

Through proper surveillance, it has been shown that behavioural change affecting HIV is possible. We have firm evidence of positive behaviour change in a number of countries. For example, in the past few years Thailand has succeeded in reducing the number of new HIV infections among young men. Thailand has made major progress in addressing its heterosexual HIV epidemic, largely fuelled by sex work. The experience of Thailand shows us the importance of good data, of openness, honesty and government commitment in recognizing the behavioural dynamics driving their heterosexual HIV epidemic.

Although not often given as examples, I would also like to note the achievements of countries such as Korea and Japan in limiting HIV epidemics in their countries. We know that prostitution occurs everywhere. In both these countries, there is a high rate of condom use, within marriage, and also to an extent in commercial sex prior to the emergence of HIV. Yet over the past decade, rates of condom use in commercial sex have greatly risen, and are now very high. The prevention of HIV epidemics in these countries is an achievement, and shows that it is possible to promote behaviour change in many different ways.

However, there is no room for complacency regarding HIV in Asia. There are an estimated 7 million people living with HIV in Asia and because of Asia's huge population base, the numbers of people with HIV and AIDS will become much larger.

Perspectives for epidemiological surveillance

SLIDE 25 Perspectives

We must continue to study and understand these dynamics if we hope to affect HIV epidemics. HIV and AIDS surveillance need to be reinforced by surveillance of Knowledge and Behaviours to better design programmes and monitor the impact before the HIV infection occurs.

HIV surveillance will also have to adapt to mature epidemics context where HIV prevalence stabilize and where monitoring of HIV incidence in selected high risk groups become more important.

Better standardization and coordination of surveillance systems should be reinforced, so comparisons will be more accurate within the region.

Finally improving the diffusion and use made of data need to be emphasized.

Thank you

Surveillance systems related to HIV/AIDS in Australia
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Introduction

Australia is constitutionally a federation, within which the legislative responsibility for public health, including communicable disease surveillance is vested in the governments of the 6 States and 2 Territories. The Commonwealth government has a coordinating and funding role in national disease control programs.

In 1986, the Commonwealth government provided funding for a national research centre, with responsibility for coordination of national surveillance for HIV/AIDS among other roles, to be established at the University of New South Wales in Sydney. Known as the National Centre in HIV Epidemiology and Clinical Research (NCHECR) since 1990, the centre works with State and Territory health departments, and a wide range of health services and other agencies, to develop and implement surveillance protocols related to HIV/AIDS. The Commonwealth also funds the National Centre in HIV Social Research, which collaborates with the NCHECR on behavioural surveillance.

National surveillance for HIV/AIDS is carried out within the overall framework of Australia's National HIV/AIDS Strategy, which was first promulgated in 1989. The Australian HIV Surveillance Strategy (attached), which addresses issues specific to surveillance, was nationally endorsed in 1990 and substantially revised and extended in 1992. As well as describing the technical components of surveillance, it identifies the principles by which surveillance is to be guided, including a strict adherence to confidentiality at all levels.

NCHECR publishes a quarterly surveillance report, and since 1997, has edited an annual surveillance report, which presents a comprehensive analysis of trends and patterns in HIV and AIDS diagnoses, sentinel surveillance for HIV infection, behavioural surveillance related to sexual activity and injecting drug use, and other sexually transmitted diseases and blood-borne viruses.

AIDS case surveillance

Organisational and legal structure: AIDS has been notifiable by doctors in all States and Territories since the early 1980s. The legislation has varied somewhat across jurisdictions, but now provides for a common reporting mechanism for AIDS cases, which are then reported by agreement to NCHECR. In the larger States, doctors report cases to their local public health unit, which then forwards the notification to the State level.

Reporting system: Case reports are made on paper forms, which are essentially identical across States and Territories. Identifiers used are date of birth and a name code made up of the first two letters of the first and last names. Other demographic characteristics recorded are postcode of residence, Indigenous status (yes or no) and country of birth (with duration of residence in Australia if overseas born). The route of HIV exposure is determined by history-taking from the

person with AIDS and the AIDS-defining illness or illnesses are noted. Month of HIV diagnosis, CD4 count at AIDS diagnosis and history (ever/never) of antiretroviral therapy are also recorded.

Linkage of AIDS and HIV diagnoses has been undertaken actively in some States, and nationally using the date of birth and namecode. Deaths subsequent to AIDS are documented by methods that vary somewhat across States and Territories. Reports of deaths following AIDS are made by States and Territories to the NCHECR.

Case definition and validation: Australia has essentially followed the US Centers for Disease Control case definitions for AIDS, but did not adopt the 1993 revision that allowed for AIDS to be defined on the base of a low CD4 cell count alone. Newly reported AIDS cases are checked for duplication at the State/Territory level, and again at the national level, using date of birth and namecode. Death registrations and cancer notifications have been used as a cross-check for completeness of AIDS case reporting. On the basis of these assessments, reporting of AIDS cases generally appears to be 90-95% complete.

Application of results: There have been several important uses of AIDS case surveillance in Australia. First, they have provided a comprehensive, if somewhat time-delayed, picture of HIV transmission patterns. Secondly, they have been systematically used as the basis for back-projection estimation of past HIV incidence, and projection of future AIDS incidence. Thirdly, AIDS cases have provided an indication of the spectrum of advanced HIV-related illness in Australia. Finally, they have been used to indicate the extent of undiagnosed HIV infection in the population.

Problems and future perspective: In the past, the main challenge in AIDS case reporting has been to sustain a high level of participation in case reporting by doctors. Linkage of funding to AIDS case counts has provided a useful incentive for both health departments and community-based organisations to actively support AIDS surveillance activities.

More recently, the advances in treatment effectiveness have focussed attention on ensuring that people with HIV infection have access to optimal therapy, and emphasised the role of AIDS case reports as indicators of treatment failure. The impact of the new therapy on HIV disease progression has also severely limited the validity of back-projection estimates of past HIV incidence, which rely on accurate knowledge of the rate at which people with HIV infection progress to AIDS.

HIV case surveillance

Organisational and legal structure: HIV infection has been notifiable by laboratories, doctors or both in some States and Territories since antibody testing first became available, while in some other jurisdictions, the relevant legislation has been put in place relatively recently. Nonetheless, all States and Territories have reported HIV diagnoses to NCHECR since 1990. The legislation still varies somewhat across jurisdictions, to a greater extent than the legislation for AIDS case reporting, but now provides for a common reporting mechanism for HIV diagnoses, which are then reported by agreement to NCHECR.

Reporting of HIV diagnoses in Australia is facilitated by the relatively small number of laboratories that are permitted to carry out confirmatory tests for HIV antibody.

Reporting system: Case reports are made on paper forms, which are essentially identical across States and Territories. Identifiers used are date of birth and a name code made up of the first two letters of the first and last names. Other demographic characteristics recorded are postcode of residence and Indigenous status (yes/no). The route of HIV exposure is determined by history-taking from the person with HIV infection. For cases not attributed to mother-to-child transmission or sexual contact between men, a more comprehensive exposure assessment form is forwarded to the diagnosing doctor. Perinatal exposure to HIV infection is separately reported to the NCHECR via the Australian Paediatric Surveillance Unit, and cross-checked against the reports from States and Territories.

Since 1991, reporting of HIV diagnoses has also included information on the recency of infection, based on previous negative testing or documented seroconversion illness, and the CD4 count at HIV diagnosis.

Case definition and validation: HIV diagnosis is determined on the basis of the respective reporting laboratory's criteria. HIV laboratories in Australia have participated in comprehensive quality assurance programs since antibody testing became available.

Application of results: HIV case surveillance has principally been used to provide a more timely indication of transmission patterns than AIDS surveillance. The analysis of recently acquired infections has been particularly valuable for this purpose.

Problems and future perspective: It is recognised that the interpretability of patterns and trends in HIV diagnoses is dependant on corresponding patterns and trends in HIV testing. Ongoing attempts are made to assess the extent of HIV testing, but no fully satisfactory method has evolved as yet.

The major practical difficulty in HIV case surveillance has been in the collection of information on individual characteristics, particularly in the States that base their HIV surveillance on laboratory reporting alone. A person's contact with the health system may be brief around the time of HIV diagnosis, and may not be conducive to good history-taking with regard to HIV exposure.

Serosurveillance for HIV infection

Virtually all serological surveillance for HIV infection in Australia has been carried out on the basis of voluntary testing with return of results to the individuals tested. Testing has either been in the context of a clinical service, such as a consultation at a clinic for sexually transmitted disease, or through the requirements of institutions such as blood banks or the Australian Defence Force. Anonymous unlinked surveillance for HIV infection has only been used on a limited basis. In a national serological surveillance program for people who inject drugs, HIV testing is on a voluntary basis, but the results are not returned to the individuals tested.

There is no legislative basis for the surveillance aspect of serosurveys in Australia. They are carried out in the framework of the National HIV/AIDS Strategy, and, where appropriate, the approval of other bodies such as institutional ethics committees is sought.

Blood donors: HIV testing of blood donors is mandatory in Australia. Prevalence of HIV infection in blood donors is reported by blood banks to NCHECR. Demographic details are available for positive donors, but not routinely for the national donor population as a whole.

Defence Force entrants: All entrants to the Australian Defence Force are tested for HIV infection, and prevalence is reported to NCHECR on a regular basis.

Prison entrants: The extent of HIV testing in prison entrants varies across jurisdictions, from under 40% to 100%. All jurisdictions report to NCHECR on the numbers of tests and HIV prevalence among those tested, separately for males and females and for remanded versus sentenced prisoners.

STD clinic attenders: A network of the larger public STD clinics in Australia reports regularly to the NCHECR on numbers of attenders tested for HIV infection and HIV prevalence in those tested. Age group, sex and previous test history (yes/no) are recorded, as well as information on sexual and injecting practice in broad categories.

Needle exchange attenders: For one week each year, attenders at some 25 needle exchanges around Australia are asked to provide a fingerprick blood specimen, which is tested for HIV infection, and complete a brief demographic and behavioural questionnaire.

Application of results: HIV prevalence measured in blood donors and Defence Force entrants provides an indication of transmission in that part of the population that might be considered to be at lower risk. Prison entrants and STD clinic attenders may be considered to be at higher risk. Within the STD clinic attenders are subgroups of injecting drug users, sex workers, men having homosexual contact, and people having sexual contact outside Australia. Monitoring of these populations provides an indication of transmission patterns in a wide range of contexts. The needle exchange-based surveillance provides a crucial window into a population group that has experienced very high levels of HIV infection in other parts of the world.

Problems and future perspective: The biggest weakness in the sentinel serosurveys is the uncertain representativeness of the populations tested, both in regard to lower and higher risk segments of the populations. Another challenge is monitoring HIV risk among some Indigenous populations, in which high levels of other sexually transmitted infections have indicated the potential for HIV transmission.

Behavioural surveillance

Behavioural surveillance has principally been carried out among population groups perceived to be at higher risk of HIV infection.

Homosexually active men: The NCHECR and National Centre in HIV Social Research have been conducting six-monthly behavioural surveys among homosexually active men identified through

clinics, venues and events in Sydney. Over the past 12 months, the survey has been extended to other capital cities.

Injecting drug users: The annual needle exchange survey provides behavioural data on injecting drug users.

Young people: The National Centre in HIV Social Research has conducted annual surveys of sexual behaviour among university entrants.

Evaluation of programs

A very close linkage has developed over the past 5-10 years between surveillance and program activities in both the government and non-government sectors. The evaluations of the National HIV/AIDS Strategy that took place in 1995 and 1998 draw extensively on surveillance data, and as the strategies are revised, new directions are based on the findings from surveillance.

The Commonwealth and State and Territory governments are in the process of developing indicators for the effectiveness of HIV/AIDS strategies that are largely based on the output of surveillance systems.

The annual surveillance report provides a comprehensive resource that is widely used in Australia for all aspects of the national response to HIV/AIDS.

1. Introduction

An estimated 50,000-54,000 cumulative HIV infections had occurred in Canada by the end of 1996, for a population rate of 175 per 100,000. The characteristics of the HIV epidemic in Canada have changed significantly over time. The epidemic in the 1980s primarily affected men who have sex with men, and now mainly affects injection drug users. In addition, other groups such as women and Aboriginal people are also becoming increasingly affected.

2. HIV/AIDS-Related Surveillance or Surveys

(a) AIDS case surveillance

- Organizational and legal structures for surveillance
The government of Canada is a federal system, comprising of ten provinces. Each of these is responsible for the delivery of health services within the respective province. Consequently, each province has a considerable degree of autonomy in the area of health.

Each province has its own system for HIV/AIDS surveillance, and AIDS is reportable in all provinces of Canada. At the national level, we support improvements to HIV/AIDS surveillance at the provincial level.

Although not required, all provinces voluntarily submit AIDS case report data to Health Canada's Division of HIV/AIDS Surveillance, where national data is analyzed and reported upon.

Health Canada has been monitoring AIDS cases since 1982, and the reporting delay adjusted total exceeds 20,000 cases for the country.

AIDS surveillance is currently based on case report forms. The AIDS case report forms contain the following information: unique identification number, reporting physician's name and address, patient initials (no names), date of birth, city of residence, gender, ethnicity, country of birth, year of immigration to Canada, laboratory and clinical data, HIV exposure information, date of AIDS diagnosis and date of receipt of form at the national level.

- Reporting system
The federal government collects standardized data from case reports to better understand the epidemic. In Canada, AIDS case report monitoring is a physician-based system, in which the physician who diagnoses the case reports it to the local medical officer of health who reports it to the provincial. After verification, the provincial level reports it to the national level without uniquely identifying information attached.
- AIDS case definition and validation
The AIDS case definition used in Canada is the 1987 definition from CDC, Atlanta with the addition of three clinical conditions in 1993: pulmonary tuberculosis, recurrent bacterial pneumonia and invasive cervical cancer. Note the CD4 count is not part of the AIDS case definition in Canada (like Europe, but unlike the USA).

Partially identifying information is used at the national level to identify potential duplicate AIDS case reports. In cases that are suspected duplicates, the national level contacts the provincial level, which in turn confirm the status of the case with the physician. This information is relayed back from the physician to the provincial level, and then forwarded back to the national level.

Reporting completeness varies, depending on the type of information. 100% of AIDS case reports report gender and age, while 96% report an associated exposure category. In contrast, 79% of cases report ethnicity information.

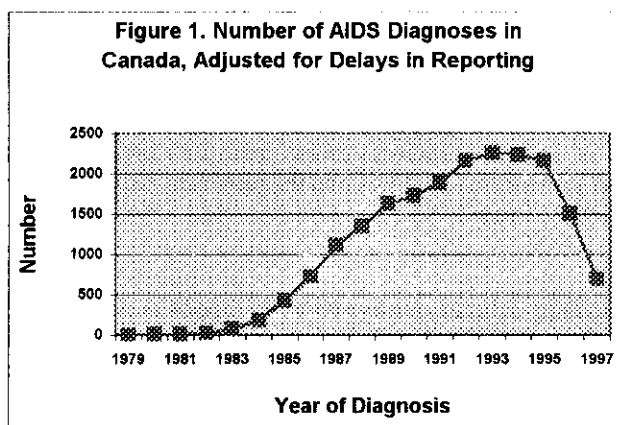
- Results of case surveillance

As of June 30, 1998, a total of 15,935 cumulative AIDS cases had been reported to the federal government in Canada. After adjusting for reporting delay, the total is estimated to be approximately 20,000 (67 per 100,000 population).

The trends in delay-adjusted AIDS cases peaked at about 2,200 cases per year in 1993, then declined gradually until 1995, when it began a sharp decline (Figure 1.). This decrease may be due to a number of factors, including anti-retroviral treatments and drug prophylaxis that delay the onset of AIDS, and perhaps also to decreased reporting by physicians and health case workers.

The exposure category of men who have sex with men (MSM) accounted for the majority of AIDS cases early in the epidemic, and the proportion of MSM among new AIDS diagnoses has steadily declined from nearly 80% in the mid-to-late 1980's to just over 50% in 1997. This change reflects the movement of the HIV epidemic into other at-risk populations, particularly injection drug users (IDU's). In 1997, 20% of adult AIDS cases were attributed to IDU transmission, compared to only 5% in 1993 and than 2% in 1990. Injecting drug use is a more common mode of transmission in women than in men, accounting for 18.3% of all AIDS diagnoses in adult women, compared to 3.7% in adult men. An additional 4.8% of adult male AIDS diagnoses are attributed to the combined exposure category of MSM/IDU.

Women NOW account for 7.2% of cumulative reported AIDS diagnoses. However, the proportion of annual diagnoses among women has increased over time: from 4-6% during 1982-1991, to 8% in 1994 and 14% in 1997. To December 1997, a cumulative total of 170 AIDS cases had been reported among children less than 15 years old in Canada, 113 (78%) of which were due to perinatal transmission.



Bureau of HIV/AIDS and STD, LCDC

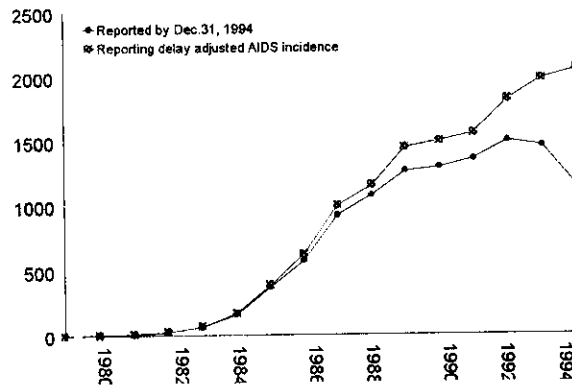
- Dissemination and actions which result

AIDS case report summary statistics are published and distributed to many internal and external stakeholders. Internally, the statistics are used to guide policy, prevention and care programs. Externally, for advocacy and educational programs. Electronic and hard copy case report data is aggregated and prepared into national reports, and together with positive HIV test report data, is published twice a year. It is also available on the WorldWideWeb at <http://www.hc-sc.gc.ca/hpb/lcdc/publicat/aids/aic11-98/index.html>.

Analyses of national AIDS surveillance data is an important aspect of standard reporting at the national level. Estimating reporting delay is a component of such analyses. Reporting delay is the time interval between the date of AIDS diagnosis and the date when the report is received at the national level.

The frequency distribution of reporting delay for AIDS cases in Canada is such that 7% of cases are reported within the first 3 months after diagnosis, 20% within the next three months, etc. Overall, 52% of cases are reported within one year and 70% within 2 years. So you can see that we have a significant degree of reporting delay in Canada.

It is important to adjust AIDS incidence curves for reporting delay since a significant proportion of cases will only be reported later in time. For example, in the mid-1990s, it was important for politicians and policy makers to realize that AIDS incidence was not declining, but rather increasing. Otherwise there would have been the tendency to misinterpret the unadjusted data and to reduce the level of funding for HIV/AIDS.



- Problems and future perspective

Problems monitoring AIDS case reports include voluntary reporting system's 'reporter fatigue' and integrating HIV and AIDS surveillance into a comprehensive single electronic database system.

(b) HIV case surveillance

- Organizational and legal structures for surveillance

The relative independence of Canada's provinces causes some difficulties for national surveillance. HIV infection is reportable in all provinces except two and the provinces vary in the amount of epidemiologic information they collect on HIV cases.

- Reporting systems

In some provinces, the laboratory submits positive HIV test reports and the surveillance system for HIV is separate from AIDS surveillance; these provinces vary by the amount of information they collect on HIV cases. In the other provinces, the physicians submit reports and the information collected is the same as for AIDS cases since the two surveillance systems are integrated.

In several provinces where HIV surveillance is integrated with AIDS surveillance, the same reporting form is used for HIV surveillance that is used for AIDS surveillance is used. The following information is collected: details on the physician and the patient, risk factors for HIV, dates of diagnosis and receipt of report, etc. These reports are sent electronically to the national level and are then combined into a special database that can be analyzed easily. This database can be made available to provinces so they can do their own custom analyses. For example, it is simple to look at trends over time by risk group or by gender, and to do analyses for a single province. Or we can look at the distribution of risk groups for AIDS in a single province. This is an important function of having surveillance centralized at the national level— support for data analysis and interpretation of provincial data can be provided by the national level, whereas this would usually not be done by the provincial level itself due to lack of resources and expertise.

In addition, at the national level, we can provide support to provinces for outbreak investigations when outbreaks are identified using the surveillance data. In Canada, we have supported the provinces to investigate HIV outbreaks among heterosexual women and among injection drug users.

- HIV case definition and validation

Currently in Canada, a specimen is considered positive for HIV if two ELISA and one Western blot test are positive.

Positive HIV test reports are received at the national level without identifying information. This makes the identification and subsequent removal of inter-provincial duplicates very near impossible. The scope of this bias has not been fully assessed.

At the same time, the national level relies on the provinces to remove within province duplicates. Their ability to do so may be compromised by a lack of information on case report forms, as the information received on HIV case reports is less comprehensive as on AIDS case reports. The provinces are always striving to identify techniques to identify duplicate positive HIV test reports, and continually update their surveillance data accordingly.

Anonymous HIV testing is a component of testing services provided by many provinces, though not all. Anonymous test data is not included in standard positive HIV test report surveillance data due to the inability to identify duplicate testers. The amount of anonymous testing varies by province, though it typically constitutes a small proportion of HIV test data.

- **Results of case surveillance**

A cumulative total of 41,669 HIV positive tests were reported in Canada to Dec. 31, 1997 with an average of 2,830 new positive tests per year during the period 1995-97. Trends in HIV surveillance data show a similar shift in the HIV epidemic from homosexual men to injection drug users, and this shift is even more pronounced than in the AIDS data.

Table 1. Shows positive HIV test reports in Canada by risk group and time period. Again we see that over time, the percentage of new HIV cases among homosexual men has decreased while it has increased among injection drug users and heterosexuals. It has also increased among women. Note that this level of detail in the HIV surveillance data is necessary to guide prevention programs properly and it only possible if the epidemiologic information is reported along with the case to the national level.

Table 1. Positive HIV test reports as reported in Canada by time period.¹

As a Percentage of all Positive HIV Test Reports

Year	Women	Injection Drug Use	Men who have Sex with Men	Heterosexual
1985-1994	9.8%	8.4%	74.6%	7.4%
1995	19.6%	26.9%	44.0%	16.2%
1996	21.7%	30.7%	39.9%	18.4%
1997	21.8%	33.2%	37.6%	21.8%

Source: Bureau of HIV/AIDS, STD and TB, LCDC, Health Canada

¹ Rows do not add up to 100% since categories are not mutually exclusive. Percentages are based on total number minus those reports for which exposure category was unknown.

- **Dissemination and actions which result**

HIV and AIDS surveillance data is used extensively to provide evidence-based information to policy makers. A key Canadian policy regarding HIV/AIDS policy was taken in 1998 when the National AIDS Strategy was renewed. This move will provide a stable source of HIV/AIDS research funding into the future.

- **Problems and future perspectives**

There are some concerns about HIV surveillance because it is relatively new compared to AIDS surveillance. The main concerns are the potential for loss of privacy, confidentiality, and the potential stigma of living with HIV since people now live longer. We are working with community groups to address these concerns and it is important to note that so far there have been no breaches of confidentiality in the Canadian public health system for any disease.

The main limitation of HIV/AIDS surveillance is that the data do not represent new infections. The data only represent those who become ill or who come forward for HIV testing. In Canada, we estimate that one-third of those infected with HIV are not aware of their infection. Therefore, to address these limitations, HIV prevalence and incidence data are needed to supplement surveillance data.

(c) Sentinel sero-surveillance

- **Organizational and legal structures for surveillance**

In the late 1980s, Canada developed ethical guidelines for the conduct of unlinked anonymous HIV seroprevalence studies for the purpose of sentinel surveillance. These types of studies continue to be done in Canada in all provinces, except Quebec, where the civil code has precluded such studies since 1995 (on the basis of the need for individual consent).

- **Sampled populations and sampling procedures**

A program of formal, regularly repeated unlinked anonymous seroprevalence studies was not established in Canada, but rather sporadic studies were done in various populations to monitor HIV prevalence. Sampled populations included low risk groups such as pregnant women, blood donors and individuals presenting for general medical examinations, and high-risk groups such as STD clinic patients. In these studies, leftover blood was analyzed in an unlinked way to determine HIV status. In addition, seroprevalence studies have been conducted in other populations where individual consent was requested to obtain a blood or saliva sample for HIV analysis: needle exchange clinic attendees, inmates, men who have sex with men, commercial sex workers, and street youth.

- **Measurements**

In these seroprevalence studies, HIV antibody status was measured in either blood or saliva samples.

- **Reporting system**

The results from these studies are not reported through a formal surveillance system, but rather collated and synthesized by the federal government (LCDC) on an ad hoc basis through literature review, conference attendance, and invited presentations at LCDC meetings.

- **Results of sentinel sero-surveillance**

In the 1980s, HIV prevalence rates among MSM in Canada's major cities ranged from 25-36% and incidence was estimated at 7-11 new infections per 100 person-years. Recent studies have found incidence rates in the range of 1-2 per 100 person-years. HIV prevalence among inner-city IDUs increased dramatically in Montreal from about 5% prior to 1988 to 19.5% in 1997. Similarly alarming increases in prevalence have been observed in the IDU communities of many other Canadian cities, such as Toronto (4.5% in 1992 to 9.5% in 1997), Ottawa (10% in 1993 to 21% in 1997), and especially Vancouver (4% in 1992 to 23% in 1996). HIV incidence in an IDU cohort in Montreal was estimated to be 3.7 per 100 person-years during 1988-91 and 6.5 during 1995-97. A small study in Vancouver in 1992/93 estimated incidence at about 5 per 100 person-years, and a current cohort study found rates of 18.2 during 1996/97 and 4.8 during 1997/98. The lower incidence in the second time period is likely due to a saturation effect (i.e. highest risk IDUs already infected).

There are several sub-populations within the IDU group that merit special mention. Injection drug users are over-represented in prisons and HIV prevalence among prisoners in Canada varies from 1-4% in men and from 1-10% in women. In both groups, HIV infection is strongly associated with a history of injection drug use. In addition, Aboriginal persons are over-represented in inner city IDU communities and among clientele using inner-city services such as needle exchange programs and counseling/referral sites. Adult Aboriginal AIDS cases are more likely than adult non-Aboriginal AIDS cases with known ethnicity (60% of total), the percentage of Aboriginal persons has increased sharply since 1994 (<4% before 1994, 6% in 1995, 11% in 1996 and 14% in 1997).

Unlinked, anonymous seroprevalence studies among pregnant women in Canada indicate an average rate of about 3.5 per 10,000, although studies in a number of large provinces have not been repeated since the early 1990s. More recent studies show that even provinces without large urban areas have significant rates (for example, 4.1/10,000 in 1994-96 for a province with no cities larger than 100,000 population). In addition, in the province of Manitoba where the largest city has a population of 600,000, there is evidence to suggest an increasing trend of HIV infection among women of childbearing age (prevalence rate of 0.7/10,000 in 1991 and 3.2/10,000 in 1995 among pregnant women).

- **Dissemination and actions which result**

The Manitoba data on increasing HIV prevalence rates among pregnant women were used by the provincial government to implement a policy of screening all pregnant women for HIV. The prevalence and incidence data indicating a worsening problem among injection drug users has been used to redirect research and prevention program money toward the HIV/IDU problem.

- **Problems and future perspectives**

Since Canada has not implemented a standard program of regular sentinel seroprevalence studies, the available data are somewhat limited in their ability to show geographic and temporal trends. Furthermore, in Quebec, there is no longer any possibility of conducting unlinked anonymous seroprevalence studies. Future directions include filling in geographic and population gaps in our understanding of HIV prevalence and incidence through targeted epidemiologic studies.

(d) Behavioral surveillance

- **Organizational and legal structures for surveillance**

No formal behavioural surveillance program exists in Canada and behavioural data are gathered from the general population through occasional national telephone surveys and from specific population subgroups through targeted epidemiologic studies.

- **Sampled populations and sampling procedures**

The general population (people aged greater than 12 or 15 years) has been sampled primarily via random telephone survey methodology. Subgroups such as injection drug users, men who have sex with men, and inmates have been sampled in face-to-face interviews in the context of epidemiologic studies.

- **Measurements**

The behavioural data collected in these surveys covers a wide range of sexual and drug injection behaviours. The wording of questions has generally been variable and so trend comparisons among behavioural data are difficult. LCDC has recently developed sets of common, core sexual behaviour questions for use among adults and among adolescents, and are planning similar core question sets for other population sub-groups.

- **Reporting system**

The results from these studies are not reported through a formal surveillance system, but rather collated and synthesized by the federal government (LCDC) on an ad hoc basis through literature reviews, conference attendance, and invited presentations at LCDC meetings.

- **Results of behavioral surveillance**

In Canada, about 50% of 17-year-old adolescents have ever had sexual intercourse; among sexually active adolescents, only 30% consistently use condoms. Sexual practices among street youth are even more risky with a median age at first intercourse of about 13 years. Depending on the study, 4-16% of Canadian adults have had more than one sex partner in the preceding year. Among this group, 18% of men and 7% of women who had casual sex partners report never using condoms with these partners in the past year. Among men who have sex with men, there has been a decrease in the number of sex partners in the past year: 70-80% had more than five such sex partners in studies carried out in the mid-1980s compared to 35-56% during the mid-1990s. However, no clear decrease is evident for rates of unprotected receptive anal

intercourse: this continues to be a common activity practised at least once in the past year with 30-40% of regular partners and 10-20% of casual partners.

Among IDUs, cocaine is the drug of choice in most areas and access to and use of needle exchange programs is the norm even in smaller cities. Nonetheless, borrowing needles and other injection equipment remains a frequent behaviour, being reported in the previous six months by about 40% of IDUs.

National surveys have found that about 17% of adult Canadians have ever been tested for HIV (excluding tests for blood donation and insurance purposes); those reporting risk factors such as MSM, IDU, or multiple sex partners were more likely to be tested. It is estimated that 11,000-17,000 (30-40%) of the approximately 40,000 Canadians living with HIV infection at the end of 1996 were unaware of their infection (not tested positive for HIV) (see below for details of national estimate of HIV prevalence).

- Dissemination and actions which result

Risk behaviour information has been synthesized at the national level, published in LCDC documents and presented at national meetings, and disseminated widely to community, academic, and government officials. The information on continued high rates of needle sharing has been used to increase counseling and HIV prevention education at needle exchange sites and other service agencies that cater to IDUs. Efforts are also being made to address the underlying social causes or contributing factors to injection drug use, such as unemployment and poor housing. Complacency about HIV/AIDS in the gay community has been challenged by risk information such as that showing continued high rates of unprotected receptive anal intercourse.

- Problems and future perspectives

As mentioned above, the major challenge for accurate behavioural surveillance is the collection of standardized information at regular intervals. Data collected in an *ad hoc* fashion inevitably results in little comparability and the resulting difficulty in assessing trends. The sensitive nature of the questions also creates problems with valid responses. In Canada, we are working to obtain agreement on and coordinate the use of standardized core questions for sexual and drug injection behaviour.

3. HIV/AIDS Program Effectiveness Monitored and Evaluated by Surveillance or Surveys

It has recently been estimated that about 40,100 Canadians were living with HIV infection at the end of 1996 (including those living with AIDS). This compares to a previous estimate of 32,000-36,000 at the end of 1994. By exposure category, 63.1% of prevalent infections in 1996 were among MSM, 4.2% among MSM-IDU, 17.7% among IDU, 13.7% among heterosexuals, and 1.3% among recipients of blood or blood products (Table 2).

Table 2. Estimated number (and row percent) of prevalent HIV infections in Canada at the end of 1996, by exposure category, for both sexes combined and for women alone.

	MSM	MSM/IDU	IDU	Heterosexual	Blood/blood products	Total
Men and women	25,300 (63.1%)	1,700 (4.2%)	7,100 (17.7%)	5,500 (13.7%)	500 (1.3%)	40,100
Women	0	0	2,000 (44%)	2,500 (54%)	100 (2%)	4,600

For incidence, it is estimated that there were 4,200 new HIV infections in Canada during 1996: 29.5% among MSM, 6.9% among MSM-IDU, 46.9% among IDU, and 16.7% among heterosexuals (Table 3). As we have seen, the majority of this recent increase in HIV infections is among IDU who now comprise nearly half of all new infections in Canada. However, MSM still comprise a significant proportion of new infections, and there are increasing HIV infections among non-IDU heterosexuals (especially women).

Table 3. Estimated number (and row percent) of incident HIV infections in Canada in 1996, by exposure category (for both sexes combined and for women alone).

	MSM	MSM/IDU	IDU	Heterosexual	Blood/blood products	Total
Men and women	1,240 (29.5%)	290 (6.9%)	1,970 (46.9%)	700 (16.7%)	0	4,200
Women	0	0	600 (63%)	350 (37%)	0	950

This estimated incidence of 4,200 is lower than the estimated peak in annual HIV incidence of about 5,000-6,000 that occurred in the mid-1980s, but is higher than a previous estimate of 2,500-3,000 per year for the period 1989-94. The demonstration of this increase in incidence at the national level played a very important role convincing the national government to continue the funding for the National AIDS Strategy in Canada. This has probably been our most important use of surveillance data in the past 5 years.

HIV and AIDS surveillance data in Canada are used to influence policy and programs. We have used surveillance data to describe the true trends in AIDS cases, to demonstrate the effectiveness of new treatments for HIV, to support the development of an HIV testing program in pregnancy, to re-direct community work toward injection drug users (the group in Canada most affected by HIV), and to renew funding for the National AIDS Strategy.

4. Conclusions

Our biggest challenge is to monitor the HIV epidemic accurately to guide and evaluate prevention and care programs. To do this, it is crucial to collect and analyze detailed surveillance data at the national or central level. We need the epidemiologic detail to properly interpret the trends in the number of cases so that the data can be used to properly guide programs. It is at the national level that one can have a sufficiently large sample size to detect trends in their early stages. It is the national level that usually has more technical expertise and resources to respond to identified problems such as outbreaks.

It is surveillance at the national level that permits the use of standardized case definitions and data collection that allows districts or smaller areas within countries to compare their situations, to share problems and solutions, and to learn from each other to more effectively develop HIV prevention and care programs.

HIV/AIDS surveillance in Denmark – country report

INTRODUCTION

Denmark is a small country in the north of Europe with 5.2 million inhabitants. The country is a democratic monarchy and the national language is Danish. All citizens are given a "CPR"-number so that the individual can be identified when attending e.g. the health care system.

There is a long tradition for surveilling infectious diseases, actually national surveillance goes back to the 17th century. Also, politically the country has a long history with democracy, that is: social-democracy. During the past hundreds of years, the population has been fairly homo-genous, although during the last 30 years some immigration has had its impact on culture, social welfare as well as the pattern of some of the infectious diseases, including HIV and tuberculosis. The immigrants mainly come from countries like Turkey and Pakistan, but also from a country like Somalia. In Denmark we pay tax – a lot – to both the State and the County, and it is the responsibility of the existing 16 counties to run the health care system locally.

HIV/AIDS-RELATED SURVEILLANCE OR SURVEYS

1. AIDS case surveillance

In Denmark, AIDS became a mandatory notifiable disease in 1983, while HIV reporting was introduced in August 1990. It is the National Board of Health who by law has the authority to demand an infection to be reported and it is the Dept. of Epidemiology at State Serum Institute who function as the surveillance unit.

The first Danish AIDS case was diagnosed in 1980 and in the early years of the 1980'ies, Denmark was the country in Europe with the highest AIDS incidence per inhabitant. During the mid-late 1980'ies and early 1990'ies the position in Europe has slowly declined, and Denmark is now taking a mid-position. However, during the first 10 years of the pandemic the annual AIDS incidence increased in Denmark. It reached a peak in 1993 with 46 pr. million inhabitants and thereafter has decreased to a level of 19 pr. million inhabitants in 1997.

AIDS being mandatory reportable means that any MD who diagnosis AIDS must report this right away and the report form request the name of the patients and the use of full personal identifiers. The report goes to the national surveillance unit at the State Serum Institute. A copy of the form is at the same time forwarded to the local health authority. Since AIDS patients are only treated in a few hospitals, the reporting-rate is close to 100%. The number of undiagnosed AIDS cases has not been evaluated, but the number is likely to be low. Also, the reporting delay is short, median time from

diagnosis to date of reporting to the unit being less than 2 weeks.

The AIDS case definition used is the same as in other European countries and was until 1993 also identical with the case definition used in the US.

Quarterly, the surveillance unit issues a one page report on the national HIV/AIDS statistics (latest issue enclosed).

Results from AIDS case surveillance, 1980-1998

In the period 1980 to 1998 a total of 2,200?? AIDS patients has been diagnosed and reported. As mentioned, the number of annually reported AIDS cases has increased up during the 1980'ies and reached a peak in 1993 (4.6 pr 100.000 inhabitants). Thereafter, there has been a decrease to 1.9 pr 100,000 inhabitants in 1997 and 1.2 per 100,000 inhabitants in 1998.

The vast majority of reported AIDS cases is men, who have sex with men (MSM), although the relative proportion of annually notified AIDS cases being MSM has decreased over the years from 92% in 1980-1985 to 51% in 1997-98. In the same period the number as well as proportion of heterosexually acquired AIDS cases has increased - from 5% in 1980-85 to 34% in 1997-98 - and this increase is also reflected in the increase of cases being women: From 3% in 1980-85 to 17% in 1997-98. Overall, only 2.5% of Danish AIDS cases are reported with an unknown mode of acquisition.

Most reported AIDS cases live in the Copenhagen area, that is 68%, and this area has also the highest AIDS incidence per inhabitants compared to other areas in the country.

During the last 3 years the decrease in AIDS incidence has been enforced due to the effect of the antiretroviral combination therapy being offered free of charge to all relevant HIV-infected persons. The indication for therapy used in Denmark is rather conservative, meaning that only patients with a high or increasing level of viral load and/or a low or decreasing CD4 count are offered treatment. Here, at the beginning of 1999, probably 1,400 HIV-infected people are in treatment with these drugs.

Also, the new antiretroviral treatments have instantly had a major effect on the number of AIDS-related deaths. In 1995, 235 persons (43 pr. million inhabitants) died from AIDS, a number that decreased to one fourth, that is 60 (11 pr. million inhabitants) in 1997 and 28 (5 pr million inhabitants) in 1998.

Due to this massive intervention in the natural history of the HIV infection, and the following change in the AIDS epidemic, the number of AIDS patients alive has now increased, and has reached the highest level ever in history in 1997 with 400 AIDS patients alive. This trend - along with its consequences on the number of people living with HIV - must lead to an increase in HIV prevalence, and has led to speculations on whether the time has come to a major change in the HIV/AIDS surveillance and prevention strategy. In Denmark, the discussion is whether to focus more on the HIV infected population along with more focused information campaigns targeted specific - so called high-risk - populations such as: the young, men who have sex with men, i. v. drug users, ethnic minorities, and Danes who travel. The discussion is still ongoing, and it includes aspects of the consequences to be taken due to the supposed decreasing infectivity of the HIV infected people receiving antiretroviral drugs as well as the expected increase in sexual activity of the infected due to a general better quality of life..

2. HIV case surveillance

As mentioned, HIV case reporting was introduced in Denmark in August 1990, and reporting is mandatory and anonymous. The system is based on the laboratories doing confirmatory HIV analyses. Along with all confirmed HIV-antibody positive test results, the lab must send the standard reporting form. This form has a unique identifier and has 4 duplicates. Before sending it, the lab must fill in the name and address of the requesting physician and send a copy to the surveillance unit. The physician must fill in the form by giving the information requested on the HIV-infected person. The data collected include gender, age, place of living, risk behaviour, previous HIV testing and results. Then another copy of the form is returned to the surveillance unit. Due to this construction of the system - which allows for sending out reminders to the reporting physicians - the report-rate is close to 98%.

The system has provided data, which has been and still is being used for guiding the focus of the national prevention and information strategies. However, although the system has given a much better insight in the prevalence of HIV in the general population as well as in some subpopulations, and although it has given some indications on where the spread of HIV is taking place - it also carries some problems.

Due to the construction of the system we still have problems in counting duplicates although studies have shown that the order of duplicates is around 5%. The system does not directly provide us with any data that can be used as prevalence nor incidence data, mainly since the tested population is based on self-selection, and the reasons for choosing or not choosing an HIV test are not known..

Therefore, although the test-activity is fairly high in Denmark, we still find it necessary every now and then to do cross-sectional studies among the tested population in order to be able to interpret the data on the HIV-positives as good as possible. Also, due to the system being anonymous, no link with the national AIDS-registry or other registries is possible.

In Denmark, HIV testing is free of charge, can be done by all GPs as well as at most hospitals and special clinics and testing can – on request - be done anonymously. After an increase in number of HIV-test done annually in the first half of the 1990'ies, where about 150,000 tests (2.9% of inhabitants) were done voluntarily per year, the number has decreased to around 110,000 tests in 1998. An extra 350,000 persons are tested as blood donors per year giving an overall annual HIV test-rate of around 8% in the total population. Except for blood donors, no reel screening programs for HIV have been implemented, but HIV testing is generally recommended for persons having or having had risk behaviour or who where raised or have lived in high-endemic areas. Also, testing is recommended whenever a person is examined for or identified with an STD.

Results of HIV case surveillance, 1990-98

The annual number of diagnosed and reported HIV positive cases has been fairly stable with a tendency of slow decrease during the last couple of years, around 300 persons (5.7 pr 100,000 inhabitants) reported per year.

During the 1990'ies, most cases has been reported to have acquired HIV sexually: Half of them has acquired the infection heterosexually and half of the cases are MSM. A stable proportion of about 10% are i. v. drug users, although some of them might have acquired HIV sexually. Overall, 7% of the cases are reported with an unreported or unknown mode of acquisition.

Since 1990, the proportion being women has increased, from 22% in 1990 to 30% in 1998. However, half of the women are of foreign origin, mainly from an African country.

Immigration plays a important role for the Danish HIV prevalence, since 24% of the new identified HIV-infected people in the 1990'ies are immigrants. Also, travelling has had an impact since at least 11% of the newly identified HIV-infected cases in the 1990'ies are in Danes who had acquired the infection abroad, mainly in South-Saharan African countries or in Thailand.

However, immigration has had a different impact on the different transmission groups. Among the heterosexually acquired cases, nearly half are immigrants - mainly from South-Saharan Africa -

while among MSM, 10% are immigrants - mainly from other West-European or North American countries.

Most identified HIV-infected persons are in the age-group 25-39 years of age, and the vast majority of infected women are in the reproductive age. However, men have a median age of 36 years, while women in general are significantly younger, having a median age of 28 years. This has not changed over the years.

HIV-infected cases are mainly from the urban areas although not as pronounced as seen among AIDS cases. That is, overall 54% of the identified HIV positive cases live in the Copenhagen area, while 9% live in the second largest city in Denmark (Aarhus). Overall, 60% of all men and 38% of women come from the Copenhagen area.

Estimations based on back-calculation using national AIDS data has shown that probably around 6,000 people have been infected with HIV since the start of the epidemic, and that the total number of HIV-infected people alive at present is about 4,300, giving a HIV prevalence in the total population of 0.1%. However, the prevalence varies from 0.03% among adult heterosexual to 4.8% among MSM.

Also, the HIV-incidence has been estimated to be fairly stable in the mid-1990'ies, around 56 per million adult inhabitants become infected with HIV per year. However, the prevalence as well as the incidence varies with gender and risk. The annual incidence has been estimated to be three times higher among men than women and being as high as 2.2 per 1,000 among MSM and 1.8 per 1000 among i. v. drug users.

3. Sentinel sero-surveillance

In Denmark, the only nationwide ongoing serosurveillance is that of HIV-screening of blood donors. Blood donors are unpaid and sign a paper stating that they have no recognised risk for blood borne infections – what so ever. Since 1986 all blood donated has been screened for HIV, and around 330,000 donors are thereby tested for HIV per year. In the period 1986-1997 a total of 4,818,552 blood portions was tested, and the overall prevalence of HIV antibodies has been as low as 0.87 per 100,000 donations. There has been a decrease in the prevalence from 1.2 per 100,000 donations in the first 6 years to 0.5 per 100,000 donations in the latest 6-year period.

Due to a European project, all STD clinic attenders since 1990 has been registered anonymously by variables such as age, gender, geography, sexual and needle risk behaviour, whether examined for and diagnosed with an STD and whether HIV-tested and the result. The data has shown that "only" around 68% of MSM who attend STD clinics are HIV tested, a proportion being 76% among heterosexual women. However, the trend has shown a fairly stable prevalence of HIV in this population although great variations has been found between the different risk groups: From 6% among tested MSM to 0.2 % among tested heterosexual women.

Data has been presented at several scientific international meetings and has been published in international journals. Also, the Danish data has been included in the EU-reports as well as in the articles published.

No systematic collection of data of the HIV tested population are taken place. However, in Denmark several times, last in 1997, cross-sectional studies among all persons seeking hiv-testing in a given 2-week period are handed a questionnaire and asked to fill it in and return it to the national surveillance unit. Usually, the response rate is around 50%, and the results has proven that a lot of people without any high risk for HIV choose to have the test – mainly young people – but has shown as well, that the test-rate among e.g. MSM is much higher than among heterosexuals. Also, it has been found that among the tested population the rate of anal sex is high, reported ever by 36% of all women tested, and as many as 63% of women reporting sex with a – to them - known bisexual man. The proportions for anal sex within the past year was 18% and 30%, respectively for these 2 groups of women. Around 75% report no condom use at last intercourse.

4. Behavioural surveillance

Unfortunately, surveillance of behaviour or systematic collection of behavioural data is not a tradition in Denmark. However, some studies among high-risk core groups have taken place as scientific projects and once - in 1989 - a random sample of Danes were contacted in order to collect data on e.g. sexual behaviour and risk behaviour in adult Danes. Data were collected by a self-administered questionnaire, and included information on sexual behaviour, hiv-testing, travelling, blood donation, along with several socio-demographic data. The results were published in international journals.

Also, studies have been done among gay men. The methods used are mainly self-administered