



CANADIAN RÉSEAU
HIV/AIDS JURIDIQUE
L E G A L CANADIEN
NETWORK VIH•SIDA



HIV Testing and Confidentiality:

Issues for the Aboriginal Community

A DISCUSSION PAPER
Second Edition



Health Canada
Santé Canada



CANADIAN | RÉSEAU
HIV/AIDS | JURIDIQUE
L E G A L | CANADIEN
NETWORK | VIH•SIDA



HIV Testing and Confidentiality:

Issues for the Aboriginal Community

A DISCUSSION PAPER
Second Edition

Prepared by
Stefan Matiation

Published by the Canadian HIV/AIDS Legal Network and the Canadian
Aboriginal AIDS Network

For further information about this publication, please contact:

Canadian HIV/AIDS Legal Network	Canadian Aboriginal AIDS Network
484 McGill Street	409-396 Cooper Street
4 th Floor	Ottawa, Ontario
Montréal, Québec	K2P 2H7
H2Y 2H2	Toll free: 1-888-285-2226
Tel: (514) 397-6828	Tel: (613) 567-1817
Fax: (514) 397-8570	Fax: (613) 567-4652
Email: info@aidslaw.ca	Email: caan@storm.ca
Website: www.aidslaw.ca	Website: www.caan.ca

Further copies can be retrieved at the website of the
Canadian HIV/AIDS Legal Network or ordered through the
Canadian HIV/AIDS Clearinghouse

Tel: (613) 725-3434
Fax: (613) 725-9826
Email: aids/sida@cpha.ca

© Canadian HIV/AIDS Legal Network
ISBN 1-896735-30-4
Second edition, 1999

HIV TESTING AND CONFIDENTIALITY: ISSUES FOR THE ABORIGINAL COMMUNITY

Prepared by
Stefan Matiation
for the

Canadian HIV/AIDS Legal Network
484 McGill Street, 4th Floor
Montréal, QC H2Y 2H2
Tel: (514) 397-6828
Fax: (514) 397-8570
Email: info@aidslaw.ca
Website: www.aidslaw.ca
and the

Canadian Aboriginal AIDS Network
404-396 Cooper Street
Ottawa, ON K2P 2H7
Toll free: 1-888-285-2226
Tel: (613) 567-1817
Fax: (613) 567-4652
Email: caan@storm.ca
Website: www.caan.ca

Acknowledgments

The author wishes to thank Ralf Jürgens for his encouragement, comments, and support of this project; Anne Malo, Health Canada, for her support; Art Zoccole, Gilbert Deschamps, and 2-Spirited Peoples of the 1st Nations for introducing me to these issues; Garry Bowers for copyediting the English text, and Roger Caron and Johanne Forget for translating the English original into French; and all those who took the time to share their expertise, provide me with valuable information, and/or comment on the first draft of the paper.

Funding for phase I of this project was provided by the HIV/AIDS Policy, Coordination and Programs Division, Health Canada, under the National AIDS Strategy Phase II. Funding for this publication was provided by Health Canada under the Canadian Strategy on HIV/AIDS.

The views expressed in this document are those of its author and do not necessarily reflect the views or policies of Health Canada, the Canadian HIV/AIDS Legal Network, or the Canadian Aboriginal AIDS Network. The views expressed by those interviewed are their personal opinions and do not necessarily represent those of any organizations or groups with which they may be affiliated.

Ce document est également disponible en français.

TABLE OF CONTENTS

SUMMARY	I
INTRODUCTION	1
Background	1
Scope of the Paper	3
Limitations	4
Changes over Time	4
Level of Detail	5
Scope of the Consultations	6
A Note about Terminology	6
WHY ARE SUCH LOW NUMBERS OF ABORIGINAL PEOPLE BEING TESTED?	8
VOLUNTARY TESTING: THE ISSUE OF CONSENT	12
Exceptions	13
Testing for Research Purposes, Unlinked Anonymous Screening, and the Response of Aboriginal People	14
Conclusions	17
HOW SHOULD VOLUNTARY TESTING BE DONE? ANONYMOUS TESTING AND ACCESS TO TESTING	18
Anonymous Testing	19
Access to Testing	21
Barriers to Accessible Testing	21
Access to Testing and HIV/AIDS Education	22
Conclusions	23
HOW SHOULD VOLUNTARY TESTING BE DONE? COUNSELLING	24
Pre- and Post-Test Counselling	25
Conclusions	26
HOME TESTING FOR HIV	27
Home Testing and Aboriginal People	28
Conclusions	29
MANDATORY OR COMPULSORY HIV TESTING	30
Conclusions	32
CONFIDENTIALITY	33
The Importance of Confidentiality	33
Concerns about Confidentiality	34
Confidentiality and Health Practitioners	35
Confidentiality and Community	37
Conclusions	38
Reporting Requirements	39
Partner Notification	39
Conclusions	40
SUMMARY OF CONCLUSIONS	41
BIBLIOGRAPHY	45
APPENDIX—List of People Consulted	48

SUMMARY

Background

In order to stimulate discussion about legal issues relating to HIV/AIDS and Aboriginal communities, the Canadian HIV/AIDS Legal Network and the Canadian Aboriginal AIDS Network are addressing three topics: (1) HIV/AIDS and discrimination; (2) problems of jurisdiction and funding; and (3) testing and confidentiality issues. This Discussion Paper deals with the third topic. A first edition of the papers was based on discussions with key informants working in the field of Aboriginal people and HIV/AIDS conducted from July to September 1997. In October 1997 draft discussion papers were distributed for comments. Follow-up discussions were conducted and revisions made to the papers in January and February 1999. To the extent possible, the comments received have been reflected and incorporated in this second edition of the Discussion Paper.

Why Is This Discussion Paper Needed?

In Phase I of the Joint Project of the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society on Legal and Ethical Issues Raised by HIV/AIDS, 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. In order to address the need for a reexamination of issues of testing and confidentiality, the Joint Project published a discussion paper on HIV testing and confidentiality in March 1997, followed – after broad consultations were undertaken – by a final report released in 1998 (the Network Report). Issues pertaining to Aboriginal people could not be dealt with extensively in that paper.

The *Ontario Aboriginal HIV/AIDS Strategy* identifies a reluctance to be tested for HIV as a risk factor for HIV transmission in the Aboriginal community. It is important that HIV testing and confidentiality issues for Aboriginal people be examined.

What Does the Discussion Paper Contain?

The Discussion Paper examines the issues raised for the Aboriginal community by HIV testing and confidentiality, based on interviews of individuals working in the field of HIV/AIDS and Aboriginal people, and on research conducted by the author.

The Paper is not a reexamination of the discussion in the Network Report. Readers are referred to that document for a broader analysis of HIV testing and confidentiality issues and for more information about HIV testing.

What Are the Issues?

The Network Report states that in Canada a consensus emerged in the late 1980s that, except in a few well-defined circumstances, people should be tested for HIV 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.

There are a number of issues that, although in theory consensus was reached, in practice remain unresolved. For example:

- access to testing remains a problem for many people;
- testing for HIV without the specific informed consent of the person being tested is allegedly taking place more frequently;
- many people often do not receive adequate counselling; and
- calls for mandatory or compulsory testing of certain groups of the population continue.

Many of these issues are as relevant to members of the Aboriginal community as to the general population of Canada. However, an examination of these issues must start from a different context. The oppression and racism experienced by the Aboriginal community has contributed to the overrepresentation of Aboriginal people among the most marginalized groups in Canada, and to problems of ill-health. These factors make many Aboriginal people more vulnerable to HIV. Statistics suggest that HIV could have a disproportionate impact on First Nations, Métis, and Inuit communities and that the spread of HIV among Aboriginal people shows no signs of abating.

Based on the interviews conducted for this paper, the following issues are particularly relevant to Aboriginal people:

- control and ownership of research and data involving Aboriginal people;
- accessible options for HIV testing that overcome problems of remoteness, cultural difference, and reluctance to use mainstream facilities;
- culturally appropriate pre- and post-test counselling; and
- confidentiality in small communities.

What Is the Goal of the Discussion Paper?

The paper does not provide definitive answers. In the end, answers to the issues raised must come from within Aboriginal communities. The goal is to provide information and identify problems related to HIV testing and confidentiality for Aboriginal people. It is hoped that the conclusions contained in the Discussion Paper will stimulate discussion about the many issues raised and contribute to the development of solutions to the problems identified.

What Does the Discussion Paper Conclude?

The Discussion Paper contains over fifteen conclusions. Among other things, it concludes that:

- Arguments for specific informed consent are as pertinent for Aboriginal people as for the rest of the population of Canada.
- Anonymous unlinked HIV-seroprevalence research involving Aboriginal people should be based on the principle of Aboriginal control over and ownership of the research and data.
- Barriers to accessible HIV testing for Aboriginal people should be removed.
- Provincial, territorial, federal, and Aboriginal government health providers should work together to develop accessible options for HIV testing for Aboriginal people, including anonymous testing.
- More Aboriginal people should be trained to provide quality pre- and post-test counselling in Aboriginal communities and in health facilities used by Aboriginal people.
- Any assessment of the desirability of home test kits for the Canadian market should be undertaken with the participation of members of the Aboriginal community.
- Due to the overrepresentation of Aboriginal people in many vulnerable groups, including prisoners and injection drug users, Aboriginal AIDS organizations and others from the Aboriginal community need to remain vigilant against proposals for mandatory or compulsory testing.
- HIV/AIDS education is an important component of efforts to reduce the impact of loss of confidentiality on people living with HIV/AIDS.
- All health-care facilities that provide services to Aboriginal people and all Aboriginal communities should adopt confidentiality policies concerning HIV/AIDS.
- Mobile testing units should be examined for their potential to overcome barriers to HIV testing for Aboriginal people.
- Aboriginal AIDS organizations and others from the Aboriginal community should be involved in and guide the development of solutions to sensitive issues regarding partner notification in Aboriginal communities.
- Partner notification should not detract from HIV/AIDS education efforts.

Aboriginal people living with or affected by HIV/AIDS continue to experience discrimination. While early detection of HIV infection is a pressing priority, it is a mistake to dismiss the importance of respecting people's rights and the risk of discrimination. Arguments in favour of accessible testing based on specific informed consent, accompanied by quality pre- and post-test counselling, and under conditions of guaranteed confidentiality, are as pertinent as ever. To date, however, the HIV testing available to Aboriginal people falls short of the ideal for a variety of reasons. In order to reduce the impact of HIV on Aboriginal people and provide timely care, treatment and support for those already living with HIV/AIDS, barriers to HIV testing for Aboriginal people must be eliminated.

Next Steps

The revised and updated Discussion Paper is intended to be a resource for Aboriginal and other HIV/AIDS organizations, Aboriginal governments, federal and provincial governments, policymakers, departments and agencies, non-governmental organizations, and others. The Paper will be widely distributed and made available on the Network's website. Articles based on the Paper will be published in the *Canadian HIV/AIDS Policy & Law Newsletter* and submitted for publication in other journals and newsletters. Fact sheets summarizing the Paper's most relevant information have been produced.

Further copies of this Discussion Paper...

can be retrieved at the website of the Canadian HIV/AIDS Legal Network at <www.aidslaw.ca>.

Copies can also be ordered through the Canadian HIV/AIDS Clearinghouse. For more information, contact:

Canadian HIV/AIDS Clearinghouse

Suite 400

1565 Carling Avenue

Ottawa, Ontario K1Z 8R1

Tel: (613) 725-3434

Fax: (613) 725-9826

Email: aids/sida@cpha.ca

INTRODUCTION

Background

In July 1997, the Canadian HIV/AIDS Legal Network (the Legal Network) started a project on legal issues relating to Aboriginal people and HIV/AIDS. Three discussion papers were produced on: (1) HIV/AIDS and discrimination; (2) problems of jurisdiction and funding; and (3) testing and confidentiality issues. Funding for the project was initially provided by the HIV/AIDS Policy, Coordination and Programs Division, Health Canada, under the National AIDS Strategy Phase II.

As part of the initial project, from July to September 1997, discussions with key informants working in the field of Aboriginal people and HIV/AIDS were conducted. In October 1997 draft discussion papers were distributed for comments. The discussion papers were published and widely circulated in March 1998.

In the fall of 1998, the Legal Network and the Canadian Aboriginal AIDS Network (CAAN) agreed to jointly produce a second, revised edition of the discussion papers and a series of info sheets summarizing the main issues raised in the discussion papers. To this end, in January and February 1999 follow-up discussions were conducted with individuals representing Aboriginal HIV/AIDS organizations and Health Canada. Taking the comments received into account, the discussion papers were then revised, in an attempt to reflect and incorporate the comments of all those consulted. A list of people interviewed appears in the Appendix of each paper. This second phase of the project was funded by Health Canada under the Canadian Strategy on HIV/AIDS.

In 1998, as part of the Joint Project on Legal and Ethical Issues Raised by HIV/AIDS, the Network and the Canadian AIDS Society released *HIV Testing and Confidentiality: Final Report* (the Network Report). The Network Report includes an extensive discussion of the history and current situation with respect to testing and confidentiality in Canada as well as an assessment of the issues raised by HIV testing. The author of the Network Report acknowledges that, although it is broad, it is not comprehensive: “issues pertaining to specific populations [including Aboriginal people] could not always be dealt with or dealt with appropriately.”¹ This paper uses the Network Report as a starting point for an examination of issues raised for Aboriginal people by HIV testing. Readers are referred to the Network Report for a broader analysis of testing and confidentiality issues and for more information about HIV testing.

Most of the testing and confidentiality issues that are relevant to the general population are also relevant to Aboriginal people. However, they must be approached within a different context. The Aboriginal community has suffered a considerable degree of oppression and racism in its relations with the rest of Canada. This has had a devastating impact on the well-being of Aboriginal people and on the cultural integrity of their communities. Aboriginal people are overrepresented among the marginalized in Canada, and often experience poorer socioeconomic conditions than the majority of Canadians. These factors make many Aboriginal people more vulnerable to HIV.

¹ Ralf Jürgens. *HIV Testing and Confidentiality: Final Report*. Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1998.

Scope of the Paper

The Paper begins with recent statistics on the number of cases of AIDS among Aboriginal people in Canada. These are generally regarded as underrepresentative of the true extent of the epidemic, partly because of low HIV testing rates among Aboriginal people. The paper outlines some of the reasons for this, as suggested by those interviewed.

The Paper then examines how the testing and confidentiality issues identified by the author of the Network Report apply to Aboriginal people. A number of particularly important testing and confidentiality issues for Aboriginal people are:

- the use of anonymous unlinked HIV-seroprevalence research;
- access to testing;
- culturally appropriate pre- and post-test counselling; and
- confidentiality in small communities.

Other issues, including home testing for HIV, mandatory testing, and anonymous testing, are also addressed. Preliminary conclusions are identified after each major section and are listed at the end of the Paper.

Limitations

Changes over Time

In *HIV Testing and Confidentiality: Final Report*, the author notes that HIV/AIDS issues may need to be reexamined over time as knowledge about HIV/AIDS increases and the epidemic evolves. It is important to note that the conclusions drawn in this Discussion Paper are far from timeless. Knowledge of the epidemic in the Aboriginal population in Canada is limited by a lack of concrete epidemiological data and a reliance on anecdotal evidence. While anecdotal evidence in this area should not be discounted, as it is generally provided by those who have the best opportunities to monitor the epidemic – namely, front-line workers working with Aboriginal HIV/AIDS organizations, health centres in reserve and urban areas, and others working in the field – it does not mean that there is not much to be learned about the evolution and impact of the epidemic in the Aboriginal population. As knowledge increases, the conclusions drawn in this Discussion Paper may have to be changed and the issues reexamined.

It is also important to note the rapid political and social changes occurring among Aboriginal communities. Many of these changes may also have an impact on the conclusions and comments made in this Discussion Paper and necessitate a reexamination of these issues in the future.

Level of Detail

The Aboriginal population is diverse, consisting of a multitude of cultures, languages, traditions, living circumstances, and experiences. It is impossible in this Discussion Paper to provide the level of detail necessary to account for these differences. In particular, it has been difficult to reflect the circumstances of Inuit and Métis communities. The impact of Nunavut, which came into being on 1 April 1999, on the lives and health of the predominantly Inuit population in the new territory has not been examined. It is acknowledged that more information concerning Métis people and Inuit and non-status Indians would be useful. It may be appropriate to address the specific issues of these groups in separate papers.

It is also important to bear in mind that the Aboriginal population has also shared in many ways in a common history. Unfortunately, this shared history has not always been positive, involving the ill effects of colonization, racism, and cultural denigration. This shared experience has contributed to the prevalence of risk factors for HIV transmission in the Aboriginal population as a whole.

The Aboriginal population also shares in a capacity to withstand the ravages of colonialism. Although their cultures and traditions have been weakened, and sadly in some cases lost, Aboriginal communities are involved in a cultural and political resurgence: recent developments suggest that the Aboriginal population remains strong and that Aboriginal people are prepared to reassert their cultures and traditions and regain control of their future.

Although this Discussion Paper may not deal specifically with the concerns and experiences of certain groups, the issues raised may nonetheless resonate with the concerns and experiences of such groups. During the preparation of these papers, an attempt has been made to bear in mind the differences and similarities among Aboriginal groups, nations, and communities.

Scope of the Consultations

A third important limitation in this project is the scope of the consultations, which have been limited by time, financial resources, and geography. The discussions have focused on representatives of Aboriginal HIV/AIDS organizations and Health Canada, with additional input where possible. Due to the different circumstances of Aboriginal people across the country, it is important to obtain input from organizations operating in different regions. This has been attempted to the extent possible. However, while some face-to-face meetings could be arranged, many interviews had to be conducted by telephone.

This project is a small contribution to discussion about legal and ethical issues related to Aboriginal people and HIV/AIDS. It is hoped that discussions will continue among an expanding group of people.

A Note about Terminology

This Discussion Paper adopts the terminology used by the Royal Commission on Aboriginal Peoples:

The Commission uses the term *Aboriginal people* to refer to the indigenous inhabitants of Canada when we want to refer in a general manner to Inuit and to First Nations and Métis people, without regard to their separate origins and identities.

The term *Aboriginal peoples* refers to organic political and cultural entities that stem historically from the original peoples of North America, rather than collections of individuals united by so-called ‘racial characteristics’. The term includes the Indian, Inuit and Métis peoples of Canada.

Aboriginal people (in the singular) means the individuals belonging to the political and cultural entities known as “Aboriginal peoples.”...

Our use of the term *Métis* is consistent with our conception of *Aboriginal peoples* as described above. We refer to the Métis as distinct Aboriginal peoples whose early ancestors were of mixed heritage (First Nations, or Inuit in the case of Labrador Métis, and Europeans) and who associate themselves with a culture that is distinctly Métis...

Following accepted practice and as a general rule, the term *Inuit* replaces the term *Eskimo*. As well, the term *First Nation* replaces the term *Indian*...²

Terms such as Eskimo and Indian continue to be used where such terms are used in quotations from other sources, where the terms are found in legislation or caselaw, or in relation to status or non-status Indians, as defined by the *Indian Act*.

Terms such as *Aboriginal community*, *First Nations community*, *Métis community*, or *Inuit community* refer to a group of Aboriginal people residing in a single locality and/or united through shared experiences. Such communities may arise in reserves, remote settlements, or rural or urban areas.

The term *two-spirited* or *two-spirit* is used in this Discussion Paper. The term has a number of meanings within different contexts and Aboriginal traditions. In general terms it means Aboriginal people who identify themselves as gay, lesbian, bisexual, or transgender. The term “two-spirited” or “two-spirit” is preferred because it is more culturally relevant to Aboriginal gay, lesbian, bisexual, and transgender people.

In some Aboriginal traditions, two-spiritedness was regarded as a gift. Two-spirited people were respected and honoured and were visionaries and healers in their communities. The term originates from the recognition of the sacredness in some traditions of people who maintain a balance by housing both the male and female spirits.³

² Royal Commission on Aboriginal Peoples. A Note About Terminology. *Final Report*. Ottawa: Minister of Supply and Services, 1996.

³ “Two-spirited” is defined in the *Ontario Aboriginal HIV/AIDS Strategy*. Toronto: The Strategy, 1996.

WHY ARE SUCH LOW NUMBERS OF ABORIGINAL PEOPLE BEING TESTED?

The Laboratory Centre for Disease Control (LCDC) reports that as of 31 December 1997, 255 of the 15,528 AIDS cases in Canada were reported as Aboriginal. Adjusted for reporting delays, the number of Aboriginal AIDS cases was estimated at 332 by the end of 1997, or 33.2 cases per 100,000 Aboriginal people.⁴ According to the accounts of Aboriginal AIDS workers and organizations, this number does not nearly approach the true number of AIDS cases among Aboriginal people. Aboriginal AIDS cases are underreported due to delays in reporting, low HIV testing rates, and variations in the reporting of ethnic status between provinces.

Statistics on reported cases of AIDS tell only a fraction of the story; rates of HIV infection are much higher. LCDC estimates that “as of the end of 1996, a cumulative total of 50,000 to 54,000 Canadians had been infected with HIV since the onset of the epidemic and that at the end of 1996, 36,000 to 42,000 Canadians were living with HIV infection (including those living with AIDS).”⁵

The number of Aboriginal people infected with HIV is largely unknown. Based on the reports of Aboriginal AIDS workers and organizations, and the prevalence of risk factors among Aboriginal people, there is a serious HIV/AIDS epidemic that threatens the resurgence of Aboriginal cultural integrity and self-determination.

⁴ Laboratory Centre for Disease Control. *Epi Update: HIV/AIDS Epidemiology Among Aboriginal People in Canada*. Ottawa: Health Canada, May 1998.

⁵ LCDC. *Epi Update: HIV and AIDS in Canada*. Ottawa: Health Canada, November 1997.

Risk factors influencing the spread of HIV within the Aboriginal community include:

- low rates of safer sex practices (as indicated by high rates of teenage pregnancy and high rates of sexually transmitted diseases);
- sexual and physical violence;
- low self-esteem;
- alcohol and drug abuse;
- poor health in general;
- high mobility among the Aboriginal population; and
- a reluctance to get HIV testing.⁶

In addition, Aboriginal people are disproportionately represented in groups at high risk for HIV infection, including injection drug users and prison populations. Aboriginal AIDS cases are younger than non-Aboriginal AIDS cases and the proportion of cases among Aboriginal women is higher than among non-Aboriginal women.⁷ All of these factors contribute to the seriousness of the threat of the Aboriginal HIV/AIDS epidemic.

Many of the people interviewed for this paper expressed concern about the low number of First Nations people and Inuit being tested for HIV infection. The low number being tested means that Aboriginal people living with HIV/AIDS are diagnosed and first receive treatment at later stages in their illness than other people living with HIV/AIDS.⁸

⁶ List based on factors discussed in the *Ontario Aboriginal HIV/AIDS Strategy*, supra, note 3.

⁷ Supra, note 4. LCDC reports the following statistics: 29.8% of Aboriginal AIDS cases are diagnosed at less than 30 years of age compared with 18.6% for non-Aboriginal AIDS cases; the proportion of women among Aboriginal AIDS cases is 15.9% vs 7.0% for the non-Aboriginal population; 50.0% of AIDS cases among Aboriginal women are attributed to injection drug use compared with 17.4% for non-Aboriginal women; 25% to 75% of clientele using inner city services, including needle exchanges, are Aboriginal in some cities; up to 40% of prison populations in some provinces are Aboriginal; and recent data (1993-97) from British Columbia, Alberta, and Saskatchewan found Aboriginal people to comprise 15%, 26%, and 43% of newly diagnosed HIV-positive cases respectively. Most Aboriginal AIDS cases are male. Of the 213 reported male Aboriginal AIDS cases, men who have sex with men account for 59.2% of them.

⁸ *Evaluation of the Native AIDS Coordinator Program*. Vancouver: The Vancouver Native Health Society and St. Paul's Hospital, 8 February 1994, at 10.

The following comments from persons consulted for this paper reflect reasons why Aboriginal people are not being tested:

Many people know they are engaging in risky behaviour but continue to deny that they are at risk.

Discrimination is experienced by Aboriginal people living with or affected by HIV/AIDS in cities and in rural and reserve communities.

Many people have concerns about confidentiality. There is no confidentiality in small communities.

Many Aboriginal people experience racism in health care and social assistance settings. Some people do not trust Western medicine and practitioners. Some people are not comfortable using mainstream testing facilities. In some cases this reflects cultural difference rather than direct racism.

Some of those consulted referred to differences between Aboriginal and non-Aboriginal values, attitudes and experiences respecting sexuality, relationships and other issues that can have a bearing on HIV testing. Some also referred to culturally based differences in communication styles and differences in language. Culturally based differences can make mainstream facilities and services less accessible to Aboriginal people.

Low self-esteem affects the number of people being tested. In some subgroups, especially street drug users and other street-involved people, there is a fatalistic and/or defeatist attitude about HIV.

Aboriginal people are a highly mobile population in Canada. As people move across jurisdictional boundaries from reserves to cities, from cities to reserves and from province to province, they often fall into a policy and service vacuum or have difficulty finding appropriate services.

These comments suggest that approaches to promoting HIV testing among Aboriginal people must address broader issues in Aboriginal communities. Further, as one person interviewed suggested, there is no single solution to testing and confidentiality issues for Aboriginal people. The situation in each community is different: remote reserves, reserves closer to built-up areas, rural communities, urban communities, and groups such as two-spirited people, women, men, and drug users may each require a different approach.

Despite recommendations for the development of HIV testing strategies in a number of reports produced in the early 1990s addressing HIV and Aboriginal people, little attention seems to have been given to testing issues until recently.⁹

⁹ Recommendations appear in the following documents: 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; Ted Myers et al. *Ontario First Nations AIDS and Healthy Lifestyle Survey*. Toronto, 1993, at 64; Report of the 2nd Canadian Conference on Aboriginal People and AIDS (appears in *Aboriginal HIV/AIDS Strategy: Summary of Existing Recommendations*. Toronto: Ontario Ministry of Health, September 1993).

VOLUNTARY TESTING: THE ISSUE OF CONSENT

This section examines the issue of consent in HIV testing. The Network Report addressed questions of whether a physician must obtain a patient's specific informed consent before administering an HIV test, and 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 to obtain a blood sample for diagnostic purposes. The Network Report concludes that

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.¹⁰

Based on the consultations conducted for this paper, there is no reason to think that a different conclusion should be drawn for HIV testing of Aboriginal people. The prevalence of HIV/AIDS-related discrimination remains a considerable threat to people living with and affected by HIV. Persons consulted related stories of people being shunned by their families and communities, sometimes threatened, and often ignored. The racism experienced by many Aboriginal people regardless of their HIV status compounds the risk to social well-being associated with a positive HIV test result. Significantly, many persons consulted suggested it is not uncommon for Aboriginal people to experience racism in health care.

Despite the severe personal, social, and financial consequences of being identified as HIV-positive, many persons interviewed reported concerns that HIV testing was being undertaken without the specific informed consent of the person tested. This reflects concerns discussed in the Network Report. Arguments for specific informed consent are as pertinent for Aboriginal people as for the rest of the population of Canada.

¹⁰ Supra, note 1 at 39.

Exceptions

The Network Report identifies two exceptions to the general rule about specific informed consent:

The testing of donors of blood, organs, semen, or similar bodily products...

[T]esting 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 Seroprevalence Research are followed.¹¹

The first exception is non-controversial with respect to Aboriginal people. Mandatory HIV testing of donors “has been universally endorsed as an essential and effective means of preventing the spread of HIV,” although “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.”¹²

The second exception was the focus of some discussion during interviews for the paper.

¹¹ Ibid at 40 and at 52.

¹² Ibid at 40.

Testing for Research Purposes, Unlinked Anonymous Screening, and the Response of Aboriginal People

Anonymous unlinked seroprevalence studies (“blind studies”) rely on HIV tests conducted on blood specimens drawn for another purpose. “Personal identifiers are stripped from blood samples prior to testing, and the results of the tests can not be linked to the individual.”¹³ Blind studies are seen as advantageous in the surveillance of HIV infection in sample populations. The use of “leftover” blood eliminates self-selection bias that might affect results of a study based on informed consent, and the procedure is seen as non-invasive because the blood is not deliberately drawn from individuals and names are unknown.¹⁴

In November 1996, 2-Spirited Peoples of the 1st Nations (TPFN) released a community-based discussion paper, *The Social, Moral, Ethical and Legal Implications of Conducting Blind HIV Seroprevalence Studies in Aboriginal Communities* (the TPFN Paper). The TPFN Paper is critical of the way in which blind studies have been used to research HIV seroprevalence in Aboriginal populations. Readers are referred to the TPFN Paper for a more in-depth examination of this issue. This section is an attempt to convey and discuss the comments of persons consulted for this paper about the issue.

The following comments reflect the concerns of persons consulted:

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.

¹³ 2-Spirited Peoples of the 1st Nations. *The Social, Moral, Ethical and Legal Implications of Conducting Blind HIV Seroprevalence Studies in Aboriginal Communities*. Toronto: TPFN, November 1996, at 1.

¹⁴ Ibid at 11.

Art Zoccole, Project Coordinator of the BC Aboriginal HIV/AIDS Task Force, argues that “Aboriginal people need to take a stronger stand on these things [research issues].”¹⁵ Zoccole suggests that studies of Aboriginal populations should be designed, owned, and controlled by Aboriginal people. Government agencies should provide funding to Aboriginal groups to conduct the research and to approach communities.¹⁶ This argument respects principles of self-government and reflects the view that Aboriginal people are the experts in Aboriginal issues. A recommendation issued in 1990 by the Joint National Committee on Aboriginal AIDS Education and Prevention (JNCAAEP) and statements in the TPFN Paper reflect these concerns:

The [JNCAAEP] recommends that HIV seroprevalence studies be undertaken within Aboriginal communities but that these studies be contingent on the approval of the community.¹⁷

Due to their unique geographical, social, cultural, ethical, and social-political differences from mainstream Canada, Aboriginal people should investigate the ethical, legal, and community issues in [blind studies] that might specifically affect them.¹⁸

To consult Aboriginal communities and stakeholders on ways to collect HIV information that are acceptable to Aboriginal people, LCDC has been involved in the following activities: (a) supporting the Aboriginal Working Group on HIV/AIDS Surveillance and Research (the Working Group); and (b) organizing annual meetings of the Working Group. Input on ways to improve Aboriginal community involvement in the area of HIV/AIDS surveillance and research is being obtained through regular reports and communications with participants at annual meetings.¹⁹

¹⁵ Personal communication with Art Zoccole, 8 August 1997.

¹⁶ Ibid.

¹⁷ JNCAAEP. *Recommendations for a National Strategy*, supra, note 8, Recommendation 9 at 39.

¹⁸ Supra, note 13 at 17.

¹⁹ Based on written response to author’s questionnaire by Mai Nguyen, Research Analyst with the Bureau of HIV/AIDS and STD of LCDC, received 12 September 1997, and on written comments respecting the discussion paper submitted on behalf of LCDC by Mai Nguyen, 22 December 1997.

²⁰ Personal communication with LaVerne Monette, 13 August 1997. Responding to this criticism, Mai Nguyen writes in her written submission of 22 December 1997, *supra*, note 19, that there are a number of reasons to conduct blind studies involving pregnant women: first, women represent a good subgroup in which to monitor the heterosexual HIV epidemic; second, results of seroprevalence studies in this group help provincial policymakers to determine HIV screening procedures in pregnant women; third, if HIV-positive pregnant women are informed, HIV transmission to infants may be prevented. Nguyen writes that LCDC has supported studies in a wide range of population groups other than pregnant women, including men who have sex with men, injection drug users, and STD clinic clientele. Despite these comments, the concern that focusing studies too narrowly may expose the group to discrimination, particularly in smaller communities where members of a group may be easily identifiable, remains.

²¹ The Guidelines were prepared by the Federal Centre for AIDS Working Group on Anonymous Unlinked HIV Seroprevalence and appear in *Canadian Medical Association Journal* 1990; 143: 625-627; revised *Canadian Medical Association Journal* 1992; 146: 1743-1744.

²² *Ibid*, *CMAJ* 1990 at 627.

²³ See Appendix D, Letters concerning Health Canada's opposition to this study, and Part 4: Presentation of the Data, of the TPFN Paper, *supra*, note 13.

²⁴ From written submission by Darcy Albert on behalf of TPFN, dated 13 November 1997, in response to the draft discussion paper.

Despite these efforts, LCDC was criticized by some of the Aboriginal people consulted for this paper. LaVerne Monette, Provincial Coordinator of the Ontario Aboriginal HIV/AIDS Strategy, argues that LCDC supports studies that focus too narrowly on groups that are particularly vulnerable to discrimination, such as pregnant Aboriginal women.²⁰

LCDC takes the position that it ensures that all studies that receive its funding support comply with the Canadian Guidelines on Ethical and Legal Considerations in Anonymous Unlinked HIV Seroprevalence Research (the Guidelines).²¹ LCDC takes the position that certain requirements of the Guidelines, including making researchers responsible for anticipating indirect harm to groups or individuals and involving "special interest groups" in the communication plan for potentially sensitive research results,²² should adequately respond to the concerns of Aboriginal people. However, as discussed in the TPFN Paper, the Guidelines are subject to some controversy.²³ For example, Darcy Albert, of 2-Spirited Peoples of the 1st Nations, raises concerns about the composition of the working group that established the Guidelines; the group was composed of researchers and government representatives, without the participation of representatives of the Aboriginal community.²⁴

Most people consulted for this paper agreed that there are benefits to blind studies as a method for gathering information about HIV/AIDS. Albert McLeod, Executive Director of the Manitoba Aboriginal AIDS Task Force, suggested that there must be some compromise between collecting information about rates of HIV infection and respecting principles of self-government and Aboriginal ownership over data.²⁵

Among other things, the Guidelines state that “universal access to individual voluntary testing under prescribed conditions of informed consent, pre-test and post-test counselling, and confidentiality [are] a prerequisite” to blind studies.²⁶ As discussed below, in too many Aboriginal communities these prerequisites are not met. Communities do not see the benefits of HIV statistics without the implementation of HIV programs and testing facilities.²⁷ While blind studies may have advantages and disadvantages, encouraging and facilitating testing based on informed consent, appropriate counseling, and confidentiality is more directly beneficial to Aboriginal communities and should be given priority.

Conclusions

1.1 Arguments for specific informed consent are as pertinent for Aboriginal people as for the rest of the population of Canada. As a general rule, HIV testing should only be undertaken with the specific informed consent of the person being tested. All health-care facilities that administer to Aboriginal people should be encouraged to adopt policies specifying that HIV testing should only be undertaken with the specific informed consent of the person being tested.

1.2 The general rule that HIV testing should only be conducted based on specific informed consent does not apply to the testing of donors of blood, organs, semen, or similar bodily products.

1.3 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.²⁸

²⁵ Personal Communication with Albert McLeod, 3 September 1997.

²⁶ *Supra*, note 21 at 626.

²⁷ Arlo Yuzicapi Fayant, Project Coordinator of All Nations Hope AIDS Network, stated that blind studies serve no purpose in Northern communities. They encourage fear and distrust and do not respond to community needs for education, training and support programs. Personal communication, 16 September 1997.

²⁸ This conclusion is endorsed in the Network Report, *supra*, note 1 at 52.

HOW SHOULD VOLUNTARY TESTING BE DONE? ANONYMOUS TESTING AND ACCESS TO TESTING

The Network Report notes that voluntary testing with the specific informed consent of the person being tested has been almost unanimously supported in Canada. There has been considerable debate, however, about how voluntary testing should be done. Three issues in particular need to be addressed in relation to Aboriginal people:

- (1) reporting of HIV test results to public health authorities and the availability of anonymous testing;
- (2) counselling and whether pre- and post-test counselling is always required; and
- (3) the availability and desirability of new testing technologies that make testing in the privacy of the home possible.²⁹

Each has important ramifications for Aboriginal people who want to be tested for HIV. The first is examined in this chapter, the second in the following chapter, and the third in the chapter on Home Testing for HIV.

²⁹ *Supra*, note 1 at 53.

Anonymous Testing

The following definitions are taken from the Network Report:³⁰

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.

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.

As discussed in the Network Report, anonymous testing is not available in every province and territory in Canada, although in practice it can sometimes be obtained in places where it is technically not allowed.³¹ 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 a few Canadian cities such as Vancouver and Toronto.³²

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."³³

³⁰ Ibid at 54.

³¹ Ibid at 59-61. Newfoundland, Nova Scotia, Québec, Ontario, Saskatchewan, and New Brunswick expressly provide for HIV testing on an anonymous basis.

³² Vancouver Native Health and Anishnawbe Health in Toronto are two examples.

³³ Medical Services Branch. *Guidelines for the Delivery of HIV/AIDS Programs and Services*. Ottawa: Health Canada, March 1995, at 35.

Many of those consulted expressed the view that anonymous testing should be available to Aboriginal people across the country. As discussed above, HIV/AIDS-related discrimination makes many people reluctant to get tested. The Network Report reports that there is evidence that: (1) the availability of anonymous testing “encourages people to be tested for HIV”; (2) anonymous testing “encourages particularly those at greatest risk to be tested”; (3) the “elimination of existing anonymous testing facilities may have a detrimental effect”; and (4) “anonymous testing facilities often offer ‘best practice’ pre- and post-test counselling.”³⁴ There is no reason to think that the same considerations do not apply to Aboriginal people.

Access to anonymous testing facilities is of significant benefit to Aboriginal people. 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, formerly the National Coordinator of the Canadian Aboriginal AIDS Network, supports 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.³⁵

One person consulted expressed the view that there is often too much emphasis on anonymous testing. Particularly since true anonymous testing may not be feasible in every Aboriginal community, the person suggested that it is important to de-dramatize HIV/AIDS and HIV testing so that the discrimination and denial experienced by many people living with or affected by HIV/AIDS is replaced by compassion and understanding.

Christina Smeja, Infectious Disease Coordinator of the Cree Board of Health and Social Services of James Bay, notes that although anonymous testing encourages people to get tested and allows time for a person to adjust to a diagnosis of HIV infection, once a person opts for treatment with antiretroviral medication, information on serologic status will be in their confidential nominal medical file. Smeja sees this as another reason to work at increasing confidentiality within medical/testing facilities in general, and increasing efforts to promote HIV testing as a responsible and respectable choice, free from any stigmatization.³⁶

These comments do not mean that, for some at least, anonymous testing is not important. Due to the continued prevalence of discrimination and denial, provincial and territorial health providers and MSB must work together to provide accessible options for anonymous testing for Aboriginal people to the greatest extent possible.

³⁴ *Supra*, note 1 at 63.

³⁵ Personal communication with Kevin Barlow, 8 August 1997.

³⁶ From written submission by Christina Smeja dated 28 October 1997.

Access to Testing

In 1990, the JNCAAEP recommended that access to confidential and free HIV testing be made available to all Aboriginal people across Canada.³⁷ Based on the comments of many of those consulted, this goal has yet to be achieved.

In many ways, Aboriginal people face greater barriers to accessible HIV testing than most other Canadians. 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. These factors make access to testing a central HIV/AIDS issue for Aboriginal people.

Barriers to Accessible Testing

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.³⁸

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.

³⁷ *Supra*, note 17, recommendation 10 at 40.

³⁸ Comment by Art Zoccole, *supra*, note 15.

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 involved in the process.³⁹ 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, Inuit, and Métis governments and political organizations have a central role to play in the development of accessible HIV testing options for Aboriginal people.

³⁹ The health transfer process is discussed in more detail in Stefan Matiation. *HIV/AIDS and Aboriginal People: Problems of Jurisdiction and Funding*. Montréal: The Canadian HIV/AIDS Legal Network and the Canadian Aboriginal AIDS Network, 1999. This is the second discussion paper in the Network's series on legal issues, Aboriginal people, and HIV/AIDS.

⁴⁰ 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.

Access to Testing and HIV/AIDS Education

Contributing to the problem of access to testing for Aboriginal people is a continuing lack of HIV/AIDS education in many Aboriginal communities. Educational 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.

The Aboriginal Nurses Association of Canada makes education the central recommendation of its report on HIV/AIDS and Aboriginal women:

a broad-based education program must be developed to prevent the potentially devastating spread of HIV/AIDS throughout Canada's Aboriginal community.⁴⁰

Education of individuals is not the only aspect of this issue. Some of the people consulted indicated that community health representatives (CHRs) and community health nurses (CHNs) often require additional training about HIV/AIDS issues and counselling. Others reported stories of doctors refusing to give an HIV test because a person was not perceived to be at risk, and of doctors refusing to be part of care, treatment and support initiatives. Medical practitioners must continue to be educated about HIV/AIDS and trained to provide testing that is voluntary, confidential and accompanied by skilled counselling. This may increase the comfort level around HIV testing.

Conclusions

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. Mobile testing is discussed in more detail in the chapter on Confidentiality, below.

- 2.1 Barriers to HIV testing for Aboriginal people need to be removed. Aboriginal AIDS organizations and others in the Aboriginal community should be consulted to determine the best approach to improve the accessibility of HIV testing for Aboriginal people.
- 2.2 Provincial, territorial, federal and Aboriginal government health providers should work together to develop accessible options for HIV testing, including anonymous testing. At a minimum, this would involve the establishment of anonymous HIV testing facilities in various locations in each province and territory, and a commitment to encourage and facilitate anonymous testing to the greatest extent possible.
- 2.3 HIV/AIDS education for Aboriginal communities should continue to be emphasized in order to help reduce stigmatization related to HIV testing.

HOW SHOULD VOLUNTARY TESTING BE DONE? COUNSELLING

The Network Report suggests that despite a broad consensus that HIV testing should only be undertaken with pre- and post-test counselling, 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 persons who seek testing may in fact discourage some people from being tested.”⁴¹ After examining the issues, the Network Report concludes that pre- and post-test counselling should not be seen as barriers to HIV testing and that “as a general rule, testing should be undertaken only with quality pre- and post-test counselling.”⁴² The consultations conducted for this paper suggest that this conclusion applies with equal force to Aboriginal people.

⁴¹ Supra, note 1 at 73.

⁴² Ibid at 82.

Pre- and Post-Test Counselling

Many of those consulted indicated that adequate pre- and post-test counselling is not being provided by all health-care practitioners and that the quality of counselling is greater in testing clinics. This is evident both in small communities and in cities.

An 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 and CHRs are not comfortable with HIV/AIDS issues and do not have adequate counselling skills.

As discussed above, HIV/AIDS education for health-care practitioners is a much-needed and continuing process.⁴³

LaVerne Monette suggests that many Aboriginal people may be more comfortable receiving counselling from Aboriginal counsellors, as cultural differences may affect the success and value of counselling sessions. Many Aboriginal people are available for training as counsellors, some of whom have experience with HIV issues.⁴⁴

The *Guidelines for the Delivery of HIV/AIDS Programs and Services* issued by MSB (the MSB Guidelines) 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.”⁴⁵ Aboriginal counsellors are the most capable of meeting these requirements. Some concerns about confidentiality may arise, however, where the counsellor and patient share the same community.

⁴³ MSB supports training sessions for community health-care workers in reserve communities. The National Indian and Inuit Community Health Representatives Organization is also involved in CHR training.

⁴⁴ Supra, note 21.

⁴⁵ Supra, note 33 at 39.

Conclusions

Aboriginal people require accessible options for counselling as much as for HIV testing generally. Some may prefer Aboriginal counsellors in their community; others may want to visit Aboriginal or non-Aboriginal counsellors in mainstream facilities in order to increase the sense of confidentiality. These options should be made accessible.

3.1 As a general rule, HIV testing should be undertaken only with quality pre- and post-test counselling. Those who may provide pre- and post-test counselling to Aboriginal people should receive training in cultural sensitivity and/or be of Aboriginal descent. It is preferable that more Aboriginal people be trained to provide counselling in Aboriginal communities and in facilities used by Aboriginal people.

3.2 Aboriginal people who wish to be tested should have a number of counselling options at their disposal, including counselling in their communities or in mainstream facilities.

HOME TESTING FOR HIV

The Network Report examines issues related to new testing technologies that make HIV testing at home a possibility. The term “HIV home testing” refers to two different forms of testing:⁴⁶

- Home Sample Collection (or Home-Access) Testing is a system whereby a person collects his/her sample at home using a home collection kit. The sample is then sent to a testing facility where the person can call for the result and receive phone counselling.
- True Home Testing, also referred to as Home Self-Testing (or Home Validated Testing) involves saliva-based testing that can be carried out entirely at home without the involvement of an outside party. If a test result is positive the person is encouraged to visit a physician or an HIV clinic for further testing.

Although home test kits have not been approved in Canada, they have been approved and on sale in the United States since mid-1996. Among its conclusions, the Network Report states that the introduction of home test kits “carries many risks that need to be better assessed before they are made widely available in Canada.”⁴⁷ As part of this assessment process it is important to consider the implications of home testing for Aboriginal people.

⁴⁶ The different forms of HIV testing are discussed in detail in the Network Report, *supra*, note 1 at 89-90.

⁴⁷ *Ibid*, Conclusion 4.1 at 110.

Home Testing and Aboriginal People

Most of the people consulted do not support home testing as an alternative for Aboriginal people who wish to be tested for HIV. The concerns of those consulted are reflected in the following statements:

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.

Art Zoccolle stated that home testing kits could be disastrous for Aboriginal people.⁴⁸ There is a disproportionately high suicide rate in the Aboriginal community.⁴⁹ 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. The added possibility of inaccuracy suggests that the advent of home testing kits should be met with caution.

⁴⁸ *Supra*, note 15.

⁴⁹ For a discussion of suicide in the Aboriginal community, see Clare Clifton Brant. *Suicide in Canadian Aboriginal Peoples: Causes and Prevention*. In: *The Path to Healing. Report of the National Round Table on Aboriginal Health and Social Issues*. Ottawa: Minister of Supply and Services, 1993, at 55-72. She describes a suicide rate three times higher than in the non-Aboriginal population, and notes the difficulty of finding accurate data on this.

A number of potential benefits of home testing were identified during the consultation process:

Home test kits may facilitate testing by some people who might not get tested otherwise.

Home testing may help overcome problems of cost and remoteness that presently hamper testing, particularly if it is combined with “live” counselling with a person trained to provide HIV counselling in the community.

However, these benefits do not outweigh the concerns about counselling and wrong or misunderstood results. 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. 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.

Conclusions

- 4.1 Further consultations are necessary to assess the level of support for home testing among Aboriginal people working in the HIV/AIDS field.
- 4.2 Any assessment of the desirability of home testing for the Canadian market should take into account the concerns of Aboriginal people and be undertaken with the participation of members of the Aboriginal community.
- 4.3 Home testing should not be used as an excuse for a failure to establish testing and counselling facilities that are accessible to Aboriginal people.

MANDATORY OR COMPULSORY HIV TESTING

Proposals for mandatory or compulsory testing that have most frequently been made in Canada are thoroughly analyzed in the Network Report and readers are referred to that document for more information about the issue.

The Network Report concludes that mandatory or compulsory testing of pregnant women, newborns, prisoners, persons accused or convicted of sexual assault, sex workers, health-care workers, and/or immigrants is not justified.

[J]ustification 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.⁵⁰

In 1990 the JNCAAEP reported the following concerns expressed by the indigenous peoples of Australia:

There was concern expressed that Aboriginal people would be coerced into being tested for HIV infection without individual and informed consent. Communities were of the view that, where community screening had taken place, those who were most at risk were least likely to present for testing. However, when testing was voluntary and encouraged in a positive way, those at risk were likely to attend.⁵¹

⁵⁰ Supra, note 1 at 122.

⁵¹ Department of Community Services and Health. *Report of the Working Panel on Aboriginals, Torres Strait Islanders and HIV/AIDS*. Commonwealth of Australia, 1989, cited in JNCAAEP, supra, note 17 at 104.

To the author's best knowledge, there have been no suggestions in Canada of mandatory testing of Aboriginal people and no one consulted expressed any concern that such a course of action would be proposed. It would be shocking if it ever were.⁵² 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.

The bad experiences of many Aboriginal people with the mainstream health-care system suggest that some Aboriginal people may be particularly vulnerable to testing that is not conducted in accordance with principles of voluntary specific informed consent and adequate pre- and post-test counselling. A number of provinces and territories are considering introducing policies for routine testing of pregnant women. It is important to ensure that in all cases testing is based on voluntary specific informed consent.⁵³

⁵² It would also be contrary to principles of human rights and to human rights legislation, including the *Canadian Charter of Rights and Freedoms*.

⁵³ Another testing issue that may raise concerns for Aboriginal people is that related to foster children. It is important to examine issues related to Aboriginal foster children and HIV/AIDS. Aboriginal people should be involved in the process and in the development of any guidelines for HIV testing of children under the care of the state. The issue was raised by Albert McLeod (personal communication, 3 September 1997) and by Arlo Yuzicapi Fayant (personal communication, 2 February 1999). The issue has not been reviewed in detail in this paper.

Conclusions

5.1 Justification for mandatory or compulsory testing remains weak. Due to the overrepresentation of Aboriginal people among groups vulnerable to proposals for mandatory or compulsory testing, Aboriginal AIDS organizations and others from the Aboriginal community need to remain vigilant against such proposals.

5.2 Proposals for the mandatory or compulsory testing of racial groups cannot be justified, and is harmful to the group, to a human rights-based approach to the HIV/AIDS epidemic, and to society generally.

CONFIDENTIALITY

Legislation and commentary in Canada on issues of confidentiality and HIV/AIDS, including reporting requirements, partner notification, and the law of confidentiality, are examined in the Network Report. What follows is not a reexamination of these issues but an assessment of the comments received from the persons interviewed for this paper and an outline of confidentiality issues for Aboriginal people.

The Importance of Confidentiality

Confidentiality was identified as a key issue. Due to discrimination and stigmatization of HIV/AIDS, confidentiality is critical to increasing the number of people being tested. Many of the people in Aboriginal communities, as in the rest of the Canadian population, most at risk of HIV infection are members of groups that are already marginalized. The additional effects of racism and poor health, social and economic conditions experienced by many Aboriginal people, make Aboriginal street-involved people, some members of the two-spirited community, and some Aboriginal women, among the most marginalized groups in Canada.

Although the assurance of confidentiality is important in encouraging people to submit to HIV testing, it is also important to note the significance of Aboriginal traditions that place an emphasis on collective over individual rights. In one situation that arose in Baffin Island, the local health board, representing the predominantly Inuit communities of the island, clashed with the Minister of Health of the Northwest Territories over confidentiality regarding one case of AIDS and two cases of HIV infection.

Some Inuit members of the Baffin board supported reporting the names of the people with HIV and identifying their home communities in order to protect members of the communities. After some discussion, the consensus was reached among the members of the board that the communities should be identified but not the HIV-positive individuals, on the ground that people in the smaller Baffin communities might otherwise continue to assume they were not at risk for HIV. The Minister of Health objected to this course of action and requested time to develop a response to the issue. The board decided to proceed without the Minister's endorsement and issued a press release stating that one case of AIDS and two cases of HIV infection had been reported in the Baffin region, without identifying the home communities of the individuals involved.⁵⁴ O'Neill argues that in cross-cultural contexts HIV/AIDS-related issues and confidentiality are "more complicated because of different moral standards and ideas about individual versus collective responsibilities and rights."⁵⁵

In some situations, the significance of collective rights might lead to inappropriate suggestions such as banning HIV-positive individuals or refusing them housing on reserve. Education about HIV/AIDS is helpful in avoiding such responses and in developing an ethic of confidentiality. LaVerne Monette suggests that where Aboriginal traditions about health and community are respected, inappropriate responses are replaced by caring, compassion, and community support for people living with or affected by HIV/AIDS.⁵⁶ In such situations, confidentiality becomes less of an issue.

So long as discrimination and stigmatization persist, however, confidentiality will be crucial. In many situations, although confidentiality may be respected by health practitioners, it may be lost for other reasons. Education about HIV/AIDS issues is therefore also essential.

Concerns about Confidentiality

Due to the potential social, financial, and health consequences to an individual of testing positive, confidentiality is particularly important with respect to HIV/AIDS. For many reasons, however, protecting confidentiality is very difficult and often unrealistic.⁵⁷ What follows is an assessment of the concerns about confidentiality expressed by those consulted for this paper.

⁵⁴ The controversy is discussed in John D O'Neill. Regional Health Boards and the Democratization of Health Care in the Northwest Territories. *Circumpolar Health 90: Proceedings of the 8th International Congress on Circumpolar Health*. Brian D Postl et al (eds). Winnipeg: University of Manitoba Press, 1991, at 52 to 53. These were the first case of AIDS and first two cases of HIV infection reported in the Baffin region.

⁵⁵ Ibid at 52.

⁵⁶ Supra, note 20.

⁵⁷ Supra, note 1 at 219. It is noted in the Network Report that confidentiality has been referred to as a "decrepit concept."

Confidentiality and Health Practitioners

The Network Report comments that confidentiality in health care is dealt with in a number of ways. In some provinces, provisions in public health legislation impose a duty of confidentiality on public health officials. Many of these provisions are weakened by exceptions permitting confidential information to be disclosed “in the public interest.” In a number of provinces and territories there are no provisions in public health acts specifically protecting confidentiality.⁵⁸

In addition, physicians have a legal and ethical duty of confidentiality to their patients. However, the Privacy Commissioner of Canada has taken the position that privacy sometimes must give way to other social goods.⁵⁹ The implication is that there are situations in which a breach of confidentiality is thought to be justified. The Network Report states that 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.”⁶⁰

The reality of the situation for Aboriginal people is best illustrated by the following stories, some of which relate to practitioners other than physicians:

A doctor in a Maritime community disclosed the HIV status of an Aboriginal child to a relative. The information spread throughout the non-Aboriginal community in which the child was attending daycare. Some parents pulled their children out of the daycare.

In some communities the CHN or CHR is the last person you want to talk to about your HIV status. A CHN in one community spread misinformation about HIV/AIDS, causing some community hysteria. In other communities the CHN or CHR may simply be someone you are acquainted with – it may be your relative, a friend, or your mother.

The relationship of Aboriginal people to Western medical practice has often been poor. People often do not trust doctors and nurses who travel periodically in and out of communities or who often change due to high turnover rates. Three doctors in a small town refused to give the test for HIV due to their reluctance to become involved in HIV/AIDS issues.

⁵⁸ Ibid at 213.

⁵⁹ Ibid at 215, citing The Privacy Commissioner of Canada. *AIDS and the Privacy Act*. Ottawa: Minister of Supply and Services, 1989.

⁶⁰ Ibid at 219.

Although there are some disturbing stories, it was emphasized by some of those interviewed that concerns about confidentiality are often based on the misperception that health-care practitioners do not respect confidentiality policies and duties. It was often reported that in practice most practitioners are professional in this regard. In this case, the development of confidentiality policies may help lower concerns about the perceived inability of health workers to maintain the confidentiality of patients. Christina Smeja indicates that such policies help develop trust in the system and help reduce concerns that confidentiality will be breached by the person conducting the HIV test.⁶¹

The need for confidentiality policies has been widely recognized. A recommendation that emerged from the Second Canadian Conference on AIDS and Related Issues in the Aboriginal Community in 1991 was that communities should establish guidelines on the confidentiality of HIV test results.⁶² HIV testing protocols that include confidentiality provisions have been developed by such Aboriginal organizations as the Cree Health Board in Québec⁶³ and the Union of Ontario Indians.⁶⁴

The MSB Guidelines set out procedures for HIV testing, counselling, and confidentiality. They are intended to assist the delivery of HIV/AIDS programs and services by MSB staff in communities in which MSB continues to be responsible for the direct delivery of health services. “First Nations and Inuit health organizations might use the [MSB Guidelines] as a starting point for consultation and development of their own HIV guidelines, as their communities assume control of health services” through the health transfer process.⁶⁵

Many communities already have confidentiality guidelines and those that do not can seek the assistance of MSB to develop policies. In all cases, it is important that confidentiality policies affecting Aboriginal people be ratified by Aboriginal governments, where applicable, and be designed and implemented, predominantly at least, by members of Aboriginal communities.

⁶¹ Personal communication with Christina Smeja, 18 July 1997.

⁶² Reported in: *Aboriginal HIV/AIDS Strategy: Summary of Existing Recommendations*. Toronto: Ontario Ministry of Health, September 1993.

⁶³ *Supra*, note 36. Christina Smeja notes that the Cree Health Board has actually developed an anonymous protocol in that the code for the test is known only to the patient and there is no record in the nominal file. The purpose of the protocol is to ensure confidentiality and the confidence of the population in the confidentiality.

⁶⁴ *Regional HIV/AIDS Protocol for Robinson-Superior Region Health Workers*. Union of Ontario Indians, January 1994.

⁶⁵ *Supra*, note 33 at 33-55.

Confidentiality and Community

Many confidentiality problems come down to the difficulty of remaining anonymous in small communities. An active rumour mill is common in many small towns and Northern and reserve communities. Confidentiality is often breached by friends, relatives or acquaintances outside the health centre or testing clinic. Confidentiality of test results may be compromised in other ways as well:

Under health transfer initiatives, bills for health services may be sent back to the band council of the person being tested.

In order to be compensated under the Non-Insured Health Benefits Program (NIHB) for transportation to a testing facility, a medical reason for the claim must be provided. There is no assurance that medical carriers (drivers) under this program will respect confidentiality.

As suggested above, education is important in reducing the impact of a loss of confidence. Art Zoccole notes that education is important in demystifying HIV/AIDS and in reducing the amount of mean or misinformed gossip.⁶⁶ In a world in which HIV/AIDS is understood and accepted, confidentiality is a less important issue.

Human rights legislation may also be useful in assisting a person living with HIV/AIDS whose confidentiality is breached. For a variety of reasons, however, most of those consulted for this paper considered the human rights system to be an unhelpful tool for Aboriginal people who experience discrimination.⁶⁷

Some suggested that mobile testing units should be considered for their potential to overcome some of the problems respecting HIV testing and Aboriginal communities, particularly communities with a small population. An example of such a model operates in the Sandy Lake (Athakakoop) Reserve and Beardy's Reserve in north-central Saskatchewan.

Marlene Allen, a nurse at the Prince Albert STD Clinic who operates the mobile unit, indicates that the unit combines anonymous HIV testing with testing for STDs and counselling about sexuality and other issues.⁶⁸ It visits Sandy Lake one day every two weeks and Beardy's one day every month and is extremely well attended in both communities, particularly by young people. Allen estimates that 70 percent of users are youth.⁶⁹ This mobile testing unit model continues to operate out of the Prince Albert STD Clinic and is now being examined as a model for mobile HIV testing in south-central Saskatchewan, with the support of MSB and a number of community-based HIV/AIDS organizations, including All Nations Hope.⁷⁰ Despite its success and growing popularity among First Nations communities in the project area, to the writer's best knowledge there is no other such initiative in Canada.

⁶⁶ *Supra*, note 15.

⁶⁷ This issue is examined in more detail in: Stefan Matiation. *Discrimination, HIV/AIDS and Aboriginal People*. Second edition. Montréal: Canadian HIV/AIDS Legal Network and Canadian Aboriginal AIDS Network, 1999.

⁶⁸ The information about the mobile unit operating in Sandy Lake and Beardy's Reserve was provided by Marlene Allen (personal communication, 23 September 1997) and Arlo Yuzicipi Fayant (personal communication, 16 September 1997).

⁶⁹ The mobile units operate outside the jurisdiction of the District Health Board that pays for the program. There is reason to be concerned that the District may discontinue funding for the project on this basis, as District managers do not necessarily see HIV as a priority in the region (personal communication with Marlene Allen, 23 September 1997).

⁷⁰ Personal communication with staff at the Prince Albert STD Clinic, 19 February 1999, and with Marlene Allen, 23 February 1999.

It was also suggested during the consultation process that the location of a testing site is important in assuring confidentiality.⁷¹ In Sandy Lake, the mobile unit is set up in a location that is accessible and private for students at the local high school, and on days when there is a lot of activity in the health centre due to the presence of other health-care providers such as doctors and dentists.⁷²

Conclusions

6.1 Aboriginal AIDS organizations and others from the Aboriginal community should be consulted as to how confidentiality can be breached by seemingly innocuous policies, such as the NIHB policy that a medical reason must be given to justify a claim for reimbursement for medical transportation. Such policies should be reviewed with a view to increasing confidentiality.

6.2 Education about HIV/AIDS issues is an important component in reducing the impact of loss of confidentiality on people living with or affected by HIV/AIDS, and in reducing discrimination and improving a community's response to HIV/AIDS.

6.3 Where they have not already done so, health-care facilities that provide services to Aboriginal people and Aboriginal communities should be encouraged to develop confidentiality policies.

6.4 Mobile testing units should be examined for their potential to overcome some of the problems related to HIV testing and Aboriginal communities. Aboriginal AIDS organizations and others from the Aboriginal community should be involved in this process.

⁷¹ Personal communication with April St. Denis, Community Animator with the Manitoba Aboriginal AIDS Task Force, 5 September 1997.

⁷² Personal communication with Marlene Allen, *supra*, note 70.

Reporting Requirements

HIV/AIDS reporting requirements fall under provincial jurisdiction whether a test is conducted on or off reserve. AIDS cases are reportable by name to public health authorities in all provinces and territories except Québec, Alberta, and Yukon, where reporting is non-nominal. HIV is reportable in all provinces and territories except Québec, British Columbia, and Yukon.⁷³

It was suggested during the consultation process that nominal reporting drives people away from HIV testing and early treatment of HIV, particularly in communities in which HIV/AIDS-related discrimination and fear are highest, including many predominantly Aboriginal communities and communities in which Aboriginal people live. The Network Report concludes that reporting of HIV and AIDS should always be non-nominal.⁷⁴ Such a conclusion should also be drawn with respect to HIV testing and Aboriginal people.

Partner Notification

The Network Report concludes that

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*.⁷⁵

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 without at least monitoring current funding levels for support programs.⁷⁶

These conclusions apply equally to Aboriginal people. While partner notification is important in some cases, it should not be used to detract from educational efforts. LaVerne Monette suggests that personal responsibility is the surest defence against the spread of HIV.⁷⁷ It is important to empower people living with HIV/AIDS to conduct partner notification themselves, as far as possible, and to empower people to protect themselves.

⁷³ From written submissions of Mai Nguyen, 22 December 1997, *supra*, note 19. See also the Network Report, *supra*, note 1 at 231-233 for more detailed information.

⁷⁴ *Ibid* at 237.

⁷⁵ The *Guidelines for Practice for Partner Notification in HIV/AIDS* were prepared by the Members of the Federal/Provincial/Territorial Advisory Committee on AIDS Working Group on Partner Notification. Ottawa: Health Canada, January 1997.

⁷⁶ *Supra*, note 1 at 253, Conclusions 14.1 and 14.4.

⁷⁷ *Supra*, note 20.

Partner notification can raise difficult issues in Aboriginal communities. In smaller communities, for example, confidentiality is soon lost when notification procedures begin, as everyone often knows everyone else. Tammy Abram, Family Liaison Worker with the Atlantic First Nations AIDS Task Force, suggested that in such cases it may be better for a health-care worker or physician to conduct notification without using any names.⁷⁸ Even in this scenario a witch hunt may ensue, to the detriment of the community.

Partner notification may also be complicated by the high incidence of sexual assault found in many Aboriginal communities, the disproportionate rate of incarceration experienced by Aboriginal people, and the high rates of STDs and teen pregnancies within Aboriginal communities. Further, a history of sexual, physical, drug and/or alcohol abuse, experiences of marginalization and racism, and cultural dislocation can all affect the ability of an Aboriginal person to protect him/herself against HIV and to conduct partner notification.

Aboriginal people need to be involved in the development of solutions to the issues raised by partner notification in Aboriginal communities. This point was recognized in the 1997 *Guidelines for Practice for Partner Notification in HIV/AIDS*, which emphasize that “involved communities must participate from the outset in the discussions and decision-making process around partner notification.”⁷⁹

Conclusions

7.1 The reporting of HIV and AIDS cases should always be done on a non-nominal basis. All provinces and territories should be encouraged to adopt such a policy.

7.2 Partner notification programs should be implemented in every jurisdiction in Canada. These programs should not detract from HIV/AIDS education efforts. Aboriginal AIDS organizations and others from the Aboriginal community should be involved in and guide the development of solutions to issues raised by partner notification in Aboriginal communities.

⁷⁸ Personal communication with Tammy Abram, 30 July 1997.

⁷⁹ *Supra*, note 75 at 8.

SUMMARY OF CONCLUSIONS

Most testing and confidentiality issues relevant to the general population are also relevant to Aboriginal people. However, these issues must be approached within a different context. The Aboriginal community has suffered from oppression, racism and colonialism in its relations with the rest of Canada. This has had a devastating impact on the well-being of Aboriginal people and on the cultural integrity of their communities. Aboriginal people are overrepresented among the marginalized in Canada, and often experience poorer socioeconomic conditions than the majority of Canadians. These factors make many Aboriginal people more vulnerable to HIV.

Aboriginal people in Canada face additional barriers to testing that is (a) accessible, (b) based on the principles of specific informed consent and respect for confidentiality, and (c) accompanied by culturally reflective pre- and post-test counselling.

The HIV testing currently available to Aboriginal people is inadequate for a variety of reasons, including: the remoteness of some communities, cultural differences, and a failure on the part of the health-care system to address the specific needs of the Aboriginal community with respect to HIV testing. As a result, despite rising numbers of HIV and AIDS cases in their community, many Aboriginal people are reluctant to get tested for HIV.

In order to reduce the spread of HIV among Aboriginal people and to provide timely care, treatment and support to those already living with HIV or AIDS, barriers to HIV testing for Aboriginal people must be reduced.

The conclusions set out in the paper are reprinted below:

1. Consent

1.1 Arguments for specific informed consent are as pertinent for Aboriginal people as for the rest of the population of Canada. As a general rule, HIV testing should only be undertaken with the specific informed consent of the person being tested. All health-care facilities that administer to Aboriginal people should be encouraged to adopt policies specifying that HIV testing should only be undertaken with the specific informed consent of the person being tested.

1.2 The general rule that HIV testing should only be conducted based on specific informed consent does not apply to the testing of donors of blood, organs, semen, or similar bodily products.

1.3 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. Anonymous Testing and Access to Testing

2.1 Barriers to HIV testing for Aboriginal people need to be removed. Aboriginal AIDS organizations and others in the Aboriginal community should be consulted to determine the best approach to improve the accessibility of HIV testing for Aboriginal people.

2.2 Provincial, territorial, federal and Aboriginal government health providers should work together to develop accessible options for HIV testing, including anonymous testing. At a minimum, this would involve the establishment of anonymous HIV testing facilities in various locations in each province and territory, and a commitment to encourage and facilitate anonymous testing to the greatest extent possible.

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

3. Counselling

3.1 As a general rule, HIV testing should be undertaken only with quality pre- and post-test counselling. Those who may provide pre- and post-test counselling to Aboriginal people should receive cultural sensitivity training and/or be of Aboriginal descent. It is preferable that more Aboriginal people be trained to provide counselling in Aboriginal communities and in facilities used by Aboriginal people.

3.2 Aboriginal people who wish to be tested should have a number of counselling options at their disposal, including counselling in their communities or in mainstream facilities.

4. Home Testing for HIV

4.1 Further consultations are necessary to assess the level of support for home testing among Aboriginal people working in the HIV/AIDS field.

4.2 Any assessment of the desirability of home testing for the Canadian market should take into account the concerns of Aboriginal people and be undertaken with the participation of members of the Aboriginal community.

4.3 Home testing should not be used as an excuse for a failure to establish testing and counselling facilities that are accessible to Aboriginal people.

5. Mandatory or Compulsory Testing

5.1 Justification for mandatory or compulsory testing remains weak. Due to the overrepresentation of Aboriginal people among groups vulnerable to proposals for mandatory or compulsory testing, Aboriginal AIDS organizations and others from the Aboriginal community need to remain vigilant against such proposals.

5.2 Proposals for the mandatory or compulsory testing of racial groups cannot be justified, and is harmful to the group, to a human rights-based approach to the HIV/AIDS epidemic, and to society generally.

6. Confidentiality

- 6.1 Aboriginal AIDS organizations and others from the Aboriginal community should be consulted as to how confidentiality can be breached by seemingly innocuous policies, such as the NIHB policy requiring that a medical reason be given to justify a claim for reimbursement for medical transportation. Such policies should be reviewed with a view to increasing confidentiality.
- 6.2 Education about HIV/AIDS issues is an important component in reducing the impact of loss of confidentiality on people living with or affected by HIV/AIDS, and in reducing discrimination and improving a community's response to HIV/AIDS.
- 6.3 Where they have not already done so, health care facilities that provide services to Aboriginal people and Aboriginal communities should be encouraged to develop confidentiality policies.
- 6.4 Mobile testing units should be examined for their potential to overcome some of the problems related to HIV testing and Aboriginal communities. Aboriginal AIDS organizations and others from the Aboriginal community should be involved in this process.

7. Reporting and Partner Notification

- 7.1 The reporting of HIV and AIDS cases should always be done on a non-nominal basis. All provinces and territories should be encouraged to adopt such a policy.
- 7.2 Partner notification programs should be implemented in every jurisdiction in Canada. These programs should not detract from HIV/AIDS education efforts. Aboriginal AIDS organizations and others from the Aboriginal community should be involved in and guide the development of solutions to issues raised by partner notification in Aboriginal communities.

BIBLIOGRAPHY

I. Legislation

Constitution Act, 1867 (UK), 30 & 31 Vict c 3.

Constitution Act, 1982, being Schedule B to the *Canada Act 1982* (UK), 1982, c 11.

II. Reports and Policy Statements

Aboriginal Health Office. *Aboriginal HIV/AIDS Strategy: Summary of Existing Recommendations*. Toronto: Ontario Ministry of Health, September 1993.

Aboriginal Nurses Association of Canada. *HIV/AIDS and its Impact on Aboriginal Women in Canada*. Ottawa: Minister of Health Canada, March 1996.

BC Aboriginal HIV/AIDS Task Force. *Workplan 1997-1998*. Vancouver: The Project Coordinator, July 1997.

Evaluation of the Native AIDS Coordinator Program. Vancouver: The Vancouver Native Health Society and St. Paul's Hospital, 8 February 1994.

Expert Committee on AIDS and Prisons. *HIV/AIDS in Prisons: Final Report of the Expert Committee on AIDS and Prisons*. Ottawa: Correctional Services Canada, February 1994.

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.

First Nations Health Secretariat. *Background Paper for the 18th Annual General Assembly*. Ottawa: Assembly of First Nations, July 1997.

BIBLIOGRAPHY

Healing Our Nations: Proceedings of the 4th Canadian Aboriginal Conference on HIV/AIDS and Related Issues. 9-13 November 1996.

Joint National Committee on Aboriginal AIDS Education and Prevention (JNCAAEP). *Findings Document.* Ottawa: Health and Welfare Canada, 1990.

JNCAAEP. *Recommendations for a National Strategy on Aboriginal AIDS Education and Prevention.* Ottawa: Health and Welfare Canada, 1990.

Laboratory Centre for Disease Control. *Epi Update.* Ottawa: Health Canada, May 1997.

Manitoba Department of Family Services. *Draft Program Standards Manual: HIV/AIDS and Other Blood-Borne Pathogens.* Unpublished draft, September 1996.

McLeod, Albert. *Aboriginal Communities and HIV/AIDS. A joint project with the Canadian AIDS Society and the Canadian Aboriginal AIDS Network: Final Report.* Ottawa: Canadian AIDS Society, 1997.

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

Myers, Ted, Liviana Calzavara et al. *Ontario First Nations AIDS and Healthy Lifestyle Survey.* Toronto, 1993.

Native Women's Association of Canada (NWAC). *NWAC HIV/AIDS Strategy.* Beverly Blanchard & Associates, October 1996.

Ontario Aboriginal HIV/AIDS Strategy. Toronto: The Strategy, 1996.

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

Regional HIV/AIDS Protocol for Robinson-Superior Region Health Workers. Union of Ontario Indians, January 1994.

Royal Commission on Aboriginal Peoples (RCAP). *Final Report.* Ottawa: Minister of Supply and Services, 1996.

RCAP. *The Path to Healing: Report of the National Round Table on Aboriginal Health and Social Issues.* Ottawa: Minister of Supply and Services Canada, 1993.

III. Books and Articles

2-Spirited Peoples of the 1st Nations (TPFN). *The Social, Moral, Ethical and Legal Implications of Conducting Blind HIV Seroprevalence Studies in Aboriginal Communities*. Toronto: TPFN, November 1996.

Jürgens, Ralf. *HIV Testing and Confidentiality: Final Report*. Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1998.

O'Neill, John D. Regional Health Boards and the Democratization of Health Care in the Northwest Territories. *Circumpolar Health 90: Proceedings of the 8th International Congress on Circumpolar Health*. Brian D Postl et al (eds). Winnipeg: University of Manitoba Press, 1991, 50-53.

APPENDIX

List of People Consulted

- Tammy Abram**
Atlantic First Nations AIDS Task Force
Halifax, Nova Scotia
- Darcy Albert**
2-Spirited Peoples of the 1st Nations
Toronto, Ontario
- Marlene Allen**
Prince Albert STD Clinic
Prince Albert, Saskatchewan
- Barbara Ames**
AIDS Yukon Alliance
Whitehorse, Yukon
- Lina Azzimatturo**
Chez Doris
Montréal, Québec
- Kevin Barlow**
Canadian Aboriginal AIDS Network
Ottawa, Ontario
- Catherine Blackstock**
Healing Our Spirit BC First Nations
AIDS Society
North Vancouver, British Columbia
- Cathie Carlick**
AIDS Yukon Alliance
Whitehorse, Yukon
- Laura Commanda**
Health Canada
Ottawa, Ontario
- Joyce Courchene**
Community Health Representative
Fort Alexander, Manitoba
- Jo-Ann Daniels**
Feather of Hope Aboriginal AIDS
Prevention Society
Edmonton, Alberta
- Marcel Dubois**
Medical Services Branch
Health Canada
Ottawa, Ontario
- Janet Dunbrack**
Health Canada
Ottawa, Ontario
- Annie Evans**
Community Health Representative
Labrador Inuit Health Commission
Labrador
- Arlo Yuzicapi Fayant**
All Nations Hope AIDS Network
Regina, Saskatchewan
- Sandra Greene**
Canadian Aboriginal AIDS Network
Ottawa, Ontario
- Roda Grey**
Pauktuutit
Inuit Women's Health Association
Ottawa, Ontario

APPENDIX

Morgan Hare

Tungasuvvingat Inuit
Ottawa, Ontario

Robert Hay

AIDS Yellowknife
Yellowknife, NWT

Margaret Horn

National Indian and Inuit Community
Health Representatives Organization
Kahnawake, Québec

Tom Howe

Atlantic First Nations AIDS Task Force
Halifax, Nova Scotia

Robert Imrie

Cree Board of Health and Social Services
of James Bay
Montréal, Québec

Denise Lambert

Alberta Aboriginal AIDS Strategy
Onoway, Alberta

Pat Matusko

CDC Unit, Public Health Branch
Manitoba Health
Winnipeg, Manitoba

Albert McLeod

Manitoba Aboriginal AIDS Task Force
Winnipeg, Manitoba

LaVerne Monette

Ontario Aboriginal HIV/AIDS Strategy
Toronto, Ontario

Mai Nguyen

Laboratory Centre for Disease Control
Health Canada
Ottawa, Ontario

Earl Nowgesic

Laboratory Centre for Disease Control
Health Canada
Ottawa, Ontario

Marion Perrin

Medical Services Branch
Alberta Aboriginal AIDS Strategy
Edmonton, Alberta

Irene Peters

Ontario First Nations HIV/AIDS
Education Circle
London, Ontario

Judith D Ross

Medical Services Branch
Health Canada
Ottawa, Ontario

April St. Denis

Manitoba Aboriginal AIDS Task Force
Winnipeg, Manitoba

Catherine Spence

Thompson AIDS Project
Thompson, Manitoba

Christina Smeja

Cree Board of Health and Social Services
of James Bay
Montréal, Québec

Louisa Ukalianuk

Pauktuutit Inuit Women's Association
Ottawa, Ontario

Art Zoccole

B.C. Aboriginal HIV/AIDS Task Force
Vancouver, British Columbia