The Privacy Commissioner
of Canada

AIDS

and the Privacy Act

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Cat. No. IP34-1/1989

ISBN 0-662-56581-9

ACKNOWLEDGEMENTS

The Privacy Commissioner gratefully acknowledges the work of Eugene Oscapella, LL.M, both his preparation of the initial discussion paper and his contributions to the report itself.

The Commissioner is also grateful to the following federal government departments for their helpful comments on the discussion paper:

Correctional Service Canada

Employment and Immigration Canada

External Affairs Canada

External Affairs Canada

Health and Welfare Canada (in particular the Federal Centre for AIDS)

Department of Justice Canada

National Defence

Statistics Canada

Treasury Board of Canada

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FOREWORD

AIDS has presented a host of unanticipated and unwanted challenges to the global community. Scientists, physicians, legislators, ethicists and lawyers are grappling with these challenges, often with little or no precedent to guide them. Compounding this difficulty is the aura of fear surrounding the syndrome, and the consequential danger of discrimination against those tainted by even a remote association with AIDS.

Among the AIDS-related issues being thrust upon society are those relating to privacy. Public reactions to this lethal syndrome are anything but predictable. Some reactions are extreme -- refusals to let lodgings to an infected person, refusals to work in the same office and refusals to provide basic public services, such as education, ambulance, fire and police services and hospital care. HIV infected persons may see their travel to foreign countries restricted. Disclosure of their infection may lead to criticism of their perceived lifestyle. Unnecessary publicity may (some say will) cause an infected person immense trauma beyond that caused by living with the infection itself.

The unpredictability of the public (and government) reaction to AIDS creates a compelling need to examine the privacy interests associated with the syndrome. Few among us might object to others knowing that we have a common cold. We might criticize the collection of this information by government as being intrusive. We would, however, face little prospect of discrimination. Yet how many among us would remain as unconcerned if information were released identifying us as carriers of the HIV -- the virus that causes AIDS?

This report examines the implications of the *Privacy Act* for the federal government's collection, use and disclosure of "AIDS-related personal information". Our concern is to ensure to the extent possible that individual privacy is not trampled as we seek to head off the AIDS epidemic in Canada. In the language of the *Privacy Act*, our concern is to identify what personal information should be collected, used and disclosed to prevent the further spread of HIV infection in Canada. The conflicting faces of the issue are immediately apparent.

The *Privacy Act* seeks to protect individuals from federal government institutions which, without sufficient cause, may want to snoop into their affairs and amass information about them. Nowhere are the dangers of amassing personal information more real than in the context of AIDS-related personal information.

The collection of this information is itself intrusive; at present it requires the taking of a person's blood. The uses of this information are manifold -- and not all benefit the individual affected or, indeed, the public. The consequences of disclosure can be dramatic. They have the potential to alter the very conditions of membership in society.

While the Privacy Commissioner of Canada is mandated to ensure that the rights which the *Privacy Act* gives every Canadian are preserved, notably the protection against unwarranted government prying into personal information, privacy sometimes must give way to other social goods. In particular, privacy must be balanced against the need to

permit the collection, use and disclosure of personal information as part of an effective public health response to AIDS.

This report assesses the collection, use and disclosure of AIDS-related personal information by federal institutions. The collection, use and disclosure of this information by other institutions (local boards of health, for example) largely falls outside the mandate of the *Privacy Act*. Accordingly, the issues addressed in this report concern only one facet of the privacy issues relating to AIDS -- the federal government response.

The study begins by defining the nature of AIDS-related personal information. The appendices provide a glimpse into the nature of the syndrome known as AIDS, its dynamics, and how it has affected and will probably affect Canada over the next several years. They also examine federal legislation that, along with the *Privacy Act*, controls the collection, use and disclosure of personal information by government institutions. Finally, there is a discussion in the appendices of the present treatment of AIDS-related personal information by several "front-line" federal government institutions.

The heart of this report -- Parts III and IV -- offers recommendations on how to treat AIDS-related personal information to conform with the requirements of the *Privacy Act*. It also examines the practical application of these recommendations to personal information about government employees, clients (such as unemployment insurance recipients or immigrants) and the general public.

A basic theme of this report is that of caution: caution in the collection of AIDS-related personal information, caution in its use and caution in its disclosure. The clear, even self-evident, perception of the need for such caution in handling this delicate information has persuaded us to recommend "supplementing", in some cases, the strict requirements of the *Privacy Act* with additional measures. In short, the extreme sensitivity of AIDS-related personal information warrants protection beyond that provided by the Act alone.

The situation calling for this extreme caution may change. Disclosure of AIDS-related personal information may one day not threaten the physical and psychological well-being of those affected by the disclosure (as has happened with other diseases, notably cancer), nor drastically alter the conditions of their membership in Canadian society. But for now, the strong possibility exists that public, and even government, opinion and actions could harm those individuals whose personal information is disclosed -- without providing any measurable benefit to society.

This report also emphasizes the need for the federal government, specifically the Treasury Board, to provide leadership to government institutions which will increasingly face AIDS-related issues. The role of Treasury Board as the public service employer makes it the most desirable centre for the development of a government-wide policy on AIDS in the public service.

To hope for an early cure or an effective vaccine is a natural human response to this terrible disease. But hoping does not diminish society's responsibilities today. The principles set forth here in responding to the privacy issues in handling the personal information of those affected by HIV infection and AIDS may not give much long-term comfort. But at least they make society's response more humane. For the moment, perhaps that is the best we can do.

PART I - INTRODUCTION

(a) General

AIDS-related afflictions have killed more than 1200 Canadians. In the absence of a cure, they will kill thousands more over the next several years. Once a person develops AIDS (as opposed to merely carrying the virus that causes AIDS), death is certain.

Rough, and perhaps ultimately unreliable, estimates suggest that approximately 50,000 Canadians carry the virus that can cause AIDS. The most pessimistic view is that, without a cure, all these infected people will eventually develop AIDS and die prematurely.

Governments around the world have begun to assume responsibility for protecting their citizens from contracting AIDS. Measures have included the following:

- educating the public about how to avoid AIDS (for example, reducing high-risk behaviour) and
- testing selected groups or the general population for the presence of the virus that causes AIDS and (a) isolating infected persons, (b) publicly identifying infected persons to warn others, (c) advising infected persons not to engage in "high-risk" activities with uninfected persons, (d) applying sanctions to those who knowingly expose others to the virus or (e) some combination of the above.

The proper extent and mix of these efforts in defining a Canadian AIDS strategy is a subject of ongoing debate. In part, the debate is concerned with whether there should be an obligation to take a test for the presence of the antibody to the virus that causes AIDS -- the HIV (human immunodeficiency virus). If so, what, if anything, should be done to identify, either publicly or to a smaller group, those who are infected? So far, there are no clear answers.

At the heart of the debate is the perennially problematic search for a balance between individual rights and the public good. Individual privacy is one important right at stake.

This report seeks to elaborate a Canadian privacy strategy which strikes a balance between the public good and the rights to the protection of personal information set out in the *Privacy Act*. It makes recommendations for the collection, use and disclosure of AIDS-related personal information by federal government institutions.

"AIDS-related personal information" can be understood as information about an identifiable person that may indicate any of the following:

- that the person has AIDS or any AIDS-related illness
- that the person has been advised or required to take an HIV antibody test or other associated test

- that the person has taken tests for the presence of the HIV antibody or has taken tests that may be associated with a diagnosis of HIV infection or AIDS
- that the person has refused to be tested
- that the person has asked to be tested
- that the person has been counselled by a health care professional about the HIV antibody test before or after taking a test, or
- the results of the test or tests.

The collection, use and disclosure of AIDS-related personal information concerns persons as individuals and as members of groups in society. Individuals may be employees of a government institution -- for example, members of the RCMP or Canadian Forces, foreign service personnel or corrections officers. They may be "clients" of government, such as inmates in federal penitentiaries, applicants for unemployment insurance, or immigrants. They may also be members of the general public.

The report reviews the present and possible future treatment of AIDS-related information by several federal government institutions. It also discusses present and planned actions by several institutions about the collection, use and disclosure of AIDS-related personal information.

The focus of this report is narrow. It cannot attempt to address the explosion of legal, medical and ethical issues that have arisen since AIDS entered daily vocabulary. It examines some of these issues, but only as they relate to privacy concerns.

CAUTION: Knowledge about AIDS is in its infancy, as are AIDS research and understanding. The syndrome was identified only in 1981. Findings about AIDS may affect the issues discussed in this report and the options for dealing with those issues. The discovery of a vaccine to protect against HIV infection or AIDS, or the discovery of new mechanisms of transmission, for example, could create new issues under the *Privacy Act*. This report will discuss some possible developments and their impact on privacy considerations; it cannot predict every one. Accordingly, the reader must remember when reviewing this document that changing scientific knowledge, changes in treatment, changes in the way HIV infection spreads or changes in the rate of spread may affect the issues and their resolution.

Some background information on the nature of AIDS may assist the reader to analyze the issues that form the focus of this report. Appendix I discusses several technical aspects of AIDS: the nature of the syndrome, methods of transmitting the HIV, international and Canadian statistics on the spread of AIDS, projections on the future number of AIDS cases in Canada, regional variations in Canada and the direct and indirect costs associated with AIDS.

(b) Testing[1]

The human immunodeficiency virus (HIV) causes AIDS. Current medical tests for AIDS do not focus on HIV. Instead, current tests detect **antibodies** to HIV. Antibodies are proteins produced by the body in response to an invasion of foreign substances, such as viruses, bacteria, or even pollen grains.

Various antibody tests are used in Canada. All use samples of blood to detect the presence of the antibody to HIV.

To test properly, a series of tests may be necessary. The first is known as the ELISA screening test. If the test produces a "negative" result (that is, the test shows no antibodies to the HIV), no further tests are performed. The person who provided the blood sample is generally assumed not to have been infected with the HIV (but see discussion of "false negatives" below).

The ELISA screening test may produce a "positive" result. This gives a preliminary indication that the person has developed antibodies to the HIV. In other words, he or she is thought to be infected with the HIV. If so, a second ELISA test is performed. Then, regardless of result, a more accurate "confirmatory" test is performed. The confirmatory test may be any one of three such tests now used in Canada.

The Federal Centre for AIDS reports that using one ELISA screening test in low risk populations may result in as many as 12 false positive results for every one truly positive result. A false positive means that a person is wrongly diagnosed as having been infected with the HIV. It is therefore essential not to conclude that a person is infected solely on the basis of a screening test. Confirmatory testing can correct false positives in the vast majority of cases.

Provincial laboratories perform virtually all screening and confirmatory tests that are carried out in Canada. The Federal Centre for AIDS Retrovirus Laboratory provides a reference laboratory for the provinces to help decide difficult cases.

The Meaning of a Positive Test Result: A positive HIV antibody test result (also called HIV "seropositivity") indicates the presence of antibodies to the virus. It is only indirect evidence of infection; it does not identify the presence of the virus itself. Seropositivity means that a person has been exposed to the HIV and has developed antibodies to it. It is now accepted that a "confirmed" positive test means the following:

- that the development of antibodies generally indicates the continuing presence of the virus in the body;
- that infection with the virus is probably lifelong, and
- that a person with antibodies is probably capable of transmitting the HIV to others.

The Meaning of a Negative Test Result: A negative antibody test result (HIV "seronegativity") generally means that a person has developed no antibodies to the HIV because the person has not been exposed to the HIV. It may also mean that the person has been exposed to the HIV but has not become infected. No antibodies are therefore produced and there is no danger of transmission of the HIV because it has not reached or remained in the person's body. A negative test, however, may sometimes be false, for the following reasons:

- antibodies normally take four to six weeks to develop after infection with the HIV. In some cases, it may take several months. A test taken before antibodies have developed will show a negative result, even though the person has been exposed to the HIV and is infected;

- some persons infected with HIV may never develop antibodies to the HIV, even though they have become infected. Some recent medical and scientific opinion supports this possibility;

- the test is not sufficiently sensitive to detect antibodies in everyone;

- rarely, some people lose antibodies to the HIV during the course of their HIV infection, although they probably remain infectious or infected, or both;

- the test was performed by inexperienced testing personnel or it was not properly administered.

If a properly tested person tests positive, he or she generally remains positive for life. It would be dangerous to make the same assumption about a "true negative" result. Even if a person is now uninfected, he or she may not remain so. The person may, for example, subsequently become infected through contact with an infected person, by injecting drugs with an HIV-contaminated needle or by accidental exposure to infected blood. To be even reasonably certain of continuing true negativity, it is therefore necessary to conduct repeat testing. Even then, that testing must take place sufficiently long after the individual encountered the virus to permit antibodies to develop. And, as explained above, other deficiencies in assessing seronegativity remain.

A negative test result therefore does not provide the same level of confidence as a true (confirmed) positive test result. It is important to recognize these limitations of negative test results. Any decision that turns on negative test results must take this into account. Accepting negative test results categorically is little short of negligent.

ENDNOTES TO PART I

1. This information was drawn largely from draft materials supplied by Joel Finlay of the Federal Centre for AIDS.

PART II

CONCERNS ABOUT THE COLLECTION, USE AND DISCLOSURE OF AIDS-RELATED PERSONAL INFORMATION

Scientific information about the nature of AIDS and statistics on AIDS are not likely to affect the privacy of an individual. This information is therefore not "sensitive" from a privacy standpoint.

Information that can be linked to an individual, however, is almost certainly sensitive. That information may include the medical condition, social contacts, sexual habits or other characteristics of a person. It may in fact include all that we have defined in Part I as "AIDS-related personal information".

(a) The Case Against Collection, Use and Disclosure

Experience with AIDS over the last seven years has identified a host of problems flowing from the collection, use and disclosure of AIDS-related personal information. Most take the form of discrimination.

In Canada, AIDS is closely associated with homosexual or bisexual behaviour. The Federal Centre for AIDS has received reports of 2323 cases of AIDS as of January 3, 1989. By far the largest number (2166) occurred in adult males. The principal risk factor for AIDS in adult males was homosexual or bisexual activity (86 per cent of adult male cases). Just over three per cent involved both intravenous drug use and homosexual or bisexual activity.

Having AIDS, or testing HIV seropositive, may therefore be enough evidence for others to conclude that a male is homosexual or bisexual, and to discriminate on that basis.

Discrimination may be based both on the perceived lifestyle of the person and on the fear of contagion. And anti-discrimination legislation may not provide the strong protection needed to deter discrimination borne of misunderstanding and overwhelming fear.

AIDS-related discrimination is not a hypothetical concern. It is real. The Canadian Human Rights Commission (CHRC) is currently investigating two complaints from men who say they lost their jobs because they were infected with HIV.

In a May 1988 policy statement the CHRC acknowledged that discrimination could result from public knowledge that a person is infected with the HIV. It may also occur, the CHRC said, against an **uninfected** person who associates with an infected person, or against an uninfected person who belongs to a group associated with a high rate of HIV infection (homosexuals, Haitians or hemophiliacs, for example). Accordingly, the CHRC will now permit these latter groups, as well as infected persons, to bring complaints of discrimination to the CHRC.

Even being tested for the presence of HIV antibodies, refusing to be tested, or being advised to be tested may provide enough "evidence" for others to conclude that a person is infected or is engaged in high risk ac-

tivities and to discriminate on those bases. Accordingly, a wide range of AIDS-related personal information should be protected to avoid such inferences.

Having AIDS-related personal information widely collected, used and disclosed can have several practical consequences:[1]

(a) loss of employment: When AIDS-related personal information becomes known to an employer or fellow workers, or those whom the employee or employer serve, the employee risks dismissal. Ample numbers of cases have illustrated that even asymptomatic infected persons risk losing employment -- human rights codes notwithstanding -- when their condition becomes known. The dismissal may be based on fear of contagion or loss of business, or result from discrimination based on the perceived homosexual lifestyle of the person;

Given that many employers provide health care plans for their employees, the loss of employment can be doubly serious. An infected person who develops AIDS may face crippling bills for drugs and dental care (hospitalization will still be provided by provincial authorities).

(b) loss of friends and family: Among the most traumatic experiences identified by infected persons or those thought to be infected is the social isolation they may experience when their condition becomes known. Friends and family may forsake them. Again, this may be due to fear of contagion or because a male's homosexuality surfaces or is inferred.

(c) alienation from the community: Families of infected persons can be driven from their communities because a family member is known or thought to be infected. Community attitudes can border on paranoia. However irrational this response, it must be acknowledged as a possible consequence of disclosure.

Even if the community does not react in a hostile or irrational fashion today, there is no guarantee that this benevolence (or apathy) will continue. New medical findings about AIDS, or a shift in community attitudes, could create an impossibly hostile climate for those thought to be infected. The potential for this shift is heightened by the association of the disease with unpopular lifestyles.

(d) loss of accommodation: Infected persons have been evicted from or refused accommodation.

(e) loss of public and private sector services: Discrimination may affect the provision of services. In the United States, the American Civil Liberties Association has challenged or threatened to challenge several authorities that collected information on infected persons. In one case, the police stored names of infected persons. Officers sent on a call were then notified that the person was infected (often via police radio, which could be overheard with little difficulty by interested individuals). This information could reinforce in the officer's mind the need to take health precautions (a good idea). Some argue, however, that the police (or ambulance attendants, or firemen) might

deliberately avoid an encounter with an infected person and thereby deprive the person of essential services.

Similar problems have arisen in schools. Infected children have been expelled or denied entry. Hospitals and health care workers may refuse to care for infected persons. Infected persons may be refused access to transportation facilities. They may be denied insurance.

(f) travel restrictions: Some countries may prohibit infected persons from entering for visits or immigration. If already in the country, they may be ordered to leave.

One example is found in the United States policy on providing military training for foreign personnel. Since May 31, 1988, all foreign personnel entering the United States for military training under the Security Assistance Training Program must certify that they are HIV seronegative. Infected persons will be prevented from taking training in the United States.

(g) government responses: To date, governments in Canada have taken no significant steps to isolate (quarantine) infected persons unless they deliberately spread infection.

The present position of any government, however, offers no guarantee for the future. Governments could decide to take any number of repressive (if sometimes impractical and ineffective) measures against infected persons. Among them are the following: isolation, banning sexual intercourse, banning homosexual activity, prosecuting those who unknowingly spread the virus, limiting access of infected persons to various government services (police, fire, ambulance, hospitalization, education) and publicizing the identity of infected persons.

Some of these government responses seem unlikely, but nothing is impossible. Hospital costs for care of AIDS patients, for example, may become staggering as the epidemic progresses. Governments may then be forced to decide who to treat -- those who health care services can cure, or those they cannot cure (AIDS patients).

Similarly, governments may one day refuse to provide advanced education to an infected person. The person faces a substantial risk (and, some say, a certainty) of premature death. Why spend several years educating an infected person when he or she may succumb to AIDS shortly after?

The American Civil Liberties Union has suggested also that future governments may hold different views on confidentiality: "There is no way to guarantee that, whatever the confidentiality provisions today, future laws won't be passed to allow insurers, school systems, or other state agencies to have access to such a list [of infected persons]."[2]

Added to the considerations in this list is the human dimension of AIDS. A diagnosis of HIV infection is traumatic. It tells the person that, although perhaps outwardly healthy, he or she may in fact be terminally ill. It is only humane to protect the person from the additional trauma of a loss of control over a very significant piece of personal information. It is therefore doubly important to recognize

what the Supreme Court of the United States has called simply "the right to be let alone by other people".[3]

Clearly, the relative privacy afforded to AIDS-related personal information will determine the extent to which issues of discrimination arise. It is better to restrict collection, use and disclosure of AIDS-related information than to invite a plague of discriminatory actions and other forms of "evil" -- such as blackmail. Anti-discrimination legislation cannot undo the damage and expense caused by playing fast and loose with AIDS-related personal information. Nor will it redress a perceived insensitivity to privacy concerns that in turn may deter individuals from seeking appropriate medical attention and testing.

Even security of information and good intentions cannot prevent some leakage and the resultant discrimination and other consequences. The *Annual Report: Privacy Commissioner 1986-87* describes 12 incidents involving the theft or loss of personal information held by government.[4] Among them were the following:

- completed census forms falling off a truck;
- theft of Parole Board files from a car; files contained institutional reports, criminal records, psychiatric records and various other reports;
- personnel information from a government department found on an Ottawa street, and
- theft of microfiche records containing information on 16 million Canadian taxpayers.[5]

Theft or loss of personal information held by government will continue, despite statutory protections, penalties and the possibility of civil lawsuits where information is mishandled.

(b) The Case for Collection, Use and Disclosure

The public interest clearly justifies collecting, using and disclosing some AIDS-related information. This may include epidemiological data to identify groups at risk, to track the spread of the disease, to assess the effectiveness of treatments and to test mechanisms for controlling the spread of AIDS and HIV infection. Governments also require information to plan the allocation of scientific and health care resources.

It is often not necessary for this information to identify individuals. The collection, use and disclosure of anonymous information creates no danger of discrimination against an individual. (As has been seen with homosexuals, however, it may still cause ill-will towards certain identifiable groups).

The real controversy lies with AIDS-related **personal** information. Those who favour collecting, using and disclosing AIDS-related personal information offer several justifications (we do not necessarily accept these arguments):

- The partner of an infected person should be told that he or she is at risk. Because there is no guarantee that the infected person will tell the partner, public authorities may be required to do so and, therefore, need the identity of the infected person.

- The infected person may need counselling. Given the trauma associated with a diagnosis of HIV infection, such counselling may be vital.

- The infected person may deliberately spread the infection. Public authorities should be aware of the identity of an infected person to be able to supervise his or her behaviour and take appropriate action. This may include criminal prosecution or taking action under provincial health protection legislation (quarantine, for example).

These arguments are frequently used to support reporting requirements under provincial legislation. The provinces typically assume the "contact-tracing" role and can ensure that persons are adequately counselled. They can (arguably) also apply provincial health protection legislation to safeguard the community at large.

Other reasons for collecting AIDS-related personal information can be advanced as being more relevant (although not exclusively so) to federal institutions:

- Those who come into contact with the infected person may need to be aware of the person's condition to protect themselves. This group includes those whose work may bring them into contact with infected body fluids -- health care personnel, police officers, corrections officers, ambulance attendants, nursery workers and undertakers. And even though there may be no scientific justification for concern, some employees who fear contagion through casual contact may also wish to know the status of their co-workers.

- Superiors may want to know the health status of their subordinates to determine suitable job assignments. Some persons performing "invasive" procedures as part of their employment (surgeons, for example) may, if infected, contaminate others. Certain occupations (for example, those directly affecting the safety of the public) demand unimpaired mental and physical health. Dementia and deterioration of the central nervous system can accompany AIDS and compromise essential safety requirements. It may therefore be necessary to remove infected persons from these occupations. Certain employees may require unimpaired health to be suitable for foreign travel or postings. The U.S. requirement for Canadians to be tested before participating in military training there (discussed in Part IV) and the concern of External Affairs for the health of personnel posted abroad provide examples of this situation.

- Certain populations (such as federal penitentiary inmates) are almost totally under the control of the federal government. The government should assume special responsibilities to protect their health.

- Certain federal activities (immigration, for example) impose corresponding responsibilities to protect the Canadian public from disease, from the financial burden of assuming the health care of others, or both. It is therefore relevant to know the HIV status of potential immigrants.

- Infected persons may be eligible for government support. Unemployment Insurance, Canada Pension Plan and

Revenue Canada authorities, for example, take medical disabilities into account for the operation of certain programs. Disclosure of medical condition is a prerequisite for obtaining some benefits.

- Some AIDS-related research may require tracking individual cases. The information must be provided in nominal form to be of any use in these limited number of cases.

Clearly there are significant pressures on government institutions to collect and use AIDS-related personal information. And while the uses are certainly supportable the debate must be resolved as to what collections are truly necessary and what limits should be placed on the uses of such sensitive information. While there are a host of laws besides the *Privacy Act* which offer protection for personal information (see Appendix II), they are not widely known or understood. Moreover, as with all laws, there is room for interpretation as to the most prudent manner in which they should be implemented in particular cases. It is imperative that the government of Canada articulate a policy which sews this patchwork together and communicates it clearly to Canadians. Only then will Canadians be assured the protection necessary to encourage them to voluntarily seek HIV antibody testing and obtain AIDS information, counselling and treatment where necessary.

ENDNOTES TO PART II

1. Most forms of discrimination identified here are based on surveys of American legal literature, which has dealt extensively with AIDS in recent years. The social and political environment in Canada may differ somewhat from that of the United States. Nonetheless, the same problems will almost certainly surface here.

2. American Civil Liberties Union, Aids and Civil Liberties Project, "*Mandatory Contact Tracing*" (1988) at 3.

3. *Katz v. United States,* (1967), 389 U.S. 347, per Stewart, J., delivering the majority opinion; referred to by Dickson, J., delivering the judgment of the Supreme Court of Canada in *Hunter v. Southam* (1984), 11 D.L.R. (4th) 641 at 652.

4. *Annual Report: Privacy Commissioner* 1986-87 (1987) at 8-19.

5. *Ibid.*.

PART III

ISSUES AND RECOMMENDATIONS

In view of the plethora of medical, legal and ethical issues associated with AIDS (of which confidentiality is but one) one might expect that government actions in this area would be guided by thoughtfully developed and consistently applied policies. Such is not the case. Although Health and Welfare Canada actively encourages employers in Canada to develop AIDS policies, the government of Canada -- our largest employer -- has not yet completed its development of one. In the absence of policy guidance from the Treasury Board of Canada (the government's administrative policy centre) other government institutions are left on their own to deal with the AIDS issues which concern their employees.

While some departments, notably the Department of National Defence (DND), Correctional Service Canada (CSC) and the Canadian International Development Agency (CIDA), have developed AIDS policies dealing with employees or clients, most have not. (A review of the practices and policies associated with the collection and use of AIDS-related personal information in selected departments is included as Appendix III).

With the exception of Employment and Immigration Canada, no departments have plans to seek authority to implement mandatory or compulsory HIV antibody testing. Employment and Immigration Canada favours the compulsory testing of all prospective immigrants and long-term visitors to Canada.

DND, as previously mentioned, requires that any military or civilian employee wishing to attend U.S. defence training be tested for the presence of the HIV antibody. While the U.S. makes this mandatory, DND points out that it is entirely voluntary for Canadians; no employee is obliged to take U.S. defence training. However, from the employee's point of view it may not appear voluntary when the consequences of refusal may be detrimental to future promotional opportunities and career options.

We were pleased to discover no general move within government to collect AIDS-related personal information about employees, clients or the general public. Equally, we were surprised by the number of federal data banks which may contain such information and the wide variety of situations in which such information may come into federal hands.

Thus, while we feel that a federal AIDS policy is overdue there is still time to implement a policy before any significant abuses occur. As confidentiality and controls on the collection of AIDS-related personal information should be integral elements of such a policy, the recommendations in this report are intended as guidance.

We also suggest that Treasury Board consider the June, 1988 "Statement from the Consultation on AIDS and the Workplace", issued by the World Health Organization in association with the International Labour Office. The statement addresses several issues relating to AIDS and employment.

The statement asserts that **pre-employment** HIV screening as part of the assessment of fitness to work is unnecessary and should not be required. Screening of this kind refers to direct methods (HIV testing) or indirect methods (assessment of risk behaviours) or to questions about HIV tests already taken. It notes concerns that pre-employment HIV screening for insurance or other purposes may lead to discrimination.

About **current employees** the statement makes several policy recommendations:

- HIV screening should not be required, whether direct (HIV testing), indirect (assessment of risk behaviours) or asking questions about tests already taken;
- Confidentiality must be maintained about all medical information, including HIV status;
- The employee should not be obliged to inform the employer about his or her HIV status;
- Employees affected by, or perceived to be affected by HIV, must be protected from stigmatization and discrimination by co-workers, unions, employers or clients. Information and education are essential to maintain the climate of mutual understanding necessary to ensure the protection;
- If fitness to work is impaired by HIV-related illness, reasonable alternative working arrangements should be made;
- HIV infection is not a cause for termination of employment. As with many other illnesses, persons with HIV-related illnesses should be able to work as long as medically fit for available, appropriate work.

Our primary recommendation, then, is this:

Recommendation 1

Treasury Board take steps to issue a comprehensive policy on AIDS in the workplace; this policy should include a clear statement on confidentiality and the controls on the collection of AIDS-related personal information, guided by the principles and recommendations set forth in this report.

Controlling Collection, Use and Disclosure

The *Privacy Act* is a blunt instrument for dealing with AIDS-related personal information. Intended to apply almost government-wide to a variety of circumstances relating to the holding of personal information, its broad approach may lack the finesse to deal with the extraordinary sensitivity of this information. The Act gives little comfort to those who fear any form of organized assembly of AIDS-related personal information. The best evidence of this lies in the extensive list of data banks that were identified to us as holding or having the potential to hold this information.

How we handle AIDS-related personal information can have a significant impact on other AIDS-related issues. If information is widely collected and disclosed it may lead to extreme forms of discrimination at work, at home and in the community. The degree of protection afforded AIDS-related personal information largely determines the extent to which many other issues will arise. Moreover, a perceived

insensitivity to privacy concerns may deter individuals from being tested voluntarily for antibodies to the virus.

(a) Limiting Collection

One defence against too much zeal in the use and disclosure of AIDS-related personal information lies in restrictions on collection. As discussed elsewhere, not only HIV antibody test results should be subject to those restrictions. The collection of AIDS-related personal information in general, as defined in Part I, should also be restricted.

A truly anonymous testing program creates few concerns under the *Privacy Act*. With an anonymous test, the person being tested is the only one who can match the results of the test with his or her blood sample. Even the person's physician is not aware of the results.

Anonymous testing, while not perfect (other AIDS-related personal information -- for example, that the person took the test -- might still be known), is the least intrusive testing option. Any form of testing that links the name of the individual with the test results is much more intrusive (although it is possibly also more useful to provincial public health authorities and to federal government institutions).

Any program of testing has the potential to create a body of AIDS-related personal information which must be stored, and which may be used and disclosed. Decisions to test must take into account the responsibilities that flow from collection.

Section 4 of the *Privacy Act* is the principal control on the collection of AIDS-related personal information:

> *No personal information shall be collected by a government institution unless it relates directly to an operating program or activity of the institution.*

It is not sufficient for an institution wishing to collect such information simply to point to or to create a program involving the use of AIDS-related personal information. Implicit in section 4 is the requirement that no such information is to be collected unless (1) the collection is part of an activity or program falling within the statutory mandate of the institution and (2) the collection is a necessary element of a mandated program or activity.

There is the potential for an institution to react to AIDS by collecting volumes of personal information. Various levels of government in the United States and elsewhere have been ingenious in justifying the collection of AIDS-related personal information.

And there will inevitably be situations where the need to collect is strongly arguable. A government institution that sends employees abroad, for example, might want to exclude those infected with the HIV from travelling to certain areas of the world. The collection of AIDS-related personal information could relate to an operating program or activity (the posting process) of the institution, even though information of that detail may not be needed to administer the posting program.

Institutions should review their reasons for collecting AIDS-related information. Is collection necessary or is a general diagnosis of medical fitness sufficient? Can non- nominal information serve the purpose just as well? If AIDS- related personal information is necessary, can it be collected by Health and Welfare Canada? Health and Welfare Canada's

general advice based on that detailed information could then be used by another institution to make administrative decisions.

"Necessity" cannot be defined precisely, given the broad spectrum of situations and persons giving rise to the collection of personal information. It will vary with the circumstances. For example, the necessity criterion applied to collecting information about immigrants may differ from that for inmates of federal institutions, given the government's differing responsibilities towards each group.

Moreover, the necessity principle will have to be considered in determining the **means** of collecting AIDS-related personal information. The principle may operate to justify voluntary HIV antibody testing but may militate against mandatory or compulsory testing. For example, DND's current HIV antibody testing of candidates for U.S. Defense Department courses could be justified as necessary in its present voluntary form. It would not be justified if mandatory.

A special word is required about public employees. The current medical knowledge about the transmission of HIV infection is clear; normal workplace contact with an infected individual does not put others at risk. As a general principle, then, section 4 of the *Privacy Act* would prohibit government institutions from collecting AIDS- related personal information about public employees.

Strong arguments have been made that the HIV status of certain employees is a matter of legitimate interest to the government as employer -- for example, where the employee performs invasive procedures, the employee travels to countries which bar entry to those infected with the HIV or the employee performs duties which affect public safety. In fact, the Canadian Human Rights Commission, in its AIDS testing policy, specifically identifies the above-mentioned situations as ones for which being HIV infection-free may be considered a bona fide occupational requirement under the *Canadian Human Rights Act*.

In our view, even in some of those situations it is doubtful whether the necessity test can be met. Health and Welfare Canada considers that with the adoption of universal precautions in high-risk work environments it is extremely rare to find an occupational setting where it is essential, in the interests of individual or public safety, to establish being HIV infection-free as a job requirement. The "necessity" principle embedded in section 4 of the *Privacy Act* would, therefore, be very difficult to demonstrate in order to justify the collection of AIDS- related personal information about federal public employees.

A caveat must be entered, however, with respect to members of the Canadian Forces. Occupational situations may arise here -- for example, in battlefield conditions -- which require that an individual's HIV status be known. DND takes the position that, while no mandatory or compulsory HIV antibody testing program is planned, it would not be prudent to rule it out in the future in specific circumstances.

In the opinion of the Privacy Commissioner, further study is required to determine whether, to what extent and under what safeguards, AIDS-related personal information may be collected by DND about members of the Canadian Forces.

Apart from the Canadian Forces situation described above, our consultations have not established any compelling public health or administrative reasons why mandatory or compulsory testing is a necessary element of

the administration of existing departmental mandates. In particular, the need for compulsory or mandatory testing of inmates of federal penitentiaries, new immigrants, long term visitors or public servants posted abroad has not been demonstrated.

It is our view, therefore, that section 4 of the *Privacy Act* would prohibit the collection of AIDS-related personal information through a process of mandatory or compulsory testing. Only if such a process were to be specifically authorized by statute would such collection conform with the requirements of the *Privacy Act*.

Recommendation 2

AIDS-related personal information available through voluntary testing, the voluntary provision of information, or both, should be collected only where the collection is a necessary element of the administration of a statutorily mandated program or activity of the institution.

Recommendation 3

No compulsory or mandatory HIV antibody testing should be implemented by government institutions unless specifically authorized by statute. Moreover, existing enabling provisions, such as section 7 of the *Financial Administration Act*, which do not specifically address the collection of AIDS-related personal information, should not be relied on to authorize such collections.

Recommendation 4

Further study should be undertaken to determine whether, to what extent and under what safeguards, DND should collect AIDS-related personal information concerning Canadian Forces members.

(i) Safeguarding Information that is Collected

Even where the above conditions for collection of AIDS-related personal information are met, it may be prudent to request that such information be collected by Health and Welfare Canada where possible (in some situations, for example, when collecting information about CF members, inmates or immigrants, this may not be possible). Health and Welfare Canada can then provide departments with conclusions about medical fitness rather than specific HIV status information.

Although centralizing most AIDS records with Health and Welfare Canada risks an information catastrophe if the information is lost, leaked or stolen, the risk can be greatly reduced by intelligent security procedures and employee education programs. And it should be easier to centralize and secure the information at Health and Welfare Canada than it would be to secure lesser quantities of AIDS-related personal information held at various locations by individual government institutions. Accordingly, we support the centralization of this information to the extent possible, and under rigid security.

(ii) Informed Collection from Individuals

Subsection 5(1) of the *Privacy Act* requires that, wherever possible, personal information be collected directly from the individual except where the individual authorizes otherwise or where personal information may be disclosed to the institution under subsection 8(2). Subsection 5(2) requires that the institution inform an individual from whom personal information is collected of the purpose of the collection.

Subsection 5(3) makes the preceding subsections inapplicable in two circumstances: where compliance with subsections 5(1)and (2) might result in the collection of inaccurate information or might defeat the purpose or prejudice the use for which the information was collected.

Wherever possible, information about HIV status should be collected directly from the person, not from other records on the person or from third parties.

We anticipate that government institutions will not rely on subsection 5(3) either to avoid direct collection or to avoid informing the individual of the purpose of collecting information. Neither direct collection or informing about purpose should defeat the purpose or prejudice the use for which the information is collected. Nor should it result in the collection of inaccurate information.

Subsection 5(3), however, has a gap. It only requires an individual from whom information is collected to be informed of the purpose. If the information is collected from a third party (perhaps a provincial health laboratory or a provincial correctional service) the individual concerned apparently has no right to be informed of the purpose of the collection. Even so, institutions should consider, if at all practical, informing persons that AIDS-related personal information is being collected about them, and the purpose of the collection. Otherwise, the person is disadvantaged on two counts. He or she does not know either that information is being collected, or the purpose of the collection.

Recommendation 5

Wherever possible, AIDS-related personal information should be collected directly from the person affected, and not by consulting records or a third party (except where the individual authorizes otherwise or where personal information may be disclosed under subsection 8(2)), and

Wherever possible, when collecting AIDS-related personal information, including collection from records or a third party, the institution should inform the person to whom the information relates of the purpose of the collection and the source of the collection.

(b) Controlling Use under Section 7

(i) Section 7 -- Consistent Uses

Section 7 states:

> *Personal information under the control of a government institution shall not, without the consent of the individual to whom it relates, be used by the institution except*
>
> *(a) for the purpose for which the information was obtained or compiled by the institution or for a use consistent with that purpose; or*
>
> *(b) for a purpose for which the information may be disclosed to the institution under subsection 8(2).*

The initial constraints we propose on the collection of AIDS-related personal information should limit the number of institutions having control over the information. If its collection were necessary in the first place, there should be few objections to its use under section 7. To be safe, however, those acting under section 7 should again consider

whether the purpose for which the information was obtained was a necessary purpose or whether the consistent use was necessary.

The nature of "consistent uses" merits further comment. Information might be collected about a military recruit, for example, to determine if the recruit should undergo a strenuous training regimen. It would not be a consistent use to disclose that information to colleagues who fear contagion through casual contact.

Subsection 9(4) of the *Privacy Act* imposes reporting requirements for certain consistent uses of personal information:

> *Where personal information in a personal information bank under the control of a government institution is used or disclosed for a use consistent with the purpose for which the information was obtained or compiled by the institution but the use is not included in the statement of consistent uses set forth pursuant to subparagraph 11(1)(a)(iv) in the index referred to in section 11, the head of the government institution shall*
>
> > *(a) forthwith notify the Privacy Commissioner of the use for which the information was used or disclosed; and*
> >
> > *(b) ensure that the use is included in the next statement of consistent uses set forth in the index.*

Due to the extremely sensitive nature of AIDS-related personal information, care must be taken to control consistent uses strictly. Where a consistent use is proposed, advance notification should be given to the Privacy Commissioner, and no such use should be undertaken without the approval of the head of the government institution.

As well, any proposed use of AIDS-related personal information which relies on subsection 7(b) (use for a purpose for which the information may be disclosed to the institution under paragraphs 8(2)(e) to (m)) should be subject to senior level review and the approval of the head of the institution. This is particularly important where the proposed use is for research or statistical purposes.

Recommendation 6

AIDS-related personal information should be used only as follows:

> **i) for the purpose for which the information was compiled or obtained by the institution,**
>
> **ii) for a use consistent with that purpose, or**
>
> **iii) for a purpose for which the information may be disclosed under subsection 8(2).**

In situation ii), no use should be undertaken without the approval of the head of the government institution. In situation iii), no use should be undertaken under paragraphs 8(2)(e) to (m) without the approval of the head of the government institution.

(ii) Accuracy of Information

Subsection 6(2) of the *Privacy Act* states:

> *A government institution shall take all reasonable steps to ensure that personal information that is used for an administrative purpose by the institution is as accurate, up-to-date and complete as possible.*

This paper has already examined the consequences which can flow from a diagnosis of infection with the HIV. It is therefore vital on two counts -- to meet the accuracy requirements of the *Privacy Act* and to prevent an erroneous diagnosis that may lead to serious discrimination -- that information on the HIV status of an individual be accurate, up-to-date and complete, if it must be kept at all.

In populations of persons undertaking high risk activities, the ELISA screening test is acceptably accurate in determining seronegative or seropositive status. In low risk populations the rate of false positives using only a screening test is unacceptably high. In both situations, confirmatory tests must be used to reduce the likelihood of false positives being recorded.

Seropositive Results: Data banks should never confirm the HIV status of a person if only screening (ELISA) tests have been performed. Only if a confirmatory test (Western Blot, IFA or RIPA) has confirmed the findings of the initial screening tests should a confirmed "seropositive" status be recorded. Otherwise, the data bank should indicate the results of the initial screening tests, but state clearly that this is not to be taken as a confirmed finding of seropositivity. A seropositive result from a screening test should not be used for an administrative purpose.

This recommendation applies to seropositive results even if the person being tested is known or assumed to fall into a high risk category. If the results of screening tests were accepted for high risk groups as confirming seropositivity, the conclusion would have to be supported by an assessment that the person belongs to a high risk group. This would inevitably invite recording that a person is homosexual or an intravenous drug user. Above all, it would represent an intrusion into privacy that can easily be avoided by conducting confirmatory tests.

This recommendation is based on the current level of accuracy of screening and confirmatory tests. Tests may become more accurate. One test may then be sufficient to diagnose seropositivity even in low risk groups. Even so, although tests may become increasingly accurate, the testing facility can make mistakes. It may still be necessary then to perform multiple tests before placing a confirmed finding in a data bank.

Where there are clinical symptoms of infection or disease, a physician should encourage a patient to be tested. Even if the patient does not get tested, the physician should be allowed to place on the medical record an opinion suggesting symptomatic HIV infection. This information should be allowed to be used for an administrative purpose.

The physician should not, however, confirm seropositivity unless the screening tests and confirmatory tests outlined above have been conducted. To attempt to confirm seropositivity without testing might violate the requirement of subsection 6(2) that the information collected be as accurate and complete as possible.

Because seropositivity is usually lifelong, an accurate initial diagnosis remains accurate. Therefore, it can be considered "as up-to-date" as possible, as required by subsection 6(2).

Recommendation 7

To meet the requirements of subsection 6(2), a record of a finding of seropositivity on the basis of screening testing only should never be used for an administrative purpose. Only

a seropositive result after a confirmatory test should be used for an administrative purpose.

A record of a medical opinion suggesting that a person has symptomatic HIV infection may be used for an administrative purpose, even without HIV antibody tests being performed. However, only a confirmatory test result should be used to confirm seropositivity.

Seronegative Results: No confirmatory testing should be required when a test result shows seronegativity.

Nonetheless, testing procedures cannot repair the deficiencies inherent in a finding of seronegativity. Even if the test is carried out in the best laboratory conditions, it does not prove that a person is free of HIV infection. The person may in fact have become infected, but might not yet have developed antibodies. Moreover, infected persons may lose antibodies as their immune system deteriorates. Some scientists now argue that some infected persons may never develop the antibodies that testing seeks to locate. In these three situations, tests would show seronegativity, when in fact those tested would be infected with the HIV. Nor is the test a guarantee that a seronegative person will not later become infected through risky conduct or accident. This leaves the door open to challenge a recording of seronegativity as not being "as accurate as possible" under subsection 6(2).

Furthermore, any record of seronegativity could be challenged as out-of-date as soon as it is taken. At first glance, this might seem to violate the requirement of subsection 6(2) that the personal information be as up-to-date as possible. There is likely no practical manner, however, to conduct the frequent repeat testing necessary to ensure the currency of a finding of seronegativity. A single finding will therefore likely be acceptable as as up-to-date as possible (although some might argue that the institution should have the obligation to ensure the currency of the information by having repeat tests performed periodically).

Ideally, one would want to abandon seronegative test results as being inherently unreliable. But these tests are today's only practical and specific indicators of seronegativity. They should therefore be accepted as complying with subsection 6(2) until a better diagnostic tool is developed. Those using seronegative results for an administrative purpose as defined by the *Privacy Act* must always be made aware of their limitations.

Recommendation 8

To meet the requirements of subsection 6(2), a finding of seronegativity based on a single screening test performed under appropriate laboratory conditions should be considered "as accurate as possible" and might be relied on for an administrative purpose. Nonetheless, those using the information for an administrative purpose should be made aware of the deficiencies inherent in any finding of seronegativity.

(c) Disclosure of AIDS-related Personal Information

The real leak in the system stems from section 8, which deals with disclosure of personal information. Subsection 8(1) states:

> *Personal information under the control of a government institution shall not, without the consent of the individual to whom it relates, be disclosed by the institution except in accordance with this section.*

Subsection 8(2) lists 13 situations where personal information may be disclosed without the consent of the individual.

For example, disclosure without consent is permitted to other governments or agencies of governments, to Members of Parliament, to the National Archives and to researchers. Under subparagraph 8(2)(m)(i), information may disclosed for any purpose where the head of the institution thinks that the public interest in disclosure clearly outweighs any invasion of privacy that could result from the disclosure.

While subsection 8(2) authorizes certain disclosures without consent, none of its provisions are mandatory. As well, although departments have discretion whether to release personal information without consent, all but two of the provisions of subsection 8(2) do not say who must exercise the discretion. Disclosures to researchers (8(2)(j)) and disclosures in the public interest (8(2)(m)) require the consent of the head of the institution.

This state of affairs is particularly troubling in the case of AIDS-related personal information. It is our view that the discretion to release this information without consent under paragraphs 8(2)(e) to (m) should be exercised only at the most senior levels -- preferably by the head of the institution.

Moreover, requests for disclosures under these paragraphs should not simply be met as a matter of course. In these cases, an attempt should be made to obtain the consent of the affected individual. If consent is refused, the onus should rest with the individual or body seeking the information to justify the disclosure. This process would involve a review of (1) why disclosure is necessary, (2) the possible adverse consequences that disclosure will bring to the individual, (3) the likelihood that the requestor can and will maintain it in confidence, and (4) the likelihood that the requestor will use it only for the purpose for which it was originally sought.

Subparagraph 8(2)(m)(i) (disclosure in the public interest) requires special mention. It is broad enough to allow the head of the institution to make it public knowledge that a person is infected with the HIV. Co-workers or a person's superiors, for example, might want disclosure on this basis. Given the severe consequences of disclosure, in what circumstances can the public interest in disclosure be said to outweigh any invasion of personal privacy?

Our strongest argument against disclosure in the public interest is evidence that AIDS is not spread by casual contact and that it need not affect a person's abilities to carry on his or her work. Only if the infected person were to attempt to spread the virus (perhaps by donating blood, sharing needles or engaging in unprotected intercourse) does there seem to be any public interest in disclosing his or her infection. Even then, there may be other far less intrusive measures that can resolve the problem.

Disclosure to co-workers cannot normally be justified, no matter how great their concern about casual contagion. Even disclosure to a superior may not be justified in the public interest, unless there is a bona fide occupational requirement that the subordinate be

seronegative. Even then, the superior may not need to know the precise details of the medical condition that impairs the subordinate.

Accordingly, there seems little justification for relying on the public interest argument to disclose AIDS-related personal information to co-workers, superiors, government institutions or the general public.

Our view is buttressed by the history of the use of subparagraph 8(2)(m)(i). Subsection 8(5) requires the head of a government institution to notify the Privacy Commissioner of any disclosure of personal information under paragraph 8(2)(m). A review of past notifications has shown that disclosure of information under subparagraph 8(2)(m)(i) has occurred in circumstances far less harmful to the person affected than would likely be the case with the release of AIDS-related personal information.

Notifications have related to a range of matters -- name and address, academic credentials, place of birth, date of birth, citizenship status and the parole status of inmates, for example.

Medical information has only rarely been released. In two cases, the medical history of a deceased parent was released to a surviving family member who may have inherited the parent's disease. In one case, medical and psychiatric records were released to the RCMP to deal with a hostage situation.

Information released under this subparagraph was typically released to another individual or to a small group of individuals. Often it was released to family members. Sometimes the media was given information through a government institution. One can therefore assume that widespread publication was anticipated.

Recommendation 9

The following policy should govern disclosures of AIDS- related personal information:

No disclosure of AIDS-related personal information should be made to third parties under paragraphs 8(2)(e) to (m) without first seeking to obtain consent from the individual for the release. There would be no need to seek consent before disclosing this information under paragraphs 8(2)(a) to (d).

Where consent to disclose is not given, no disclosure should be made to third parties under paragraphs 8(2)(e) to (m) without the approval of the head of the institution. This approval would not be required for disclosures under paragraphs 8(2)(a) to (d).

In exercising discretion to disclose under subsection 8(2)(e) to (m) the head of the institution should review

(1) why disclosure is necessary

(2) the potential adverse consequences of the disclosure on the individual(s) to whom it relates,

(3) the likelihood that the requestor can and will maintain the confidentiality of the information and

(4) the likelihood that the requestor will use it only for the purpose for which it was originally sought.

Where a third party requests disclosure of AIDS-related personal information under paragraphs 8(2)(e) to (m), the onus should be placed on the requestor to justify the disclosure of the information.

(i) Disclosure to Provincial Governments

Most HIV antibody testing is done in provincial laboratories. Legislation in seven of ten provinces requires positive results to be reported to provincial health authorities.

There may, however, be situations where laboratories do not report test results to provincial authorities. Should a federal institution report test results to provincial authorities?

Tests may have been performed outside Canada -- for example, on a foreign service officer posted abroad. Should External Affairs or Health and Welfare Canada report the test results to authorities in the foreign service officer's Canadian province of residence? Is the federal institution or an employee of the institution (a physician, for example) obliged to report under provincial law? If not, would reporting violate the *Privacy Act*?

There appears to be a conflict between the disclosure provisions of the *Privacy Act* and provincial legislation requiring that persons with AIDS or those infected with HIV be reported to provincial health authorities. Subsection 8(2) defines the situations in which disclosure of personal information may be made without consent. The subsection 8(2) disclosure provisions are subject only to "[the disclosure requirements of] any other Act of Parliament" and do not include reporting under provincial legislation.

Paragraph 8(2)(f) would allow a federal institution to disclose AIDS-related personal information to a province for the purpose of administering or enforcing any law or carrying out a lawful investigation. If an agreement is in place, reporting to a province clearly would not violate the Act.

Information-sharing agreements were entered into between the federal government and most (though not all) provinces in 1983, just prior to the coming into force of the *Privacy Act*. These agreements were narrowly drafted to cover the exchange of information for law enforcement. Before any federal institution discloses AIDS-related personal information to a provincial health authority, appropriate agreements should be in place. In rare cases it could also be argued that there is a public interest in disclosing the information under paragraph 8(2)(m), even if no agreement is in place.

Recommendation 10

AIDS-related personal information should be disclosed to provincial governments or their agencies only under paragraph 8(2)(f) agreements, except in rare cases where the public interest calls for disclosure without an agreement being in place.

Existing federal/provincial information sharing agreements should be reviewed to determine whether the sharing of AIDS- related personal information with provincial health authorities is covered.

No information should be disclosed pursuant to paragraph 8(2)(f) agreements unless the conditions contained in Recommendation 9 are also met.

(ii) Disclosure to Foreign Governments

This report does not deal extensively with disclosures of AIDS-related personal information to foreign governments. Part IV discusses ways to limit access by the U.S. government to AIDS-related personal information that Canada collects about those taking part in U.S. Department of Defense courses. But it does not address disclosures beyond this one limited situation. Yet the disclosure of this information to foreign governments should be of equal, if not greater, concern than the disclosure of information to provincial governments.

The *Privacy Act* permits an "agreement or arrangement" to disclose personal information to foreign governments and international organizations (paragraph 8(2)(f)) for the purpose of administering or enforcing any law or carrying out a lawful investigation.

Once information is given to a foreign institution, there may be little control over its use. Even if the agreement or arrangement sets strict terms on the uses of the information, there may be no effective way of ensuring compliance. Given the panic associated with AIDS, foreign recipients of AIDS-related personal information could put it to uses that were prohibited by an agreement.

There are probably few, if any, situations where Canada should share AIDS-related personal information with foreign institutions. We stress the danger of sharing this information across borders -- the primary one being the **practical** loss of control over use and disclosure. Of course, there is no privacy concern arising from the transfer of epidemiological data, as long as it is not possible to identify an individual from the data.

The same restrictions that we recommend for disclosures of information to provincial institutions should apply to disclosures to foreign states or international institutions.

(d) Access to a Person's Own AIDS-related Personal Information

(i) General

Subsection 12(1) of the *Privacy Act* gives individuals a right of access to personal information about them. The information may be contained in a personal information bank or it may be otherwise under the control of a government institution.

Subsection 12(2) sets out the rights of individuals given access. The subsection applies only where the information has been used, is being used or is available for use for an administrative purpose.

The subsection permits the individual to do any or all of the following:

> *(a) request correction of the personal information where the individual believes there is an error or omission therein;*
>
> *(b) require that a notation be attached to the information reflecting any correction requested but not made; and*
>
> *(c) require that any person or body to whom such information has been disclosed for use for an administrative purpose within two years prior to the time a correction is requested or a notation is required under this subsection in respect of that information*

> *(i) be notified of the correction or notation, and*
>
> *(ii) where the disclosure is to a government institution, the institution make the correction or notation on any copy of the information under its control.*

The right of access and the right to request correction, or to require notation and notification are generally available only to Canadian citizens or permanent residents. Under subsection 12(3), the Governor in Council may also extend the right of access to other individuals. In June 1983 these rights were extended to inmates of federal penitentiaries who are not Canadian citizens or permanent residents[1].

The right of access is not absolute. Access is not permitted to several categories of information: that obtained in confidence from a foreign government, an international organization of states, a government of a province or a municipal or regional government[2]. Other categories of personal information that cannot be released include information that could reasonably be expected to be injurious to the conduct of federal-provincial affairs or the conduct of international affairs or the defence of Canada or her allies[3]. Similarly, under section 22, the release of personal information relating to certain law enforcement activities may be refused.

Where provinces provide non-nominal information, the *Privacy Act* does not apply. However, if a provincial government provides nominal information in confidence, an individual could not obtain access at the federal level. A federal government institution may not release it.

If the individual is permitted to review the information at the provincial level, any correction can be passed on by the province to the federal institution. If, however, the province does not allow the individual to correct the information, or if the information was collected without the knowledge of the individual, errors could reach federal data banks. Even accurate information received from a province could be transcribed incorrectly by the federal institution. Decisions may then be based on this inaccurate information.

This predicament can be avoided. The federal government can refuse to accept AIDS-related personal information supplied confidentially by a province. As an alternative, it can negotiate an agreement with the province that will permit a federal institution to process such information under the *Privacy Act* as if it were federal information. Thus, even if the person has no recourse at the provincial level, he or she would be able to review and correct or contest the information once it is stored in federal data banks. We would allow three exceptions to this general rule: where acceptance of the information in confidence by the federal government is necessary for the safety of an individual, where it is necessary for the public safety, or where it is essential for the operational effectiveness of a federal statutory program.

In general, whenever information originates from a provincial government institution, a person should be permitted access to that information as if it were collected directly by a federal institution. This rule would be subject to the exceptions listed immediately above and to other limitations contained in the *Privacy Act*, some of which are discussed below. If a provincial institution attempts to

restrict access to personal information banks unreasonably, the federal government institution should not collect the information.

Similarly, federal institutions should collect AIDS-related personal information from a foreign institution only where the collection meets the collection requirements of the *Privacy Act* and the other recommendations made in this report. Among the requirements for receiving AIDS-related personal information from a foreign institution would be the right for Canada to treat the information as if it were collected under the Act. As well, special care might be needed to ensure the accuracy of the information.

Recommendation 11

A federal government institution should ordinarily accept AIDS-related personal information from a provincial government institution only where the providing institution agrees that the information may be processed in accordance with the *Privacy Act* as if it were federal information.

Exceptions to this general rule should be permitted where it is necessary for individual or public safety or where it is essential to the operational effectiveness of a statutory program.

The right of access under section 12 is subject to other constraints. Section 28 permits the head of a government institution to refuse to disclose to individuals personal information about their physical or mental health if examining the information would be contrary to their best interests.

Only rarely would it be possible for a government institution to refuse to disclose AIDS-related personal information under this provision. The individual would probably already have been informed about his or her HIV status by a physician. There seems little point in refusing to allow access to that or related information by relying on section 28. Furthermore, a person who is refused information about his or her HIV status is almost certain to interpret the refusal as meaning that he or she is seropositive (why, after all, would an institution head fear telling someone that he or she is **not** infected?).

Refusal to disclose under section 28 is therefore largely a non-issue. In the unlikely event that the head of the institution still wishes to refuse to disclose AIDS-related personal information (perhaps, for example, that a test has been performed without the subject's knowledge), the refusal should be supported by the opinion of a qualified medical practitioner that disclosure would be contrary to the best interests of the individual. In addition, the individual must be informed of the right to complain to the Privacy Commissioner under subsection 29(2).

Recommendation 12

The head of a government institution should refuse under section 28 to disclose AIDS-related personal information requested under subsection 12(1) only in rare circumstances. The refusal should be supported by the opinion of a qualified medical practitioner. The person requesting the information must be told of the right to complain to the Privacy Commissioner about the refusal.

Section 25 of the Act permits the head of a government institution to refuse to disclose personal information requested under subsection 12(1) where the disclosure could reasonably be expected to threaten the safety of individuals. As with section 28 refusals, it

is unlikely that section 25 will be relied on to refuse access to AIDS-related personal information.

Disclosing to an individual that he or she is seropositive may threaten the safety of others if the person blames someone else for the HIV infection and seeks revenge. However, a refusal to disclose for this reason must be supported by some objective evidence. But even if the head of the institution refuses to disclose the information, the person will normally have learned about his or her status from a physician. Thus information about seropositivity sought by the person via the *Privacy Act* will have been readily available through other means. Only where the information was not readily available to the person (for example, if the person was unaware of having been tested) should consideration be given to refusing disclosure under section 25.

Recommendation 13

Section 25 should not be relied on to refuse disclosure of AIDS-related personal information unless

> **(1) there is some objective evidence indicating that the safety of individuals could be threatened, and**
>
> **(2) the person requesting the information does not have independent knowledge of the requested information.**

(ii) Challenging or Confirming Conclusions about Seronegativity or Seropositivity

Challenging or confirming test results that are stored in personal information banks presents difficulties. HIV antibody testing is done almost exclusively by provincial laboratories (although tests on potential immigrants may be conducted in other countries). Only where results from provincial laboratories are equivocal are samples sent to the Federal Centre for AIDS Retrovirus Laboratory. Accordingly, a federal government institution often will have no direct control over a blood sample. A person will not be able to obtain a sample under the authority of the *Privacy Act* to challenge the results derived **from that sample**. The person may need to approach provincial laboratories to obtain the sample, provided it has been retained.

Positive Test Results: In practice, a person can easily challenge a positive test result by giving another blood sample and being retested. Seropositivity is usually lifelong (although antibodies may disappear as the disease progresses or, rarely, an individual may lose antibodies; both situations will result in a finding of seronegativity). If an accurate subsequent test shows seronegativity, the original test likely will have been wrong.

If the person is still alive to provide a subsequent blood sample, there is most likely no practical need to retain the original blood sample to challenge a finding of seropositivity. Where the person has died, and no subsequent blood sample is available, the only way to challenge the accuracy of the original test will lie in retesting the original sample. We think that the need for retesting after death will arise infrequently. Generally, only where the person's estate has an interest in challenging the finding would the need arise.

Negative Test Results: The results from a blood sample taken subsequently cannot be used to challenge a previous seronegative test result. Unlike seropositivity, seronegativity

may not be lifelong. The original test showing seronegativity may have been accurate, even if a test on a sample of blood that was drawn later proves positive. The second test may simply show that the person became infected after taking the first test. Only if the blood sample used for the first test is available for retesting can it be shown that the first test was wrong.

To summarize:

- a finding of seropositivity could be **challenged** by testing a blood sample drawn subsequently. Generally, only in limited circumstances (the estate example) where a later blood sample is not available is the original blood sample necessary to challenge the original finding. A finding of seropositivity **as of a past date** can be **confirmed,** however, only by retesting the sample of blood on which the first test was performed.

- a finding of seronegativity can be **challenged** only by retesting the sample of blood on which the first test was performed. A test performed on a later sample of blood cannot be used to dispute the original finding of seronegativity; it can only confirm the original finding and, even then, may not always be accurate. (For example, a seropositive person may have been mistakenly described as seronegative, but could in the meantime have lost antibodies or ceased producing them).

At issue is how far government institutions must go to facilitate challenges under the *Privacy Act* to information stored in personal information banks. Subsection 6(1) of the Act reads as follows:

> *Personal information that has been used by a government institution for an administrative purpose shall be retained by the institution for such period of time after it is so used as may be prescribed by regulation in order to ensure that the individual to whom it relates has a reasonable opportunity to obtain access to the information.*

Subsection 4(1) of the *Privacy Regulations* [4] sets out time limits for retaining information:

> *Personal information concerning an individual that has been used by a government institution for an administrative purpose shall be retained by the institution*
>
> *(a) for at least two years following the last time the personal information was used for an administrative purpose unless the individual consents to its disposal; and*
>
> *(b) where a request for access to the information has been received, until such time as the individual has had the opportunity to exercise all his rights under the Act.*

The Act and Regulations may be interpreted to mean that only the information about HIV status is required to be kept (and not the actual blood samples). If so, there will be little problem in complying with the Act and Regulations. The institution will merely store information, not blood samples.

The duty to retain and the right of access, however, might be interpreted to require the retention of blood samples, and not merely the results taken from those samples.

This issue presents no small problem. The logistics of storing blood samples for at least two years probably were not in the minds of the drafters of the *Privacy Act* when such a broad definition of personal information was included.

The *Privacy Act* will probably be interpreted to require that only the recorded results need be retained, not the original blood samples. This would disadvantage those who wished to challenge a finding of seronegativity by relying on the section 12 "correction" or "notation" procedure. Not retaining blood samples could also disadvantage a small number who wished to challenge seropositive findings.

Without judicial direction to the contrary, it would appear reasonable for those few institutions that may collect blood samples (for example, Health and Welfare Canada and Correctional Service Canada) to assume that the Act's information retention periods relate only to any information generated from tests performed on the samples.

Recommendation 14

In responding to requests to correct the results of HIV antibody tests, institutions should adopt the following guidelines:

> **(1) A record of a seropositive test result may be corrected if the physician of the person requesting the correction confirms that a subsequent test has been performed with a negative result. When assessing the request, the institution should consider that, ordinarily, seropositivity is lifelong; subsequent negative test results, if properly conducted, most likely (although not certainly) invalidate the original test result. The institution should consider whether repeat testing of the more recent blood sample is necessary to support the validity of the challenge to the original finding. After weighing these factors, the institution may change the original finding or decide to place a notation on the file about the recent seronegative test result.**
>
> **(2) A record of a seronegative result should not be corrected if challenged. However, a notation should be added to the record indicating that a correction was requested and its nature.**
>
> **(3) A record of either a seronegative or seropositive result must, however, be corrected if it was recorded through administrative or clerical error.**

(e) Remedies for Improper Practices by Government Institutions

Penalties for the improper handling of AIDS-related personal information also figure in the discussion. Legislative directions are of little value without enforcement mechanisms.

Apart from penalties for obstructing the Privacy Commissioner (section 68), the *Privacy Act* imposes no penalties on those who breach its provisions. Legislation that governs the handling of personal information by specific institutions sometimes imposes penalties for improper actions. The *Criminal Code* breach of trust provisions can be applied where there has been criminal conduct. The Government Security Policy issued by Treasury Board provides still other sanctions, including discharge from employment. Civil

actions may be possible. Finally, the *Charter of Rights* permits a range of (unspecified) remedies where its provisions have been breached. Section 74 of the *Privacy Act*, however, limits the criminal and civil liability of the Crown, government institutions and employees of those institutions. Section 74 protects them from civil or criminal liability where personal information is disclosed in good faith under the Act. It also protects against liability for the consequences that flow from the disclosure.

Except for the *Charter* and some civil actions, penalties and remedial measures tend to be applied only for improper use or disclosure. There appear to be fewer statutory remedies for improper collection of information.

This plethora of remedies and penalties may comfort those who fear that AIDS-related personal information will be improperly used. Perhaps it should not. Serious breaches of security of personal information still occur, despite the potential for severe penalties, as the 1986-87 Annual Report of the Privacy Commissioner chronicles.

No system of security is perfect. No range of penalties will deter everyone from conduct that threatens the security of personal information. Accordingly, we return to our earlier theme: what is not collected cannot be disclosed improperly or misused.

Government institutions can also enhance the protection given personal information by educating their employees about the extreme delicacy of AIDS-related personal information. They must be reminded of the consequences of unauthorized collection, use and disclosure, both for the infected person and for the employee. Well informed custodians of information will not be as likely to be reckless. Education, however, may not deter those who intend to abuse the information. Penalties, strict security procedures and constraints on collection, use and disclosure must remain as additional safeguards.

Sections 35 and 37 give the Privacy Commissioner the power to make recommendations to Ministers for dealing with what the Commissioner considers infringements of the *Privacy Act*. To date, the Privacy Commissioner has not recommended penalizing errant employees who breached the collection, use and disclosure provisions. Any criminal misconduct was pursued through criminal investigations.

Because of the sensitivity of AIDS-related personal information, the Privacy Commissioner will in future consider recommending sanctions against public officials who have not handled AIDS-related personal information in accordance with the *Privacy Act*. This does not represent a call for the expansion of existing powers. It simply means making greater use of the powers of recommendation afforded by sections 35 and 37.

In addition, the Privacy Commissioner may, under subsection 64(2), disclose to the Attorney General information relating to the commission of an offence.

The Privacy Commissioner will continue to have no authority to enforce the recommended penalties. Enforcement would be left to the institution or courts. They could act (or not act) on the Privacy Commissioner's recommendations.

In any event, heads of institutions must accept the onerous responsibility placed on them for the care and control of such sensitive information. When abuses of AIDS-related per-

sonal information occur, it is simply not good enough to be apologetic and vow to do better in the future.

ENDNOTES TO PART III

1. SOR/83-553.

2. R.S.C. 1985, c. P-21, s. 19.

3. R.S.C. 1985, c. P-21, s. 21.

4. SOR/83-508.

PART IV

SPECIFIC SITUATIONS

The recommendations in Part III focus on collection, use and disclosure. Many of the practical issues arising in government institutions, however, relate more directly to disclosure. This section examines how the disclosure and other principles raised in Part III apply to several groups: employees of government institutions (not including the Canadian Forces), Canadian Forces personnel and civilian DND employees, members of the public eligible for special benefits from government due to illness or disability, inmates in federal institutions and applicants for immigration.

(a) Public Service Employees

Some may argue that if a public servant (or, indeed, any person employed by a government institution) is HIV seropositive, co-workers should be permitted to know. They advance two justifications for disclosure. First, co-workers can take preventive measures to avoid contagion. Second, supervisors who are aware of an employee's HIV-status can decide what work duties the employee should perform.

We recognize the real (if insupportable) fear of contagion through workplace contact. Nonetheless, this alone does not justify notifying co-workers of a person's HIV status. Educating public servants about mechanisms of transmission intrudes far less into the privacy of the individual affected. It is also more humane. Those who understand the nature of AIDS and HIV infection will be less likely to ostracize a person who is already undoubtedly suffering from psychological or physical trauma.

Even an infected employee's superiors need not know the person's condition. A medical certificate indicating that the person can or cannot perform certain functions should suffice. Only the person's physician or a physician from Health and Welfare Canada would be aware of his or her specific condition.

This medical certificate could also serve foreign service personnel and others whose work takes them to foreign countries. Some concern has been expressed (although there is no consensus) that seropositive personnel who are posted to certain foreign countries may have the onset of AIDS hastened by being exposed to a range of foreign viruses and bacteria. In addition, inoculating symptomatic seropositive personnel with live vaccines could create grave health risks.

An employee about to be posted abroad should be informed of the possible risks of accepting such assignments and of being inoculated if seropositive. The employee should then be told that he or she may wish to undergo an antibody test before receiving inoculations or being posted abroad.

If the person decides not to be tested, he or she assumes the risks to health posed by the inoculation or posting. If the person decides to be tested, he or she could see a Health and Welfare Canada physician or his or her per-

sonal physician. There would be no need to disclose to a superior that a test has been taken or refused.

If the person decides to be tested and is seropositive, the physician could inform the employer that the person cannot accept certain postings or inoculations for health reasons. This process safeguards the privacy of the individual. Yet it still addresses the concerns of employers about to send employees abroad.

Need has been expressed (particularly by the United States government) for a "walking blood bank" in some countries. Employees of an embassy or High Commission may provide blood for transfusions to other employees instead of having them rely on possibly unsafe local blood supplies. This may lend weight to the call for testing all personnel sent to foreign postings. Each person would therefore know whether he or she could safely donate blood.

Still, there is no need here for co-workers or superiors to know that the person is seropositive or even whether the person has been tested. Those wishing to contribute to a walking blood bank could be required to be placed on an eligibility list. Health and Welfare Canada could determine the criteria for eligibility and arrange for candidates to be tested. No one in a candidate's department would need to know the precise reason why a candidate's name was not on the eligibility list.

Similarly, even where seronegativity may be a bona fide occupational requirement, it is not necessary that test results be made known to the superior of the infected person. A medical certificate could simply indicate that the person is not to perform such duties. This may invite speculation about the reason for restricting activities, but will not disclose seropositivity to the person's superiors. The infected person's physician alone (and perhaps Health and Welfare Canada) will possess details of the health condition.

Accordingly, we suggest that in most public service employment (even on foreign postings) there is little, if any, justification for providing co-workers or superiors with AIDS-related personal information. Because this information will then not appear in personnel files the danger of information leaks is reduced. (Even if the person volunteers the information, it should not be kept on file).

(b) Canadian Forces Personnel and Civilian Department of National Defence Employees

Rigorous physical activity is often part of the military regimen. Consequently, it may be argued that AIDS-related personal information has greater relevance to the conditions of service in the Canadian Forces than it would to more sedentary forms of employment.

At present, only medical personnel and senior military authorities (including Commanding Officers) with a need to know are made aware of a member's seropositivity. We question whether senior military authorities truly need to be informed about seropositivity. Is it not sufficient to know that a member falls within a medical category that will not permit certain types of activity, just as could be the case with employees of government institutions in general? We also ask whether senior military authorities should be

permitted access to other AIDS-related personal information. This information could in general be handled as we recommend for public service employees.

The Department of National Defence faces one particular difficulty. Certifying seronegativity of military members and civilian employees for training in the United States will dictate testing approximately 1000 members and 200 civilian employees annually. This will result in the collection of AIDS-related personal information. Above all, it will result in the sharing of some of this information with a foreign government. American military authorities will not reconsider this testing requirement.

While it seems relatively innocuous to confirm that a person is seronegative, this sets a precedent which concerns us. A foreign government has imposed testing requirements when Canada is in no position to refuse. We are concerned about the United States collecting AIDS-related personal information on Canadians, particularly given, in our view, the misdirected zeal that American authorities have shown for obtaining and using this type of information.

Under no circumstances should DND disclose to the United States military authorities the names of Canadians being tested. This would allow U.S. military authorities to speculate that those who did not subsequently attend training courses in the United States had tested seropositive. Only the names of those who test seronegative and are asked to attend should be passed on.

Testing of military and civilian personnel, where it must be carried out, can be handled as follows. Military personnel medical records are maintained by the Canadian Forces. The results of antibody tests will therefore appear on those records. If a Canadian Forces member tests positive, a medical certificate should be prepared indicating that for medical reasons the member cannot participate in the U.S. training program. Again, we question whether senior military authorities need to know the specific medical condition.

With civilian personnel, the situation will differ slightly. Antibody test results should be maintained by Health and Welfare Canada or by a private physician if the employee chooses to be tested through the physician. If the employee tests positive, a medical certificate should be issued indicating that the person cannot undergo training for medical reasons. There is no need for the certificate to disclose the exact medical condition.

(c) Members of the Canadian Public Eligible for Special Illness or Disability Benefits from Government

Many government programs provide benefits or concessions to persons with disabilities. All these programs cannot be described here. The following suggestions are aimed at limiting the unnecessary collection of AIDS-related personal information.

There should be a review of programs that require a statement of medical disability to determine whether a general statement will suffice. Is it truly necessary for a person to divulge the intimate details of a medical condition to obtain a benefit or concession under a government program?

Unemployment insurance provides one common example of a program that benefits those who are ill. The *Unemployment Insurance Act* permits benefits to be paid to unemployed workers. Under section 14 of the Act, however, a claimant is not entitled to be paid "initial benefit" for any working day in a benefit period for which he fails to prove that he was "incapable of work by reason of prescribed illness, injury or quarantine".

Subsection 47(1) of the *Unemployment Insurance Regulations* requires a person alleging that he is ill to furnish a medical certificate to the Unemployment Insurance Commission. The certificate must supply such information as the Commission may require "with respect to the nature of the illness ...".

In addition, subsection 47(2) permits the Commission to require the claimant to undergo another (independent) medical examination to determine the nature of the illness, and other matters, such as the probable duration of the incapacity.

The disclosure of detailed medical information to the Commission may be unnecessary. Section 47 of the Regulations does not compel the Commission to obtain details of a medical condition. It has a discretion to do so. It would not violate the Act or Regulations to accept a physician's certificate that does not specify the nature of the illness.

Some may argue that details of illnesses are necessary to prevent a claimant from relying on a "friendly" physician to warrant inability to work, or to extend the period of incapacity. If this is the fear of the Commission, it could offer a claimant two choices:

> (1) supply a detailed medical opinion from the claimant's own physician (this would disclose HIV infection), or
>
> (2) (if the claimant wants the precise condition kept from the Commission) send the claimant to a physician approved by the Commission; this physician will operate under Commission guidelines detailing acceptable illnesses and times off work. If the claimant has AIDS, the physician would report a medical illness and estimate its term. The Commission would accept the certificate of the physician without knowing the details of the illness.

Variations on this theme might be applied elsewhere in government. Less AIDS-related personal information about claimants will then be stored in an institution's personal information banks.

We acknowledge, however, that some government institutions must collect detailed medical information because legislation, judicial pronouncement or policy compel them to. These must be obeyed. However, their impact can be softened by ensuring adequate security of records and adopting reasonable information disposal schedules.

In the long term, legislation, judicial pronouncements and government policies can be changed. If the protection of AIDS-related personal information is considered important, revisions to policy and legislation are appropriate long term options.

(d) Inmates in Federal Correctional Institutions and Correctional Staff

Inmates pose special problems. Like few other groups in Canadian society, their daily activities are strictly controlled by a govern-

ment institution. With that extraordinary degree of control comes an extraordinary responsibility for inmate welfare.

This has implications for the treatment of AIDS-related personal information. A diagnosis of HIV infection is to be noted on the inmate's medical record.

Commissioners' Directive 821 provides for release of information relating to HIV status to "agency/supervisory staff" without the inmate's consent if there is cause to believe that the inmate's actions may constitute a danger to himself or others. Health care staff may then, "in accordance with the Privacy Act", provide information to the appropriate personnel without the inmate's consent.

Should incarceration diminish the rights of an inmate to maintain AIDS-related personal information in confidence? With other groups, such as public servants, we have suggested that supervisors normally need not be informed of a person's HIV status.

Nonetheless, there may be merit in a policy that allows disclosure where an infected inmate's conduct threatens others (for example, through unsafe sexual practices or the sharing of needles). This policy may even be necessary because prison policy dictates that no condoms will be issued to inmates. The likelihood of needles being issued is even more remote, as it might be seen as condoning drug use in prisons. Even educating inmates about the dangers of unprotected intercourse or the sharing of needles may not reduce risky conduct, as the means they need to reduce the risk (condoms and needles) are not available to them.

We anticipate that risky conduct will continue in prisons because prison policies will not reduce risk by allowing condoms and needles. It may be necessary therefore to protect inmates by warning them away from infected inmates who engage in risky activities. This will seriously compromise the privacy of infected inmates and may endanger their physical safety. But it may be one of only a limited number of actions available to protect other inmates.

One other possibility is to segregate an infected inmate who does not stop dangerous conduct. It would then not be necessary to disclose the grounds for segregation to other inmates. Before an inmate's infected status is made known to other inmates, however, he should be asked whether he prefers to be segregated from other prisoners (while keeping his HIV infection confidential) or whether he wishes to remain in the general population (which will then be told of his status and warned to avoid risky behaviour with him). This is an unpalatable choice. But it may be forced on the inmate given current prison policies about condoms and needles.

Whether corrections officers and others administering prison facilities need to know the HIV status of inmates remains a question. Corrections officers may pass the information negligently to other inmates. At the same time, some corrections officers may fear that inmates will attempt to infect them, given the hostile relations between the two groups. How significant a risk this is must be assessed before a decision is made about informing corrections officers of an inmate's HIV infection.

(e) Applicants for Immigration

The health criteria for admissibility of immigrants are determined by Health and Welfare Canada. At present, immigrants with AIDS are inadmissible, as are those who are identified as HIV seropositive.

Health and Welfare Canada does not indicate to Employment and Immigration the precise medical grounds for refusing to allow an applicant to immigrate. It merely certifies that the applicant is medically unfit. This procedure seems appropriate to us. It protects against the broad dissemination of HIV status information by holding the information in Health and Welfare Canada data banks.

Should an applicant for immigration be rejected, the sponsors have a right to know the grounds for the rejection, including any relevant medical condition (see Appendix III). While the applicant should be made aware of this justification for refusal, we question whether sponsors should be informed.

This represents one of the few situations we have encountered where AIDS-related personal information about one person is disclosed by government to someone **outside government.** An applicant sponsored by parents or relatives may not want them to learn of any HIV infection because, for example, it may reveal sexual practices or drug use. The applicant may fear that they will disclose it to others. Unlike the situation in which AIDS-related personal information is disclosed within government, the *Privacy Act* places no controls on what sponsors do with the information.

Yet the information may be important for sponsors who want to appeal a refusal to allow entry. They might, for example, challenge the reliability of an HIV antibody test that was taken in a Third World country. If they did not know the reason for the refusal, they would not know how to frame the challenge.

One possible solution is to allow disclosure of AIDS-related personal information to sponsors only with the consent of the applicant. EIC confirms that this is in fact done at present. The applicant is asked to consent to the release of medical information to relatives in Canada. But legislation and jurisprudence seem to require that **family** sponsors be made aware of the reasons for refusal. Perhaps a legislative amendment is needed. It would clearly give a sponsored applicant the right to refuse the release of medical information, even to family members, without prejudicing the immigration application.

PART V

SUMMARY OF RECOMMENDATIONS

Recommendation 1

Treasury Board take steps to issue a comprehensive policy on AIDS in the workplace; this policy should include a clear statement on confidentiality and the controls on the collection of AIDS-related personal information, guided by the principles and recommendations set forth in this report.

Recommendation 2

AIDS-related personal information available through voluntary testing, the voluntary provision of information, or both, should be collected only where the collection is a necessary element of the administration of a statutorily mandated program or activity of the institution.

Recommendation 3

No compulsory or mandatory HIV antibody testing should be implemented by government institutions unless specifically authorized by statute. Moreover, existing enabling provisions, such as section 7 of the *Financial Administration Act*, which do not specifically address the collection of AIDS-related personal information, should not be relied on to authorize such collections.

Recommendation 4

Further study should be undertaken to determine whether, to what extent and under what safeguards, DND should collect AIDS-related personal information concerning Canadian Forces members.

Recommendation 5

Wherever possible, AIDS-related personal information should be collected directly from the person affected, and not by consulting records or a third party (except where the individual authorizes otherwise or where personal information may be disclosed under subsection 8(2)), and

Wherever possible, when collecting AIDS-related personal information, including collection from records or a third party, the institution should inform the person to whom the information relates of the purpose of the collection and the source of the collection.

Recommendation 6

AIDS-related personal information should be used only as follows:

> **i) for the purpose for which the information was compiled or obtained by the institution,**
>
> **ii) for a use consistent with that purpose, or**
>
> **iii) for a purpose for which the information may be disclosed under subsection 8(2).**

In situation ii), no use should be undertaken without the approval of the head of the government institution. In situation iii), no use should be undertaken under paragraphs 8(2)(e) to (m) without the approval of the head of the government institution.

Recommendation 7

To meet the requirements of subsection 6(2), a record of a finding of seropositivity on the basis of screening testing only should never be used for an administrative purpose. Only a seropositive result after a confirmatory test should be used for an administrative purpose.

A record of a medical opinion suggesting that a person has symptomatic HIV infection may be used for an administrative purpose, even without HIV antibody tests being performed. However, only a confirmatory test result should be used to confirm seropositivity.

Recommendation 8

To meet the requirements of subsection 6(2), a finding of seronegativity based on a single screening test performed under appropriate laboratory conditions should be considered "as accurate as possible" and might be relied on for an administrative purpose. Nonetheless, those using the information for an administrative purpose should be made aware of the deficiencies inherent in any finding of seronegativity.

Recommendation 9

The following policy should govern disclosures of AIDS-related personal information:

No disclosure of AIDS-related personal information should be made to third parties under paragraphs 8(2)(e) to (m) without first seeking to obtain consent from the individual for the release. There would be no need to seek consent before disclosing this information under paragraphs 8(2)(a) to (d).

Where consent to disclose is not given, no disclosure should be made to third parties under paragraphs 8(2)(e) to (m) without the approval of the head of the institution. This approval would not be required for disclosures under paragraphs 8(2)(a) to (d).

In exercising discretion to disclose under subsection 8(2)(e) to (m) the head of the institution should review

(1) why disclosure is necessary

(2) the potential adverse consequences of the disclosure on the individual(s) to whom it relates,

(3) the likelihood that the requestor can and will maintain the confidentiality of the information and

(4) the likelihood that the requestor will use it only for the purpose for which it was originally sought.

Where a third party requests disclosure of AIDS-related personal information under paragraphs 8(2)(e) to (m), the onus should be placed on the requestor to justify the disclosure of the information.

Recommendation 10

AIDS-related personal information should be disclosed to provincial governments or their agencies only under paragraph 8(2)(f) agreements, except in rare cases where the public interest calls for disclosure without an agreement being in place.

Existing federal/provincial information sharing agreements should be reviewed to determine whether the sharing of AIDS-related personal information with provincial health authorities is covered.

No information should be disclosed pursuant to paragraph 8(2)(f) agreements unless the conditions contained in Recommendation 9 are also met.

Recommendation 11

A federal government institution should ordinarily accept AIDS-related personal information from a provincial government institution only where the providing institution agrees that the information may be processed in accordance with the *Privacy Act* as if it were federal information.

Exceptions to this general rule should be permitted where it is necessary for individual or public safety or where it is essential to the operational effectiveness of a statutory program.

Recommendation 12

The head of a government institution should refuse under section 28 to disclose AIDS-related personal information requested under subsection 12(1) only in rare circumstances. The refusal should be supported by the opinion of a qualified medical practitioner. The person requesting the information must be told of the right to complain to the Privacy Commissioner about the refusal.

Recommendation 13

Section 25 should not be relied on to refuse disclosure of AIDS-related personal information unless

(1) there is some objective evidence indicating that the safety of individuals could be threatened, and

(2) the person requesting the information does not have independent knowledge of the requested information.

Recommendation 14

In responding to requests to correct the results of HIV antibody tests, institutions should adopt the following guidelines:

(1) A record of a seropositive test result may be corrected if the physician of the person requesting the correction confirms that a subsequent test has been performed with a negative result. When assessing the request, the institution should consider that, ordinarily, seropositivity is lifelong; subsequent negative test results, if properly conducted, most likely (although not certainly) invalidate the original test result. The institution should consider whether repeat testing of the more recent blood sample is necessary to support the validity of the challenge to the original finding. After weighing these factors, the institution may change the original finding or decide to place a notation on the file about the recent seronegative test result.

(2) A record of a seronegative result should not be corrected if challenged. However, a notation should be added to the record indicating that a correction was requested and its nature.

(3) A record of either a seronegative or seropositive result must, however, be corrected if it was recorded through administrative or clerical error.

Appendix I

AIDS - ITS CHARACTERISTICS

(a) General[1]

AIDS stands for Acquired Immunodeficiency Syndrome. AIDS is caused by a virus called HIV (Human Immunodeficiency Virus). The HIV (or, colloquially, the "AIDS" virus) attacks and seriously disrupts the body's immune system, its defence against disease.

The syndrome leading to AIDS is divided into stages:

- infection with the HIV
- asymptomatic (no overt symptoms) carrier state
- development of symptomatic HIV infection, (also called AIDS Related Complex, or "ARC")
- development of AIDS.

AIDS is properly the name given only to the last of these stages. Here, the breakdown in the immune system leaves the body vulnerable to life-threatening infections and cancers. These diseases, not the destruction of the immune system as such, eventually result in death. At present, contracting AIDS always leads to death. Medical treatments may delay death, make persons with AIDS ("PWA's") more comfortable, or both.

AIDS may not develop in a person for several years after he or she becomes infected with the virus. It may not develop at all. It is not yet known whether every person infected with the HIV will eventually develop AIDS. Based on observations to date, Canada's Federal Centre for AIDS suggests that approximately 35-50 per cent of infected persons will develop AIDS within seven years of infection. Over time, an even greater percentage may develop the disease.

The New York Times[2] reported one study of 155 infected homosexual and bisexual men in San Francisco. Their approximate date of infection was known. Very few developed AIDS in the first two years after infection. Five per cent had developed AIDS after three years, 10 per cent after four years, 15 per cent after five years, and 24 per cent after six years.

After seven years and four months, 36 per cent had developed AIDS. An additional 40 per cent showed other signs of infection, such as severe weight loss, prolonged fever or oral fungi. Only one in five remained free of symptoms.

Dr. Anthony Fauci, Director of the National Institute of Allergy and Infectious Diseases (of the United States), has asked: "Will virtually everyone who is infected develop full-fledged AIDS after 35 or 40 years? Or will it plateau at 35 to 40 per cent?".[3]

Dr. Fauci recently told the President's AIDS Commission that evidence from the Walter Reed Army Medical Centre suggests that 80 to 90 per cent of all infected individuals experience some level of deterioration in their immune systems over a few years, suggesting that the vast majority of them will be adversely affected over time.[4]

Even if a person infected with the HIV does not develop AIDS, it is accepted that he or she is probably capable of transmitting the virus for life. As well, it is assumed that the presence of the antibodies to the HIV indicate the continuing presence of the HIV itself.

A cure for AIDS or a vaccine to protect against it may not be available for several years, if at all. Estimates of the time required to develop such remedies vary widely, but are almost always stated in years. Some suggest that a cure may be impossible.

(b) Methods of Transmission

Public fear of AIDS and calls for radical responses (such as publicizing the names of infected persons or placing them in quarantine) stem largely from not knowing how AIDS is spread.

The HIV may be present in blood, semen and vaginal fluid of a person infected with the virus. The virus is transmitted in several ways:

- Through sexual activity. In Canada, this is the most frequent means of transmission. The virus can be transmitted from an infected person to his or her sexual partner (man to woman, woman to man, and man to man);

- Through blood or blood products. The main ways a person can become infected are through receiving blood transfusions (or blood products) infected with the HIV or by using blood-contaminated needles or other skin-piercing equipment;

- From infected mother to child during pregnancy, at or about the time of birth, and possibly from breast milk;

- From sperm, tissue, breast milk or solid organ donations from an infected donor.

AIDS is not highly contagious. Medical and scientific opinion accepts that AIDS is NOT spread through casual contact, such as occurs at work or at school; touching or hugging; handshakes; coughing or sneezing; insects; water or food; cups, glasses, plates; toilets; using communal swimming pools or public baths; using communal dining facilities; or using communal dormitories. The normal mixing and mingling of infected persons with others therefore carries no danger.

While the HIV has occasionally been detected in low concentrations in body fluids such as saliva, urine and tears, there is no evidence that these fluids have caused infection. The virus is not spread by the airborne route.

The Statistical Picture

(a) International

AIDS was first identified as a disease in 1981, although the widespread epidemic of infection probably started in the mid-1960s.[5] Since then it has been reported in over 160 countries.

Recent (1987 and 1988) reports from countries and international statistics assembled by the Federal Centre for AIDS indicate a total of 127,611 cases of AIDS world-wide.

This figure is almost certain to be an underestimate. Barriers to diagnosis, recognition and reporting of the disease exist throughout the world. Even in the United States, with a highly developed AIDS surveillance network, an estimated 10 per cent of AIDS cases are not reported to government. In some countries, particularly developing countries which may lack the tools to make a firm diagnosis, the reported number of cases may be only a fraction of the total.[6] Furthermore, some countries may be reluctant for political reasons (such as a fear of losing tourist trade) to report a high incidence of AIDS.

The World Health Organization (WHO) in 1988 estimated that about 250,000 cases of AIDS have occurred since the beginning of the epidemic.[7]

The January 3, 1989, report from the Federal Centre for AIDS show that Canada had a **cumulative** (that is, since 1979) rate of 90 cases of AIDS per million population. In figures from the same general period (1988) from the United States, the cumulative rate was significantly higher, at 317.5 per million. Denmark reported a rate of 62.5 per million. The United Kingdom reported 31.6 per million and France reported 76.6 per million.[8]

There is no way to determine accurately the number of persons who have been infected by the HIV. WHO broadly estimates the number to be between 5 and 10 million. Although, as stated above, there is debate over what percentage will eventually develop AIDS, WHO in 1987 accepted a figure of between 10 per cent and 30 per cent. If these broad estimates hold true, there will be from 10 to 30 times more AIDS cases in the next five years than in the past five years.[9]

(b) Canada[9a]

As of January 3, 1989, the Federal Centre for AIDS had received reports of 2323 cases of AIDS. All occurred since 1979. Adults accounted for 2284 cases, (2166 men and 118 women); 39 were children less than 15 years old (18 males and 21 females). Of this total, 1259 deaths have been reported.

The number of reported cases of AIDS in Canada doubled in the seventeen months prior to January 3, 1989.

The Federal Centre for AIDS *Surveillance Update: AIDS in Canada* reports projections of the number of new cases of AIDS that will occur between 1988 and 1992. Two empirical modelling techniques were used to arrive at the projections - the logistic model and the polynomial model.

The logistic model estimates that the number of new cases reported annually will remain almost constant from 1987 to 1991. It predicted 562 new cases in 1987 (in fact, there were 684, and more will be reported over time) and predicts 1036 new cases in 1992. Using this model, a total of 6849 AIDS cases will have occurred in Canada between 1979 and the end of 1992. The model predicts the growth rate in AIDS cases will plateau early in the 1990's.

The polynomial model estimates a substantial increase in new cases over the next several years. It predicted 653 new cases in 1987, with the number of cases rising each successive year. The model predicts 2656 new cases in 1992, for a cumulative total of 10,842 between 1979 and the end of 1992. This model does not predict a levelling off of new cases by the end of the prediction period (1992).

The Federal Centre for AIDS accepts the polynomial model as more likely than the logistic model to predict accurately the spread of AIDS in Canada over the next several years.

Both models may be affected by changes in the dynamics of the spread of infection. For example, if intravenous drug use becomes a major mechanism for transmitting AIDS in Canada (as it has in the United States and several other western countries), heterosexual AIDS cases may increase substantially.

The Federal Centre for AIDS estimates that there are 30 - 50 infected persons in Canada for every person with AIDS. The Royal Society of Canada suggested early in 1988 that approximately 30,000 Canadians were then infected, although this estimate was general at best. The number may be as low as 10,000 or as high as 100,000. [10]

(i) Risk groups

By far the largest number of AIDS cases in Canada have occurred in adult males (2166 cases to date). Among adult males there are several identified risk groups.

According to statistics supplied by the Federal Centre for AIDS as of January 3, 1989, the principal risk factor for AIDS in adult males was homosexual or bisexual activity (86 per cent of adult male cases). Less than 1 per cent of adult male cases involved intravenous drug use alone. Just under 3 per cent involved both intravenous drug use and homosexual or bisexual activity. Male recipients of blood or blood products accounted for 3.9 per cent of cases. Heterosexual contact with a person at risk of contacting AIDS accounted for 1 per cent of the cases. Heterosexual males originating from an AIDS-endemic area accounted for 3.2 per cent of the cases. In 2.5 per cent of adult male cases, there were no identified risk factors.

The male age group most heavily affected is 30 - 39. Over 45 per cent of adult males with AIDS fall into this age group.

The number of AIDS cases in adult females is considerably smaller - only 118 to date. Of these, 2.5 per cent involved intravenous drug use. Recipients of blood or blood products accounted for 28 per cent of the total. Females originating from an endemic area accounted for 31.4 per cent of cases. Sexual activity with a male at risk accounted for 32.2 per cent of cases. No identified risk factors were present in 5.9 per cent of adult female cases.

To date, 33.1 per cent of reported adult female AIDS cases have occurred in the 20 - 29 age group. A slightly lower percentage (30.5 per cent) have occurred in the 30 - 39 age group.

Among pediatric cases of both sexes, perinatal (from mother to child) transmission accounted for 84.6 per cent of the 39 cases. Receiving infected blood or blood products accounted for the remainder. Over 80 per cent of pediatric cases have occurred in children under five.

(ii) Deaths from AIDS and Other Causes

The Royal Society of Canada reports that in 1985 AIDS ranked tenth as a cause of death among Canadian men aged 25 - 44. [11] Ahead

on the list were causes such as suicide, motor vehicle accidents, coronary disease, stroke and cirrhosis.

Preliminary data for 1986 indicate that AIDS moved to fourth place that year. The Royal Society report continues:

> If current epidemiological trends remain constant, AIDS will surpass coronary heart disease to become the third leading cause of death for men in this age group and by 1992 could even become the leading cause of death. [12]

Nonetheless, AIDS ranks far behind several other causes of death in the population as a whole. The following chart compares deaths from AIDS with those from cancer ("malignant neoplasms"), heart disease and motor vehicle accidents. The chart totals deaths for both sexes and covers all age groups.

It may be argued that this chart is largely irrelevant. It does not differentiate death rates among age groups. Still, it shows the relative scope of the problem (in absolute numbers) for Canada as a whole.

The social and economic consequences of AIDS, however, may differ substantially from those associated with many other diseases. These are discussed briefly below under the heading "Direct and Indirect Costs Associated with AIDS".

CAUSE OF DEATH

YEAR	AIDS*	CANCER	HEART DISEASE	MOTOR VEHICLE
1982	22	41,964	59,383	4,232
1983	51	42,865	58,446	4,334
1984	126	44,784	58,215	4,133
1985	329	46,333	58,331	4,234
1986	507	Not Avail.	N/A	N/A
1987	727	N/A	N/A	N/A
1988	525	N/A	N/A	N/A

Sources: Federal Centre For AIDS, *Surveillance Update: AIDS in Canada*, January 3, 1989 (AIDS statistics only); Statistics Canada, *Mortality Summary List of Causes* (Vital Statistics Catalogue 84-206). *To be technically correct, AIDS does not kill. Opportunistic diseases arising because of AIDS kill. Note as well that the AIDS statistics for recent years may increase later due to the late receipt of confirmed diagnoses of AIDS.

(iii) Regional Variations

British Columbia reports the highest rate of cumulative (since 1979) AIDS cases per capita in Canada. As of January 3, 1989, B.C. reported 158.1 cases (cumulative) per million population. Quebec followed, with 105.7 per million. Ontario stood third, with 98.9 per million. Alberta reported 51.4 cases per million, Nova Scotia reported 37.1 and Yukon reported 43.1. Other provinces and territories reported under 30 cases per million. The national average as of January 3, 1989, stood at 90 cases per million.

(iv) Direct and Indirect Costs Associated with AIDS

The Royal Society of Canada estimates that HIV-related health care expenditures in 1987 were the equivalent of 0.3 per cent of Canada's total health care expenditures in 1985 (1985 was the most recent year for which comprehensive statistics on health care expenditures were available). In 1985, private and government health care expenditures totalled $39.2 billion and comprised 8.5 per cent of Canada's gross domestic product (GDP). [13]

Direct costs -- those incurred in the treatment and prevention of AIDS and HIV infection -- totalled approximately $129 Million in 1987.[14]

Indirect costs consist of an estimate of the value of the loss when a person dies prematurely. A component of these costs is the economic loss to society of a person's productive capacity. Because AIDS affects a relatively young segment of Canadian society, those who die might otherwise have contributed energetically to the economy. Instead, society has expended resources on them (for example, for their education) only to see them die before they can fully return their contribution.

The indirect costs of HIV infection in 1987 were estimated at between $150 million and $350 million. That amounted to between 0.3 per cent and 0.6 per cent of Canada's GDP. [15]

Another (unquantifiable) cost lies in the energies that must be devoted to new legal and ethical issues relating to AIDS, and to research. This report examines only a narrow range of those issues -- those associated with privacy. An incomplete list of other issues that society will be forced to consider includes the following: allocation of scarce health care resources to infected persons, rights of infected workers versus rights of their co-workers and employers, protection of infected persons against discrimination, controlling the spread of HIV infection through quarantine or criminal or civil measures, the ethics of medical experimentation, and restrictions on employment, travel and immigration.

Addressing these issues will consume money and time. None are easy to resolve. They will cause debate, misunderstandings and ill-feeling. Providing an intelligent and humane response to these issues will challenge politicians, government officials and interest groups for considerable periods of time.

The final (and, again, unquantifiable) cost associated with AIDS is the human suffering that it has caused and will continue to cause. Death of a family member after a full life, while still creating a profound sense of loss, is accepted as normal in the cycle of life in the developed world. But there is little normalcy in parents burying an adult or infant child who dies of an AIDS-related illness.

ENDNOTES TO APPENDIX I

1. Drawn largely from draft materials supplied by Joel Finlay of the Federal Centre for AIDS.

2. *The New York Times* (15 February 1988) at A14.

3. *Ibid.*.

4. *Ibid.*.

5. Discussions with Dr. Alastair Clayton, Director General, Federal Centre for AIDS, Ottawa.

6. World Health Organization, Media Service, "Focus on AIDS, An Interview with Dr. Jonathan Mann, Director of the World Health Organization's Special Program on AIDS" (December, 1987, Issue No. 114) at 2.

7. Discussions with Dr. Clayton.

8. International Statistics (compiled by the Federal Centre for AIDS). Although the statistics were collected from various countries as of different dates, most were collected during 1988.

9. *Supra* note 6 at 2.

9a. Unless otherwise indicated, all Canadian statistics are taken from the January 3, 1989 *Surveillance Update: AIDS in Canada*, a weekly report prepared by the Federal Centre for AIDS.

10. The Royal Society of Canada, *AIDS: A Perspective for Canadians (Summary Report and Recommendations)* (1988) at 5. Note that this is only a general estimate.

11. *Ibid.*, at 4.

12. *Ibid.*, at 5.

13. *Ibid.*, at 8.

14. *Ibid.*.

15. *Ibid.*, at 9.

Appendix II

CURRENT CONTROLS ON COLLECTION, USE AND DISCLOSURE OF AIDS- RELATED PERSONAL INFORMATION

(a) General

This appendix briefly examines laws relating to the collection, use and disclosure of AIDS-related personal information. Although this report focusses on how the *Privacy Act* treats this information, it is useful to understand how provinces and other jurisdictions handle similar information.

This appendix describes in general selected provincial health legislation relating to AIDS. It then reviews the provisions of the *Privacy Act* and several other federal statutes that impose restrictions on the collection, use and disclosure of information. It also discusses the range of remedies available where legislation or policy on collection, use and disclosure are violated.

(b) Reporting AIDS or HIV Infection

i) In the Provinces

In every province and territory, AIDS is reportable to health authorities. Infection with HIV is reportable in seven of ten provinces. Not only physicians are required to report, but also others involved in health care. Physicians are generally involved in diagnosing and reporting cases of AIDS. Laboratories are usually involved in reporting seropositivity. Sometimes the reporting requirement falls on any person who knows or suspects that another is infected or has AIDS. Often the infected person's name must be reported.

What is important is the great extent to which reporting of AIDS or infection with HIV is required under provincial law. Confidentiality provisions do exist in many provinces to protect some forms of AIDS-related personal information. Nonetheless, the potential for breaches of confidentiality must be recognized wherever legislation requires nominal reporting.

Because of the breadth of nominal reporting requirements, provincial laws and policies may create privacy concerns of even greater magnitude than those created by federal laws and policies. In fact, concerns about confidentiality are frequently directed at provincial governments. They seem to be much less often directed at the federal government.

Provincial rules on AIDS-related personal information nonetheless provide a context for examining the treatment of similar information at the federal level. Provincial reporting requirements also serve to emphasize that, whatever is done at the federal level, the provinces have already "let the cat out of the bag". Systematic collection of AIDS-related personal information takes place across Canada and will continue to do so, no matter what course of action federal government institutions pursue.

The following outlines the major tenets of provincial legislation requiring the reporting of AIDS, ARC or HIV infection. Every attempt has been made to ensure that the summaries of the legislation are accurate. The legislation is more extensive than the parts excerpted here, however, and legislation in this area is changing rapidly. The reader should therefore refer directly to the legislation for full details.

Alberta:

The *Public Health Act* permits the making of regulations requiring the reporting to the local provincial board by a physician of every person under his treatment for any communicable disease or any disease dangerous to public health [1]. Under the *Communicable Diseases Regulation*, [2] occurrences of AIDS are reportable by all sources to the medical officer of health within 48 hours. Sections 32 to 37 of the Act impose similar reporting requirements. In certain instances, subsection 63(2) of the Act permits the Director appointed under the Act to require the name and address of a person with AIDS to be reported.

British Columbia:

Regulations made under the *Health Act*[3] impose broad reporting requirements.

The *Health Act Communicable Disease Regulation* [4] lists AIDS as a reportable communicable disease and sets out several reporting protocols. Subsection 2(1) requires anyone who knows or suspects that a person is suffering from or has died from a communicable disease to report this to a medical officer of health without delay. The regulation does not specify in this instance what identifying information must be reported.

Subsections 2(2) and 2(3) require physicians and persons in charge of laboratories to make a report that complies with section 4 of the Regulation. In addition, section 3 requires the administrator or other person in charge of a hospital to report to the medical officer of health a patient who has been admitted to the hospital with a reportable communicable disease.

The information to be reported varies according to who is reporting. In every case involving a physician or person in charge of laboratory or hospital, section 4 requires at least the name and address of the infected person.

Manitoba:

Manitoba Regulation P210-R2, amendment,[5] lists AIDS as a sexually transmitted disease and sets out reporting requirements. Subsection 40(1) requires a physician to report AIDS cases to the Director of Communicable Disease Control using a notification form set out in the Regulation. The wording of the Regulation does not itself require the physician to report the name of the person he or she attends. Nonetheless, the notification form provides space for the patient's name, address, date of birth and other personal information.

Paragraph 44(e) requires a person in charge of a laboratory to report all positive results of a serologic test for the presence of antibodies or positive results of the laboratory identification of the HIV. Here, the Regulation appears to impose no obligation to report the name or other personal details about the infected person.

New Brunswick:

New Brunswick Regulation 86-66 adds AIDS, ARC and any confirmed HTLV-III virus antibody reactive status to the list of notifiable diseases listed in subsection 96(1) of the Regulation. Subsection 96(2) sets out reporting requirements:

> Where any physician, nurse, householder or other person recognizes or suspects the presence of any notifiable disease listed in subsection (1), a notification shall be sent to the district medical health officer or the nearest public health inspector who shall immediately notify the district medical health officer.

Subsection 96(3) requires that the notification contain the name of the person infected or suspected to be infected, the place of residence and the name of the disease, if known. Subsection 99(2) requires a physician to report within 24 hours a notifiable disease which occurs in any patient under medical care.

Newfoundland:

Newfoundland Regulation 60/87 adds AIDS, ARC and HIV antibody positivity by confirmatory testing to the Schedule to the *Communicable Diseases Act* [6]. Subsection 4(1) of the Act sets out the following reporting requirements for physicians:

> Whenever any physician knows, or has reason to believe, that any person is infected with any communicable disease he shall within twenty-four hours give notice thereof to the Deputy Minister of Health, or to the health officer in whose jurisdiction such person is, and to the hotel-keeper, keeper of a boarding house or tenant within whose house or rooms such person resides.

Besides being obliged to report to medical health authorities, the physician is obliged to report to those in charge of the accommodation where the infected person resides.

Subsection 4(2) requires the physician, where possible, to state the name of the disease, the name, age and sex of the person, and the address of the person.

Subsection 5(1) requires several other classes of people to report communicable diseases to the Deputy Minister of Health. The classes include the manager or recognized official head in charge of any hospital or residential institution, or any teacher who knows or has reason to believe that a person has a communicable disease. The report must contain the name of the person with the disease, and information to permit the person to be located.

Nova Scotia:

Nova Scotia Regulation 171/85 adds to the list of communicable diseases listed in the *Regulations in Respect of Communicable Diseases* made under the *Health Act.* [7] The list now includes the following:

> *(15A) Acquired immune deficiency syndrome (known as AIDS), including*
>
> *(a) a diagnosis of AIDS, or*
>
> *(b) one positive result on an ELISA test.*

Ontario:

Ontario Regulation 161/84 adds AIDS to the list of communicable diseases under the *Health Protection and Promotion Act, 1983* [8]. *Ontario Regulation 162/84* designates AIDS as a reportable disease under the Act.

Because AIDS is both a reportable and a communicable disease, any of several persons may be involved in reporting AIDS to health authorities.

Section 25 of the Act requires a physician or certain persons entitled to practise a health discipline who, while providing professional services to a person who is not a patient or out-patient of a hospital, forms the opinion that a person has or may have a reportable disease to report this to the medical officer of health.

Section 26 requires a physician providing professional services to a person to report any communicable disease to the medical officer of health.

School principals must report communicable diseases. Laboratory operators must report reportable diseases. Hospital administrators must report both.

Section 30 requires a physician who signs a medical certificate of death to report to the medical officer of health any death from a reportable disease.

Where AIDS is reported under the *Health Protection and Promotion Act, 1983*, the person reporting must specify at least the following: name and address of affected person, date of birth and sex. [9] In addition, *Ontario Regulation 490/85* requires physicians or certain other health care professionals to include specific information in their report. That information includes date of diagnosis, the name and address of the physician, the name of hospital and date of admission, if applicable, medical conditions, including laboratory findings and date of diagnoses that may be indicative of cellular immune deficiency and AIDS, other medical conditions that may have caused immunosuppression, date and place of donation of blood or blood products, current status of infected person (alive or dead), and whether the person is a homosexual or bisexual, an intravenous drug abuser or a hemophiliac.

Prince Edward Island:

In 1985, the *Notifiable and Communicable Diseases Regulation* [10] made AIDS a reportable disease. Section 17 of the Regulation stated that an occurrence of AIDS "must be reported to the Chief Health Officer or his delegate".

A 1987 amendment to the Regulation added "HIV antibodies" to the list of notifiable diseases. Section 17 was also amended to require that an occurrence "must be reported to the Chief Health Officer or his delegate in such manner as the Chief Health Officer may direct". [11] It therefore appears that the Chief Health Officer may require the infected person to be identified.

Quebec:

The *Regulation respecting the application of the Public Health Protection Act*[12] was amended on October 1, 1986 to add "acquired immune deficiency syndrome" to the list of diseases that must be declared.

Section 30 of the amended regulation requires that a diagnosis of AIDS be declared by the attending physician to the public health department within 48 hours. The informa-

tion to be indicated on the reporting form includes the patient's name, date of birth, sex and locality. The form also provides a place for clinical observations and test results.

Saskatchewan:

AIDS was made a notifiable communicable disease in 1984. In 1988, new regulations were to come into force making HIV infection a notifiable communicable disease.

ii) In Other Countries

Many other countries and jurisdictions within those countries have also opted to require reporting of AIDS, infection with HIV, or both. Information supplied by the World Health Organization [13] indicates that among those countries are Australia, Austria, Bermuda, Brazil, Brunei Darussalam, Chile, Costa Rica, Denmark, Egypt, Finland, France, Federal Republic of Germany, Greece, Hungary, Israel, Italy, Malta, Mexico, Monaco, Mozambique, New Zealand, Norway, Panama, Paraguay, Peru, Poland, Singapore, Spain, Sweden, Switzerland, Thailand, USSR (implicitly), and the United States.

In some countries, a diagnosis of AIDS triggers the notification requirement. In others, a finding of seropositivity or a diagnosis of an affliction normally associated with AIDS (Israel) is enough to bring the reporting requirements into play.

The precise details of each piece of legislation requiring notification are not relevant. What is important is the broad similarity of responses by many governments. AIDS, ARC (symptomatic HIV infection), seropositivity or diseases normally associated with AIDS appear to be reportable in at least 34 countries. Systematic collection of AIDS-related personal information and non-nominal information is permitted or required by legislation throughout the world. Legislation about AIDS is evolving so rapidly that the number of countries with reporting requirements probably far exceeds 34. *The New York Times* noted in a 1988 article, for example, that nearly 600 AIDS-related laws had been proposed across the United States alone, and that nearly 90 had been enacted in the previous year.[14]

Beyond legislation, countries may have instituted policies that require or facilitate the collection of AIDS-related personal information.

(c) Federal Legislation

As yet, there is no federal legislation specifically requiring the reporting of AIDS or infection with HIV. Several government institutions nonetheless collect AIDS-related personal information, or are contemplating collection. Several collection programs are discussed briefly in Appendix III.

When AIDS-related personal information is collected, used or disclosed by a federal government institution, the *Privacy Act* comes into play.

Government institutions are also controlled by specific legislation, such as the *Canadian Human Rights Act*. The *Canadian Charter of Rights and Freedoms* may impose other constraints on collection, use and disclosure as well.

(i) The Privacy Act

Unlike provincial health care legislation, the *Privacy Act* does not **require** the collection of information. Instead, it restricts collection. Like many provisions of provincial health care legislation, however, it controls what use may be made of the information, and the extent to which disclosures of the information are permitted.

Section 2 of the *Privacy Act* describes its purpose:

> *The purpose of this Act is to extend the present laws of Canada that protect the privacy of individuals with respect to personal information about themselves held by a government institution and that provide individuals with a right of access to such information.*

"Personal information" is defined in section 3 to mean "information about an identifiable individual that is recorded in any form including, without restricting the generality of the foregoing, ... (b) information relating to the ... medical ... history of the individual ...".

It seems clear that the Act covers information indicating whether a person is infected with the HIV or has developed AIDS or symptomatic HIV infection. Given that the Act applies to information **relating** to the medical history of the individual, it therefore encompasses information indicating whether an individual has been tested for the presence of the HIV antibody and the test results. It encompasses as well whether the person was advised to take an HIV antibody test or any tests associated with AIDS, whether the person asked for one or refused one, or whether the person received any form of pre-test or post-test counselling. In short, the personal information protected by the Act includes all the information we defined in Part I as "AIDS-related personal information".

Collection of Personal Information

The principal restriction on **collecting** personal information is stated in section 4 of the Act:

> *No personal information shall be collected by a government institution unless it relates directly to an operating program or activity of the institution.*

Subsection 5(1) requires that, wherever possible, a government institution collect directly from the individual any personal information that is intended to be used for an administrative purpose. There are two exceptions to this general rule: the individual may authorize another form of collection or the personal information may be disclosed to the institution in one of the circumstances set out in subsection 8(2).

Subsection 5(2) requires that the government institution inform any individual from whom it collects personal information of the purpose for which the information is collected.

It is not necessary to fulfil the requirements of subsections 5(1) and 5(2), however, in two situations set out in subsection 5(3): where compliance with subsections 5(1) and (2) might result in the collection of inaccurate information or where it might defeat the purpose or prejudice the use for which information is collected.

The Act imposes the obligation to collect accurate, up-to-date and complete information. Subsection 6(2) states:

A government institution shall take all reasonable steps to ensure that personal information that is used for an administrative purpose by the institution is as accurate, up-to-date and complete as possible.

Subsection 6(1) states that, once collected, personal information that a government institution uses for an administrative purpose must be retained for a period prescribed by regulation.

Subsection 4(1) of the *Privacy Regulations* [15] sets out time limits for retaining information:

Personal information concerning an individual that has been used by a government institution for an administrative purpose shall be retained by the institution

(a) for at least two years following the last time the personal information was used for an administrative purpose unless the individual consents to its disposal; and

(b) where a request for access to the information has been received, until such time as the individual has had the opportunity to exercise all his rights under the Act.

Use of Personal Information

Section 7 addresses the **use** of personal information:

Personal information under the control of a government institution shall not, without the consent of the individual to whom it relates, be used by the institution except

(a) for the purpose for which the information was obtained or compiled by the institution or for a use consistent with that purpose; or

(b) for a purpose for which the information may be disclosed to an institution under subsection 8(2).

Disclosure of Personal Information

Section 8 deals with **disclosure** of personal information. Subsection 8(1) states:

Personal information under the control of a government institution shall not, without the consent of the individual to whom it relates, be disclosed by the institution except in accordance with this section.

Subsection 8(2) lists some 13 situations where personal information may be disclosed **without** the consent of the individual. Among them are the following: where the information is used for the purpose for which it was obtained by the institution, or for a consistent use; for certain types of research, and where the public interest in disclosure clearly outweighs any invasion of privacy that could result.

Access to Personal Information

Section 12 of the *Privacy Act* provides individuals a right of **access** to their own personal information. That information may be contained in a personal information bank. It may also be personal information otherwise under the control of a government institution.

Subsection 12(2) sets out the rights of individuals given access to information contained in a personal information bank. The subsection applies only where the information has been used, is being used or is available for use for an administrative purpose.

Subsection 12(2) offers the individual three options. The individual may:

> *(a) request correction of the personal information where the individual believes there is an error or omission therein;*
>
> *(b) require that a notation be attached to the information reflecting any correction requested but not made; and*
>
> *(c) require that any person or body to whom such information has been disclosed for use for an administrative purpose within two years prior to the time a correction is requested or a notation is required under this subsection in respect of that information*
>
> > *(i) be notified of the correction or notation, and*
> >
> > *(ii) where the disclosure is to a government institution, the institution make the correction or notation on any copy of the information under its control.*

The right of access and the right to require correction, notation or notification are generally available only to Canadian citizens or permanent residents. Under subsection 12(3), however, the Governor in Council may extend the right of access to other individuals. In June 1983 these rights were extended to inmates of federal penitentiaries who are not Canadian citizens or permanent residents. 15

The right of access is not, however, unlimited. Several sections limit access. These exceptions to the right of access are specific. Sometimes the head of a government institution has the discretion to override the exception. Other times, the exception cannot be waived; it is mandatory. We mention here three relevant exceptions to the right of access.

Section 19 deals with personal information obtained by a government institution in confidence from certain other bodies. Where, for example, a province provides personal information to a government institution in confidence, the information cannot be disclosed where the affected individual seeks access under subsection 12(1). Only if the province consents to the disclosure or makes the information public can the government institution permit access under subsection 12(1).

Section 25 permits a head of a government institution to refuse to disclose any personal information requested under subsection 12(1) where the disclosure could reasonably be expected to threaten the safety of individuals.

Section 28 permits the head of an institution to refuse to disclose any personal information requested under subsection 12(1) that relates to the physical or mental health of the individual who requested it where the examination of the information by the individual would be contrary to the individual's best interests.

(ii) Other Federal Legislation

Several other federal acts provide for the handling of personal information, some of which could be AIDS-related. Following are examples of such provisions.

Section 8 of the *Canadian Human Rights Act*[16] labels as discriminatory practices the use of certain employment forms that express or imply any limitation, specification or preference based on a prohibited ground of discrimination. Making written or oral inquiries to the same effect is also considered a discriminatory practice. Among prohibited grounds of discrimination is that based on disability. The definition of disability means any existing or previous mental or physical disability. Accordingly, the collection of AIDS-related personal information by an employer or prospective employer may violate the Act unless exceptions set out in the Act are met.

The Act provides for the investigation of complaints, the making of orders to cease discriminatory practices and the imposition of criminal penalties for various breaches of its provisions.

Subsection 104(1) of the *Canada Pension Plan* [17] establishes a general rule protecting the confidentiality of information about any individual contributor or beneficiary. Accompanying subsections set out several exceptions to the general rule. Subsection 104(8) creates an offence punishable on summary conviction where an officer, clerk or employee of the Crown contravenes the section.

Section 96 of the *Unemployment Insurance Act* [18] states as follows:

> *Information, written or oral, obtained by the Commission or the Department of Employment and Immigration from any person under this Act or any regulation thereunder shall be made available only to the employees of the Commission or the Department in the course of their employment and such other persons as the Minister deems advisable....*

Section 96 also places controls on the use of information as evidence in any proceedings not directly concerned with the enforcement or interpretation of the Act.

Section 241 of *The Income Tax Act* [19] places restrictions on use and disclosure of tax information. The general rule prohibits communication of information and access by any person to certain tax information.

The section places restrictions on use of the information in legal proceedings. It also specifies when an official or authorized person may communicate information. These instances include communications such as those made for the purposes of the Act, communications to provincial governments, communications to the taxpayer involved, and communications to evaluate or enforce the *Unemployment Insurance Act, 1971*.

Subsection 241(9) creates a summary conviction offence if an official or authorized person contravenes the confidentiality provisions.

The *Statistics Act* [20] authorizes the collection of information and statistics. These are then used to analyze the characteristics and behaviour of Canadian households, businesses, institutions and government for research, policy development, program administration, decision-making and general information. The Act also sets limits on using and disclosing the information collected. Subsection 17(1) contains a broad prohibition against allowing unauthorized persons to examine an identifiable individual return. It also prohibits disclosure by authorized persons of information that would make it possible to relate particulars of the information to any

identifiable individual person, business or organization. Every person who contravenes subsection 17(1) is guilty of an offence under section 30. He or she may be imprisoned for up to six months, fined, or both.

Subsection 17(2) gives the Chief Statistician the discretion to disclose certain types of confidential information. These disclosures are regulated by internal policy and do not include disclosure of personal information unless consent is obtained from the individual to whom the information relates.

Subsection 18(1) states that information obtained by Statistics Canada is privileged, except for a prosecution under the *Statistics Act*.

(iii) Penalties for Improper Collection, Use and Disclosure

The *Privacy Act* provides no statutory remedy for breaches of its provisions. As can be seen above, however, several provisions of legislation dealing with specific government activities do. In addition, a person who in bad faith made public AIDS-related personal information might face a civil lawsuit; section 74 of the Act would not protect an employee of government in such circumstances. He or she might also face criminal prosecution for breach of trust under section 122 of the *Criminal Code*.[21] Criminal charges, for example, were used in one recent case [22] involving the unauthorized use of taxation records.

Section 122 of the Code reads:

> *Every official who, in connection with the duties of his office, commits fraud or a breach of trust is guilty of an indictable offence and is liable to imprisonment for a term not exceeding five years, whether or not the fraud or breach of trust would be an offence if it were committed in relation to a private person.*

In addition, the Government Security Policy[23] issued by the Secretary of the Treasury Board sets out policy measures to safeguard sensitive information maintained by government. Section .3.1 states:

> **Personal information, as defined in Section 3 of the Privacy Act, is a special case and shall be given enhanced protection ... where its unauthorized disclosure would, in the opinion of the deputy head, be certain to cause an unwarranted invasion of privacy.** Examples include sensitive medical files .... (their emphasis)

The policy requires government institutions to protect sensitive information

- by limiting access to those persons who have a "need to know" in relation to the performance of their duties or tasks, and who have met the requirements of an enhanced reliability check; and

- by applying government-wide standards approved by Treasury Board covering physical, EDP, communications-electronic and technical intrusion security.[24]

Breaches of security relating to sensitive information (the unauthorized disclosure of or access to) are handled as follows:

> **Possible breaches of security shall be reported immediately to the deputy head. Institutions shall then assess the circumstances to determine whether it is probable that a breach has occurred.**

> **Suspected breaches constituting criminal offences shall be reported to the appropriate law enforcement authority.** (their emphasis)[25]

Injury assessments and investigations may follow a breach of security. A violation of security may include any of the following:

- failure to protect sensitive information
- modifying, retaining, destroying or removing sensitive information without authorization, or
- causing unauthorized interruption to the flow of sensitive information. [26]

Sanctions are to be applied after breaches or violations of security where the deputy head concludes that there has been misconduct or negligence. The sanctions may be administrative, disciplinary or statutory. Deputy heads may apply any of the following disciplinary or administrative sanctions:

- termination of classification authority
- removal of security clearance and access to classified information
- removal of enhanced reliability status and loss of access to sensitive information, and
- disciplinary sanctions (oral reprimand, written reprimand, suspension with or without pay, discharge). [27]

Finally, the *Canadian Charter of Rights and Freedoms* may be used to challenge actions by government institutions. Whatever actions government institutions take, they must ensure compliance with the *Charter.*

From the privacy perspective, two *Charter* sections are germane. Section 7 states:

> *Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.*

Section 8 states:

> *Everyone has the right to be secure against unreasonable search or seizure.*

The 1988 Supreme Court of Canada decision, *R. v. Dyment,*[28] underlined the potential power of section 8 to protect individual privacy. In concurring reasons for judgment, Mr. Justice La Forest stressed:

> And that right [contained in section 8], like other *Charter* rights, must be interpreted in a broad and liberal manner so as to secure the citizen's right to a reasonable expectation of privacy against governmental encroachments.[29]

Mr. Justice La Forest spoke specifically about privacy in relation to information:

> As the Task Force [on *Privacy and Computers*] put it ... "This notion of privacy derives from the assumption that all information about a person is in a fundamental way his own, for him to communicate or retain for himself as he sees fit." In modern society, retention of information about oneself is extremely important. We may, for one reason or another, wish or be compelled to reveal such information, but situations abound where the reasonable expectations of the individual that the information shall remain confidential to the persons to whom, and restricted to the purposes for which it is divulged, must be protected.[30]

Later, Mr. Justice La Forest referred to the facts of the *Dyment* case, which involved the taking of a blood sample without consent to allow the blood to be tested for evidence of impairment. "[T]he use of a person's body without his consent to obtain information about him, invades an area of personal privacy essential to the maintenance of his human dignity".[31]

Any form of coercion to consent to an HIV antibody test, or the testing of blood without consent, might well be challenged as being an unreasonable search or seizure under section 8. The collection of AIDS-related personal information may be seen in a similar light. The outcome of challenges on these grounds cannot be predicted. Among the factors courts will have to consider are the size of the threat from AIDS, the accuracy of the tests, beneficial or detrimental consequences of administering the test and the usefulness of personal information. The relative weights of these factors may change over time.

Even if the courts find the search or seizure to be unreasonable, they may nonetheless allow the absolute prohibition of section 8 to be softened by section 1. Section 1 guarantees the rights and freedoms set out in the *Charter* "subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society".

Section 7 is similarly difficult to analyze. Will the collection, use or disclosure of information about a person's HIV status be construed as a deprivation of liberty or security? Courts will be obliged to review matters such as the size of the threat posed by AIDS, the accuracy of the information being stored and the beneficial or detrimental consequences of storing the information. And, as above, the courts may allow section 1 to soften the strict prohibitions of section 7.

This report makes no attempt to analyze in detail the implications of the *Charter* for AIDS. There are many instances besides those listed above where the *Charter* will be brought into service to tackle AIDS issues. The report merely reminds the reader that government collection, use and disclosure of AIDS-related personal information may one day be assessed against the *Charter*, and that the *Charter* may provide remedies besides those discussed above. If a court finds a breach, subsection 24(1) of the *Charter* permits it to provide "such remedy as the court considers appropriate and just in the circumstances".

ENDNOTES TO APPENDIX II

1. R.S.A. 1980, c. P-27, s. 6(1)(g.1).

2. *Alta. Reg. 238/85*, Schedule 4 and title "Acquired Immune Deficiency Syndrome".

3. R.S.B.C. 1979, c. 161.

4. *B.C. Reg. 4/83*, Schedule A.

5. *Manitoba Reg. 139/87* (April 10, 1987).

6. R.S.N. 1970, c. 52.

7. R.S.N.S. 1967, c. 247.

8. S.O. 1983, c. 10.

9. *Ont. Reg. 490/85*, ss. 1-4.

10. E.C. 330/85 (July 13, 1985).

11. E.C. 409/87 (August 8, 1987).

12. R.S.Q., c. P-35, r. 1.

13. *Tabular Information on Legal Instruments Dealing with AIDS and HIV Infection*, November, 1987.

14. 18 February 1988 at B10.

15. SOR/83-553.

16. R.S.C. 1985, c. H-6.

17. R.S.C. 1985, c. C-8.

18. R.S.C. 1985, c. U-1.

19. S.C. 1970-71-72, c. 63, as am..

20. R.S.C. 1985, c. S-19.

21. R.S.C. 1985, c. C-46.

22. *Regina v. Hackner* (14 December, 1987) (Ont. S.C.) [unreported].

23. Treasury Board No. 802143 (Circular No.: 1986-26).

24. *Ibid.*, at ss. .3.2 and .3.3.

25. *Ibid.*, at s. .7.1.

26. *Ibid.*, at s. .7.5.

27. *Ibid.*, at s. .8.1.

28. Dec. 8, 1988 (Reasons for judgment by Lamer, J.; concurred in by Beetz and Wilson, JJ.; concurring reasons by La Forest, J.; concurred in by Dickson, C.J.; dissenting reasons by McIntyre, J.).

29. *Ibid.*, at 7.

30. *Ibid.*, at 11.

31. *Ibid.*, at 13.

Appendix III

DEPARTMENTAL POLICIES ON HIV INFECTION AND AIDS

Treasury Board

From a safety and health perspective, Treasury Board is responsible only for federal public service employees. The remainder of public employees are dealt with under the *Canada Labour Code*.

There will be no testing for the public service in the foreseeable future. Treasury Board is preparing a written policy on AIDS. Information kits will be made available to employees. Employees can be tested in the private sector (as can anyone else).

There are 17 standard employee information banks. All employee medical records are held by Health and Welfare Canada only.

The public service has access to an Employee Assistance Program to provide counselling for various problems -- for example, alcoholism. Employees are referred to private sector agencies. Information is held strictly in confidence by the counsellor; the employee's department is not allowed access to this information.

Legal counsel at Treasury Board identified the following information banks as being most likely to contain information arising from a diagnosis of AIDS or seropositive status. There was no indication, however, that these information banks actually do contain this information.

- TBS/P-CE-705 - Personnel Management Information System
- TBS/P-CE-706 - Special Groups Identification Survey
- TBS/P-CE-718 - Leave Reporting System
- TBS/P-CE-803 - Complaints - Canadian Human Rights Commission
- TBS/P-CE-804 - Personal Harassment Complaints.

In addition, Treasury Board identified the following standard banks (each department has its own set of files, but the description of the bank is the same throughout government):

- TBS/P-SE-901 - Employee Personnel Record
- TBS/P-SE-903 - Attendance and Leave
- TBS/P-SE-919 - Personal Harassment.

Department of Justice

The department treats AIDS-related personal information as any other medical information about an identifiable individual. The department believes that information about AIDS should not be treated any differently than other medical information. For example, a person should have the right to examine the information and to correct it. There is therefore much protection to be offered by the *Privacy Act* to AIDS-related personal information as a species of "medical information". The department recognizes

the various controls that are placed on the collection of this information -- for example, direct collection.

The department is sensitive to the requirement of section 4 of the Act permitting collection of personal information only where it relates directly to an operating program or activity of the institution. The department believes that such information may properly be collected under section 4 for the following purposes: the Employee Assistance Program, Canada Pension Plan, Unemployment Insurance and for statistical purposes under the *Statistics Act*.

Individuals should be told why information is being collected from them. *Privacy Act* controls on retention should also apply.

The greatest *Privacy Act* concern is disclosure in the public interest. The department invites other departments to be sensitive to issues of disclosure under section 8.

The department recognizes that the *Privacy Act* merely affords one form of protection. Other legislation directed at specific government institutions may offer even greater protection than the *Privacy Act*.

Where there is a wilful spread of HIV infection, the department feels the best action is to provide information to public health authorities who can then rely on the police to act.

Correctional Service Canada

Correctional Service Canada has identified three personal information banks that may identify persons who have AIDS or who test antibody-positive:

CSC/P-PU-060 - Offender Health Care Record (Bank description: This bank permits the storage and retrieval of records on an offender's health care within the federal institution and the community)

CSC/P-PU-061 - Psychiatric Treatment Centres (Bank description: This bank contains psychiatric records and some medical information pertaining to offenders treated in Psychiatric Treatment Centres)

CSC/P-PU-070 - Psychology (Bank description: This bank permits the storage and retrieval of psychological records and data).

The first bank - Offender Health Care Record - is the most likely repository of AIDS-related personal information.

On January 1, 1988, Commissioner's Directive 821 was issued. The directive is entitled "Management of Inmates with Human Immunodeficiency Virus (HIV) Infections". The directive deals with several issues. Among them are penitentiary placement, testing, preventive measures, education and confidentiality.

(i) Inmate Testing

Section 9 of the directive states that upon entry into the correctional system or during incarceration, inmates shall not be routinely screened for presence of antibodies to HIV.

Section 10 states that testing shall be governed by criteria for valid consent set out in Commissioner's Directive 803. The latter directive sets out several criteria for a valid consent. Section 2 reads as follows:

In order for consent to be valid, it shall be:

(a) freely given;

(b) informed, that is, based on sufficient information provided to the individual by a qualified professional;

(c) specific to the treatment or procedure;

(d) given by a competent individual or by someone competent on his/her behalf, that is, having the mental ability to understand the nature and risks of accepting or refusing the treatment [testing];

(e) based on or in compliance with provincial legislation, such as age of majority; and

(f) normally written and witnessed although, in some circumstances, consent may be given verbally or it may be implied.

Section 3 states that consent is required for any medical examination, procedure or treatment. Section 4 states that during his incarceration, the offender may refuse consent when he does not put his life in danger, even if the security of the institution or of other persons may be threatened.

Several exceptions to the consent requirement are permitted by Commissioner's Directive 803. None of them, however, appear to apply to HIV antibody testing. Accordingly, it appears that Commissioner's Directive 803 gives the inmate an absolute right to refuse testing.

Commissioner's Directive 821 permits inmates to request testing. Section 11 requires inmates wishing to be tested to make the request to the institutional physician. The institutional physician shall determine if testing is indicated, based on the need to confirm physical examination or laboratory studies suggestive of HIV infection. Requests for testing from inmates with a history of high risk activities associated with HIV infection shall be carried out at the discretion of the institutional physician.

Section 11 appears, therefore, to require approval of the institutional physician if an inmate wishes to be tested.

(ii) Confidentiality and Disclosure of AIDS-related Personal Information about Inmates

Section 19 of Commissioner's Directive 821 requires that all diagnoses of HIV infection be noted on the problem sheet of the medical record. Once informed, health care staff must comply with the confidentiality and disclosure provisions of Commissioner's Directive 835.

Section 12 of that Directive reads as follows:

> Offenders have the same rights to confidentiality of information obtained by a health care professional as exists in the general community. However, it is the responsibility of a health care professional, **when there is reasonable cause to believe that the offender's intentions or possible actions may constitute a threat to the safety of him/herself or others**, to provide information to the appropriate personnel without the offender's consent (our emphasis).

Section 11 states that a medical administrative summary outlining significant findings of interest to those involved in the case management of an offender shall be provided for placement on the offender record. (The administrative summary, is not intended, we are told, to relay diagnostic or medical confidential information. Details of an inmate's medical condition or HIV status should not be disclosed in this document.)

Accordingly, information about an inmate's HIV status can be held in the institutional health care record. This record moves with the offender throughout his or her sentence.

Section 13 of the directive states that health care records are to be retained until ten years after the most recent warrant expiry date or according to the provincial legislation where the offender was last treated medically, whichever is the longer period of time.

Commissioner's Directive 821 contains further instructions on disclosure of information about HIV status. Section 21 states as follows:

> The HIV status of an inmate is medical confidential. This information shall not be released to supervisory/agency staff without the inmate's consent. However, if there is cause to believe that an offender's actions may constitute a danger to himself or others, and in accordance with the Privacy Act, health care staff shall provide information to the appropriate personnel without the offender's consent.

Generally, however, staff members are considered not to have a need to know about the HIV infection status of an inmate.

Section 23 of Commissioner's Directive 821 deals with notification of public health authorities:

> HIV infection reporting shall be in accordance with relevant provincial public health legislation and practice. Regional Headquarters, through Regional Instructions, shall ensure that institutions are aware of the provincial legislation.

The Commissioner's Directives to which we have referred do not directly address disclosure of HIV infection to other inmates. It may be implied, however, that because this information is considered personal medical information, it will not be disclosed to other inmates.

Commissioner's Directive 821 envisages isolating those who do not cooperate by reducing high-risk behaviour:

> 17. The Director may decide to isolate an inmate who fails to cooperate and continues to engage in activities that place others at risk for infection with HIV.

Employment and Immigration Canada (EIC)

(i) Unemployment Insurance Applicants

There appear to be no special policies of the Unemployment Insurance Commission relating to collection of AIDS-related personal information.

A claimant for Unemployment Insurance benefits because of illness must prove entitlement. To this end, a medical certificate indicating diagnosis is required. Sickness benefits are available for some six to seven hundred conditions. The benefit period varies with the period of incapacity and with the success of treatment. A numeric code is assigned to a particular condition.

Employment and Immigration Canada (EIC) states that it is essential that an exact diagnosis be supplied. It would not be practical to single out AIDS sufferers by not recording the identity of their illness. Treating them differently, EIC argues, would clearly identify them and could lead to accusations of discrimination.

Counsel from Legal Services at Employment and Immigration identified the following Unemployment Insurance banks which may contain AIDS-related personal information:

- EIC/P-PU-005 - Registration for Employment File
- EIC/P-PU-150 - Unemployment Insurance Claim File
- EIC/P-PU-155 - Unemployment Insurance Claimant's Bi- Weekly Report Card
- EIC/P-PU-170 - Interstate Unemployment Insurance Claims
- EIC/P-PU-180 - Benefit and Overpayment Master File.

Counsel indicated that claims have been received under the *Unemployment Insurance Act, 1971* from claimants suffering from AIDS. There are no statistics available on the precise number of such claims. Officials at EIC estimate the number to be between 10 and 50.

Section 96 of the current *Unemployment Insurance Act* restricts the release of information:

> *Information, written or oral, obtained by the Commission or the Department of Employment and Immigration from any person under this Act or any regulation thereunder shall be made available only to the employees of the Commission or the Department in the course of their employment and such other persons as the Minister deems advisable, and neither the Commission, nor the Department nor any of the employees of the Commission or Department is compellable to answer any question concerning that information, or to produce any records or other documents containing that information as evidence in any proceedings not directly concerned with the enforcement or interpretation of this Act or the regulations.*

In addition, the Employment and Immigration Insurance Services Policy Manual (Subject 20) deals with the privacy of information contained in a claimant's file. It outlines to whom and when information contained in a claimant's file may be disclosed.

Section 4 of the manual (Subject 20) states:

> [I]nformation regarding diagnosis of sickness, disability, quarantine or maternity, cannot be divulged to any party, except where it is part of an exhibit to a Board of Referees or the Umpire. In addition, medical information issued by the treating physician may be disclosed to the claimant or his lawyer if the information is already known to the claimant

> and is non-controversial ... or if it was provided by the claimant in the first place.... Both medical information and other types of controversial information must be released as part of the UI appeal process.

Section 4 therefore appears to exclude any disclosure of medical information except in narrowly defined circumstances.

Elsewhere, the manual spells out when information about a claimant can be disclosed. It is not clear from the manual whether this discussion of disclosure relates as well to information about the medical condition of the claimant. We assume that it does not, due to the restrictive wording of section 4. Nonetheless, we reproduce the substance of the manual as it deals with permissible disclosure.

Section 6 of the manual states:

> Information contained in the claimant's file may be disclosed to the following persons and organizations to the extent indicated.... [the claimant, the claimant's representative, Revenue Canada, Taxation, welfare agencies, Canada or Quebec Pension Plan representatives, other government departments or agencies, employers].

Under section 6, several qualifications are placed on the dissemination of information about claimants. Qualifications that appear to affect the release of medical information are set out below:

> (1) **Revenue Canada, Taxation:** The administration of the Act is divided between Revenue Canada, Taxation and the Unemployment Insurance Commission. Information in a claim file required for the administration of Section 3 and Part IV of the Act is to be made available to Revenue Canada on request.
>
> (2) **Welfare Agencies:** Information in a claimant's file relating to the reason for separation from employment, among other matters, may be given to municipal, provincial or federal welfare agencies. Section 6.4 states that the information should be restricted to that required to enable the welfare agencies to determine the claimant's eligibility for welfare benefits.
>
> (3) **Employers:** In normal fact-finding for adequate adjudication, the claimant's reason for separation may be divulged to his former employer, within the limitation of this guideline.
>
> When an employer wishes to appeal a decision to a Board of Referees or the Umpire, information that has led to the decision being appealed may be released to that employer. This may include controversial information relating to labour disputes or reason for separation from employment given by the claimant.
>
> (4) **Criminal Cases:** Section 7 provides that an employee who is subpoenaed to a criminal court will disclose any information necessary for the conduct of the hearing. In any other case, the employee will inform the court that section 114 of the *Unemployment Insurance Act, 1971* [now section 96 of the *Unemployment Insurance Act*] does not permit the release of information contained in the claimant's file.

(ii) Immigrants

Section 11 of the *Immigration Act* requires the medical examination of all immigrants. Paragraph 19(1)(a) sets out criteria for inadmissibility. Regulations specify which visitors must be tested. Also, individuals who are eligible to apply for employment authorization may be required to undergo medical tests. Regulations specify what factors a medical officer will consider. None of these provisions deal specifically with AIDS.

The present legislative and policy position of EIC can be summarized as follows:

- immigrants or long term visitors with AIDS or HIV seropositivity are not admissible to Canada
- no mandatory testing of immigrants or visitors for HIV infection takes place (although some Health and Welfare Canada physicians posted abroad have apparently decided nonetheless to conduct HIV antibody tests)
- EIC favours the compulsory HIV antibody testing of both immigrants and long-term visitors.

Some provisions of the *Immigration Act* can lead to disclosure of medical conditions. The sponsors of a potential immigrant have a right to know the grounds for rejecting an application. This right is based on subsection 77(1) of the *Immigration Act*, subsection 4(1) of the *Immigration Regulations* and on jurisprudence (*Palta v. Minister of Employment and Immigration* (Federal Court of Appeal, File No. A937-82)).

The criteria for admissibility of immigrants are determined by Health and Welfare Canada in consultation with EIC. Responsibility for enforcing the *Immigration Act* lies with EIC. Any person with a communicable disease is a member of an inadmissible class under subsection 19(1) of the *Immigration Act*.

All prospective immigrants require medical tests, including blood tests. The embassy refers applicants for landed immigrant status to a list of local physicians. Physicians are given a list of necessary procedures. They sometimes test for HIV antibodies (embassies do not require HIV tests, but there is no way of controlling "surplus" information given by a local physician). The physician normally passes medical information directly to Health and Welfare Canada. Where there are difficulties with the local mail system, however, reports will be passed on to Health and Welfare Canada through the embassy.

In general, EIC holds no data banks that identify individuals with AIDS or HIV infection. Only Health and Welfare Canada's decision about medical inadmissibility is passed on to EIC, not the reasons for the decision. Some individual files might contain AIDS-related personal information, but most would not.

In theory, AIDS-related personal information might be contained in the following files:

- EIC/P-PU-225 - Immigrant Case File
- EIC/P-PU-240 - Sponsors of Immigrants
- EIC/P-PU-245 - Guarantors of Assisted Relatives
- EIC/P-PU-280 - Adjudication Case File

- EIC/P-PU-285 - Visitor Case File
- EIC/P-PU-290 - Foreign Student Records and Case File
- EIC/P-PU-295 - Temporary Worker Records and Case Files
- EIC/P-PU-300 - Minister's Permit Case File.

(iii) Employees

Health and Welfare Canada states that an employee has a medical disability, but does not identify the disability. Therefore, a medical certificate does not disclose the nature of the disability. Personnel files might disclose that an employee has AIDS or HIV infection, but this would likely only happen if the person volunteered the information.

RCMP

The RCMP arranges for physical examinations of applicants. In addition, members have regular medical examinations.

The RCMP does not attempt to collect AIDS-related personal information. The Force is not even considering such a policy.

Nonetheless, there may be AIDS-related information in two personal information banks:

- CMP/P-PU-005 - Operational Case Records. This bank contains information about individual operations investigations and may incidentally include information about a person's HIV-status.
- CMP/P-PU-055 - Protection of Personnel and Government Property. These records relate to civilian and police members. Access to the bank is described by the RCMP as being very restricted. The information in the bank would have to be disclosed through the medical officer, who might not disclose details of a person's state of health. Instead, the medical officer might simply state whether the person is fit to assume certain duties.

The RCMP has prepared an operational bulletin dealing with encounters with persons who are infected. Bulletin AM-1196, on Occupational Biological Hazards, centres on concerns about AIDS. The bulletin notes that there are "very few" cases of occupational contact. It also states that there are no documented cases of police officers, paramedics or firefighters contracting AIDS while performing their duties.

The bulletin summarizes the means of transmission of the HIV. It also describes preventive actions that officers can take. The bulletin does not, however, address issues relating to confidentiality.

Department of National Defence

In April 1988 the Department of National Defence provided to us a substantial briefing note on its handling of AIDS- related information. We have also received further correspondence on this topic. The following paragraphs reproduce or summarize some of the contents of that note and subsequent correspondence.

The Canadian Forces (CF) possess and collect information about persons who are infected with the HIV and those who have AIDS.

(i) Testing

At present, the CF has no compulsory HIV antibody testing program, whether for recruits, serving members or others for whom the CF provides medical care (in certain locations, dependants).

CF voluntary antibody testing is performed primarily in two circumstances: where indicated clinically (a present illness suggesting HIV infection) or where indicated epidemiologically (contact tracing, needlestick injury, or a health care worker or patient in a high risk group who requires testing).

Occasionally, testing could be done for a low risk patient who, despite counselling, is extremely anxious about infection.

Recently, DND has agreed to test personnel selected for Security Assistance Training Program training in the United States. Only personnel who test antibody negative will be sent on such training. This testing prerequisite was imposed on the Department of National Defence by the U.S. Department of Defense. The CF considers it necessary to comply to satisfy Canadian defence training requirements.

This testing program began in May 1988. It involves about 1000 CF members and 200 Department of National Defence employees annually. A training candidate could refuse to be tested and would not suffer any direct consequences in the CF -- apart, that is, from not being able to obtain the U.S. training. The CF has not ruled out the possibility of ordering individuals to take the test in rare circumstances. Department of National Defence correspondence to the Office of the Privacy Commissioner, dated January 19, 1989, states as follows:

> In circumstances where the Canadian Forces have a limited number of individuals who may be able to undertake the training and the training is required in order to perform the duties of certain positions in the Canadian Forces, it may not always be possible to operate on a voluntary basis. If an insufficient number of individuals agree to take the test, it may be necessary to order individuals to take the test so that the mission of the Canadian Forces can be carried out. Presumably, this will be a very rare occurrence but it clearly would be justified.

The correspondence indicated that the CF AIDS situation will be studied further. For now, all CF HIV antibody testing, including that for the U.S. training, involves pre-test counselling, informed consent and appropriate post-test counselling.

The CF has no capacity to conduct the tests itself. All testing is done through provincial or federal laboratories.

At the patient-physician level, test results are linked to an individual. The laboratory requisition sent to the provincial or federal laboratory may identify the individual. The Surgeon General (of the CF) has recommended in "Medical Directive 1/88: HIV Infection" that, where the receiving laboratory permits, specimens or requisitions be coded to protect the identity of the patient outside the CF medical unit. The testing program for the U.S. DoD training requires that the specimens be coded.

Those tested are told personally of their test results by their physician.

Information about a person's HIV status is stored in DND/P- PE-810 - Medical Records.

(ii) Positive Test Results

CF members infected with the HIV are handled like those with other medical diagnoses. They are assigned a "medical category" based on how their disease may be affected by the requirements of military service and how their disease may affect the operation of the CF.

Categories below a certain level, varying by specific trade/classification, result in deliberation of the Career Medical Review Board (CMRB). The CMRB may decide to retain the member on an unrestricted career, retain on a restricted career, release or remuster the member. Each case is dealt with individually. Until the CMRB decides, individuals who are well enough to work are allowed to do so, but "within certain germane limitations based on their clinical status". There is no blanket release policy based solely on HIV infection.

(iii) Policies on the Use and Disclosure of AIDS- related Personal Information

In February 1986 a Canadian Forces general message was issued about the use and disclosure of information on infection and the further disposition of infected CF members. The message states in part:

> [M]edical information, including reports and records relating to the condition of HTLV-III [former name for HIV] infected members, including those who are antibody positive only, will not be released to non-medical personnel other than to Senior Military authorities (including Commanding Officers) with a need to know. Further, a member will not be released solely on the basis of HTLV-III infection unless there are demonstrable medical restrictions placed on the member which would require CMRB consideration.

A similar message is contained in "Medical Directive 1/88: HIV Infection":

> Medical information, including reports and records, relating to the condition of HIV infected members, including those who are asymptomatic, will not be released to non-medical personnel other than to senior military authorities (including CO's) with a "need to know"....

Non-CF personnel who receive their medical care from the CF (e.g., dependants in certain locales) and who are found to be infected with the HIV would have such information recorded in the relevant local individual medical documents. They would also be reported to civilian public health authorities according to provincial law. This information would not, however, be recorded in the CF hospitalization database. There is currently no requirement to report these persons to military public health authorities.

Apart from the Commanding Officer, CF members are not informed of the HIV status of another member. Members and others for whom the CF provides medical care who are known to be infected are reported to civilian public health authorities in accordance with provincial laws.

(iv) Civilian Employees

The Department of National Defence has no policy on the collection, use and disclosure of information relating to **civilian** employees who may be infected. It does not conduct testing or maintain medical records on its civilian employees, except to allow them to take part in training in the U.S.. As is the current policy for CF members, civilian DND employees may refuse to take the test. The department has indicated that it would welcome a Treasury Board policy for its civilian employees.

Statistics Canada

(i) General Public

Two databanks contain AIDS-related personal information:

(1) Mortality database (part of Integrated Vital Statistics Database) (STC/P-PU-035): This information is provided by provincial registrars. One element of the database is "cause of death". Statistics Canada receives copies of death certificates, which include name, address, cause of death, etc..

Uses: To produce information and estimates on death, as well as inter-censal population estimates. This information is also used for record linkage, for example, for epidemiological studies. If a mining company provides a list of names, Statistics Canada may link this with the Mortality database to enable the company to assess worker health care programs. Such studies in general aim at better detecting and estimating possible risks to individuals exposed to potentially harmful agents and to the impact of occupational, environmental and social influences on health.

Statistics Canada will carry out linkages for statistical/research purposes only if the benefits clearly outweigh the invasion of privacy. Requests for record linkages are screened and submitted to a multi-level review process. Even then, ministerial approval is required. Information resulting from these linkages is not used for making administrative decisions affecting an individual.

(2) Hospital Morbidity (STC/P-PU-055): Deals with patients who have been discharged from or who die in hospital. The information includes the diagnosis. Statistics Canada receives morbidity information and a patient number to which the agency does not have a key. Statistics Canada requires an identification number for follow-up -- for example, to clarify personal information supplied by a hospital.

A third databank, Notifiable Diseases, contains aggregate data only. It contains no personal information.

In general, information relating to AIDS or HIV infection would be treated like any other information collected under the *Statistics Act*. The *Statistics Act* (section 17) contains stricter provisions on confidentiality than those in the *Privacy Act*. Information that identifies an individual can only be released as specified in section 17 (for example, if the individual consents) or, under the *Privacy Act*, if the information is released to the legal representative of a minor or the representative of a deceased or incompetent person, to administer the affairs of the person.

(ii) Public Service Employees

Employee assistance files may indicate that an employee has a medical problem, but will not identify the problem. Health and Welfare Canada stores this information.

The issue of treating AIDS-related personal information about employees has not been addressed by Statistics Canada. Information would most likely not be collected about employees with AIDS. The department does not request such information.

If an employee volunteered information about AIDS to a superior, it would likely be treated as confidential, like any other medical information.

An HIV infection "situation" has apparently not yet arisen at Statistics Canada. If the situation did arise, the department would look to Treasury Board policy first, but might develop its own policy to deal with some circumstances.

(iii) Non-Public Service Employees

Individuals are hired for short periods under the authority of the *Statistics Act* (that is, they are not public servants). Typically, these persons are involved in work relating to the census. They are not subject to Treasury Board guidelines. Information about these individuals is contained in a special bank in the employment register. The register does not contain medical information.

External Affairs

There are two areas where AIDS cases arise as a policy question: employees and families of employees, and Canadians living abroad who fall ill abroad and become consular cases. External Affairs also carries out immigration interviews abroad. Therefore, EIC AIDS policy may affect External's dealings with immigrants.

A departmental circular, "Consular Implications of the AIDS Epidemic", states that "Canadian missions provide certain forms of facilitative assistance to Canadians who suffer illness abroad". While the department regularly assists travelling Canadians who encounter health problems, there is no formal obligation to do so.

For an External Affairs employee, falling ill may necessitate early return to Canada, administrative disruptions, and substantial moving costs for the employee and family.

In some countries, as in some Canadian provinces, anyone who tests positive for antibodies must be reported under local law. Some countries require visitors to be tested for HIV antibodies, but diplomats are exempted from the testing.

Health and Welfare Canada retains all employee (and their families') medical files. Health and Welfare Canada physicians assess these persons to see if they are fit for proposed postings. Health and Welfare Canada simply reports fitness for certain postings, but does not specify the nature of the medical condition that may limit postings.

AIDS-related personal information would appear in External Affairs files only in unusual circumstances. There is generally no systematic collection of such information. Immigration files held by External Affairs, however, might contain medical information about immigrants and potential immigrants.

External Affairs AIDS policy for non-employees is already well in place. A policy for employees is also in place. Employees are educated and informed of developments about AIDS, and the department has a policy on handling AIDS among its employees.

Canadian International Development Agency (CIDA)

In May 1988 the Canadian Public Health Association delivered to CIDA a document entitled *CIDA AIDS Policy Study*. The study made several recommendations, among them the following:

- CIDA should develop and adopt its own AIDS Policy Directives (APD's) to manage direct-contract cooperants, trainees and students, and locally engaged staff of CIDA field offices. These directives would set policy and procedures on disseminating information, HIV testing, insurance requirements, the requirement for a pre-departure medical examination and protection measures. They would also describe roles and responsibilities for managing healthy, HIV-infected and potentially exposed personnel;

- Mandatory testing for HIV infection as a qualification for selecting or posting CIDA direct cooperants, dependants and CIDA-funded students and trainees is not warranted at this time;

- CIDA should develop effective materials to disseminate information on AIDS to CIDA-funded personnel;

- CIDA should take necessary steps to ensure that all development workers have eventual access to basic AIDS protection materials. For the present, personnel should be provided sterile syringes and needles. These items should be replaced when used from AIDS kits, on request from the post;

- CIDA should monitor its adopted policy annually.

In November 1988 CIDA issued *Guidelines for Management of Technical Assistance Personnel with AIDS and HIV Infection*. The guidelines provide information and advice to project managers of CIDA and Canadian Executing Agencies (CEA's) on AIDS-related questions. The CIDA AIDS Protection Policy outlined in the guidelines applies to the following:

- Canadian technical assistance personnel in less developed countries (these may be employed by or contracted by a CEA or a non-governmental organization; they may be advisors under CIDA Technical Assistance Regulations or Foreign Service Directives; they may be CIDA consultants employed or contracted by multilateral agencies or clients of CIDA's Industrial Cooperation Division) and

- CIDA-funded students or trainees and eligible accompanying dependants.

The policy does not apply to CIDA employees.

The policy states that any information of a personal medical nature, including HIV infection or AIDS, is confidential. It acknowledges that the disclosure of such information is subject to the *Privacy Act*.

The policy states that at this time mandatory blood testing for the HIV antibody is not advisable. Nor is it a useful method of controlling HIV infection.

CIDA does not require mandatory testing of Canadians destined for overseas assignment. However, where the countries to which individuals are assigned require testing, CIDA will ensure the requirement is met. The policy does not specify how CIDA will ensure testing. Presumably, if a person refuses to be tested, the person will be refused the posting.

Similarly, CIDA imposes no testing requirement of its own for CIDA-funded students, trainees or their accompanying dependants entering Canada. For students or trainees destined for third countries, CIDA also does not impose mandatory testing. However, where a third country requires a test as a prerequisite for a visa, CIDA will ensure the requirement is met. If the person refuses testing, CIDA will presumably refuse access to the studies or training.

Persons diagnosed as having AIDS: If clinically diagnosed as having AIDS or other conditions rendering him or her unfit to perform duties in the country of assignment or training, a person will be classed as ineligible on medical grounds. The refusal to post Canadian Technical Assistance Personnel, where necessary, can be attributed to "medical reasons", while the details remain confidential.

Federal Centre for AIDS

The only systematic collection of AIDS-related information is the aggregate data bank (Health Protection Branch, Federal Centre for AIDS). The bank description is "timely, reliable, epidemiological information on AIDS incidence and mortality surveillance programs, including epidemiological research". Its former identifier is NWC/CDC-165 Epidemiology. The bank description is as follows:

> Bank type: public. Discrete personal data elements will be: race, colour, religion, ethnic origin; age, sex, marital status; country of birth, citizenship and/or nationality.
>
> Purpose of the data bank is surveillance, and monitoring trends in disease progression. The proposed period of retention is ten years, to be reviewed in five years.

The information in this bank is non-nominal and unlinked. Information from the provinces arrives in non-nominal form, except where names are needed for epidemiological surveillance. If the Federal Centre for AIDS needs additional information, it may ask provinces for surveillance. The resulting surveillance report does not identify individuals. The Federal Centre for AIDS requires nominal information only for specific studies. For example, it may perform population-based studies that require linkages. This is done only with the informed consent of those involved.

Individual files are never kept systematically, although there may be some AIDS-related information contained in Health and Welfare Canada files.