

# Aboriginal People and HIV/AIDS: Legal Issues

info sheet 8

*This info sheet discusses some of the issues relating to HIV testing that are particularly relevant to Aboriginal people in Canada.*

## HIV TESTING

### WHY IS HIV TESTING IMPORTANT?

The fact that only a small number of Aboriginal people seek voluntary testing for HIV is cause for concern. It means that Aboriginal people with HIV/AIDS are often diagnosed and first receive treatment at late stages in their illness.

Approaches to promoting HIV testing among Aboriginal people must address broader issues, including the experience of racism, oppression, and cultural denigration, and the accompanying prevalence of social, economic, and health problems.

With improvements in treatment options, early detection of HIV infection is increasingly important.

### WHAT ARE THE ISSUES?

In *HIV Testing and Confidentiality: Final Report*, the Canadian HIV/AIDS Legal Network reports that in Canada a consensus emerged in the late 1980s that, except in a few well-defined circumstances, people should be tested for HIV only:

- with their informed, voluntary and specific consent;
- when counselling and education before and following testing are available and offered; and

- when confidentiality of results or anonymity of testing can be guaranteed.

Unfortunately, HIV testing available to Aboriginal people often does not meet these basic conditions. This contributes to the low number of Aboriginal people being tested and to the risk that the disproportionate impact of HIV on the Aboriginal community will continue to rise.

In the context of HIV testing, the following issues are particularly relevant to Aboriginal people:

*Control and ownership of research and data involving Aboriginal people:* Anonymous unlinked seroprevalence studies (“blind studies”) rely on HIV tests conducted on blood specimens drawn for another purpose. Personal identifiers are stripped from the blood so the results of the test cannot be linked to the individual. Blind studies are used for research in the surveillance of HIV infection in sample populations.

Testing for research purposes is regarded as controversial by many Aboriginal people. There is a feeling that there must be a better compromise between collecting information about rates of HIV infection and respecting principles of Aboriginal control and ownership of research and data.

This is one of a series of nine info sheets on Aboriginal People and HIV/AIDS: Legal Issues

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The Canadian Guidelines on Ethical and Legal Considerations in Anonymous Unlinked HIV Seroprevalence Research (*Canadian Medical Association Journal* 1990; 143: 625-627; revised *CMAJ* 1992; 146: 1743-1744) state that universal access to individual voluntary testing under prescribed conditions of informed consent, pre- and post-test counselling, and confidentiality is a prerequisite to blind studies. In too many cases this prerequisite is not met in studies involving Aboriginal people. The development of appropriate conditions for HIV testing should be a priority.

Finally, the training and employment of Aboriginal people in the conduct of this research should be emphasized as a crucial component of Aboriginal capacity-building in this area.

*Accessible options for HIV testing that overcome problems of remoteness, cultural difference, and reluctance to use mainstream facilities:* Access to testing issues are discussed in more detail in info sheet 9 in this series: *Access to HIV Testing*.

*Culturally appropriate pre-and post-test counselling:* Many indicate that adequate pre- and post-test counselling is not being provided by all health practition-

ers and that the quality of counselling is greater in testing clinics. HIV/AIDS education for health-care practitioners, both in smaller communities and cities, and including Community Health Representatives, is therefore much needed and should be an ongoing process.

In addition, many Aboriginal people may be more comfortable receiving counselling from trained Aboriginal counsellors, as cultural differences may affect the success and value of counselling sessions.

Training and employment of Aboriginal people in care, treatment, and support and in counselling is a crucial component of Aboriginal capacity-building in the field of health care.

*Confidentiality, particularly in smaller communities:* Confidentiality issues are discussed in more detail in info sheet 7 in this series: *Confidentiality*.

For further information on HIV testing and confidentiality, see also *HIV Testing and Confidentiality: Final Report* (Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998; the report can be obtained from the Canadian HIV/AIDS Clearinghouse at the address below).

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The information in this series of info sheets, prepared in partnership by the Canadian HIV/AIDS Legal Network (Legal Network) and the Canadian Aboriginal AIDS Network (CAAN), is taken from three discussion papers prepared by Stefan Matiation, based on discussions with key informants working in the field of Aboriginal people and HIV/AIDS: (1) *Discrimination, HIV/AIDS and Aboriginal People*; (2) *HIV/AIDS and Aboriginal People: Problems of Jurisdiction and Funding*; and (3) *HIV Testing and Confidentiality: Issues for the Aboriginal Community*. Copies of the revised, second edition of the papers and of the info sheets are available on the Legal Network website at [www.aidslaw.ca](http://www.aidslaw.ca), through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434, email: [aids/sida@cpha.ca](mailto:aids/sida@cpha.ca)), or through CAAN (tel: 613 567-1817; fax: 613 567-4652; email: [caan@storm.ca](mailto:caan@storm.ca)). Reproduction of this info sheet is encouraged. However, copies may not be sold, and the Legal Network and CAAN must be cited as the source of this information. For further information, contact the Legal Network (tel: 514 397-6828; fax: 514 397-8570; email: [info@aidslaw.ca](mailto:info@aidslaw.ca)) or CAAN.

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