Urge Stepped-Up HIV Prevention. *Dallas Voice* July 1998.

Neron C. *HIV and Sexual Assault Project Report*. (Unpublished report). Ottawa: Health

Canada, 1997.

Neron C. *HIV and Sexual Violence Against Women. A Guide for Counsellors Working with Women Who Are Survivors of Sexual Violence.* Ottawa: Health Canada, March 1998.

New South Wales Ministerial Review HIV/AIDS Legal Working Party. *The Courage of our Convictions: HIV/AIDS: The National Strategy and the Laws of New South Wales*. 1993.

New Zealand Medical Association. *Policy Relating to HIV/AIDS*, 1990.

New Brunswick Needs Anonymous HIV Testing. Fredericton: AIDS New Brunswick, 1996.

New Home HIV Test Goes on Sale Nationwide. *Bangor Daily News*, 25 July 1996.

New Public Health Service Recommendations on Rapid Testing Results. *NASTAD HIV Prevention Community Planning Bulletin* April 1998.

New South Wales Anti-Discrimination Board. *Discrimination – The* Other *Epidemic. Report of the Inquiry into HIV and AIDS Related Discrimination*. The Board: 1992.

Newfoundland and Labrador, Department of Justice, Adult Corrections Division, Policy Directive 16.40.06, section: Special Health Care Services—HIV/AIDS, revised 1 April 1992.

Nguyen M et al. Involving Aboriginal Communities in HIV/AIDS Surveillance and Research. 12th World AIDS Conference, Geneva, 1998. Abstract no 44269.

Nightmares of Uncertainty: HIV Test is Proper on Accused or Convicted Rapists. *The* [Montréal] *Gazette* 10 January 1993.

NJ Court Rules on AIDS Testing. [Newark] *Star-Ledger*, October 1997.

Noel A. Guards Urge Mandatory Blood Tests to Combat AIDS in Prisons. *The* [Montréal] *Gazette* 21 September 1996.

North RL, KH Rothenberg. Partner Notification and the Threat of Domestic Violence Against Women with HIV Infection. *New England Journal of Medicine* 1993; 329: 1194-1196.

Northwest Territories Health and Social Services. *HIV Infection and AIDS Information for Health Professionals*. November 1996.

Nova Scotia Department of Health. Four Month Progress Report on the Anonymous Testing

Program in Nova Scotia. Halifax: The Department, November 1994.

Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS. *HIV/AIDS and Human Rights. International Guidelines*. United Nations, New York and Geneva, 1998 (HR/PUB/98/1).

Ohi G et al. Notification of HIV Carriers: Possible Effect on Uptake of AIDS Testing. *Lancet* 1988; ii: 947-949.

Ontario Ministry of Health. *HIV Antibody Testing: Guidelines for Pre- and Post-Test Counselling in Anonymous Testing*. Toronto: The Ministry, June 1992.

Ontario Law Reform Commission. *Report on Testing for AIDS*. Toronto: The Commission, 1992.

Ontario Ministry of Health, AIDS Bureau. *Anonymous HIV Testing Evaluation, January 1992 to June 1993*. Toronto: The Ministry, November 1994.

Oral HIV Test Available in NY This Week. *United Press International* 24 June 1998.

Orr A. AIDS: Adapting the Law. *New Law Journal* 1988; 138: 388.

Ott D. Camden County to Use New AIDS Test. *Philadelphia Inquirer* 16 April 1997, B2.

Padian N et al. Clinical and Immunological Correlates of the Heterosexual Transmission of HIV. In: Program and Abstracts of the 28th Interscience Conference on Antimicrobial Agents and Chemotherapy. 23-26 October 1988, Washington, DC. Abstract 344.

Padian N. Heterosexual Transmission: Infectivity and Risks. In: NJ Alexander et al (eds). *Heterosexual Transmission of AIDS*. New York, NY: Wiley-Liss, 1990.

Paiement RA. La perception du SIDA par les médecins québécois. *BULLETIN* 1990; 30(4): 19.

Painter K. HIV Home Test Kits Catching on But Still Criticized. *USA Today* 12 May 1997.

Painter K. Oral HIV Test Gains Important Support. *USA Today* 15 January 1997.

Paringer L et al. The Impact of Risk, Knowledge, and State Regulatory Policy on Testing Decisions. *Inquiry* 1991; 28: 226-235.

Parliamentary Ad Hoc Committee on AIDS. *Confronting a Crisis: The Report of the*

*Parliamentary Ad Hoc Committee on AIDS*. Ottawa: The Committee, 1990.

Parran T. *Shadow on the Land*. New York: Waverly Press, 1937.

PASAN. HIV/AIDS in the Transgendered Prison Population: A Comprehensive Strategy. A Brief from the Prisoners' HIV/AIDS Support Action Network (PASAN) to the Solicitor General of Canada, the Minister of Health of Canada, the Ontario Minister of Solicitor General and Correctional Services, the Ontario Minister of Community and Social Services, and the Ontario Minister of Health. Toronto: The Network, October 1998.

PASAN. HIV/AIDS in Prison Systems: A Comprehensive Strategy. A Brief from the Prisoners with HIV/AIDS Support Action Network (PASAN) to the Minister of Correctional Services and the Minister of Health. Toronto: The Network, June 1992.

Patterson D. Québec Court Finds Asymptomatic HIV Infection a Charter "Handicap." *Canadian HIV/AIDS Policy & Law Newsletter* 1994; 1(1):1, 3-4.

Pavia AT et al. Partner Notification for Control of HIV: Results after Two Years of a Statewide Program in Utah. *American Journal of Public Health* 1993; 83: 1418-1424.

Peckham C, D Gibb. Mother-to-child transmission of the human immunodeficiency virus. *New England Journal of Medicine* 1995; 333: 298-302.

Perelson AS et al. HIV 1 dynamics in vivo: virion clearance rate, infected cell life-span, and viral generation time. *Science* 1996; 271: 1582-1586.

Perkins R. AIDS Preventative Practices among Prostitutes in New South Wales. [Australian] *National AIDS Bulletin* September 1991.

Perpête C et al. Treatment Adherence: An Analytical Approach. 7th Annual Canadian Conference on HIV/AIDS Research, April/May 1998. Abstract no 405.

Persky S. The Practical Case Against Mandatory Testing. In: J Russell (ed). *Liberties*. Vancouver: New Star Books, 1989, 176–185.

Peterman TA et al. Risk of Human Immunodeficiency Virus Transmission from Heterosexual Adults with Transfusion-Associated Infections. *Journal of the American Medical Association* 1988; 259: 55-58.

Phanuphak P et al. Thailand's First Anonymous Alternative Test Site: A Lesson for Asian Countries. In: *VII International Conference on AIDS/III STD World Congress*; July 1992; Amsterdam, The Netherlands. Abstract MoC 0061.

Phillips KA. The Relationship of 1988 State HIV Testing Policies to Previous and Planned Voluntary Use of HIV Testing. *AIDS* 1994; 7: 403-409.

Phillips KA et al. Who Plans to Be Tested If No One Else Could Find Out the Result? *American Journal of Preventive Medicine* 1995; 11: 1561-1562.

Phillips KA et al. Potential Use of Home Testing. *New England Journal of Medicine* 1995; 332: 1308-1310.

Phillips KA. The Relationship of 1988 State HIV Testing Policies to Previous and Planned Voluntary Use of HIV Testing. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1994; 7: 403-409.

Phillips K, J Stryker. What Is Testing's Role in HIV Prevention? Website of the Center for AIDS Prevention Studies, University of California at San Francisco. Section Prevention Fact Sheets.

Phillips KA et al. HIV Counseling and Testing of Pregnant Women and Women of Childbearing Age by Primary Care Providers: Self-Reported Beliefs and Practices. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1997; 14(2): 174-178.

Phillips KA. The Experience of Home Collection HIV Tests. In: *Understanding the Impact of New Treatments on HIV Testing. Summary of a January 28-30, 1998, Henry J. Kaiser Family Foundation Forum*. Henry J Kaiser Family Foundation, 1998.

Philp M. Rights Panels Losing to Abuse, Commission Says. *Globe and Mail* 25 March 1998.

Picard A. Home HIV Test Sparks Hot Debate. *The Globe and Mail*, 10 July 1996, A5.

Picard EI. *Legal Liability of Doctors and Hospitals in Canada*. 2nd ed, 1984.

Pies C. AIDS, Ethics, Reproductive Rights: No Easy Answers. In: B Schneider and N Stoller (eds). *Women Resisting AIDS: Feminist Strategies of Empowerment*. Philadelphia, Temple University Press, 1995, 322-334.

Pinwall S. Sex Industry Law Reform Across Australia. *HIV/AIDS Legal Link* 1998; 9(2): 8-9.

Plant M. Conclusions and Strategies. In M Plant (ed): *AIDS, Drugs and Prostitution*. London and New York: Tavistock/Routledge 1990.

Policy Paper on the Forced Testing and Quarantining of Prostitutes. Prostitutes Safe Sex

Project (Maggies). Toronto: The Project, 1993.

Policy Statement on the Rights of HIV Positive Sex Workers for the Asia-Pacific Network of Sex Worker Projects. *HIV/AIDS Legal Link* 1998; 9(2): 13.

*Pregnancy and HIV: Recommended Code of Best Practice.* AIDS Law Project, Centre for Applied Legal Studies, University of the Witwatersrand, October 1997.

Prison Visitors Unwittingly Exposed to HIV – And Corrections Canada Knows About It. Abbotsford: Randy White Campaign Office, press release of 30 April 1997.

Proposal for Secret AIDS Tests Attacked. *Sydney Morning Herald* 1 April 1995, 3.

Protease Inhibited. *POZ* March 1998.

Public Health Service Task Force Recommendations for the Use of Antiretroviral Drugs in Pregnant Women Infected with HIV-1 for Maternal Health and for Reducing Perinatal HIV-1 Transmission in the United States. *Morbidity and Mortality Weekly Report* 47(RR-2); (30 January 1998).

Rachel A et al. Sexual Transmission of HIV. *The New England Journal of Medicine* 1997; 336 (15): 1072-1078.

Rachlis A, DP Zarowny. Guidelines for Antiretroviral Therapy for HIV Infection. *Journal of the Canadian Medical Association* 1998; 158(4): 496-505.

Randall L. HIV Counselling and Testing Using Oral Mucosal Transudate. *NASTAD HIV Prevention Community Planning Bulletin* April 1998.

Rapid HIV Tests: Issues for Laboratories. *CDC Issues*, March 1998.

Rapport du comité ad hoc sur la surveillance épidémiologique de l’infection par le VIH au Québec. Déposé à la Direction générale de la santé publique, Ministère de la Santé et des Services sociaux. Draft, Montréal, August 1998.

Reardon J et al. Are HIV-infected Injection Drug Users Taking HIV Tests? *American Journal of Public Health* 1993; 83: 1414-1417.

Reduction of HIV Transmission from Mother to Infant. *Canada Communicable Disease Report* 1994; 20(12): 100.

Reed GM et al. An Assessment of the Impact of Mandatory Name Reporting on HIV Testing and Treatment. XI International Conference on AIDS, Vancouver, 1996, abstract Th.D.4958.

Reese S. CDC Ends AIDS Tracking of Newborns, Mothers. *Star Tribune*, 31 December 1995, 3E.

Reid E. Gender, Knowledge, and Responsibility. In: JM Mann, DJM Tarantola, TW Netter (eds). *AIDS in the World*. Cambridge, MA: Harvard University Press, 1992, 657–667.

Reproductive Care Program of Nova Scotia. *Guidelines for Antenatal Laboratory Screening and Testing*. May 1994.

*Reproductive Care Program of Nova Scotia Newsletter*, Spring 1998.

Reuter B. Sex Work Law Reform, Transmission Offences, & Regional Issues. *HIV/AIDS Legal Link* 1998; 9(3): 14-15.

Revised Guidelines on Ethical and Legal Considerations in Anonymous Unlinked HIV Seroprevalence Research. *Canadian Medical Association Journal* 1992; 146(10): 1743-1744.

Roberts D. Manitoba Bill Still Flawed, Critics Say. *The Globe and Mail* 25 June 1997, A6.

Roemer R. The Law and Public Health – Historical and Current Perspectives. In: RF Schinazi, AJ Nahmias (eds). *AIDS in Children, Adolescents & Heterosexual Adults: An Interdisciplinary Approach to Prevention*. New York: Elsevier, 1988.

Rogers MA, LM Mofenson, RR Moseley. Reducing the Risk of Perinatal HIV Transmission through Zidovudine Therapy: Treatment Recommendations and Implications. *Journal of the American Medical Women's Association* 1995; 50(3&4): 78-82, 93.

Rothon D et al. Prevalence of HIV Infection in Provincial Prisons in British Columbia. *Canadian Medical Association Journal* 1994; 151(6): 781-787.

Roy D (ed). HIV Infection and AIDS, Ethical-Legal Issues 1991, A Report. Montréal: Centre québécois de coordination sur le SIDA, 1991.

Royal Society of Canada. *AIDS: A Perspective for Canadians – Background Papers*. Ottawa: The Society, 1988.

Royal Society of Canada. *AIDS: A Perspective for Canadians – Summary Report and Recommendations*. Ottawa: The Society, 1988.

Royce R et al. Sexual Transmission of HIV: Current Concepts. *The New England Journal of Medicine* 1997; 336: 1072.

Salbu SR. HIV Home Testing and the FDA: The Case for Regulatory Restraint. *Hastings Law Journal* 1995; 46(2): 403-457.

Sanford D. AIDS Hasn't Left, but a Future Is Back. One Man's Account. *The Globe and Mail* 23 November 1996.

Savage D. The AIDS Crisis Is Over. *The Ottawa XPress* 7 August 1997.

Schopper D, G Vercauteren. Testing for HIV at Home. What Are the Issues? *AIDS* 1996; 10: 1455-1465.

Sears A. The Politics of HIV-Related Testing: A Review Essay on the Ontario Law Reform Commission *Report on Testing for AIDS/ The Windsor Review of Legal and Social Issues* 1993; 4: 157-163.

Selwyn P, R Carter, E Schoenbaum et al. Knowledge of HIV Antibody Status and Decisions to Continue or Terminate Pregnancy among Intravenous Drug Users. *Journal of the American Medical Association* 1989; 261(24): 3567-3571.

Séro Zéro. Positively Sexual. A psychosexual counseling service for HIV-positive gay men. Montréal: Séro Zéro, 1998.

Sestito J. The Duty to Warn Third Parties and AIDS in Canada. *Health Law in Canada* 1996; 16 (3): 83-97.

Sex Industry and the AIDS Debate '88. Report and Conference Papers from the First National Sex Industry Conference, Melbourne, Australia, 25-27 October 1988. St Kilda, Victoria: Prostitutes Collective of Victoria, 1988.

Sharpe G. The Ethics and Legality of Seroprevalence Studies. *Health Law in Canada* 1991; 11 (4): 102.

Shaw M et al. Survey of Patients' Views on Confidentiality and Non-Discrimination Policies in General Practice. *British Medical Journal* 1996; 312(7044): 1463-1464.

Sherr L, S Quinn. HIV Testing, Counseling and Behaviour Change. In: L Sherr (ed). *AIDS and the Heterosexual Population*. Langhorne, PA: Harwood Academic, 1993, 179-197.

Siegler M. Confidentiality in Medicine – A Decrepit Concept. *The New England Journal of Medicine* 1982; 307(24): 1518-1521.

Sikkema KJ, RT Bisset. Concepts, Goals, and Techniques of Counseling: Review and Implications for HIV Counseling and Testing. *AIDS Education and Prevention* 1997; 9(Suppl B): 14-26.

Silverman D, A Perakyla, R Bor. Discussing Safer Sex in HIV Counselling: Assessing Three Communication Formats. *AIDS Care* 1992; (4): 69-82.

Snell JG. Note. Mandatory HIV Testing and Prostitution: The World's Oldest Profession and the World's Newest Deadly Disease. *Hastings Law Journal* 1994; 45: 1565.

Solomon L. Experience [with the Maryland HIV reporting system]. *NASTAD HIV Prevention Community Planning Bulletin*, April 1998.

Somerville MA. AIDS: A Challenge to Health Care, Law, and Ethics. In: D Snowden, DF Cassidy (eds). *AIDS: A Handbook for Professionals*. 1989, 200-220.

Somerville MA, N Gilmore. 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.

Somerville MA. The Case against HIV Antibody Testing of Refugees and Immigrants. *Canadian Medical Association Journal* 1989; 141: 889-894.

Sontag D, L Richardson. Doctors Withhold H.I.V. Pill Regimen from Some. *The New York Times* 2 March 1997.

South African Law Commission. Discussion Paper 68, Project 85. *Aspects of the Law Relating to AIDS*. Pretoria: The Commission, 1996.

South Africa – National Policy on HIV Testing and Informed Consent Proposed. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 11-12.

Sowadsky R. Home HIV Testing – The Good and the Bad. The Body: An AIDS and HIV Information Resource. At <http://www.thebody.com/sowadsky/homehiv.html>.

Sowadsky R. The New Saliva Tests. Available at http://www.thebody.com/sowadsky/saliva.html

Spencer ETH. The Sexually Active, HIV-Infected Patient: Confidentiality Versus the Duty to

Protect. *Psychiatric Annals* 1988; 18(10): 571-576.

Sperling RS et al. Maternal Viral Load, Zidovudine Treatment and the Risk of Transmission of Human Immunodeficiency Virus from Mother to Infant. *New England Journal of Medicine* 1996; 335: 1621.

Spielberg F, WJ Kassler. Rapid Testing for HIV Antibody: A Technology Whose Time Has Come. *Annals of Internal Medicine* 1996; 125: 509-511.

*Statement on Women's HIV Testing and Care*. New York, NY: The Coalition for Women's Choice in HIV Testing and Care, The HIV Law Project, no date.

Steigbigel NH et al. Heterosexual Transmission of HIV Infection. In: Program and Abstracts of the Fourth International Conference on AIDS. 12-16 June 1988, Stockholm, Sweden. Abstract 4057.

Steinbrook R. Battling HIV on Many Fronts. *New England Journal of Medicine* 1997; 337(11): 779-781.

Sternlight J. Mandatory Non-Anonymous Testing of Newborns for HIV: Should it Ever Be Allowed? *John Marshall Law Review* 1994; 27: 373 at 381.

Stevenson EM, SC Thompson, N Crofts. HIV Testing and Policy Change, an Analysis Based on Statewide HIV Testing Data. Abstract Mo.C.212, XI International Conference on AIDS, Vancouver, 1996.

Stoltz L, L Shap. *HIV Testing and Pregnancy: Legal and Ethical Issues*. Prepared by the Joint Project on Legal and Ethical Issues of the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society, for Health Canada. Ottawa: Health Canada, forthcoming.

Strathdee et al. Needle Exchange Is Not Enough: Lessons from the Vancouver Injecting Drug Use Study. *AIDS* 1997; 11(8): F59-F65.

Strathdee SA et al. Barriers to Use of Free Antiretroviral Therapy in Injection Drug Users. *Journal of the American Medical Association* 1998; 280(6): 547.

Subkommission Serologie, Immunologie und Virologie (SIV) der Eidg. Kommission für Aids-Fragen (EKAF). Stellungnahme zum Gebrauch von Home Tests für HIV. Berne: Bundesamt für Gesundheit, *Bulletin* 29 (28 July 1997): 4-6.

Supreme Court to Hear *Cuerrier* Case. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3 (2/3): 1, 52-54.

Surgeon Blamed in HIV Case. *The Globe and Mail* 17 January 1997, A8.

Sutherland D et al. HIV Testing Behaviour of Canadians. Abstract Mo.C.210, presented at the XI International Conference on AIDS, Vancouver, 1996.

Swartz MS. AIDS Testing and Informed Consent. *Journal of Health Politics, Policy and Law* 1988; 13: 607.

Terry J. The Body Invaded: Medical Surveillance of Women as Reproducers. *Socialist Review* 1989; 19: 13-43.

Texas Department of Health. Recommendations on HIV Infection Reporting. Austin: The Department, Bureau of HIV and STD Prevention, 21 March 1998.

The Progressive Conservative Caucus Committee on Family Issues. Recommendations for HIV/AIDS Testing of Federal Prison Inmates on Conditional Release Programs. Ottawa, 8 June 1993.

The HIV/AIDS Community Ad Hoc Committee on the *Personal Health Information Protection Act, 1997*. *Position Statement*. Toronto: The Committee, 1998.

The Privacy Commissioner of Canada. *AIDS and the Privacy Act*. Ottawa: Minister of Supply and Services Canada, 1989.

The Editor. Policy for Persons Living with HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(2): 14-15.

The Editor. Australia – Segregation of HIV-Positive Prisoners Illegal. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 34.

The Editor. Australia: Allowing People with HIV Permanent Residence. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(3): 16-17.

The Editor. US – Asylum Granted to Person Living with HIV. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 19.

The Panos Institute. *The Third Epidemic: Repercussions of the Fear of AIDS*. London: Norwegian Red Cross, 1990.

The International Community of Women Living with HIV/AIDS. *ICW's Position on the Key*

*Issues Affecting Women Living with HIV/AIDS*. London, UK: ICW, 1998.

The Society of Obstetricians and Gynaecologists of Canada. *HIV Testing in Pregnancy. It's Best to Test!* Ottawa: The Society, 1997.

Toomey KE, W Cates. Partner Notification for the Prevention of HIV Infection. *AIDS* 1989; 3 (Suppl 1): S57-S62.

Tougher Sex Trade Penalties Planned – Rock to Propose Changes in Code. *The Globe and Mail* 6 November 1995.

Turkington RC. Confidentiality Policy for HIV-Related Information: An Analytical Framework for Sorting Out Hard and Easy Cases. *Villanova Law Review* 1989; 34: 871.

U.S. Public Health Service Recommendations for Human Immunodeficiency Virus Counselling and Voluntary Testing for Pregnant Women. *Morbidity and Mortality Weekly Report* 44(RR-7); 1 (7 July 1995).

UK NGO AIDS Consortium. *Access to HIV Treatments in Developing Countries. Interim Report*. London, UK: The Consortium, 1997.

Under Pressure, CDC Ends Push for Name Reporting. *AIDS Policy & Law* 1998; 13(17): 6.

*Understanding the Impact of New Treatments on HIV Testing. Summary of a January 28-30, 1998, Henry J Kaiser Family Foundation Forum*. The Foundation, 1998.

Update: Provisional Public Health Service Recommendations for Chemoprophylaxis after Occupational Exposure to HIV. *Morbidity and Mortality Weekly Report* 1996; 45(22): 468-472.

Valdiserri RO et al. A Study of Clients Returning for Counseling After HIV Testing: Implications for Improving Rates. *Public Health Reports* 1993; 108: 12-18.

Valdiserri RO. HIV Counseling and Testing: Its Evolving Role in HIV Prevention. *AIDS Education and Prevention* 1997; 9(Suppl B): 2-13.

WA prisons discriminate against HIV positive prisoners. [Australian] *HIV/AIDS Legal Link* 1996; 7(4): 5.

WA prison segregation ends. [Australian] *HIV/AIDS Legal Link* 1996; 7(4): 3.

Walli RK et al. Peripheral Insulin Resistance Leading to Impaired Glucose Tolerance in HIV-1

Infected Patients Treated with Protease Inhibitors. 12th World AIDS Conference, Geneva, 1998, abstract no 41177.

Ward C. Interview: HIV Positive Sex Workers. *HIV/AIDS Legal Link* 1998; 9(2): 12-13.

Wasserman S. Notifying People Exposed to HIV. Issue Brief. Health Policy Tracking Service, National Conference of State Legislatures, 1998 (available at http://stateserv.hpts.org).

Watershed Writing and 2-Spirited People of the 1st Nations. A Community-based Discussion Paper on: The Social, Moral, Ethical and Legal Implications of Conducting *Blind* Seroprevalence Studies in Aboriginal Communities. Toronto: 2-Spirited People, 1996.

Weber JT. Publicly Funded HIV Counseling and Testing in the United States. *AIDS Education and Prevention* 1997; 9(Suppl B): 79-91.

Weiss SH. Occupational Exposures and Risks Related to the HIV Epidemic. In: GP Wormser (ed). *AIDS and Other Manifestations of HIV Infection, Third Edition*. Philadelphia: Lippincott-Raven Publishers, 1998, 699-716.

Werdel AA. Mandatory AIDS Testing: The Legal, Ethical and Practical Issues. *Notre Dame Journal of Law, Ethics & Public Policy* 1990; 5: 155–255.

West GR, KA Stark. Partner Notification for HIV Prevention: A Critical Reexamination. *AIDS Education and Prevention* 1997; 9(Suppl B): 68-78. Bayer R, K Toomey. HIV Prevention and the Two Faces of Partner Notification. *American Journal of Public Health* 1992; 82: 1158-1164.

West WT. Assault and Battery – Testing for "AIDS." *Justice of the Peace* 22 December 1990.

What Are Sex Workers' HIV Prevention Needs? A publication of *HIV Prevention: Looking Back, Looking Ahead*, a project of the Center for AIDS Prevention Studies, University of California, San Francisco, April 1996.

Wilke M. J&J's Confide Faces Legal Battle, New Rival. *Advertising Age* 1996; 67(32): 3.

Wills AE. Public Health, AIDS and Sex Workers in New South Wales. [Australian] *National AIDS Bulletin* November 1991: 39-43.

Wilson JMG, G Jungner. Principles and Practice of Screening for Disease. *WHO Public Health Paper, 34*. Geneva: World Health Organization, 1968.

Wilson P. Medical Confidentiality – A Decrepit Concept? Paper presented at the Law and

Society Association Meeting, Toronto, 2 June 1995.

Wilson P. Testing the Boundaries of Consent. *New Law Journal* 1994; 144: 574.

Wilson S. HIV-Positive Refugee Admitted to Canada. *Canadian HIV/AIDS Policy & Law Newsletter* 1995; 1(3): 5.

Wilson S. Recent Developments in Immigration Law. *Canadian HIV/AIDS Policy & Law Newsletter* 1994; 1(1): 9-10.

Wolitski 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.

World Health Organization. *WHO Guidelines on HIV Infection and AIDS in Prisons*. Geneva: WHO, 1993.

World Health Organization. *Unlinked Anonymous Screening for the Public Health Surveillance of HIV Infections – Proposed International Guidelines*. Geneva: WHO Global Programme on AIDS, 1989 (WHO/GPA/SFI/89.3).

World Health Organization. Consensus Statement Consultation on Partner Notification for Preventing HIV Transmission. *Venereology* 1990; 3(1): 17.

World Health Organization. *Effective Approaches to AIDS Prevention*. Report of a Meeting. Geneva: WHO, Global Programme on AIDS, May 1992.

World Health Organization. *Consensus Statement from Consultation on Partner Notification for Preventing HIV Transmission, Geneva, 11-13 January 1989*. Geneva: WHO, Global Programme on AIDS, 1989, Doc No: WHO/GPA/INF/89.3.

World Health Organization. Joint United Nations Programme on HIV/AIDS (UNAIDS) – WHO. Revised Recommendations for the Selection and Use of HIV Antibody Tests. *Weekly Epidemiological Record* 1997; 72(12):
81-88.

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

Wortley P et al. HIV Testing Patterns: Where, Why and When Persons with AIDS Were Tested for HIV? *AIDS* 1995; 9: 487-492.

Yovetich T. *Community Consultation on Surveillance Needs. Final Report*. Ottawa: Canadian AIDS Society, June 1998.

Zeegers Paget TDM. Droit et sida: perspectives aux Pays-Bas. In: J Foyer, L Khaiat (eds). *Droit et sida: comparaison internationale*. Paris: CNRS éditions, 313-340.

Zeegers Paget TDM. *AIDS and Public Health Measures: A Global Survey of the Activities of Legislatures 1983-1993*. Proefschrift, Rijksuniversiteit Groningen, 1996.

Zowall H et al. HIV Antibody Screening among Immigrants: A Cost-Benefit Analysis. *Canadian Medical Association Journal* 1990; 143(2): 101-107.

## Cases

*AB v CD* (1851), 14 Sess. Cas. (Second Series) 177 (Scot Ct Sess).

*Frenette v Metropolitan Life Insurance Company*, [1992] 1 SCR 647-696.

Biggs & Cole *v Hudson* (1988), 9 CHRR D/5391 (BC Human Rights Council).

*Bragdon v Abbott*, 1998 WL 332958 (25 June 1998).

*Canadian AIDS Society* v *Ontario* (1996), 25 OR 3rd 388; (1996) 31 OR (3d) 798.

*Davis v Rodman*, 147 Ark 385, 227 SW 612 (1921).

*DC v Paul Bernardo et al*, Court File No 93-CQ-46124, Notice of Motion of 8 September 1996.

*DC* v *Paul Bernardo et al*, Court File No 93-CQ-46124, unreported decision of 23 September 1996, Ontario Court (General Division), MacDonald J.

*Earle v Kuklo*, 26 NJ Super 471, 98 A.2d 107 (1953).

*Edwards v Lamb*, 69 NH 599, 45 A. 480 (1899).

*Fosgate v Corona*, 66 NJ 268, 330 A.2d 355 (1974).

*Halls v Mitchell*, [1928] SCR 125.

*Hamel v Malaxos*, 25 November 1993, no 730–32–000370 929, Small Claims Court, Joliette, unreported.

*Hill v Evans*, No 91-A-626-N, 1993 WL 595676 (MD Ala 7 October 1993).

*Kliegel v Aitken*, 94 Wis 432, 60 NW67 (1896).

*Love v Superior Court*, 276 Cal Rptr 660 (Ct App 1990).

*McInerney v MacDonald*, [1992] 2 SCR 138.

*People v Adams*, 597 N.E.2d 574 (Ill 1992).

*Pittman v Bain*, (1994), 112 DLR (4th) 257.

*Québec Human Rights Commission v Dr G G*, QHRT, Québec, no 200–53–000002–944, 11 April 1995, Rivet J.

*R* v *Beaulieu*. Roberge J. CQ Bedford (Cowansville) 455-01-000963-920, 1992-11-03. Decision no 92-1769 (Court of Québec).

*R* v *Cornier*, unreported, 1991 CA 12803 BCCA.

*R v Cuerrier* [1996] BCJ No 2229 (BCCA) (QL); aff’g Court File No CC941279, unreported decision of 5 January 1995, Supreme Court of British Columbia (Vancouver), Drost J.

R v *Cuerrier*, (1998) 162 DLR (4th) 513 SCC.

*R* v *Dyment*, [1988] 2 SCR 417 at 431-432.

*R* v *GDM* (1987), 2 WCB (2d) (BC Prov Ct).

*R* v *JPB*, [1992] NWTJ No 207 (Northwest Territories Youth Court).

*R v Legere, [1988] 43 CCC (3d) 502 at 513.*

*Ratte* v *Kingston Penitentiary (Warden)*, Ontario Judgments: [1991] OJ No 1745 (Ontario Court of Justice – General Division).

*Re K(R)* (1987), 79 AR 140 (Family Court).

*Re Inquiry into the Confidentiality of Health Records in Ontario* (1979), 98 DLR (3d) 704; 24 OR (2d) 545 (Ont CA).

*Re Eve* (1987), 31 DLR (4th) 1.

*Schneider v R*, [1982] 2 SCR 112.

*Skillings v Allen*, 143 Minn 323, 173 NW 663 (1919).

*Tanner v Norys*, [1980] 4 WWR 33 (Alta C.A.).

*Tarasoff v Regents*, 17 Cal 3d 425, 551 P 2d 334, 131 Cal Rptr 14 (1976).

*Virgin Islands v Roberts*, 756 F Supp 898 (D.V.I. 1991).

*Wendon v Trikha et al* (1991), 116 AR 81 (Q.B.); (1994), 112 DLR (4th) 257.

*Winnipeg Child and Family Services (Northwest Area)* v *DFG*, [1997] SCJ No 96 (unreported; 31 October 1997).

*Wojick v Aluminium Company of America*, 18 Misc 2d 740, 183 NYS 2d 351 (Sup Ct 1959).

**Return to the top of this page**

**Return to Table of Contents**

# HIV Testing and Confidentiality: Final Report

### Prepared by Ralf Jürgens

ISBN 1-896735-16-9

---

# Appendix A

# GLOSSARY

## HIV Testing

The tests that are currently most accessible detect the presence of antibodies to HIV rather than HIV itself (polymerase chain reaction testing, which detects the presence of the virus itself, is less accessible). It is therefore more accurate to refer to such tests as HIV-antibody tests. However, for the sake of convenience and to follow common usage, the terms "HIV testing" and "HIV-positive" are used in this document.

## Voluntary Testing

Where testing is done only with the informed consent of the person to be tested (or, if the person is incompetent, of his or her parent, legal guardian, or next of kin, as required by law), and the testing does not fall within the definitions of mandatory or compulsory testing.1

Informed in this context means that, in discussion (pre-test counselling), the person seeking HIV testing has been made aware of all the ramifications of HIV testing, including the risks and benefits, as well as of alternatives to such testing, in language s/he can understand.

Consent means the giving of express agreement to HIV testing in a situation devoid of coercion, in which the client should feel equally free to grant or withhold consent.2

## Mandatory Testing

Where testing is either a necessary prerequisite for a person to obtain a specified status, benefit, service or access to a given situation, or is a necessary consequence of being provided with one or more of these. However, the element of choice rests with the person considering the "service, benefit or specified status."

## Compulsory Testing

Where testing is required by law, or policy, and the person cannot choose to refuse testing and cannot legally avoid it.

## Unlinked Testing

Testing in which results cannot be linked, associated or connected with the person being tested (this can be done with or without knowing the personal identity of the person tested).3

## Linked Testing

There are three types of linked testing:

Anonymous: testing in which the results can be linked to the patient by a code known only by the patient; the physician, etc cannot know the identity of the person being tested.

Non-nominal: testing in which results can be linked to the person being tested by a code (which does not include personal identification of the person being tested) known by the person being tested. The physician also knows the identity of the person being tested.

Nominal: testing in which the results are linked to the person being tested by a personal identifier.

## Sensitivity

is the ability of a test to detect infection when it is present (to return a positive result when the sample is positive).4

## Specificity

is the ability of a test to detect the absence of infection when the sample is uninfected (to return a negative result when the sample is negative).

**Return to the top of this page**

**Return to Table of Contents**

---

ENDNOTES

1 Definitions for voluntary, mandatory, and compulsory testing are taken from Human Immunodeficiency Virus Antibody Testing in Canada. Recommendations of the National Advisory Committee on AIDS. *Canada Diseases Weekly Report* 1989; 15(8): 37-43 at 37.

2 The definition of informed consent is taken from World Health Organization. *Statement from the Consultation on Testing and Counselling for HIV Infection*. Geneva: WHO Global Programme on AIDS, 1992, at 11.

3 Definitions for unlinked and linked testing are taken from Confidentiality in Relation to HIV Seropositivity. Report of the Federal/Provincial/ Territorial Advisory Committee on AIDS. *Canada Diseases Weekly Report* 1989; 15(8): 43-47 at 43.

4 Definitions for sensitivity and specificity are taken from MA Field. Testing for AIDS: Uses and Abuses. *American Journal of Law & Medicine* 1990; 16: 33-106 at 39.

**Return to the top of this page**

**Return to Table of Contents**

# HIV Testing and Confidentiality: Final Report

**Prepared by Ralf Jürgens**

**ISBN 1-896735-16-9**

---

# Appendix B

# List of Workshop Participants

Joan Anderson, AIDS Committee of Toronto, Toronto

Sharon Baxter, Canadian AIDS Society, Ottawa

Reeta Bhatia, HIV/AIDS Care, Treatment and Support Program,
Health Canada, Ottawa

Ruth Carey, HIV & AIDS Legal Clinic Ontario (HALCO), Toronto

Dr Michel Châteauvert, Physician, Montréal

Richard Cloutier, Centre québécois de coordination sur le sida, Montréal

Tracey Donaldson, HIV/AIDS Prevention & Community Action Program,
Health Canada, Ottawa

Richard Elliott Iler, Campbell, Toronto

Bruno Guillot-Hurtubise, AIDS Community Care Montréal, Montréal

Nora Hammill, Canadian Public Health Association AIDS Program, Ottawa

Gens Hellquist, Gay and Lesbian Health Services, Saskatoon

Anne Malo, HIV/AIDS Policy, Coordination and Programs Division, Health Canada, Ottawa

Julia Martin, HIV/AIDS Prevention & Community Action Programs, Health Canada, Ottawa

Laverne Monette, Ontario Aboriginal HIV/AIDS Strategy, Toronto

Christian Moralès, Ste-Justine Hospital, Montréal

Dr Ted Myers, Faculty of Medicine, University of Toronto, Toronto

Eugene Oscapella, Privacy Commission, Ottawa

Dr David Patrick, BC Centre for Disease Control, Vancouver

Diane Riley, International Harm Reduction Association, Toronto

Lori Stoltz, Goodman and Carr, Toronto

Elaine Sussey, AIDS New Brunswick, Fredericton

Janis Tripp, AIDS Bureau, Ontario Ministry of Health, North York

Robert Trow, Hassle Free Clinic, Toronto

Anne Vassal, Reseau sida et maladies infectueuses, Montréal

Micheal Vonn, AIDS Vancouver, Vancouver

Tasha Yovetich, Canadian AIDS Society, Ottawa

**Return to the top of this page**

**Return to Table of Contents**