

Focus Group Meeting on Aboriginal HIV Estimates

**February 6-7, 2001
Dartmouth, Nova Scotia**

**Hosted By:
Division of HIV/AIDS Epidemiology and Surveillance
Bureau of HIV/AIDS, STD and TB
Centre for Infectious Disease Prevention and Control
Population and Public Health Branch
Health Canada**

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April 30, 2001

Dear Reader:

This report summarizes the proceedings of the Focus Group Meeting on Aboriginal HIV estimates that was held by the Division of HIV/AIDS Epidemiology and Surveillance on February 6-7, 2001, in Dartmouth, Nova Scotia. The main objectives of the meeting were: (1) to obtain input from the Aboriginal community related to the estimates of HIV infections among the Aboriginal populations; (2) to discuss data needs from surveillance programs and targeted studies to improve the HIV estimates among the Aboriginal populations; and (3) to discuss issues related to the interpretation, dissemination and use of these data.

Participants of the meeting brought forward many good points which are currently under consideration by the Bureau of HIV/AIDS, STD and TB. We have also communicated your recommendations to other programs of Health Canada.

For further information on any presentation, the reader is encouraged to directly contact the relevant speaker or the Division at (613) 954-5169.

Sincerely,

Dr. Chris Archibald
Chief

Ms. Mai Nguyen
Senior Research Analyst

TABLE OF CONTENTS

SUMMARY	1
DAY 1		
1.0 OPENING	2
2.0 RE-ALIGNMENT AT HEALTH CANADA	2
3.0 ABORIGINAL COMMUNITY INPUT ON THE 1999 ESTIMATES	2
4.0 PRIORITY DATA NEEDS FOR SURVEILLANCE PURPOSES	3
4.1 Capacity Building	3
4.2 Improved Surveillance and Research	4
4.3 Data Content and Presentation As Tools For Intervention	4
DAY 2		
5.0 DISSEMINATION OF ABORIGINAL HIV EPIDEMIOLOGY REPORTS	5
6.0 CLOSING	6
A) APPENDIX 1 - Participants List	7
B) APPENDIX 2 – Estimates of National HIV Prevalence and Incidence in 1999	10
C) APPENDIX 3 – Priority Data Needs to Improve National Monitoring of the HIV Epidemic among the Aboriginal Population	15
D) APPENDIX 4 - Report on the Estimated Number of HIV Infections Among Aboriginal People in Canada	19

SUMMARY

The Focus Group Meeting on 1999 Aboriginal HIV estimates was held on February 6th-7th, 2001 in Halifax Nova Scotia by the Division of HIV/AIDS Epidemiology and Surveillance, Bureau of HIV/AIDS, STD and TB, Centre for Infectious Disease Prevention and Control, Health Canada. The meeting brought together representatives from front line Aboriginal AIDS workers, national Aboriginal political organizations and governments to discuss the 1999 estimates of HIV infection among Aboriginal populations. In addition, the gaps in the HIV/AIDS surveillance and epidemiology data from Aboriginal communities in Canada were discussed.

The meeting consisted of several presentation and discussion sessions on these topics. The objectives of the meeting were: to obtain input from the Aboriginal community related to the estimates of HIV infections among Aboriginal populations; to discuss data needs from surveillance programs and targeted studies to improve the Aboriginal HIV estimates; and to discuss issues related to the interpretation, dissemination and use of these data.

The discussions opened with presentations by Mai Nguyen and Dr. Chris Archibald on the re-alignment at Health Canada, the process for deriving the 1999 HIV estimates and the needs for improved HIV/AIDS surveillance among Aboriginal people in Canada. The meeting was conducted in an informal manner, so as to encourage discussion from all participants on all points. Besides the feedback on the format and content of the HIV estimates, one of the most important discussions to come out of the day-and-a-half meeting was the identification of areas of priority for HIV/AIDS surveillance among Canada's Aboriginal community.

The meeting was presided over by Josephine Augustine, a Micmac elder from Big Cove, New Brunswick. A feast was held at the end of the day of February 6th at Healing Our Nations offices in Dartmouth, where a feather feast was conducted by the elder in honour of a focus group participant, Quinn Wade.

Day 1 - February 6th, 2001

1.0 OPENING

Mai Nguyen welcomed participants, reviewed the goals of the meeting, and introduced the elder, Josephine Augustine from Big Cove, who led the meeting in an opening prayer. Round table introductions were made by the group.

2.0 RE-ALIGNMENT AT HEALTH CANADA

Dr. Chris Archibald reviewed the re-alignment of Health Canada and the resulting creation of a Centre for Infectious Disease Prevention and Control (CIDPC) under the Population and Public Health Branch. Within CIDPC, there are the Bureau of HIV/AIDS, STD and TB, Bureau of Infectious Diseases, the Hepatitis C Division, and the HIV/AIDS Policy Coordination and Programs Division.

Dr. Chris Archibald explained the differences in the roles and activities between the field epidemiologist housed under the Centre for Surveillance Coordination and the field surveillance officer housed under Bureau of HIV/AIDS, STD and TB. Several participants expressed the need for field surveillance officers in provinces that don't presently have them. Dr. Archibald explained that work is underway to complete the assignment of all field surveillance officers.

Richard Jenkins highlighted the need of more Aboriginal epidemiologists in government. Dr. Archibald stated that the Bureau is aware of this need, and Mai Nguyen said that the Bureau, in partnership with the First Nations and Inuit health Branch (FINHB), is trying to institute a program that would bring an Aboriginal student into the Bureau to train in epidemiology.

3.0 ABORIGINAL COMMUNITY INPUT ON THE 1999 ESTIMATES

Dr. Archibald gave a brief explanation of the report on 1999 estimates of HIV infection in Canada released by CIDPC in November of 2000. He explained the process by which the estimates for the general population were made by the Division of HIV/AIDS Epidemiology and Surveillance, and how that information was then used to estimate incidence and prevalence in the Aboriginal populations. (See Appendix 2).

Following Dr. Archibald's presentation, the group commented that the estimates needed to be broken

down into population-specific (Inuit, First Nations, and Métis) numbers, and to some extent by province. Dr. Archibald replied that breaking the numbers down into further categories might make the numbers statistically invalid because of the small sample sizes, and that there could also be some confidentiality issues in certain regions where there are few HIV infections among Aboriginal populations. Mai Nguyen mentioned that the Aboriginal Working Group has developed a set of standardized Aboriginal identifiers for the studies to help eliminate inconsistency in identifying Aboriginal cases. Patty Tait stated that it was still important to have the break-downs between the three groups for the community regardless of statistical relevance. Others mentioned the need of using these numbers for funding purposes, and that the estimates seem low compared to what community members are seeing in the regions. One participant stated that we need to have this information and move beyond the numbers in terms of prevention. Another re-iterated that his community needs the numbers in order to gauge how relevant this information is for them.

4.0 PRIORITY DATA NEEDS FOR SURVEILLANCE PURPOSES

Dr. Chris Archibald stated the purpose of the afternoon session was to identify HIV/AIDS surveillance needs in relation to the Aboriginal community. He cautioned that although it may not be possible to implement all suggestions at this time, due to resource and practical limitations, it would be beneficial to the Bureau to identify as many needs as possible in this session.

Dr. Archibald began with five questions to help improve the Aboriginal HIV estimates.

- 1) What are the population sizes of Aboriginal groups at risk for HIV?
- 2) For those groups at risk, what are their prevalence rates?
- 3) What are their incidence rates?
- 4) What are the HIV testing behaviour of these groups and their access-to-care characteristics?
- 5) What are the frequencies of HIV risks behaviours among these risk groups?

The Focus Group identified three areas that needed to be worked on in terms of surveillance among the Aboriginal community. By consensus, it was agreed that none of the identified areas should take priority over the other, but all must be given priority and implemented together. It was also suggested that all these priorities and other surveillance efforts must be:

- 1) conducted under the principles of OCAP - Ownership, Control, Access and Possession by and for Aboriginal people
- 2) conducted in compliance with ethical research standards

3) conducted with fully informed consent of those being studied or researched

4.1 Capacity Building

- capacity building to strengthen existing and create new partnerships/collaborations (more training/ scholarships in epidemiology and surveillance)
- studies and research led by the Aboriginal community
- pilot studies in the Aboriginal communities to make use of epidemiology data in program evaluation and development
- collection of population specific data (Inuit, First Nations and Métis)

4.2 Improved Surveillance Research

- population-specific HIV/AIDS risk assessment (using surrogate markers¹, cultural and social determinants, etc)
- region-specific risk assessment (using surrogate markers, cultural, social and regional determinants, HIV testing and AIDS case databases, etc)
- standardization of Aboriginal HIV/AIDS surveillance statistics by gender, exposure category, and comparison to the general population
- consider environment as a risk factor

4.3 Data Content/Presentation (As tools For Prevention)

- community support for use of epidemiology data in prevention
- consider statistics in the context of cultural relevance
- placing Aboriginal HIV surveillance data in larger context of Aboriginal population health

In addition, the Focus Group highlighted areas of concern that need to be taken into account when these areas for priority are considered. They are:

- certain high risk groups need special consideration - eg. Prisoners - when considering research and surveillance studies
- present data with information specific to Inuit, Métis and First Nations
- must be a commitment to share finances and resources in order to assist communities in this data gathering
- it must be in the Aboriginal community
- hepatitis C and HIV should be considered together for prevention purposes
- that the gathering of surveillance data and research must be done by Aboriginal people

¹By definition, surrogate markers are a clinical measurement known to be statistically associated with, and believed to be pathophysiologically-related to, a clinical outcome. In the case of HIV, rates of other STD infection among specific populations can be used as surrogate markers to identify populations at risk for HIV (e.g., those practising unsafe sex).

- to enhance the legitimacy and usefulness of the data for those it is intended to benefit
- mobility should be considered as an environmental and social determinant of health

For more information, please refer to Appendix 3.

DAY 2 February 7th, 2001

The opening prayer was conducted by elder Josephine Augustine

5. 0 DISSEMINATION OF HIV/AIDS EPIDEMIOLOGY INFORMATION

Following the session, Mai Nguyen and Darren Greer led the group in a discussion on the HIV estimates report. Mai also went over the surveillance needs identified by the group on Day 1. The Focus Group revised some of the priorities, added others and had a lengthy discussion about the importance of surveillance data to the Aboriginal community.

The group was asked to provide input on the content and format of reports produced by the Bureau of HIV/AIDS, STD and TB and how they would be best disseminated to the Aboriginal community.

The general consensus was that surveillance reports from the Bureau of HIV/AIDS, STD and TB are difficult to understand for many Aboriginal people, and that there was a need to change the format and presentation of these reports in order to make them relevant to Aboriginal communities. Todd Armstrong noted that presentation and content are directly linked to data content that will then guide capacity building.

Darren Greer briefly went over the process of developing the draft report on Aboriginal HIV estimates prepared for the meeting and asked for participants' input on the content, presentation and format of the document. There was much discussion that this report, like other reports from Health Canada, needs to be presented in a way that is relevant, clear, concise, current and accessible. Surveillance documents need to have comparison with other Canadian populations and international ethno-cultural groups. They need to be more visual as well.

There was some discussion about who was responsible for interpreting data and making it relevant to communities. It was decided that the methodology in the report should be presented as end notes, that the estimates should be shortened in a one-to-two page fact sheet with estimated incidence and prevalence numbers and a brief discussion of possible reasons why the numbers for 1999 were high among the Aboriginal population, and a section for application of the data at the community level.

In terms of dissemination, it was decided that the report should be intended for front line Aboriginal HIV/AIDS workers and assume a knowledge of basic HIV/AIDS vocabulary. It was also suggested that this information be published in Aboriginal community newspapers. Earl Nowgesic suggested that real numbers and percentages be presented together in the report and that the actual incidence and prevalence estimates be moved to the very front of the report. Earl also suggested including a section on the precision of these numbers in the fact sheets as well as a section on data limitations in the methodology.

Todd Armstrong stated that these estimates are not relevant to the communities he serves because there is no Inuit breakdown. He says that it needed to be stated that the majority of HIV and AIDS cases are predominantly First Nations. He also stated that the best way to distribute the information is through an Inuit Organization, like Pauktuutit, to maximize the community use of such information.

Art Zoccole suggested that a reading list be added at the end of the report for those who wish to look into HIV estimates and AIDS case data further. Lisa Allgaier stated that the information as presented is not useful to the community. After various other related comments, it was agreed that the report should be re-drafted - that a two page fact sheet would be more useful, followed by methodological endnotes.

The Report on Aboriginal HIV estimates were sent again to all participants at the meeting for final input. The final copy of this report is in the Appendix 4.

6.0 CLOSING

The meeting ended with a prayer led by the Elder.

Appendix 1 – List of participants

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Appendix 2 - Estimates of National HIV Prevalence and Incidence in 1999



Estimates of National HIV Prevalence and Incidence in 1999

Jennifer Geduld and Chris Archibald

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Acknowledgements

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Drs Martin Schechter, Michael O'Shaughnessy, Mark Tyndall, Bob Hogg,
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Acknowledgements

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Dr. Donald Sutherland, Bureau of HIV/AIDS STD and TB
Dr. Ping Yan and Dena Schanzer, Division of Modelling and
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Tanya Guenther, Division of HIV/AIDS Epidemiology and
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Outline of talk

- ♦ Estimates of HIV prevalence and incidence for general Canadian population
- ♦ Estimates for Aboriginal population



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Introduction

- ♦ National HIV prevalence and incidence estimates
 - to monitor the HIV epidemics in Canada
 - to guide and evaluate prevention programs
 - to predict the need for HIV care and treatment
 - to identify gaps in data
- ♦ Previous estimates in Canada done for 1996
- ♦ Estimate for 1999



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Methods

- ♦ Triangulation technique using data from a wide variety of sources:
 - HIV/AIDS Case Reporting Surveillance System (HACRSS)
 - Provincial HIV serodiagnostic data
 - Provincial vital statistics
 - Targeted epidemiologic studies
 - Population-based surveys of risk and testing behaviour
 - Census data and projected population estimates (1999)
- ♦ Direct and indirect methods with Monte-Carlo simulation to estimate uncertainty



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Appendix 2 - Estimates of National HIV Prevalence and Incidence in 1999

Methods

- ♦ **Exposure categories:**
 - Homosexual/bisexual men (MSM)
 - Injecting Drug Users (IDU) and MSM-IDU
 - Heterosexual
 - heterosexual contact with a person at risk for HIV
 - origin in a country where HIV is endemic
 - heterosexual as the only identified risk
 - Other (includes blood/clotting factor, perinatal and occupational transmission)
- ♦ **Four provinces: British Columbia, Alberta, Ontario, and Quebec**
 - represents 85% Canada's population
 - 95% of HIV test reports and reported AIDS cases

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Prevalence - Direct Method

Prevalent No. HIV infections at end of 1999:

= Prevalence Rate	*	Estimated Population Size
- Epidemiologic studies		- Census and Survey data
- Population-based studies		- Capture-Recapture (IDU)
- Expert Opinion		- Expert Opinion

- ♦ **Divided into three regions:**
 - Major cities (Vancouver, Edmonton, Calgary, Toronto, Ottawa, Montreal)
 - Area outside major cities
 - Total province

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Prevalence - Indirect method

Method A: HIV prevalence to the end of 1999

$$= \frac{(\text{Cumul. No. HIV +ve tests to end 1999}) - (\text{Cumul No. AIDS Deaths to end 1999})}{\text{Proportion ever tested for HIV}}$$

Method B: HIV prevalence to the end of 1999

$$= \left[\frac{(\text{No. HIV +ve tests in 1999})}{\text{Proportion tested per year}} \right] + (\text{Cumul No. HIV+ve tests 1985-98}) - (\text{Cumul No. AIDS Deaths to 1999}) + (\text{1999 Incidence Estimate})$$
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Incidence

Direct Method

Incident No. HIV infections in 1999:
Incidence rate * (Estimated Pop'n - Prevalent Infections to 1998)

Difference of Prevalence Method:

Incident No. HIV infections 1997 -1999:
(Prevalence at end of 1999 - Prevalence at end of 1996)
+ AIDS Deaths 1997-1999

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Using HIV/AIDS Surveillance Data

- ♦ **Recent reported HIV diagnoses and AIDS cases used to derive:**
 - Rest of Canada (Prairies/Territories, Atlantic Provinces)
 - Females
 - Aboriginal Population
 - Divide heterosexual exposure category

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Participation from Provinces

- ♦ **Draft estimates by exposure category and methodology sent to the four provinces (BC, AB, ON PQ)**
- ♦ **Review and discussion via teleconference or meeting**
- ♦ **Discussion: Prevalence/incidence rate/number, population size, proportion tested for HIV, adjustment for duplicates**

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Appendix 2 - Estimates of National HIV Prevalence and Incidence in 1999

Table 1: Estimated prevalent HIV infections in Canada at end of 1996 and end of 1999, by exposure category

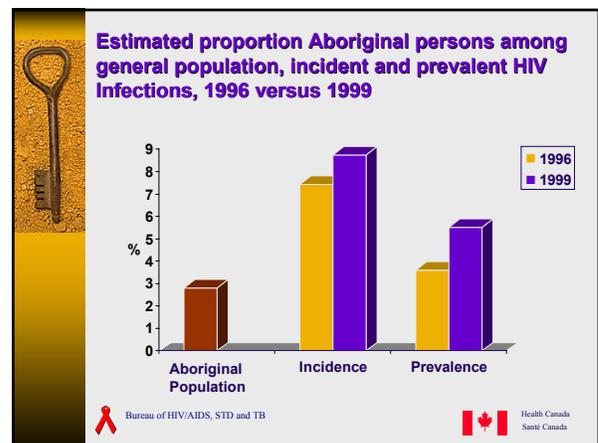
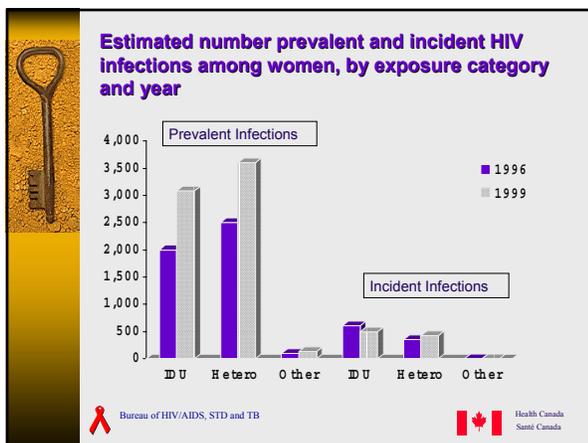
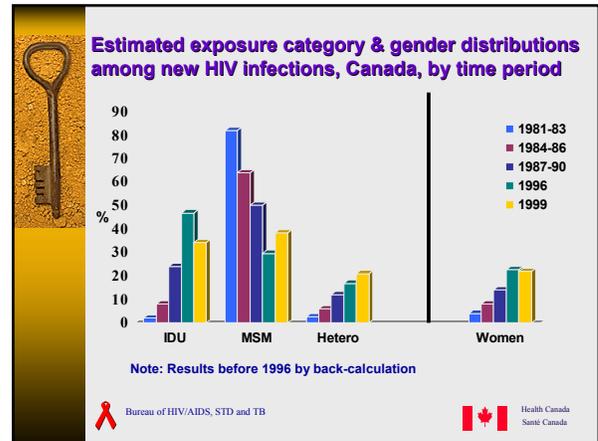
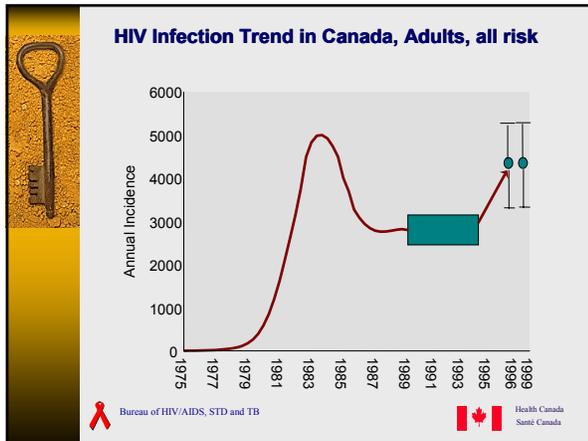
	MSM	MSM-IDU	IDU	Hetero	Other	Total
1999	29,600 59%	2,100 4%	9,700 20%	8,000 16%	400 1%	49,800
Range of Uncertainty	26,000-33,400	1,700-2,600	8,100-11,800	6,300-10,100	330-470	45,000-54,600
1996	25,300 63%	1,700 4%	7,100 18%	5,500 14%	500 1%	40,100

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Table 2: Estimated incident HIV infections in Canada in 1996 and in 1999, by exposure category

	MSM	MSM-IDU	IDU	Hetero	Other	Total
1999	1,610 38%	270 7%	1,430 34%	880 21%	0 0%	4,190
Range of Uncertainty	1,190-2,060	190-360	1,030-1,860	610-1,170		3,310-5,150
1996	1,240 30%	290 7%	1,970 47%	700 16%	0 0%	4,200

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Appendix 2 - Estimates of National HIV Prevalence and Incidence in 1999

Estimates for Aboriginal persons

- ✦ **Methods:**
 - Proportion of Aboriginal persons among reported HIV and AIDS cases, by exposure category and geographic cell
 - Multiplied by estimate for general population for that cell



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- ✦ Refer to Excel spreadsheet “national summary....”

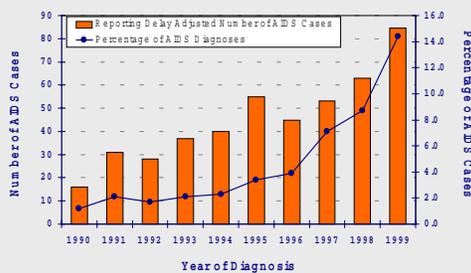


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Number and Percentage of Aboriginal Persons among Canadian AIDS Cases



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Limitations

- ✦ **Direct method:**
 - population size not precisely known for exposure groups
 - limited prevalence/incidence data and what is available in existing studies has problems with representativeness
 - lack of standardization in definition of exposure categories between studies
- ✦ **Indirect method:**
 - variable rate of duplicate test removal between provincial HIV databases
 - paucity of data on HIV testing behaviour



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Limitations

- ✦ **Limited data available**
 - small-to-mid-size cities or rural areas
 - smaller provinces/territories
 - especially for women and ethnic groups
- ✦ **Extrapolation procedure for Rest of Canada, Females and among Aboriginal Populations**
 - Assumes regional, exposure category and gender distribution among recent HIV diagnoses and AIDS cases is similar to distribution among prevalent and incident HIV infections.
 - Some provinces do not report ethnic status for HIV data



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Assessment of estimation procedure

- ✦ **Maximum use of wide variety of surveillance and research data**
- ✦ **Degree of certainty improved using different methods**
- ✦ **Advantages to Method:**
 - Flexible
 - Can readily incorporate new data
 - Serves to highlight gaps in existing knowledge



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Appendix 2 - Estimates of National HIV Prevalence and Incidence in 1999



Conclusions

- ♦ **Estimated number of new HIV infections in Canada in 1999 is essentially unchanged from 1996 at about 4,200 per year**
- ♦ **However, the pattern of infections continues to change:**
 - Decreased infections among IDU
 - Increased infections among MSM
 - Increased infections in Aboriginal Populations
 - New infections in women continue at about 22% of total



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Implications for Surveillance

- ♦ **Fair degree of uncertainty associated with these estimates**
- ♦ **Many assumptions had to be made to carry out the process**
- ♦ **Indicates the urgent need for better surveillance data to improve estimates in order to more effectively monitor the HIV epidemics in Canada**



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Appendix 3 - Priority Data Needs to Improve National Monitoring for the HIV Epidemic among the Aboriginal Population



Priority data needs to improve national monitoring of the HIV epidemic among the Aboriginal populations

Focus Group Meeting on Aboriginal HIV Estimates organized by
The Division of HIV/AIDS Epidemiology & Surveillance
February 6-7, 2001, Dartmouth, Nova Scotia

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Goals of meeting

- ♦ To present 1999 estimated numbers of Aboriginal persons currently living with HIV (prevalence) and those newly infected (incidence).
- ♦ To discuss data needs to improve monitoring of the HIV epidemic among the Aboriginal populations.
- ♦ To discuss issues related to interpretation, dissemination and use of Aboriginal data.

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Questions for discussion

- ❶ What are the population sizes of the Aboriginal population groups at risk for HIV?
- ❷ What are their HIV prevalence rates?
- ❸ What are their HIV incidence rates?
- ❹ What are their HIV testing behaviour and access-to-care characteristics?
- ❺ What are the frequencies of HIV-associated risk behaviours?

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Outline for discussion session

- ❶ What are the possible data sources to answer these questions?
- ❷ Which one are the most feasible and important with respect to Aboriginal populations?

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❶ Why do we need to know the populations sizes of the various groups at risk for HIV?

- ♦ Indicate the pool of populations at risk for HIV infection
- ♦ Estimate denominator size

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❶ Population sizes : data sources

- ♦ Direct method (population survey data)
- ♦ Variants of indirect method:
 - HIV testing databases
 - IDUs in treatment for substance abuse
 - HIV treatment databases
 - mortality among IDUs
- ♦ Capture-recapture techniques using multiple data sources
- ♦ Proportion of men ≥ 45 who were never married (MSM)
- ♦ Expert opinion

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Appendix 3 - Priority Data Needs to Improve National Monitoring for the HIV Epidemic among the Aboriginal Population



② Why do we need to know HIV prevalence rates in groups of interest?

- ♦ Key to monitor the epidemic
- ♦ Develop targets/goals to achieve (ex: reduction in prevalence)
- ♦ Health economic aspects



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② HIV prevalence rates in population groups of interest: data sources

- ♦ unlinked anonymous studies
 - samples from pregnant women
 - STD clinics
 - general medical testing
- ♦ voluntary linked studies
 - blood donors
 - HIV testing databases
 - venue based (gay bars, prisons, drug treatment, NEPs)
 - “outreach” recruitment
 - testing data for insurance purposes



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③ Why do we need to know HIV incidence rates in groups of interest?

- ♦ Estimate new infections in a given population



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③ HIV incidence rates in population groups of interest: data sources

- ♦ back-calculation from clinical data (eg. AIDS, CD4 counts, HIV diagnoses)
- ♦ cohort studies
- ♦ repeat presentations to health care settings (ex: abortion attendees, voluntary testing, needle exchange sites)



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③ HIV incidence rates in population groups of interest: data sources

- ♦ incidence estimate from a single sample
 - young age
 - testing history or seroconverting illness history (ask about prior testing)
 - laboratory analysis:
 - indeterminate followed by confirmed positive (WP)
 - to detect recent infection (detuned assay used by the BSHT’s Integrated Surveillance System)



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④ Why do we need to know HIV testing behaviour?

- ♦ Link between HIV serodiagnostic data and HIV incidence
- ♦ Indirect method for estimate of HIV prevalence (ever, past year)
- ♦ Improve models of HIV epidemic & understanding of the hidden epidemic
- ♦ Estimate potential bias in incidence estimates from repeat-tester studies and detuned assay
- ♦ Guide testing and counseling programs
- ♦ First step to access treatment and support



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Appendix 3 - Priority Data Needs to Improve National Monitoring for the HIV Epidemic among the Aboriginal Population



④ HIV testing behaviour: data sources

- ♦ general population surveys
- ♦ surveys of risk groups
- ♦ reason for testing and not testing
- ♦ comparison of HIV testing databases with census data
- ♦ questionnaires within other prevalence/incidence studies



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④ Why do we need to know access to care?

- ♦ Evaluate equality of access to care
- ♦ Improve access to care



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④ Access to care: data sources

- ♦ comparison of HIV treatment databases with diagnostic databases
 - characterization of AIDS diagnoses that are late testers
 - Proportion of early/late testers among all HIV diagnoses (CD4 count)
- ♦ questionnaires within other prevalence/incidence studies



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⑤ Why do we need to know risk behaviour information?

- ♦ Indicate potential for HIV spread
- ♦ Corroboration of other epidemiology data
- ♦ Evaluate prevention programs
- ♦ Estimate denominator size
- ♦ Need to monitor trends in risk behaviours and assess their environment, determinants and characteristics
- ♦ Definitions



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⑤ Risk behaviours: data sources

- ♦ Risk behaviours among those found to be HIV-infected:
 - HIV test requisitions
 - follow-up of newly diagnosed HIV cases:
 - to assess behaviour that led to infection
 - to assess subsequent behaviour
 - analysis of factors associated with HIV infection in prevalence/incidence studies
 - risk behaviour among those HIV exposed (PEP)



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⑤ Risk factors: data sources

- ♦ Risk behaviours among those at risk:
 - Survey of risk groups and general population (behavioural surveillance)
 - Surrogate markers (STD data like rectal Gonorrhoea, teen pregnancies, HCV)



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Appendix 3 - Priority Data Needs to Improve National Monitoring for the HIV Epidemic among the Aboriginal Population



What data are needed to improve monitoring of the HIV epidemic in Aboriginal populations?

Suggestions:

- Improved HIV/AIDS surveillance data
- Risk behaviour data and determinants
- HIV testing behaviour data
- HIV prevalence data
- Mobility as part of risk environment

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Summary of identified needs by the Focus Group on Aboriginal HIV estimates

- ♦ Capacity building in epidemiology and surveillance
 - enhancing and establish partnerships /collaborations
 - providing opportunities for training
 - more studies led by the Aboriginal community
 - Pilot studies that use the epi information in program evaluation
- ♦ Improve surveillance/research data
 - Population specific (1st Nations, Inuit, Metis)
 - Data on HIV related risk behaviour, testing, prevalence
 - Making use of STD surrogate markers and social environment determinants when doing HIV risk assessment
 - Regional relevant data

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Summary of identified needs by the Focus Group Meeting (cont.)

- ♦ Presentation and dissemination of data
 - interpreting data in the cultural and health promotion context
 - presenting only statistics that are relevant to Aboriginal communities
 - packaging information to enhance its use
 - data specific to First Nations, Inuit, Metis if possible

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HIV and Aboriginal People in Canada: A Report on the Estimated Number of HIV Infections Among Aboriginal People in Canada

Prepared by the Focus Group on Aboriginal HIV Estimates and Bureau of HIV/AIDS, STD and TB, Centre for Infectious Disease Prevention and Control, Health Canada, May 2001

In Canada, the Aboriginal populations are very diverse with many sub-groups (First Nations, Inuit and Metis) that reflect variations in historical backgrounds, language and cultural traditions. The term Aboriginal in this report refers to First Nations, Inuit and Metis.

Here are the facts!

- Aboriginal people are over-represented in recent estimates of HIV infections among the Canadian population: while Aboriginal people represent 2.8 % of the Canadian population, they accounted for approximately 9% of new HIV infections in 1999.
- From 1996 to 1999, there was an estimated 91% increase (from 1,430 to 2,740 infections) in the number of Aboriginal people living with HIV and an estimated 19% increase (from 310 to 370 infections) in the number of Aboriginal people newly infected by HIV.
- Among these 370 Aboriginal people estimated to have been newly infected with HIV in 1999, their risk factors for HIV infection were:
 - 64% through injection drug use
 - 17% through heterosexual sex
 - 11% through male to male sexual activity
 - 8% through male to male sexual activity and injection drug use
- Among the 2,740 Aboriginal people estimated to be living with HIV infection at the end of 1999, their risk factors for HIV infection were:
 - 54% through injection drug use
 - 15% through heterosexual sex
 - 23% through male to male sexual activity
 - 6% through male to male sexual activity and injection drug use

Why are these numbers so high?

We don't know for sure why the numbers are so high among Aboriginal populations. Several hypotheses might explain this situation. Aboriginal people are disproportionately affected by many adverse social, economic and behavioural factors (such as high rates of poverty, exploitation, racism and cultural oppression leading to substance abuse, sexually transmitted diseases, limited access to or use of health care services). These factors increase their vulnerability to HIV infection. Furthermore, the high rates of mobility of some Aboriginal people from rural communities to urban centres without appropriate education, prevention tools and resources is another factor which may increase the risk of HIV transmission.

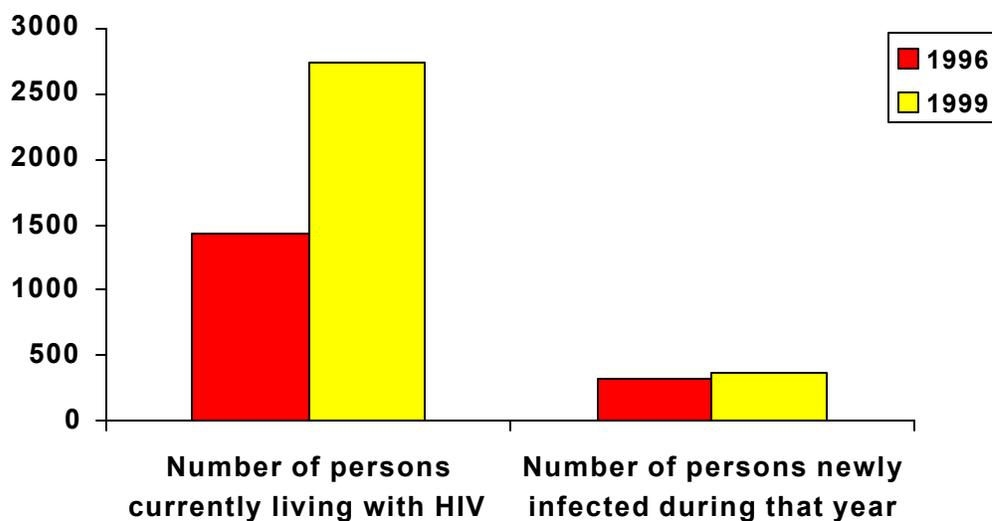
How accurate are these HIV estimates?

The methods to estimate HIV infections in Canada make use of available surveillance and research data. Aboriginal HIV estimates are mainly determined by data from large cities as well as HIV and AIDS cases with reported ethnicity. The resulting estimates are therefore imprecise, but the degree of certainty is improved by using several methods in a combined approach. Overall, these statistics indicate that HIV infection among Aboriginal people in Canada is on the rise. Sufficient data specific to First Nations, Inuit and Metis populations were not available to produce separate estimates (for more information, see Endnotes – Limitations of data).

What can be done to help?

The message that HIV infection among Aboriginal people is on the rise must be broadly communicated. This information can help Aboriginal prevention workers and community activists in their work. For example, knowing that 64% (235) of the new infections among Aboriginal persons in 1999 were attributed to injection drug use can help focus prevention efforts to target these specific risk behaviours. In this case, the estimates can also be used as a tool to advocate for more Aboriginal specific needle exchanges and harm reduction programs, as well as to target prevention efforts to women and youth through schools and community programs. Using these estimates to target relevant prevention and education efforts to those most affected may help reduce the numbers of Aboriginal people who become infected with HIV in the future.

Estimated of HIV infections among Aboriginal populations, by year



Glossary

HIV Prevalence

The total number of persons currently living with HIV in a given population at a specific time

HIV Incidence

The number of persons newly infected by HIV over a certain time period (in epidemiological studies, usually over a period of one year)

Methodology

A set of procedures used in a particular study or investigation.

End Notes

How were these estimates derived (Methodology)

1. The estimates for this report were drawn from the Canada Communicable Disease Report published in December 1, 2000 by the Centre for Infectious Disease Prevention and Control, Health Canada.
2. National estimates of HIV prevalence and incidence in the Canadian population were done based on a combination of methods. These included incorporating data from a wide variety of sources such as AIDS case reports, provincial HIV testing databases, population-based surveys, targeted epidemiological studies and population census data.
3. HIV estimates were carried out separately for the provinces of British Columbia, Alberta, Ontario, and Quebec, as these four provinces account for 85% of Canada's population and 95% of HIV and AIDS diagnoses in Canada. The remaining provinces and territories, because of the small number of HIV/AIDS cases in them, were grouped into two categories: Prairies/Territories (Saskatchewan/Manitoba/NWT, Yukon and Nunavut) and the Atlantic Provinces (Nova Scotia, New Brunswick, PEI, and Newfoundland). The combined data for these two categories was obtained by using regional distribution in the AIDS case and HIV test report databases.
4. Health officials group those infected with HIV and AIDS into categories based on how they become infected, or *exposure categories*. HIV estimates for Aboriginal populations were drawn from the national HIV estimates grouped by exposure category and province. These were then multiplied by the percentage of Aboriginal persons in the AIDS case reports and HIV positive test reports in each exposure category and province (where such data are available).

5. Information on AIDS cases and HIV diagnoses are collected at the local and provincial levels and forwarded to the Centre for Infectious Disease Prevention and Control to be included in the semi-annual HIV/AIDS surveillance reports. Types of information collected includes exposure category, gender, age and ethnicity. One of the most important pieces of information when estimating the number of Aboriginal people in the population diagnosed with HIV/AIDS are ethnic identifiers (the information reported in the data base that tells a person's ethnic background.).

Limitations of data

1. Ethnic identifiers allow for researchers to tell which cases are Aboriginal (First Nations, Inuit, or Métis) in the HIV test reports and AIDS cases. However, for a variety of reasons, not all of the information is complete for all cases and this is a limitation of the data and the resulting estimates based on these data. It should be noted that HIV test report data does not include those who are HIV positive but have never had a test to diagnose HIV.
2. If the ethnic status of an Aboriginal person is not completely recorded in AIDS case or HIV diagnoses data, then these cases would not be counted in the Aboriginal HIV estimates. This may tend to under estimate the problems of HIV infection among Aboriginal people in Canada.
3. Provincial variation in reporting ethnicity is another limitation of this data. For example, there is currently no ethnic information for HIV test reports from the provinces of Quebec and Ontario. For these provinces, the ethnic data from the AIDS case database, combined with the methods explained in Endnotes 2 and 3 and 4, were use to derive the estimates of Aboriginal people diagnosed with HIV among the population.