

## Mandatory Reporting of HIV Infection: What Does it Mean?

Source: Quebec AIDS Surveillance Program- Public Health Branch, Ministère de la Santé et des Services sociaux (English traduction by the FNQLHSSC).

Since April 18 2002, HIV infection (human immunodeficiency virus) has been included on the list of diseases that must be reported in Quebec. An infection surveillance system will soon be established to follow the evolution of the disease in Quebec. Following are a few questions and answers to give you more information on this subject.

### *What is the purpose of an HIV infection surveillance system in Quebec?*

Currently, there is not enough data available on HIV infection that will allow the drawing up of an overall portrait for determining how to plan prevention activities and offer the necessary support and services.

### *What are the objectives of the surveillance system?*

The objectives of the surveillance system are to improve our knowledge on the HIV situation in Quebec and to support physicians in their treatment of patients living with HIV by informing them of the tools and resources that are available.

### *Must HIV-infected persons report their condition?*

No. Mandatory reporting means that it is the responsibility of physicians and the Quebec Public Health Laboratory (QPHL) to report the situation. The Laboratory has the job to verify all positive HIV test results. It then sends the results to the physician who ordered the test. Physicians are required to obtain certain information from patients who have been tested so that they can create case profiles for submission to the surveillance system.

### *Does this mean that infected persons are under no obligation to report their condition?*

Legally, HIV-infected persons are not obligated to report their condition. However, since HIV can be transmitted, it is essential that they inform all sexual partners, past and future, as well as anyone with whom they have been or will be sharing needles.

### *What information about an HIV-infected person must the treating physician send?*

This information includes: year and month of birth; sex; place of residence; the first 3 characters of the postal code; ethnic origin; country of birth; date of arrival in Canada; risk factors linked to transmission of the virus; history of past HIV tests, organ, tissue or blood donations; clinical status of the condition; the reason for the test and; in the case of women, whether or not they are pregnant. Physicians must also provide their patients' health insurance numbers if the Laboratory has not already done so.

### *Is all this information necessary?*

Yes, because the HIV virus does not affect every segment of the population the same way. The data that is collected will provide more knowledge of affected groups. And this knowledge will enable the drawing up of more accurate profiles of infected people, particularly those who have been recently infected, in order to establish prevention programs targeting specific groups. It will also allow for better planning and organization of services and support for HIV-infected persons, whose characteristics will be better known thanks to the surveillance system.

### *Why is the health insurance number necessary?*

All residents of Quebec must have health insurance cards to access the health care system, and a different number is assigned to every person. Recording the health insurance numbers in the surveillance system ensures that each case is reported only once.

### *How can an HIV-infected person be certain that the data will be kept confidential?*

When the process is initiated, the Laboratory will encode the patient's health insurance number into a series of indecipherable characters and, once verified, the number will not be retained by the surveillance system. The information collected will thus compiled anonymously. Furthermore, access to the data will monitored by strict security measures. There will thus be no way in which people can be identified.

### *Can the data in the surveillance system be merged with the data in other information banks?*

No. Since the data reported to the system is anonymous, any merger with another databank cannot take place.

### *Can people be tested for HIV anonymously if they wish?*

Yes. Anonymous screening services are already in place in Quebec and they will continue to be offered. In using these services, people can be screened for HIV without revealing their identity.

### *Must anonymous screening services report positive results?*

No. Since anonymous screening services do not ask people who wish to be screened for their name, they cannot report people who test positive.

### *Are there other circumstances in which a positive HIV test need not be reported?*

Yes. For example, positive results of tests carried out for the purpose of research, blood donations or insurance applications do not need to be reported. Only positive results of a test ordered by a physician must be reported.

### *Why was it decided to institute mandatory reporting of HIV infection in Quebec?*

A committee made up of experts and representatives of people living with HIV decided that this method would be the most effective one for obtaining the data necessary to monitor the infection.

### Is the reporting of HIV infection mandatory only in Quebec?

No. Quebec is not the only jurisdiction with an HIV surveillance system. Most Canadian provinces as well as several U.S. states and European countries have their own system for the mandatory reporting of HIV infection.

## HIV/AIDS and Native American

From: National Minority AIDS Council: [www.nmac.org](http://www.nmac.org)

The HIV/AIDS epidemic among Native People in the United States seems to share similarities with our situation here in Canada. Here is extracts from a fact sheet on HIV/AIDS and Native Americans produced by the National minorities AIDS Council (NMAC).

Despite the fact that the health of the United States (U.S.) population has improved significantly over the last 50 years, ethnic and racial minority groups still continue to lag behind the white population, experiencing substantial disparities in health outcomes on many significant indicators.

The disparities in health experienced by ethnical and racial minority groups are particularly evident in the case of HIV and AIDS in the United States. Ethnic and racial minority groups in the U.S. make up 24% of the U.S. population yet they represent 67% of the new AIDS cases.

The AIDS epidemic among Native Americans - American Indians and Alaska Natives - continues to grow. As of December 1996, the Centers for Disease Control and Prevention (CDC) had reported a cumulative total of 475 cases of HIV infection and 1,569 cases of AIDS among Native Americans. By December 1998 - a two year period - the cumulative HIV infection cases increased by 33% to 632, and the AIDS cases increased by 24% to 1,940. It is probable that the number of AIDS and HIV cases among Native Americans is higher than what has been reported to the CDC due to misclassification of the ethnicity of Native Americans by health workers and officials as either white, Hispanic or Asian. The Native American population is disproportionately affected by many social and behavioural factors that contribute to the disparities in health outcomes and in increased vulnerability for HIV infection.

The Native American population is relatively young, and has high rates of poverty, sexually transmitted diseases and drug and alcohol abuse. Moreover, the policy of forced relocation of Native Americans throughout the U.S. and the attempts to relocate them to urban areas, coupled with the racism and discrimination they encountered, have led to a legacy of high rates of poverty, unemployment, welfare dependency, obesity, diabetes, alcoholism, substance abuse and family violence (...).

### Barriers to HIV Prevention and Care Services for Native Americans

#### Prevention

To curb the spread of HIV infection among Native Americans HIV prevention must be a priority. Targeted culturally and linguistically appropriate prevention interventions are needed. To make an impact, these interventions must be on-going and sustained and consider the social, economic, cultural, religious, spiritual, and geographic contexts in which the diverse sub-populations of Native Americans live.

HIV prevention efforts must take into consideration the rapid population growth and the diversity of Native Americans sub-populations that vary by region, tribal origin, language, urban/rural and reservation residence, and culture. (...)

#### HIV care

A variety of factors contribute to the disparities in AIDS incidence and mortality experienced by Native Americans. These include late identification of HIV infection, less access to experienced HIV/AIDS physicians, less access to HIV therapy that meets the Public Health Service Guidelines and lack of health insurance to cover HIV care and medications.

HIV/AIDS like so many infectious diseases to which white have exposed Native American is viewed as a "white man's disease". Moreover HIV and AIDS do not have meaning in indigenous languages nor can indigenous healing processes be applied to them.

The lack of confidentiality in IHS clinics also serves a barrier to HIV counselling and testing

The failure of health care providers and substance abuse programs to incorporate healing elements from Native cultures, such as medicine wheel, into their service delivery creates barriers to care. Euro-American treatment models that focus on single disease rather than the whole person are viewed as another form of oppression.

Social-economic problems such as poverty, alcoholism and substance abuse, and low self -esteem may interfere with the ability of many Native Americans to seek preventive care, particularly when it is delivery by culturally insensitive providers and the services are located at great distances.

The whole Fact sheet.) (English only) may be download at: [www.nmac.org](http://www.nmac.org) (go to publications and search: American Indians )