

A GUIDE TO HIV/AIDS EPIDEMIOLOGICAL AND SURVEILLANCE TERMS

Published collaboratively by
the **CANADIAN AIDS SOCIETY (CAS)**
and **HEALTH CANADA**

Canadian AIDS
Society



*Société canadienne
du sida*



Health
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Santé
Canada

To speak as the national voice and act as a forum for a community-based response to HIV infection and to advocate for persons so affected; and

To act as a resource for its member organizations and coordinate community-based participation in a national strategy on HIV and AIDS.

Canadian AIDS Society

Our mission is to help the people of Canada maintain and improve their health.

Health Canada

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the CANADIAN AIDS SOCIETY (CAS) and
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PREVENTION AND CONTROL (CIDPC), HEALTH CANADA**

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The contents of the final document remain the responsibility of the CAS/CIDPC project team.

About the Organizations

The Canadian AIDS Society

The Canadian AIDS Society (CAS) is a national coalition supporting community action on HIV/AIDS issues in Canada. The Society represents more than 100 community-based organizations across the country, providing the bulk of education, support and advocacy programs and services for individuals and communities affected by HIV/AIDS.

The role of CAS is to speak as the national voice and to act as a national forum for a community-based response to HIV infection and AIDS. The Society also undertakes advocacy on behalf of people affected by HIV and AIDS, acts as a resource on HIV and AIDS issues for its member organizations, and coordinates community-based participation in a national strategy to combat HIV and AIDS. CAS carries out this role through national initiatives in prevention, education, treatment, care and support.

CAS is incorporated federally and is a registered Canadian charity.

The Centre for Infectious Disease Prevention and Control

The Centre for Infectious Disease Prevention and Control (CIDPC), within the Population and Public Health Branch (PPHB) at Health Canada, provides leadership and expertise in the collection, analysis, interpretation, and dissemination of data pertaining to infectious disease in Canada. Activities include national and international surveillance, targeted field investigation, and applied research and laboratory science.

The role of CIDPC includes the collection of HIV and AIDS surveillance data from all provinces and territories in Canada and the publication of a semi-annual report entitled *HIV and AIDS in Canada: Surveillance Report*. This report summarizes and interprets HIV and AIDS surveillance data at the national level. Its production is undertaken by the Division of HIV/AIDS Epidemiology and Surveillance, the part of CIDPC responsible for monitoring trends in the HIV epidemic in Canada. The Division also participates in the dissemination of epidemiological HIV and AIDS data through other publications, such as the *Inventory of HIV Prevalence and Incidence Studies in Canada* and *HIV/AIDS Epi Updates*.

Preface

HIV/AIDS epidemiology and surveillance is an important part of the fight against HIV/AIDS, providing information to design prevention and policy initiatives as well as to allocate resources for care and treatment. Currently CIDPC compiles such information into reports that are then distributed to the community and other interested parties.

While this work can be of great use to AIDS service organizations to direct their support and prevention efforts, those without a background in epidemiology or research may have difficulty fully comprehending the contents of these documents. Community members developing programs and policies for work with diverse populations affected by HIV/AIDS need a solid understanding of the different research designs and data reported in HIV/AIDS epidemiology and surveillance documentation. For this reason, CAS and CIDPC have worked collaboratively to produce *A Guide to HIV/AIDS Epidemiological and Surveillance Terms*.

Previous work completed by the Canadian Aboriginal AIDS Network (CAAN) in collaboration with CIDPC produced a resource titled *Understanding HIV/AIDS Epidemiology: HIV/AIDS Surveillance Among Canada's Aboriginal Peoples*. The purpose of this manual was to make important information such as the HIV/AIDS surveillance reports published by Health Canada more accessible to those working at the community level with Aboriginal populations.

A Guide to HIV/AIDS Epidemiological and Surveillance Terms builds on the excellent work completed by CAAN and CIDPC by providing additional relevant information for community members. The guide contains a detailed catalogue of epidemiological and surveillance terminology, and responses to Frequently Asked Questions (FAQs) about epidemiology and HIV/AIDS surveillance reporting. Entries include plain language definitions, followed by examples to illustrate how each concept is applied within the context of HIV/AIDS community work. The guide also contains a list of bibliographic and website resources geared to assist the user in attaining additional information on HIV/AIDS, epidemiology, research and statistics.

We at CAS and CIDPC hope you find this document to be a valuable resource. Our organizations will continue to collaborate to enhance the relationship between the work of community groups and government. We welcome and appreciate your feedback and suggestions for future initiatives.

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Acronyms

AIDS	Acquired immunodeficiency syndrome
APHA	Aboriginal person living with HIV/AIDS
CAAN	Canadian Aboriginal AIDS Network
CAS	Canadian AIDS Society
CATIE	Canadian AIDS Treatment Information Exchange
CBR	Community-based research
CDC	Centers for Disease Control and Prevention (Atlanta, USA)
CIDPC	Centre for Infectious Disease Prevention and Control (Health Canada)
CPARG	Canadian Paediatric AIDS Research Group
CTAC	Canadian Treatment Advocates Council
EIA	Enzyme immunoassay
ELISA	Enzyme-linked immunosorbent assay
HBV	Hepatitis B virus
HCV	Hepatitis C virus
HIV	Human immunodeficiency virus
IDU	Injecting drug user
MSM	Men who have had sex with men
MSM/IDU	Men who have had sex with men and who also have injected drugs
MTCT	Mother-to-child transmission
NEP	Needle exchange program
NIR	No identified risk

NIR-HET	No identified risk-heterosexual
PHA(s)	Person(s) having HIV/AIDS
PLWA(s)	Person(s) living with HIV/AIDS
POC	Point of care testing
SEP	Syringe exchange program
STD	Sexually transmitted disease
STI	Sexually transmitted infection
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
WSW	Women who have had sex with women
WHO	World Health Organization

Frequently Used Terms

in HIV/AIDS Monitoring and Epidemiological Research in Canada

Before you start

The table of contents lists terms defined in this guide.

Terms are listed alphabetically.

A term entry may have other related terms listed in this guide.

- If the listed term definition includes other frequently used terms contained within this guide, these other terms appear in the definition in **bold**. These terms are only bolded the first time they appear in the definition.
- If other terms contained in this guide are related to the term listed, but do not appear in the definition in **bold**, these other terms are provided in parentheses following the entry of the listed term, e.g. **CASE** (See also **AIDS CASE**).
- If the listed term is further explained in the Frequently Asked Questions (FAQs) section, the number of the FAQ is listed in parentheses following the entry of the listed term, e.g. **EPIDEMIOLOGY** (See also **FAQ 23**).
- If a term is listed because of its frequent use, but is best defined under another term listed in this guide, a reference is made to the other term, e.g. **DEMOGRAPHIC PROFILE** (Refer to **DEMOGRAPHICS**).

An example of how the term is most frequently used in reporting or describing HIV/AIDS is also included where appropriate in boxes.

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AIDS CASE (See also **AIDS CASE REPORT, CASE**)

An AIDS case is a person who has received an **AIDS diagnosis**. Once the health care provider reports the AIDS case to the local public health authority, this person is described as a **reported AIDS case** in **surveillance** databases and reports.

AIDS CASE REPORT (See also **AIDS CASE, REPORTED AIDS CASES** and **FAQs 6, 8, 9**)

An AIDS case report is documentation of a person's confirmed and reported **AIDS diagnosis**.

These reports include patient information, laboratory data and the activities that put the person at risk for transmission of HIV. The information recorded forms the basis of the **surveillance** data reported at the provincial and territorial level, as well as to the Centre for Infectious Disease Prevention and Control (CIDPC) at the federal level. Information reported to CIDPC does not include names nor does it identify anyone.

AIDS DIAGNOSIS (See also **FAQs 8, 16, 17**)

In Canada, AIDS is diagnosed if a person has

1. undergone testing for HIV and received a positive result and
2. has one or more of the clinical illnesses, or indicator diseases, that characterize AIDS.

This is the current definition of AIDS (2002) and is uniform across all Canadian provinces and territories. This definition also applies to 48 countries of the World Health Organization European Region, Australia and New Zealand. It is important to note that in the United States, a person must also have a CD4 T-lymphocyte count less than 200 cells per cubic millimetre of blood ($< 200/\mu\text{L}$) in order to meet the definition of an **AIDS case**.

The Canadian definition of an AIDS diagnosis has changed over time as more information was gathered on the disease. For example, the list of indicator diseases from 1987 expanded in 1993 to include the following:

- Pulmonary tuberculosis: tuberculosis (TB) in the lungs;
- Recurrent pneumonia: a pneumonia that keeps coming back or does not go away, often due to bacterial or fungal infections that do not usually cause pneumonia in people with intact immune systems; and
- invasive cervical cancer.

This was done to help solve the concerns of under-diagnosis of AIDS in women, injecting drug users and others.

ANONYMOUS HIV TESTING (Refer to **HIV TESTING OPTIONS**)

ANONYMOUS UNLINKED HIV TESTING

Anonymous unlinked HIV testing is the testing of a sample of either blood or saliva for the presence of HIV antibodies. No personal information is retained about the person to whom the sample belongs. As a result, there is no way to link the HIV test results back to the person who provided the sample. No one, including the person being tested, can ever know whose test results are positive or whose are negative.

Anonymous unlinked HIV testing is often carried out on blood left over after collection and testing for a different purpose, such as tests for rubella in pregnancy. All personal identifying information is stripped from the leftover blood sample before it is used for anonymous unlinked testing.

This kind of testing has been used in many countries for **surveillance** purposes, but in Canada, at present, it is most often carried out in research. It is used when the presence of existing HIV infection in a specific group, rather than in an individual, is to be determined.

The results of anonymous unlinked HIV testing have no direct individual use, but can provide important information about the level of HIV infection among a specific population.

For example, anonymous unlinked testing was performed on all left-over sera (blood) from eligible men and women attending two sexually transmitted disease (STD) clinics in Alberta from May 1994 to May 1995. The blood had been drawn for routine testing for syphilis, hepatitis B or HIV. The study found an overall group HIV **prevalence rate** of 1.5%. (Romanowski, Campbell, Preiksaitis, et al., 1997)

B

BASELINE DATA

Data are a collection or set of information. Baseline data describe the information that is collected at the beginning of a research study, or the information collected when someone, called a research participant, first enters a study. If a questionnaire was used to collect baseline data it is called a baseline questionnaire.

Data are often collected at the beginning of a study to see whether the set of information changes over time, or if it changes as a result of a particular treatment or intervention that is being investigated.

Follow-up data are collected any time after the first (baseline) data have been collected. Follow-up data can be collected once at the end of a research study or gathered multiple times throughout the duration of a study.

The term data is a plural noun:

The data *were* collected over a two-year period from January 2000 to December 2001.

BEHAVIOURAL RISK FACTOR (Refer to **RISK FACTOR**)

CASE (See also AIDS CASE)

A case is a person who has a particular disease. A variety of criteria may be used to identify cases. Cases can include people who are included in **surveillance** databases and reports. Often, this term is used generally to refer to individuals seeking the advice of a health care provider.

For example, a person with a diagnosis of HIV infection may be referred to as an HIV case, or there were 2,119 HIV cases reported in Canada in the year 2000. More generally, “Dr. Smith reviewed the files of the 100 cases seen this month at his clinic.”

COHORT

A cohort is a group of people followed over a specified period of time. The term may be used generally, such as a group of students following the same program in school, but is more often applied to a group of people who are the subject of a research study.

In research, each member of a cohort has specific characteristics. These known characteristics can include

- being free of the disease under investigation at the time the study begins;
- either having or not having specific risk behaviour patterns (**risk factors**);
or
- having or not having prior experience of the treatment under investigation.

In the context of HIV studies, for example, subjects who have tested negative for HIV are followed for a prolonged period to see how the later development of new HIV infections is related to HIV-related risk factors.

The term cohort is frequently used in HIV/AIDS research to refer to the participants in a **cohort study**.

For example, the participants in Montreal’s OMEGA Study are frequently referred to as the “Omega cohort”. The OMEGA cohort is explained under the term **COHORT STUDY** below.

COHORT STUDY

The purpose of a cohort study is to investigate the development of new occurrences of a disease or to investigate how responses to treatment are related to specific factors. These factors can be recorded at the beginning of the study and/or during the course of the study.

A cohort study starts with a group of people who will be participants in the study. This group of people is called a **cohort**.

The cohort is followed for a specified time period, which can be weeks, months, years or decades. **Follow-up data** are collected at regularly defined periods either through the use of questionnaires, personal interviews, laboratory testing, medical examinations, or a combination of these methods.

A cohort study is sometimes referred to as a prospective study or a longitudinal study.

For example, recruitment for the OMEGA cohort study began in the Montreal region in October 1996. Each participant was tested for HIV and completed a questionnaire at study entry. Participants also completed the same questionnaire every 6 months afterwards. Men who tested negative for HIV and who gave their consent for participation in the study became study participants. During the first four years of the study, 15 men in the cohort became infected with HIV. Statistical analysis of the participants’ questionnaire data showed that having a new HIV infection was related to a number of factors. These included low income, drug use, and having six or more casual sexual partners. (Remis et al., 2001)

CO-INFECTION

Having two infections at the same time. For example, a person infected with both HIV and hepatitis C (HCV), or HIV and tuberculosis (TB), has a co-

infection. With co-infection the progression of either disease can potentially be accelerated as a result of infection with the other disease.

CONFIDENCE INTERVAL (CI) (See also **STATISTICAL SIGNIFICANCE, P VALUE**)

Statistical analysis of research study data will not produce a result that is 100% accurate. The result reported for a study is the most likely result. A confidence interval is an estimate of the spread between the lowest likely result (lower confidence limit) and the highest likely result (upper confidence limit) of a study. The true result of the study probably lies somewhere within this confidence interval. The smaller the spread of the confidence interval, the more precise the result is likely to be.

Most research studies display results using 95% confidence intervals. A 95% confidence interval means that there is a 95% chance that the true study result lies between these two confidence limits. In opinion surveys, a 95% confidence interval is sometimes expressed by the phrase, “the result is accurate 19 times out of 20”, which is equal to 95%. That is, the true study result lies within the interval with a 95% probability.

Confidence intervals are determined by the use of mathematical formulas with a set of data.

The term confidence interval is abbreviated as CI.

In a hypothetical example, it may be reported that “The estimated number of people living with HIV (**prevalence**) among a group of injecting drug users (IDUs) was 18.6% with a 95% CI of 12.9–24.0.” This means that the study investigators are 95% sure that the true prevalence lies somewhere between the two confidence limits of 12.9% and 24.0%.

If there were 1,000 injecting drug users in the group under study, it would be reported that approximately 186 (18.6%) of them were living with HIV. It is most accurate to say that the study investigators are 95% sure that between 129 (12.9%) and 240 (24.0%) of the injecting drug users in the study were living with HIV.

CUMULATIVE INCIDENCE (See Appendix on page 57)

D

DEMOGRAPHIC PROFILE (Refer to DEMOGRAPHICS)

DEMOGRAPHICS

The term demographics is commonly used to describe the personal characteristics of a population or specific group. These characteristics can include information describing age, gender, occupation and ethnicity. Demographics do not include a person's behaviour.

For example, individual outpatient interviews were used to collect personal information from HIV-positive outpatients identified through the HIV Ontario Observational Database (HOOD). The interview included questions about the participant's gender, age, income, education, and employment status. This demographic information was used to determine whether there were differences in the characteristics of those outpatients who used antiretroviral medication and those who did not use such medication. (Furler et al., 2001)

A “demographic profile” characterizes a population or a specific group of people in terms of current demographic characteristics.

Researchers have reported the following demographic profile of a group of 229 young adult injecting drug users in Baltimore, Maryland: “The **median** age was 23.5 years (**range** 18-29 years); 79% were of African-American ethnicity; 54% were female; and 61% had not completed high school or obtained a high school equivalency.” (Garfein et al., 1998)

DENOMINATOR

The denominator is the bottom number in a fraction, and the **numerator** is the top number. The fraction can be used to calculate a **proportion** or **rate**.

The denominator usually represents a population group or a group of people at risk of a specific disease (**population at risk**). In **epidemiology**, the numer-

ator usually represents the number of people in the population at risk who are affected by a specific event.

For example, at the end of 1999 there were an estimated 49,800 people in Canada living with HIV infection (including those living with AIDS). Of these people, 6,800 were estimated to be women. (Bureau of HIV/AIDS, STD and TB, Centre for Infectious Disease Prevention and Control, Health Canada, 2001a)

Using this information in the numerator and demoninator, we can calculate how much of the estimated Canadian population with HIV/AIDS are women:

$$\begin{aligned} \frac{\text{numerator}}{\text{denominator}} &= \frac{\text{estimate of women with HIV/AIDS}}{\text{estimate of all Canadians with HIV/AIDS}} \\ &= \frac{6,800}{49,800} = 0.1365 \end{aligned}$$

This means that at the end of 1999 approximately 13.65% (0.1365×100) of the estimated Canadian population with HIV/AIDS are women.

DESCRIPTIVE STATISTICS

Descriptive statistics are used to organize and describe data. The **mean**, **median**, **mode** and **range** are examples of descriptive statistics.

For example, here are the ages of 12 women who tested positive for HIV in 2001 with no descriptive statistics applied:

18, 23, 27, 34, 21, 31, 36, 23, 19, 42, 32, 33

As can be seen, it is difficult, if not impossible, to determine general **trends** until some order is applied to the data. Applying descriptive statistics will tell you much more about the data.

If we calculate the mean in the example above, we would know that the mean, or more commonly average, age of the 12 women who tested positive for HIV in 2001 was 28 years.

Examples of descriptive statistics can be found under the terms mean, median, mode and range.

E

ENDEMIC (See also **EPIDEMIC**)

The standard **epidemiological** definition of the term endemic is the constant presence of a disease in a given geographic area or within a given population. It may also refer to a disease that is usually present at a relatively high **prevalence** and **incidence rate** in comparison with other areas or populations.

In the area of HIV/AIDS research, there is another definition of the term endemic that may be used. It may be used to refer to a country where the predominant way people become infected with HIV is through heterosexual contact. An “endemic” country is also commonly referred to as a Pattern II country.

In Canadian HIV/AIDS **surveillance** reporting, there is an **exposure category** that can be assigned to a person infected with HIV whose highest risk of HIV transmission was being born in an endemic country.

EPIDEMIC (See also **EPIDEMIOLOGY**)

An epidemic is the occurrence of a greater number of **cases** of a disease than would normally be expected to occur in a population, community or region.

The AIDS epidemic was first identified soon after the first cases were diagnosed in the early 1980s. By the late 1980s, HIV/AIDS was affecting the entire world, an epidemic to which the word “pandemic” is applied.

EPIDEMIOLOGY (See also **FAQ 23**)

Epidemiology refers to the study of the occurrence, distribution and determining factors associated with health events and diseases in a population.

The aims of epidemiology are to discover the sources and causes of health events and disease occurrences and to find ways to control and prevent them.

For example, the Polaris Study currently under way across Ontario is an example of an epidemiological study. The objectives of the study include determining the **rates** of new HIV infections, identifying factors associated with HIV infection, and evaluating the impact of early treatment and care on outcomes.

ETHNIC CATEGORY (See also **ETHNICITY REPORTING**)

In reporting **AIDS cases** and **positive HIV test reports** in Canada, the person receiving the diagnosis and/or the health care provider may record one of seven choices describing the person's ethnic status.

An ethnic group is a group of people who share a distinctive cultural and historical tradition, and is often associated with race or nationality.

The choices of ethnic categories are as follows:

■ **Aboriginal**

This category includes, for example, Inuit, Métis, Native Indian and "Aboriginal Unspecified" people.

■ **Asian**

This category includes, for example, people from Cambodia, China, Indonesia, Japan, Laos, Korea, the Philippines and Viet Nam.

■ **Black**

This category includes, for example, people from Zimbabwe, Angola, Haiti and Jamaica.

■ **Latin American**

This category includes, for example, people from Central America, Mexico and South America.

■ **South Asian/West Asian/Arab**

This category includes, for example, people from Armenia, Bangladesh, Egypt, Iran, Lebanon, Morocco, Pakistan and Sri Lanka.

■ White

This category includes people who identify themselves as White or whose health care provider identifies them as White.

■ Other

If none of the above choices describes the individual's status, "Other" is marked off on the form.

ETHNICITY REPORTING (See also **FAQs 8, 14**)

Ethnicity reporting is recording the ethnic group of the individual with a diagnosis of HIV infection or AIDS. Ethnicity may be either **self-reported** by the person being tested or may be identified by the health care provider. Documentation of ethnicity for **reported AIDS cases** and **positive HIV test reports** is helpful in driving the development and evaluation of prevention and treatment programs.

In considering information about reported AIDS cases or positive HIV test reports in ethnic groups in Canada, it is very important to consider some of the following, which may affect the usefulness of ethnicity reporting:

- Reporting of ethnicity is not complete for either reported AIDS cases or positive HIV test reports. Since the beginning of reporting to the end of the year 2001, approximately 15% of reported AIDS cases and 93% of positive HIV test reports in the national AIDS and HIV **surveillance** system did not contain information on ethnicity.
- People may not wish to identify their ethnicity. This will result in under-representation. This means that the number of individuals who accurately identify their ethnicity may not be the only people who should be in that category. Therefore, the number of people reported in an ethnic category may not be the true number in that category.
- In AIDS case reporting, patients and health care providers are currently limited to six **ethnic categories** and one "Other" category listed on the AIDS Case Report Form. As one must choose from this defined list, the choices could be restricted, which may affect the accuracy of ethnicity reporting.
- Variations in the completeness of ethnicity reporting within and among provinces and territories may result in under- or over-representation of HIV infection among specific ethnic groups.

EXPOSURE CATEGORY (See also FAQs 1 –3, 8)

In HIV/AIDS **surveillance**, exposure category refers to the most likely way a person became infected with the HIV virus, that is, the most likely route through which HIV was transmitted to that person.

A person may report many or no **risk factors** for HIV. Even though all risk factors associated with a positive HIV test result are included in the **positive HIV test report** and entered into the national HIV/AIDS database, only one exposure category is assigned to a positive HIV test report for national HIV/surveillance reporting. A person reporting many HIV-related risk factors will be placed in the exposure category corresponding to the activity or situation that is considered to have the highest risk of HIV transmission of the risk factors reported.

For example, Jeff explains to the health care provider ordering his HIV test that he injects drugs and also that, on occasions, he has not used a condom when having sex with his female sexual partner, who is infected with HIV.

As injecting drug use is considered to be the higher risk activity according to the accepted **exposure category hierarchy**, Jeff's exposure category would therefore be recorded and reported as an injecting drug user (IDU).

As another example: Nathan explains to the health care provider ordering his HIV test that he injects drugs and also that, on occasions, he has not used a condom when having sex with his male sexual partner, who is infected with HIV.

In HIV/AIDS surveillance reporting, the risk behaviours of injecting drug use and being a man who has had sex with other men are considered to carry equal risk of HIV. Nathan's exposure category would therefore be recorded and reported as MSM/IDU.

The exposure categories used in Canadian HIV/AIDS surveillance and reporting are explained below:

■ MSM

Men who report having had sex with men; this includes men who report either homosexual or bisexual contact (i.e. some will also report having had sex with women as well). It is important to note here that this exposure category refers to sexual behaviour and not a person's self-identified sexual identity.

■ MSM/IDU

Men who have had sex with men and have injected drugs.

■ IDU

People who inject drugs, also called injecting drug users. The acronym IDU is also often applied to the *behaviour* of injecting drug use, or what is also commonly referred to as *injection* drug use.

■ Blood/Blood Products

- (a) **Recipient of Blood/Blood Products:** Before 1998, it was not possible to separate this combined exposure category. However, where possible after 1998 it has been separated into subcategories (b) and (c).
- (b) **Recipient of Blood:** Received transfusion of whole blood or blood components, such as packed red cells, plasma, platelets or cryoprecipitate.
- (c) **Recipient of Clotting Factor:** Received pooled concentrates of clotting factor VIII or IX for treatment of hemophilia/coagulation disorder.

■ Heterosexual Contact/Endemic

Before 1998, this was a combined exposure category but has since been separated into two subcategories:

- (a) **Origin from a Pattern II Country:** People who were born in a country in which the predominant means of HIV transmission is heterosexual contact;
- (b) **Sexual Contact with a Person at Risk:** People who report heterosexual contact with a person who is either HIV-infected or who is at increased risk for HIV infection.

A person at increased risk for HIV infection would be considered in this case to include someone who is an injecting drug user, a bisexual man, a person born in a country in which the predominant means of HIV transmission is heterosexual contact, a person with hemophilia/coagulation disorder, or a person with suspected HIV infection or AIDS.

■ **NIR-HET**

If heterosexual contact is the only **risk factor** reported and nothing is known about the HIV-related risk factor(s) associated with the partner, the **case** would be classified as No Identified Risk-Heterosexual (NIR-HET).

■ **Occupational Exposure**

Exposure to HIV-contaminated blood or body fluids, or concentrated virus in an occupational setting.

■ **Other**

Used to classify a person whose mode of HIV transmission is known but who cannot be classified into any of the major exposure categories listed.

■ **NIR (No Identified Risk)**

Where the history of exposure to HIV through any of the other categories is unknown, or there is no reported history. This exposure category may include:

- people who are currently being followed up by their local health department;
- people whose exposure history is incomplete because they have died;
- people whose exposure history is incomplete because they declined to be interviewed or were lost to **follow-up**; and
- people who cannot identify any mode of transmission.

■ **Exposure Category Not Reported**

In certain provinces, it is not possible to report information regarding exposure category. In these situations, people are classified as Exposure Category Not Reported. This category is used only for **positive HIV test reports**.

■ Perinatal Transmission

The transmission of HIV from an HIV-infected mother to her child either

- during pregnancy,
- during labour,
- at birth, or
- after birth through breastfeeding.

It should be noted that the term “mother-to-child-transmission” (MTCT) is also used to describe transmission of HIV from an HIV-infected mother to her child.

EXPOSURE CATEGORY HIERARCHY

(See also **FAQs 1, 3**)

Reported AIDS cases and **positive HIV test reports** are assigned to a single **exposure category** according to a hierarchy of HIV-related risk factors. The exposure or HIV-related risk factor considered to carry the highest risk of HIV infection is listed at the top of the hierarchy, and the exposure or HIV-related risk factor considered to carry the lowest risk of HIV infection is listed at the bottom of the hierarchy.

The exposure category hierarchy is used to determine the one exposure category that will be recorded for each positive HIV test report and each reported AIDS case. If more than one risk factor is reported, the **case** is classified in the exposure category listed first (or highest) in the hierarchy.

The exposure category hierarchy is currently under review to ensure that it reflects the most up-to-date information on HIV transmission risk.

F

FOLLOW-UP DATA (Refer to **BASELINE DATA**)

H

HIV POSITIVITY RATES (See also **PREVALENCE**)

HIV positivity rates measure the **proportion** of HIV tests that are positive among all the HIV tests that are carried out in a specific population over a given period of time. This **rate** is used to monitor **trends** in the proportion of HIV positive test results in a specific population.

$$\text{HIV positivity rate} = \frac{\text{Total number of positive HIV tests}}{\text{Total number of all HIV tests}}$$

The total number of all HIV tests includes both positive and negative test results.

HIV TESTING OPTIONS (See also **FAQs 4, 11**)

Canadians choosing to be tested for the presence of HIV infection may have three different testing options depending on the province or territory in which testing takes place:

1. Anonymous HIV testing;
2. Nominal/name-based HIV testing; and
3. Non-nominal/non-identifying HIV testing.

1. Anonymous HIV testing

- Usually available at specialized clinics, organized and supported by public health departments.
- Currently available in eight provinces (2002): British Columbia, Alberta, Saskatchewan, Ontario, Quebec, New Brunswick, Nova Scotia and Newfoundland and Labrador.
- The person ordering the HIV test does not know the identity of the person being tested for HIV.
- The HIV test is carried out using a code. The person ordering the HIV test and the laboratory carrying out the testing on the blood sample do not know to whom the code belongs.

- Only age, gender and HIV-related **risk factors** of the person being tested for HIV are collected. Other personal characteristics, such as ethnicity, may also be collected, depending on the province or territory in which the test is ordered or on the test site. This information is often collected to determine who is accessing test sites, allowing better service to those using, or not currently using, this type of testing.
- If the HIV test result is positive, the person being tested is responsible for notifying his or her sexual partners and drug use contacts, but can ask the person ordering the test for assistance with this task. Contacts should be advised that they may have been exposed to a sexually transmitted infection and should go to their own health care provider, health unit or community health centre for counselling and testing.
- Test results are not recorded on the health care record of the person being tested. It is only the person being tested who may decide to include the test result in his or her record.

2. Nominal/name-based HIV testing

- May be carried out at numerous locations, including clinics and the office of a health care provider.
- Currently available in all provinces and territories except Manitoba (2002).
- The person ordering the HIV test knows the identity of the person being tested for HIV.
- The HIV test is ordered using the name of the person being tested.
- There is collection of patient information (such as age and gender as well as city of residence, name of diagnosing health care provider, country of birth); information detailing the HIV-related **risk factors** of the person being tested (such as whether that person is an injecting drug user); and laboratory data (which may include information related to the person's first positive HIV test).
- If the HIV test result is positive, the person ordering the test is legally obligated to notify public health officials of the person's name in those provinces and territories where HIV infection is a **notifiable disease**.
- If the HIV test result is positive, the person ordering the test takes responsibility with the person who has been tested for notifying the sexual partners and drug use contacts.

- If this does not occur, the public health official will ask for the names of the contacts and advise them that they may have been exposed to a sexually transmitted infection and should go to their own health care provider, health unit or community health centre for counselling and testing. The official will not use the name of the person who tested positive for HIV infection.
- The test result is recorded on the health care record of the person being tested.

3. Non-nominal/non-identifying HIV testing

Similar to Nominal/Name-based testing on all points except:

- Currently available in all provinces and territories (2002).
- The HIV test is ordered using a code or the initials of the person being tested.
- In the event of a positive test, a public health official will check with the person who ordered the test to determine whether the sexual partners and drug use contacts of the person being tested have been notified. Contacts should be advised that they may have been exposed to a sexually transmitted infection and should go to their own health care provider, health unit or community health centre for counselling and testing. If satisfied that partners have been notified of possible exposure, the official will not ask for the name of the person being tested.

INCIDENCE (See also **INCIDENCE RATE** and **FAQs 18-21**)

Incidence is the number of *new* events of a specific disease during a specified period of time in a specified population.

HIV incidence is the number of *new* HIV infections occurring in a specified period of time in a specified population.

Knowing or estimating the number of new events of a specific disease during a specified period of time gives a sense of how quickly a disease is spreading. In HIV/AIDS research, incidence gives us a sense of how fast the HIV **epidemic** is spreading.

Incidence may be expressed as a number or a rate (see below).

Incidence is different from **prevalence**; however, the two terms are frequently confused.

INCIDENCE DENSITY (See Appendix on page 57)

INCIDENCE RATE

The incidence rate is the **rate** at which new events, or new **cases**, occur in a specified time in a defined population that is “at risk” of experiencing the condition or event.

$$\text{Incidence rate} = \frac{\text{Number of new events in a specified period}}{\text{Number of people exposed to risk in this period}}$$

It is very important to know the number of new people infected with a disease (**incidence**) in relation to the total **population at risk** of contracting that disease.

For example, a report of HIV infection diagnosed in 5 new people over 12 months only tells us the number of new HIV infections that are occurring during a specific time period. However, 5 new cases of HIV infection reported over 12 months in a population of 10 people at risk (example 1) has a different meaning from 5 new people diagnosed with HIV infection over 12 months in a population of 100 people at risk (example 2). To take account of this, incidence is expressed as a rate.

Using this example, we would calculate incidence rate as either of the following:

Example 1

$$\text{Incidence rate} = \frac{5 \text{ new people with a diagnosis of HIV}}{\text{Population of 10 people}} = 0.50$$

Example 2:

$$\text{Incidence rate} = \frac{5 \text{ new people with a diagnosis of HIV}}{\text{Population of 100 people}} = 0.05$$

In the first example, the incidence rate is 0.50 ($\times 100 = 50\%$). This means that in a group of 100 people, we would expect 50% of them, or 50 of 100, to be newly diagnosed with HIV over the 12 months. In the second example, we would expect 5%, or 5 of 100 people.

Incidence rate can also be calculated using **person years**:

$$\text{Incidence rate} = \frac{\text{Number of new events in a specified period}}{\text{Number of person years}}$$

For example, in a study investigating the number of new cases of HIV among young gay and bisexual men, an overall incidence rate of 1.3 per 100 person years was reported. (Martindale et al., 2001)

To understand what this 1.3 means, consider this example:

If there were 1,000 men in the study and they were followed for two years, 26 of them would have gone from being HIV negative to HIV positive over the study time period of two years. This is calculated by:

1. Calculating the person years of the study:

$$(1,000 \text{ men} \times 2 \text{ years} = 2000 \text{ person years})$$

2. Multiplying this result with the incidence rate in person years:

$$(1.3 \text{ new infections}/100 \text{ person years}) \times (2000 \text{ person years}) = 26 \text{ new infections}$$

A more detailed explanation of incidence rate and the related terms “cumulative incidence” and “incidence density” appears in the Appendix on page 57.

M

MEAN

The mean, or average, is an example of a **descriptive statistic**. Of all descriptive statistics, the mean is the one reported most often.

To calculate the mean, you add the individual results of the item being measured and then divide by the total number of results.

The mean is often reported as M or \bar{X} .

For example, if there were 11 injecting drug users (IDUs) who reported testing HIV positive at the following ages

19, 24, 32, 32, 27, 29, 21, 32, 36, 39, 31

the average or mean age of the 11 IDUs reporting testing positive would be 322 (the sum of the individual ages) divided by 11 (the number of IDUs). This results in a mean age of 29 years.

MEDIAN

The median is an example of a **descriptive statistic**. It is the value that divides a set of numbers exactly in half when they are placed in order from lowest to highest. In other words, half of the values occur before the median and half of the values occur after the median.

The median is often abbreviated as Md. or Mdn.

Using the following ages at which 11 injecting drug users (IDUs) reported testing HIV positive

19, 21, 24, 27, 29, 31, 32, 32, 32, 36, 39

the median age at which the IDUs reported testing HIV positive is the sixth value or 31.

If the total number of values is even, the median is the average (**mean**) of the two middle items.

Using the following ages at which 10 injecting drug users (IDUs) reported testing HIV positive

19, 21, 24, 27, 29, 31, 32, 32, 32, 36

the median age at which the IDUs reported testing HIV positive is the average of the two middle values or 30 ($29 + 31 = 60$ and divided by 2).

METHODOLOGY

The methodology section of a report or research study describes how the study was conducted (the methods) and the principles used by study investigators. These methods include how participants were recruited, and how the data were collected, organized and analyzed.

For example, the Vancouver Injection Drug Users Study (VIDUS) study might say “the methods used in this investigation include” or may simply state that “over 1,400 injecting drug users (IDUs) were enrolled between May 1996 and December 2000. **Follow-up** visits were conducted every six months, at which time a detailed questionnaire was administered and blood testing was done. Behavioural and drug use information was compared between follow-up visits using statistical tests.” This information is referred to as the study’s methodology or the methods section of a report. (Tyndall et al., 2001)

MODE

The mode is an example of a **descriptive statistic**. It is the value that occurs most frequently. The mode, in other words, identifies the most popular or typical value.

Using the following ages at which 11 injecting drug users (IDUs) reported testing HIV positive

19, 24, 32, 32, 27, 29, 21, 32, 36 39, 31

the most frequently reported age at which these IDUs tested positive for HIV was 32 years. Thus, the mode is 32.

N

NOMINAL/NAME-BASED HIV TESTING

(Refer to **HIV TESTING OPTIONS**)

NON-NOMINAL/NON-IDENTIFYING HIV TESTING (Refer to **HIV TESTING OPTIONS**)

NOTIFIABLE DISEASE (See also **FAQs 6, 7**)

A notifiable disease is a disease that is considered to be of such importance to the public health that its occurrence is required to be reported to public health authorities.

A notifiable disease is a disease that, by law, must be reported to the public health authority in the area in which the diagnosis is made.

As a *notifiable* disease must be *reported*, the two terms, notifiable disease and **reportable disease**, are frequently used interchangeably in discussing HIV/AIDS reporting in Canada.

In Canada, *AIDS* is a notifiable disease. AIDS is legally notifiable in all Canadian provinces and territories. AIDS is legally notifiable at the provincial or territorial level.

In Canada, *HIV* infection is legally notifiable at the provincial or territorial levels in all Canadian provinces and territories except British Columbia.

AIDS and HIV data are shared with the Centre for Infectious Disease Prevention and Control (CIDPC) at the federal level by all provinces and territories. This is done on a voluntary basis either through the provincial or territorial health department or, for HIV in British Columbia and Quebec, through provincial testing laboratories.

NUMERATOR (Refer to **DENOMINATOR**)

P

PERSON YEARS (See also INCIDENCE)

Person years describes the length of time of experience or exposure of a group of people who have been observed for varying periods of time. It is the sum total of the length of time each person has been exposed, observed, or at risk.

You will sometimes see person years reported as PY or py.

For example, 100 people studied for one year, or 50 people studied for two years, are both equivalent to 100 person years of observation:

1. $100 \text{ people} \times 1 \text{ year} = 100 \text{ person years}$
2. $50 \text{ people} \times 2 \text{ years} = 100 \text{ person years}$

Person years is often used as the **denominator** in expressing **incidence rate**. An example of how the term person years has been used this way can be found under that term.

Person years is also often used as the **denominator** in expressing **incidence density**. If some participants in a research study do not stay in the study for the entire length of the study, person years may be used in order to calculate incidence.

For example, let us assume that there were 100 people in a study that continued for five years. Of these, 85 remained until the end of the study, but the other 15 dropped out after only 2 years. Person years would be calculated by:

$$\begin{aligned} &+ (85 \text{ people} \times 5 \text{ years}) = 425 \text{ person years} \\ &\quad \underline{(15 \text{ people} \times 2 \text{ years}) = 30 \text{ person years}} \\ &= 455 \text{ person years} \end{aligned}$$

POINT PREVALENCE (See also PREVALENCE)

The number of people living with HIV divided by a defined population at a specified time (**prevalence rate**) can be reported as point prevalence. Reporting a prevalence rate as a point prevalence emphasises the “point” in time at which the prevalence rate was calculated.

The “point” can refer to a specific point in *calendar* time at which the prevalence rate was calculated. This point will be the same for all participants in a research study.

For example, HIV point prevalence among the 60 injecting drug users (IDUs) who participated in the Ottawa SurVIDU study during the month of June 2000 was 13.3% (95% **confidence interval** (CI): 5.9-24.6). That is, in June 2000, 13% of study participants were HIV positive. (Leonard, Navarro, and Birkett, 2001)

The “point” can also refer to a specific point in a research study that will not necessarily be the same in calendar time for all subjects. For example, the number of people with HIV may be measured at the time (or point) at which each participant first joins a study. This date may be different in calendar time for each participant. However, it will relate to the same specific point in the research study – the point at which each participant joined the study.

As a hypothetical example, let us assume that as inmates enter the Carlson Road Detention Centre, they are interviewed and asked if they have tested positive for HIV. This is the collection of **baseline data**. There are currently 1,800 inmates at the Detention Centre, and it is recorded that 266 of them said they had previously tested positive for HIV when they were asked the question on the entry interview.

Therefore it can be said that the HIV point prevalence at study entry for 1,800 inmates at the Carlson Road Detention Centre was 14.8%.

$$\frac{\text{Inmates answering yes}}{\text{Current number of inmates}} = \frac{266}{1,800} = 14.8\% (0.1477 \times 100)$$

This can also be expressed as,

HIV point prevalence at the time of baseline interview for 1,800 inmates at the Carlson Road Detention Centre was 14.8%.

POPULATION AT RISK

The population at risk represents those persons at risk of contracting a disease.

It is often the **denominator** in a **rate**, such as **incidence** or **prevalence rates**. The size of the population at risk is usually estimated when national or regional rates are calculated. In some research studies of small populations, it may be a number that is exactly known as opposed to one that is estimated.

POSITIVE HIV TEST REPORTS

(See also **REPORTED AIDS CASE** and **FAQs 7, 8, 10, 11, 13, 14, 18**)

A positive HIV test report is documentation of a person's confirmed and reported HIV infection.

These reports include patient information, laboratory data and the activities that put the person at risk for transmission of HIV. The information recorded forms the basis of the **surveillance** data reported at the provincial and territorial level as well as to the Centre for Infectious Disease Prevention and Control (CIDPC) at the federal level. Information reported to CIDPC does not include names nor does it identify anyone.

The term does not include individuals who may be positive and have not been tested or individuals who have received a positive HIV test result, but the result has not been forwarded to CIDPC.

A positive HIV test report applies to the time of *diagnosis* of HIV infection, not to the time of infection with HIV. HIV infection may have been much earlier. It is therefore important to refer to positive HIV test reports as new *diagnoses* of HIV infection that are reported, not as new *infections*.

PREVALENCE (See also **POINT PREVELANCE, PREVALENCE RATE** and **FAQs 18-22**)

Prevalence is the total number of people with a specific disease or health condition living in a defined population at a particular time.

HIV prevalence among Canadians is the total number of people living with HIV infection (including those with AIDS) in Canada at a particular time.

Prevalence may be expressed as a number or a rate (see below).

Prevalence is different from **incidence**; however, the two terms are frequently confused.

PREVALENCE RATE (See also **POINT PREVELANCE**)

The prevalence rate is the number of *existing cases* of a disease at a specified time divided by a defined population that is “at risk” of experiencing the condition.

$$\text{Prevalence rate} = \frac{\text{Number of existing events in a specified period}}{\text{Number of people exposed to risk in this period}}$$

It is very important to know the number of people living with a disease in relation to the total **population at risk** of contracting that disease. For example, 25 people with HIV infection in a population at risk of 100 people has a different meaning from 25 people with HIV infection in a population at risk of 500 people. To take account of this, **prevalence** is expressed as a **rate**.

Using this example, we would calculate prevalence rate as either:

$$\text{Prevalence rate} = \frac{25 \text{ people who currently have HIV}}{\text{Population of 100 people}} = 0.25$$

or

$$\text{Prevalence rate} = \frac{25 \text{ people who currently have HIV}}{\text{Population of 500 people}} = 0.05$$

In the first calculation, the prevalence rate is 0.25 ($\times 100 = 25\%$). This means that in a group of 100 people, we would expect 25% of them or, 25 of 100, to have HIV at the specified time period, such as the year 2000. In the second calculation, we would expect 5% or 5 of 100 people.

As another example, let us calculate the prevalence rate of HIV in a general practice. A physician has 1,000 patients registered with him. Looking at his records at the end of 2001 for an annual audit, he notes that 200 of his patients were living with HIV infection (prevalence) at the time of the audit.

The HIV prevalence rate among the patients registered in his practice at the end of 2001 is the *existing* number of people with HIV infection at the end of 2001 (the specific point in time) divided by the total number of registered patients (the population at risk).

The HIV prevalence rate among the physician's patients at the end of 2001:

$$\frac{\text{existing number of patients with HIV}}{\text{population at risk}} = \frac{200}{1,000} = 0.20 \text{ (20\%)}$$

PROPORTION

A proportion is a type of **ratio** in which the **numerator** is included in the **denominator**. It is an expression of a comparative part or share of the total at a specified period of time. In HIV/AIDS research, the proportion can be the number of people with a common characteristic, such as gender, as compared with the total population that shares the same “event”, such as HIV infection, at the same specified period of time.

A proportion is calculated by dividing the number of people with a common characteristic at a given time period by the total population that shares the same event in the same time period.

For example, *HIV and AIDS Among Women in Canada* in the May 2001 HIV/AIDS Epi Updates states that “Women represent an increasing proportion of reported HIV **cases** in Canada, and accounted for 24% of **positive HIV test reports** in 2000”. (Bureau of HIV/AIDS, STD and TB, Centre for Infectious Disease Prevention and Control, Health Canada, 2001b)

In other words, the proportion of women among positive HIV test reports was 24% in the year 2000.

This was calculated by:

$$\frac{\text{Positive HIV reports among women in 2000}}{\text{Positive HIV reports among adults in 2000}} = \frac{484}{2,039} = 0.237$$

This can be rounded up to 24% (0.237 x 100).

P VALUE

The symbol p (or P) means probability. It appears frequently in the “Results” section of published research papers or reports.

The symbol p followed by the mathematical symbol $<$ (less than) 0.05 is used to indicate that the result could be expected to occur by chance less often than five times in 100, or once out of 20. Another way of expressing this is to say that the result is “significant at the 5% level”. The p value is closely linked to **confidence intervals**.

For many routine research studies, a 5% level of **statistical significance** is considered to be good enough. However, if the findings are likely to have very important consequences for medical interventions or public policy, for example, a higher level of statistical significance is demanded, such as $p < 0.01$. A statistical significance level of less than 0.01 means the result might occur by chance less than one time in a 100. In other words, the smaller the p value, the less likely the results happened by chance.

If there is an asterisk (*) by a p value, it indicates that the result had statistical significance.

In the Montreal Street Youth **Cohort**, the authors reported that 79% of women who were engaged in the sex trade had run away from home compared with 59% of women who had never engaged in the sex trade ($p < 0.05$). Because a p value of 0.05 is often associated with statistical significance, the p value indicates that women engaged in the sex trade are *significantly* (statistically) more likely to have run away from home than women not in the sex trade. The $p < 0.05$ value associated with this result indicates that there is a 95% chance that this statement is accurate. That is, there is only a 5% (100% minus 95%) chance that the study result is an error and that it happened by chance. (Weber, Roy, Blais, et al., 2001)

Q

QUALITATIVE RESEARCH

Qualitative research is one approach to gathering scientific information. Qualitative data are non-numeric and can include detailed descriptions of situations, interactions, personal histories and direct quotations from people about their experiences.

Qualitative research is often contrasted with **quantitative research**, which uses primarily numerical data. In qualitative research it is more important to characterize the nature of an individual's experience than to count the number of experiences or to measure how often they happen.

Qualitative methods of data collection include interviews, focus groups, observational studies and open-ended responses to written questions. Qualitative analysis involves the organization and interpretation of non-numeric data to discover underlying themes and patterns that help to explain the phenomena under study. Qualitative data provide depth and detail about individual experiences.

For example, qualitative research methods have been used in a study to explore pregnant women's experiences of HIV testing in terms of their reasons for accepting a prenatal offer of HIV testing, their reasons for declining the offer, their reactions to a positive HIV test result in pregnancy and their perspectives on best practices in prenatal HIV counseling and testing. (Leonard, Gahagan, Doherty, et al., 2001)

QUANTITATIVE RESEARCH

(See also **QUALITATIVE RESEARCH**)

Quantitative research is one approach to gathering scientific information. Quantitative research methods attempt to capture the measurable attributes of human experience. Data collected through the use of quantitative methods are systematically collected in numeric form.

Methods of data collection include clinical and laboratory tests, survey questionnaires and measurements.

Quantitative analysis involves the interpretation of numeric data using statistical procedures to describe the phenomena under study or assess the magnitude and reliability of relationships under study.

For example, quantitative methods could be used to examine pregnant women's experiences of prenatal HIV testing. The objective could be to measure the number of pregnant women who were offered testing during prenatal visits, the number who accepted the offer, the number who declined the offer and how many received a positive HIV test result.

R

RANGE

The range is an example of a **descriptive statistic**. The range describes the spread of scores. The range is the highest value minus the lowest value in any set of values.

Using the following ages at which 11 injecting drug users (IDUs) reported testing HIV positive:

19, 21, 24, 27, 29, 31, 32, 32, 32, 36, 39

There is a 20-year range (39 minus 19) in the ages of IDUs reporting testing positive for HIV.

This result can also be expressed as, “The age **range** at which IDUs reported testing HIV positive is 19 to 39 years.”

RATE (See also **RATIO**)

A rate is an expression of the frequency with which an event occurs in a defined population in a specified period of time. In HIV/AIDS research, a rate can be the **proportion** of a population with a particular “event”, such as HIV infection, occurring during a specified time period.

A rate can be obtained by dividing the number of **cases** in a given time period by the **population at risk** in the same time period and then usually multiplying the result by a multiple of ten. In epidemiological reports, 100,000 is commonly used as this number (the multiplier). The rate can then be expressed as the number of people with the “event” per 100,000 population. Expressing the rate as the number of people per 100,000 per year is done so that rates can be compared between population groups and from year to year.

You can compare rates between different populations as long as the rate has been calculated using the same multiplier.

For example, we could calculate the rate of needle exchange at one needle exchange site in Canada in the year 2000. Let us assume that there were 1,500 injecting drug users (IDUs) accessing this site in 2000, and there were 27,000 needles exchanged at that site in the same year. The needle exchange rate at that site for the year 2000 would be:

$$\frac{\text{Number of needles exchanged}}{\text{Number of injecting drug users}} = \frac{27,000}{1,500} = 18 \text{ per injecting drug user}$$

This means that in 2000, 18 needles were exchanged for every injecting drug user accessing the site.

RATIO

A ratio is a combination of two numbers that shows their size relative to each other.

The ratio of one number to another is the first number (the **numerator**) divided by the other number (the **denominator**), and can be expressed as a fraction or a decimal. A ratio can also be expressed as two numbers separated by a colon (:).

For example, the total number of **positive HIV test reports** among White and Aboriginal persons between 1998 and 2000 was reported in the May 2001 *HIV/AIDS Epi Updates: AIDS/HIV Ethnicity in Canada* to be 1,474. Of these, 1,103 were among White persons and 371 were among Aboriginal persons. (Bureau of HIV/AIDS, STD and TB, Centre for Infectious Disease Prevention and Control, Health Canada, Bureau of HIV/AIDS, 2001c)

The ratio of positive HIV test reports among White persons to Aboriginal persons could be expressed as 1,103/371 or 1,103:371. More often, it may be expressed as 2.97:1, which is obtained by dividing 1,103 by 371. This could be expressed as approximately 3:1.

REPORTABLE DISEASE (Refer to NOTIFIABLE DISEASE)

REPORTED AIDS CASES (See also AIDS CASE REPORT and FAQs 6, 8, 14, 16, 17)

Reported AIDS cases are those **AIDS cases** on which information about the individual has been sent to the provincial or territorial government and then reported to the Centre for Infectious Disease Prevention and Control (CIDPC).

For example it may be stated that “The **proportion** of reported AIDS cases attributed to injecting drug use has increased from 8.3% in 1995 to 21.7% in 2000.” (Bureau of HIV/AIDS, STD and TB, Centre for Infectious Disease Prevention and Control, Health Canada, 2001d)

This means that of all the AIDS cases reported to CIDPC in 1995, 8.3% reported injecting drug use as the highest risk of HIV transmission.

It is important to note that the number of reported AIDS cases at any point in time is not a true reflection of the total number of AIDS cases that have been diagnosed in Canada since the beginning of the epidemic. This is because some AIDS cases never get reported for a variety of reasons, such as health care providers being unaware of the legal requirement to report AIDS cases. You will often see this situation referred to as “under-reporting”.

Also, there are often substantial delays in reporting AIDS cases. It is currently estimated that 23% of newly diagnosed AIDS cases are reported to CIDPC within three months, 45% within six months, 65% within one year, 82% within two years and 95% within five years. You will often see this situation referred to as “delayed reporting”.

RISK FACTOR (See also FAQ 3)

A risk factor is an aspect of someone’s behaviour or lifestyle, a characteristic that a person was born with, or an event that he or she has been exposed to, that is known to be associated with a health-related condition.

A *behavioural* risk factor describes a specific behaviour that carries a proven risk of a particular outcome. In HIV/AIDS research, you will often see the term “HIV-related risk behaviour” to describe a behaviour that, when practiced, carries a proven risk of HIV infection.

An individual's HIV-related risk factors determine the **exposure category** assigned to a report of a positive HIV test.

For example, a risk factor documented to be associated with HIV infection is injecting drug(s) with used needles. As this risk factor is an aspect of a person's behaviour, it may be referred to as an "HIV-related behavioural risk factor". It may also be more generally referred to as an "HIV risk factor".

S

SELF-REPORTED DATA

In research studies, self-reported data is a term applied to information that is directly reported by the study participants.

Self-reported data may not always be accurate for several reasons. For example, in responding to questions about recent HIV-related risk behaviour

- a person may not always correctly remember all of the details of their past behaviours that may have placed them at higher risk of HIV;
- a person may choose not to report these details for fear of stigmatization or of a negative reaction from the interviewer;
- a person may exaggerate these details because they think that this may help or impress the interviewer.

As self-report is not always be the best method of collecting data, additional sources to verify self-report data are sometimes used.

SENTINEL SURVEILLANCE

Sentinel surveillance is a type of **surveillance** activity in which specific facilities such as offices of certain health care providers, hospitals or clinics across a geographical region are designated to collect data about a disease, such as HIV infection. These data are reported to a central database for analysis and interpretation.

These sources of surveillance information can provide information not otherwise available through **positive HIV test reports** and **AIDS case reports**. For example, information on specific populations, such as specific ethnic groups, may be gathered by sentinel surveillance.

SEROCONVERSION

The root “sero” means the serum or the watery portion of blood.

In HIV/AIDS research, seroconversion refers to the development of detectable antibodies to HIV in the blood as a result of HIV infection. A person who

goes from being HIV negative to HIV positive is said to have seroconverted or is a seroconverter.

A seroconverter is a person who has had one or more HIV blood tests (repeat tester) with negative results and who then, as a result of HIV infection, receives a positive HIV blood test result. The initial negative **serostatus** has converted to positive serostatus.

Antibodies to HIV are the proteins the body produces in response to HIV infection. Once HIV antibodies have developed, they remain in the body for life.

SEROCONVERSION PERIOD (See also **SEROCONVERSION**)

In HIV/AIDS research, the seroconversion period refers to the period of time it usually takes to develop detectable antibodies to HIV following infection with HIV. In 75% of persons, antibodies are produced in 4 to 8 weeks; in almost all persons, antibodies are produced within 14 weeks.

The seroconversion period is frequently described as the “window period”. It is very significant in relation to the timing of HIV tests. Persons who are tested during the window period may receive a negative HIV test result although they may be infected with HIV. Persons disclosing HIV-related **risk factors** in the 14 weeks before testing negative for HIV are encouraged to be retested at the end of the window period.

SEROCONVERTER (Refer to **SEROCONVERSION**)

SERODIAGNOSTIC DATABASES

Most public health laboratories across Canada maintain serodiagnostic databases. In relation to HIV, these laboratories maintain a collection of information regarding the diagnostic results of all HIV blood tests. These databases monitor HIV subtypes and HIV mutations, and provide useful data regarding the characteristics and **proportions** of various groups, such as men who have had sex with men (MSM) and injecting drug users (IDUs), who test HIV positive.

SERONEGATIVE (Refer to **SEROSTATUS**)

SEROPOSITIVE (Refer to **SEROSTATUS**)

SEROPREVALENCE

The term seroprevalence refers to the **prevalence** or **prevalence rate** of a disease determined by testing blood rather than by testing saliva, urine, or sputum.

SEROSTATUS (See also **SEROCONVERSION**)

The result of a blood test. The serostatus or blood test result of an individual tested for HIV can be HIV negative or HIV positive.

A person who tests positive for HIV through a blood test is considered to be seropositive for HIV. If that person tests negative, he or she is seronegative.

STATISTICAL SIGNIFICANCE

(See also **CONFIDENCE INTERVAL**)

Statistical significance is the degree to which the observed study result could have occurred by chance alone. This can be determined by the application of a statistical test to a set of data to generate a **p value**. Statistically significant results mean the study results are unlikely to be due to chance alone. P values are reported so that anyone using the data will know how much confidence to place in the reported results.

SURVEILLANCE (See also **FAQs 6, 7, 23**)

Surveillance is the ongoing collection, analysis and interpretation of data about a disease such as HIV or about a health condition. The objective of surveillance is to assess the health status of populations, detect changes in disease **trends** or changes in how the disease is distributed, define priorities, assist in the prevention and control of the disease, and monitor and evaluate related treatment and prevention programs.

In Canada, many groups contribute to the surveillance of HIV/AIDS, such as research investigators and provincial and territorial laboratories. The Centre for Infectious Disease Prevention and Control (CIDPC) compiles and

monitors many of these data, which it publishes in the HIV/AIDS Epi Updates and Surveillance Reports.

HIV/AIDS surveillance in Canada is conducted by the collection of **AIDS case reports** and **positive HIV test reports** as well as data collected through **sentinel surveillance**.

T

TRENDS

Trends are changes in frequencies, **proportions** or **rates** of a disease, such as HIV, or an event observed over time. Trends may be irregular, flat or move in one direction. Trends can be expressed in many forms, including tables, graphs and pie charts.

For example, the Surveillance Report to Dec. 31, 2000, reports a declining trend in the number of **positive HIV test reports** since 1995. There were 2,983 in 1995, 2,772 in 1996, 2,537 in 1997, 2,330 in 1998, 2,240 in 1999, and 2,104 positive HIV tests reported to the Centre for Infectious Disease Prevention and Control (CIDPC) in 2000. (Health Canada, 2000)

You can see that the number of positive HIV test reports is generally decreasing over time. We could say there was a downward or decreasing trend between 1995 and 2000.

This declining trend is better expressed graphically:

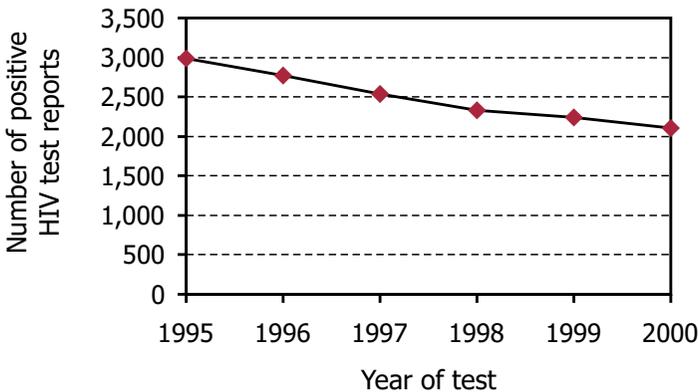


Figure 1. Number of positive HIV test reports

V

VOLUNTARY HIV TESTING

(See also **ANONYMOUS UNLINKED TESTING**)

Except in a few well-described circumstances, explained below, Canadians can be tested for HIV only when they have given their informed consent and have voluntarily agreed to be tested for antibodies to HIV.

Voluntary HIV testing does not apply, for example, to the testing of donors of organs, semen or other similar bodily products. In addition, Ontario Bill 105, passed in December 2001, permits compulsory testing (that is, consent not required) for HIV and other communicable viruses when someone has been exposed through their occupation or when Good Samaritans or crime victims may have been exposed to the risk of infection.

W

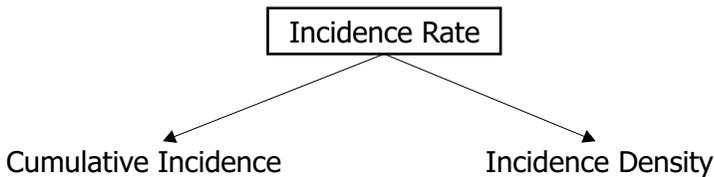
WINDOW PERIOD (Refer to **SEROCONVERSION PERIOD**)

Appendix

Incidence rate, cumulative incidence, incidence density

There are two different ways to describe the **rate** at which new infections are occurring.

Cumulative Incidence



The **incidence rate** can be described as the number of people who become infected during a specified period of time as a **proportion** of a specific **population at risk** of the disease. This is called cumulative incidence.

Cumulative Incidence

$$= \frac{\text{Number of new **cases** during a given period of time}}{\text{Population at risk}}$$

In a hypothetical example, among 60 people attending a 12-month residential detoxification program in Edmonton, 50 tested HIV negative at the start of the program in January 1998. At the end of the program in December 1998, 3 of the 50 participants tested positive for HIV. This results in a cumulative incidence of HIV among attendees of the detox program of 3 per 50 participants or 6% ($3/50 \times 100$) during this 12-month period.

It is important to pay attention to the time period to which the cumulative incidence relates. A cumulative incidence of 6% among attendees of a detox program would be viewed very differently if it referred to a three-month period or a three-year program period.

Incidence Density

Unlike participants in a residential program who can be followed for the specified time period of the study, most participants in **cohort studies** enter the study over a period of time, often over several years. Others will become lost to contact during the **follow-up** period so that their information is not available at the end of the study. The length of time of the study or follow-up will therefore not be the same for each participant. This can be seen in Figure A below.

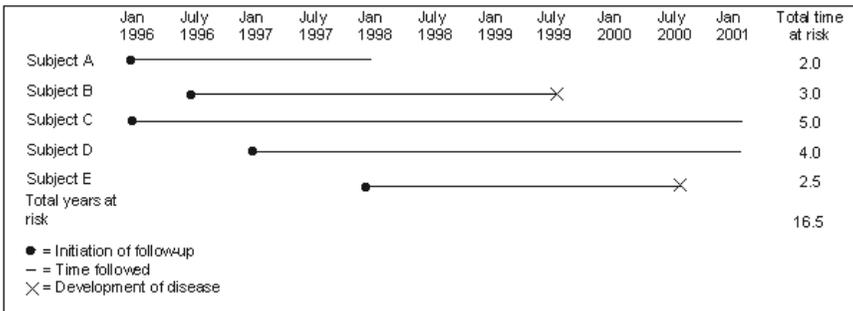


Figure A

Incidence rate can therefore also describe the proportion of people who become infected during a specified period of time as the proportion of the total time at which individuals in a population are at risk. You may sometimes see this way of calculating the number of people who become infected with a specific disease written as incidence density. Incidence density accounts for the varying time periods of follow up. Incidence density is therefore a more precise estimate of the rate of occurrence of a particular disease.

$$\text{Incidence Density} = \frac{\text{Number of new cases during a given period}}{\text{Total person-time of observation}}$$

Although the **numerator** is the same as in the calculation of cumulative incidence, the **denominator** is now the sum of each individual's time at risk or the sum of the time that each person remained under observation and free from disease.

Summary Example

Figure A, above, shows 5 people, 2 of whom developed HIV in the five-year follow-up period of the study. The *cumulative incidence* of HIV would thus be:

$$\begin{aligned}\text{Cumulative incidence} &= 2 \text{ cases}/5 \text{ individuals over a 5-year period} \\ &= 0.4 \text{ over a 5 year period} \\ &= 0.08 \text{ over a 1 year period} \\ &= 8 \text{ per } 100 \text{ over a 1 year period}\end{aligned}$$

However, this measure of the development of HIV is misleading as it does not reflect the fact that only 1 of the 5 individuals (subject C) was in fact observed for the entire follow-up period. Subject A was observed for only 2 years before being lost to follow-up, while subjects B, D and E were followed for 3.0, 4.0, and 2.5 years respectively. The total time at risk for this population of five subjects, observed by adding their individual times, would be 16.5 **person years**.

Incidence density would be calculated as follows:

$$\begin{aligned}\text{Incidence density} &= 2 \text{ cases}/16.5 \text{ person years} \\ &= 12.1/100 \text{ person years of observation}\end{aligned}$$

Incidence density is therefore a more accurate measure of the rate at which new infections are occurring.

Frequently Asked Questions (FAQs)

in HIV/AIDS Monitoring and Epidemiological Research in Canada

Before you start

The table of contents lists Frequently Asked Questions (FAQs) answered in this guide.

The FAQs are organized around the issue they address.

If the answer to the listed FAQ includes frequently used terms contained within this guide, these terms appear in the answer in **bold**. These terms are only bolded the first time they appear in the answer.

If the listed FAQ is further explained in another FAQ, the number of the other FAQ is in parentheses following the entry of the listed FAQ or may be listed in the answer.

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Exposure Categories, Risk Behaviours

1. What are the exposure categories used for HIV and AIDS surveillance by the Centre for Infectious Disease Prevention and Control (CIDPC) at Health Canada and how are they determined? (See also FAQ 8)

CIDPC uses **exposure categories** in HIV/AIDS **surveillance** to keep track of the most likely route through which HIV was transmitted.

In discussing an HIV test with a health care provider, a person may report one or several behaviours known to carry a risk of HIV infection (**risk factors**). Even though all risk factors associated with a positive HIV test result are included in the positive HIV test report and entered into the national HIV/AIDS database, only one exposure category is assigned to a positive HIV test report for national reporting. That exposure category will correspond to the activity or situation (risk factor) that is considered to have the highest risk of HIV transmission of all those that the person has reported to a health care professional during HIV testing.

The exposure categories are listed in an **exposure category hierarchy**. The categories are listed from the one considered to carry the highest risk of HIV infection to the one considered to carry the lowest risk.

The exposure categories currently in use in Canadian HIV/AIDS surveillance and reporting are described in the TERMS section under the term “**EXPOSURE CATEGORY**”.

2. Are the exposure categories used by the Centre for Infectious Disease Prevention and Control (CIDPC) different from those used by the provinces and territories? (See also FAQ 1 and FAQ 8)

In Canada, collection of AIDS **surveillance** data is the responsibility of each *provincial or territorial* health authority. The same applies to the collection of HIV surveillance data in provinces or territories where HIV infection is **notifiable**. As a result, **exposure categories** used for data collection may vary slightly among provinces and territories and from those reported in a national summary by CIDPC.

It is important to recognize that provincial and territorial surveillance coordinators and CIDPC representatives meet regularly to ensure agreement on the definitions and assignment of exposure categories used at the national level.

3. How are the exposure categories used in reporting HIV/AIDS surveillance data different from reported risk behaviours? (See also FAQ 1)

In discussing an HIV test with a health care provider, a person may report *one or several* behaviours known to carry a risk of HIV infection (**risk factors**). However, the risk factors will be used to assign *only one* **exposure category** to a positive HIV test report for national reporting.

It is important to note that this assigned exposure category is the most *likely* way that the individual became infected with HIV according to the **exposure category hierarchy**. It is possible for someone who has engaged in more than one HIV-related risk behaviour to have contracted HIV through one of the other HIV transmission routes listed as risk factors.

HIV Testing

4. What is the difference between non-nominal HIV testing and anonymous HIV testing?

In both **non-nominal HIV testing** and **anonymous HIV testing** the name of the person being tested is not used. However, there are some differences between these two types of testing for HIV infection.

Although it varies by province and territory, in general, the differences are that in anonymous HIV testing, the person ordering the test usually does *not know* and does not want to know the identity of the person being tested. The person ordering the test and the laboratory carrying out the testing on the blood sample use only a code, and they do not know to whom the code belongs. If the person being tested wants an anonymous HIV test, he or she would need to go to a specialized clinic, where the identity of the person being tested is unknown to those who order the test and no personal information is recorded. In contrast, in non-nominal HIV testing, although the test may be ordered using a code or the initials of the person being tested, the person ordering the test *knows* the identity of the person being tested. For example, if the person being tested goes to their health care provider to request an HIV test but does not want the test ordered using his or her name, the test would be considered non-nominal. The test would not be anonymous however, as the health care provider who ordered it knows the identity of the person being tested and could contact that person if required.

A second difference between these two types of HIV testing lies in how the information relating to a positive HIV test result is recorded in the health care record of the person being tested. If the test is ordered anonymously, test results are *not* recorded. It is only the person being tested who may decide to include the test result in the health care record. In contrast, in non-nominal HIV testing, the information relating to a positive HIV test *is* entered into the health care record of the person being tested.

The other major difference between these two types of testing is the availability of anonymous HIV testing. Whereas non-nominal HIV testing is available in all provinces and territories, anonymous HIV testing is available in only eight provinces (British Columbia, Alberta, Saskatchewan, Ontario, Quebec, New Brunswick, Nova Scotia and Newfoundland and Labrador). This information was collected in a 1998 survey of all provinces and territories. Usually, anonymous HIV testing is only available in specialized clinics,

organized and supported by local public health departments. In British Columbia, anonymous HIV testing is available in any physician’s office.

Availability of anonymous, non-nominal/non-identifying, and nominal/name-based HIV testing by province/territory¹

Province/territory	Anonymous HIV testing	Non-nominal/non-identifying HIV testing	Nominal/name-based HIV testing
British Columbia	✓	✓	✓
Yukon Territories	✗	✓	✓
Alberta	✓	✓	✓
Northwest Territories	✗	✓	✓
Nunavut	✗	✓	✓
Saskatchewan	✓	✓	✓
Manitoba	✗	✓	✗
Ontario	✓	✓	✓
Quebec	✓	✓	✓
New Brunswick	✓	✓	✓
Nova Scotia	✓	✓	✓
Prince Edward Island	✗	✓	✓
Newfoundland and Labrador	✓	✓	✓

¹ Based on a survey conducted in 1998.

More information on anonymous and non-nominal/non-identifying as well as nominal/name-based HIV testing is available in the TERMS section under the term “**HIV TESTING OPTIONS**”.

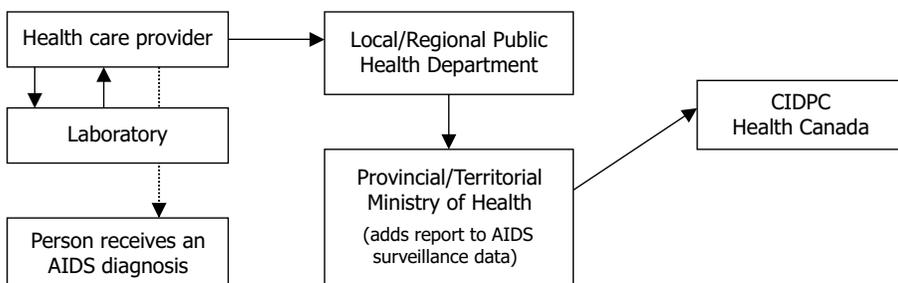
Notification and Reporting of Positive HIV Test Results and AIDS Diagnoses

5. What does it mean when AIDS and HIV infection are described as notifiable diseases?

A notifiable disease is a disease that, by law, must be reported to the public health authority in the area in which the diagnosis is made. Please refer to the TERMS section under the term “**NOTIFIABLE DISEASE**” to obtain additional information for this question.

6. When a person receives an AIDS diagnosis, who will be notified?

AIDS is a **notifiable disease**. This means that, by law, a new **AIDS diagnosis** must be reported to the public health authority in the area in which the diagnosis was made. Information must be sent first to the local health department then to the provincial or territorial health authority. The province or territory then sends selected information to the Centre for Infectious Disease Prevention and Control (CIDPC). The stages in notifying an AIDS diagnosis are best explained by use of the figure below:



The information reported to CIDPC does not include names nor is it identifying. However, the information reported may include

1. **demographic** data, such as

- the person's age;
- the person's gender;

- his or her city of residence;
 - the name of the diagnosing health care provider;
 - the country of birth; and
 - ethnicity.
2. risks associated with the transmission of HIV, listing possible ways the person may have become infected with HIV; and
 3. laboratory data, which may include information on the date of the person's first positive HIV test result and the disease that defined the AIDS diagnosis.

7. If a person tests positive for HIV, who will be notified?

The law requires that information relating to a positive HIV test result be sent to the local health department and the provincial or territorial health authority in all provinces and territories except British Columbia (HIV infection became **notifiable** in Quebec on April 18, 2002). However, HIV infection is not legally notifiable *at the national level* by any Canadian province or territory.

Although notification of positive HIV test results to the Centre for Infectious Disease Prevention and Control (CIDPC) by provincial or territorial health authorities is not legislated by law, notification is voluntarily undertaken by all provinces and territories where HIV infection is notifiable. In addition, CIDPC receives information relating to **positive HIV test reports** from the provincial laboratory in British Columbia and Quebec. All positive HIV test reports are provided non-nominally to CIDPC. The information on what may be included in the report is available in FAQ 6.

8. Do all provinces and territories submit the same information relating to AIDS diagnoses and positive HIV test reports?

In Canada, collection of HIV/AIDS **surveillance** data is not carried out by the Centre for Infectious Disease Prevention and Control (CIDPC). Collection of AIDS surveillance data is the responsibility of each provincial or territorial health authority. The same applies to the collection of HIV surveillance data

in provinces or territories where HIV infection is **notifiable**. As a result, each provincial or territorial health authority will not necessarily collect the same data. Thus, CIDPC does not receive the same surveillance data from each province and territory.

It is important to note, however, that most provinces and territories use a standardized form to report AIDS diagnoses. More information on the forms used to report to CIDPC is available in FAQ 9.

Some provinces and territories provide more information than others when notifying CIDPC of an **AIDS diagnosis** and a **positive HIV test report**. This particularly applies to information on ethnicity, age, and **exposure category**.

Ethnicity

Among some provinces and territories, the **ethnic category** is either not provided, is incomplete, or is generalized. For example, some provinces and territories report general ethnic categories such as *Aboriginal person*, while other provinces and territories report more specific ethnic information such as *Inuit*. Information on ethnicity associated with reported AIDS diagnoses (**AIDS case reports**) has improved since reporting of AIDS began. Since the beginning of reporting to the end of the year 2001, approximately 85% of **AIDS case reports** contained ethnic origin.

Age

When reporting the age of the person with a positive HIV test result, some provinces and territories will report an age group as opposed to a specific age. For example, some may report the age as 24 years, while other provinces and territories may report 20-29 years.

Exposure category (See also FAQ 2)

There is variation among provinces and territories in terms of assigning an exposure category. For both AIDS and HIV,

- reports may be received at CIDPC with an exposure category already assigned by the province or territory;
- reports may be received at CIDPC with only a list of risk factors, used to assign only one exposure category for national reporting;
- reports may be received at CIDPC with no information at all on the possible way or ways by which the person became infected with HIV.

If risk factor information is available, CIDPC assigns the exposure category associated with the greatest risk of HIV transmission. Reports with no risk factors recorded are assigned to the “NIR” (no identified risk) exposure category. The assigned exposure category is then compared with the exposure category assigned by the province or territory, if one is available. If the national and provincial/territorial exposure category assignments do not match, the report will be followed up with the province or territory to determine the most accurate of the two exposure category assignments. Provinces and territories may have information available to them that was not forwarded to CIDPC.

9. Do all provinces and territories use a standardized HIV and AIDS reporting form? If not, how does this affect the accuracy of the data reported in the Epi Updates and Surveillance reports?

When AIDS **surveillance** first began, the Centre for Infectious Disease Prevention and Control (CIDPC) developed an *AIDS Case Report Form* in consultation with the provinces and territories to encourage standardized AIDS data reporting. In 1996-97 the name of the form was changed to the *HIV/AIDS Case Report Form* as the need for HIV surveillance at the national level was recognized.

Some provinces and territories use this form to record information, some use their own form. Regardless of the reporting form used, CIDPC receives selected information from each province and territory as described in FAQ 6.

The accuracy of the data reported in surveillance-related documents is limited by the differences in HIV/AIDS reporting among provinces and territories. As described in FAQ 8, these differences are not specifically related to the form itself but to differences in reporting completeness, and recording and interpretation of information.

10. How long does it take before a positive HIV test result appears in national HIV statistics?

Depending on the time of the year the HIV test took place, the Centre for Infectious Disease Prevention and Control (CIDPC) usually receives the **positive HIV test report** in the same year.

There may be a time lag between the time of testing and the time at which the positive HIV test report is entered into the national HIV/AIDS **surveillance** database. A positive HIV test report travels through several steps from the health care provider to the local health department and then to the provincial or territorial health authority before it is received by CIDPC. The positive HIV test report can be held up at any or each of these steps for a variety of reasons, including technological limitations as well as time and staffing constraints. This results in a delay between the time of testing and the time at which the positive HIV test report is entered into the national HIV/AIDS surveillance database. This time lag is frequently referred to as a “reporting delay”.

Consequently, because of reporting delays, the most recent positive HIV test reports may not be included in the current year’s surveillance reports. However, as CIDPC continues to receive positive HIV test reports from previous years, national HIV/AIDS surveillance data are updated to reflect the year in which the HIV test was conducted. For example, if a person tested positive for HIV in 1990, but the positive HIV test report was not received at CIDPC until 1991, the positive HIV test report would be recorded for the year 1990 and not 1991.

11. Will positive HIV test results be counted more than once at the national level if a person is tested both anonymously and using their name, or if a person tests positive in more than one province or territory?

A person who undergoes testing for HIV more than once is referred to as a “repeat tester”. If this person is tested for HIV both anonymously and using their name and the result is positive, it is possible that more than one **positive HIV test report** is contained in the national HIV/AIDS **surveillance** database for this person.

Similarly, if a person tests positive for HIV each time with a different health care provider either in the same province or territory or in different provinces or territories, it is possible that more than one positive HIV test report is contained in the national HIV/AIDS surveillance database for this person.

In both cases, these are called “duplicate tests”. The inclusion of duplicate positive HIV test reports affects the accuracy of the information contained in the national HIV/AIDS surveillance database. For example, the number of

positive HIV test reports will be higher, and some demographic groupings may be under- or over-represented.

Within provinces and territories, provincial and territorial surveillance coordinators attempt to identify and remove duplicate positive HIV test reports before the data are submitted to the Centre for Infectious Disease Prevention and Control (CIDPC). However, identifying and subsequently removing duplicate positive HIV test reports is difficult because of the non-nominal (without a name) or non-identifying nature of HIV infection reporting in some provinces and territories.

Provincial and territorial files are also reviewed for duplicates at the national level. This is done by determining whether the age and gender of one report match those of a previously entered report. Where there is a match, other information relating to the person will be looked at to see whether or not the new report is really a duplicate.

If a duplicate is suspected, the provinces and territories involved are notified, and the decision as to where the report will be attributed is made between the provinces and territories involved. Generally, positive HIV test reports and **AIDS diagnoses** are assigned to the province or territory in which the person was living at the time of the positive HIV test or at the time at which the AIDS diagnosis was made.

12. In reporting HIV and AIDS data :

a) What is the definition of a pediatric case?

An **AIDS case report** or a **positive HIV test report** is described as pediatric if the person received a diagnosis of AIDS or tested positive for HIV before his or her 15th birthday.

Pediatric cases are included in both the HIV and AIDS section of the **surveillance** report. For AIDS, information is reported on children of all ages and from all provinces and territories. However, this is not the case for HIV.

Surveillance of HIV infection in children is more challenging than surveillance of AIDS, because children under two years of age (infants) can test positive (**seropositive**) at the time of their first HIV test but may test negative (**seronegative**) in subsequent HIV tests. This is a result of the circulating maternal antibodies in the blood. As a result, HIV surveillance information on infants needs to be monitored very carefully.

Monitoring these changes in **serostatus** is difficult because, for most provinces and territories, HIV information on children under two years of age cannot be separated out from the data received by the Centre for Infectious Disease Prevention and Control (CIDPC). Data are received as one group of all children under 15 years of age. Therefore, CIDPC does not have the ability to follow children under two years of age. CIDPC can only remove children under two years of age from the data received from British Columbia, Quebec and, since 2000, Ontario. Thus, in the HIV section of the surveillance report, pediatric cases include data on children under two years of age except for the data specific to these three provinces.

In order to carefully monitor changes in the serostatus of children under two years of age, a separate initiative was started with the purpose of collecting HIV surveillance data only on infants. Information on infants known to be exposed perinatally to HIV infection is obtained through a national non-nominal, confidential survey of infants known to pediatricians in tertiary care centres and HIV specialists in HIV clinics across Canada. These data are collected from *all* provinces and territories by the Canadian Perinatal HIV Surveillance Program, coordinated by the Canadian Pediatric AIDS Research Group (CPARG). Support for the program is provided by the Canadian HIV Trials Network and CIDPC. The data from this source are reported in a separate section in the surveillance reports produced by CIDPC.

b) Why are children defined as less than 15 years of age and adults 15 years of age or older?

This definition is used because the Centre for Infectious Disease Prevention and Control (CIDPC) sometimes receives only age group data for **positive HIV test reports** (i.e., not individual ages) from provinces and territories. Often, these age group data are not well defined for people aged 0 to 14 years.

This definition of “children” is also applied to **AIDS case reports** to allow them to be compared and contrasted with HIV data.

More information on grouped data is available in FAQ 8.

c) Why are AIDS surveillance data for adults divided into 5-year groups?

Five-year age groupings for AIDS surveillance data are consistent with the surveillance guidelines developed by the World Health Organization/Joint United Nations Programme on HIV/AIDS (WHO/UNAIDS).

Limitations in HIV/AIDS Reporting

13. Are all positive HIV test results reported? If not, which do not get included in the Surveillance Report and Epi Updates?

The information relating to positive HIV test results contained in the national HIV/AIDS database and reported in the Epi Updates and Surveillance Reports is limited to those positive HIV tests *reported to* the Centre for Infectious Disease Prevention and Control (CIDPC).

The positive HIV test results that are reported to CIDPC are from *only* those

- who test positive for HIV through **nominal, non-nominal** or **anonymous testing** in British Columbia and Quebec and whose results are reported to CIDPC by their provincial testing laboratories;
- who test positive for HIV through nominal, non-nominal or anonymous testing in all other provinces and territories and whose results are reported to their local health department and subsequently to CIDPC by the provincial or territorial health authority.

The positive HIV test results that are not included in the Surveillance Report and Epi Updates are those that are *not reported to CIDPC*. The reasons why some **positive HIV test** reports are not reported are further explained in FAQ 14.

14. What limitations affect the reporting of HIV and AIDS data?

A data limitation is something that may affect the accuracy of data.

It is important to keep data limitations in mind when reading reports describing **surveillance** data. Some limitations that affect the reporting of HIV and AIDS data in Canada include the following.

Ethnicity Data

Not all provinces or territories routinely collect or report data on ethnic origin. Many of the data reported on ethnic origin at the national level vary in completeness and may result in underrepresentation among certain communities. Such data may also vary in accuracy, as **ethnicity reporting** is

restricted to predefined **ethnic categories** and thereby limits the choice of ethnic designation. In addition, many individuals may not wish to self-identify to a specific group.

Underreporting

The number of **reported AIDS cases** and **positive HIV test reports** at any point in time is not a true reflection of the total number of people living with AIDS or HIV infection. This is because

- some individuals do not come forward after HIV testing but may be positive for HIV;
- some **AIDS diagnoses** and positive HIV test reports never get reported to provincial or territorial health authorities or to the Centre for Infectious Disease Prevention and Control (CIDPC).

Reporting Delay

There is often a substantial delay between the time at which a person tests positive for HIV or receives a diagnosis of AIDS and the time at which the report of that diagnosis is received by the Centre for Infectious Disease Prevention and Control (CIDPC). For additional information on reporting delay, please refer to FAQ 10.

Death Reports

Legislation requires registration of all deaths, regardless of cause, with the provincial and territorial registrars of the Offices of Vital Statistics. As a result, underreporting of deaths for which the underlying cause of death is HIV infection is minimal. The information collected is available annually by Statistics Canada.

The number of deaths among reported AIDS cases published in surveillance documents produced by CIDPC is a significant underestimate. There are a couple of reasons for this.

First, death is *not* a mandatory variable to be reported in the HIV/AIDS surveillance system in any Canadian province or territory or to CIDPC. As a result, the death of a person may not be reported at all (underreporting), or there may be a delay in the death report reaching CIDPC (reporting delay). Even though a health care provider may list AIDS as a cause of death in the medical record or on the death certificate, this information may never be reported to CIDPC as an “update”. It is these updates that are reported in surveillance documents as deaths due to AIDS.

Second, deaths due to *causes other than AIDS* are less likely to be reported to CIDPC than deaths due to AIDS. For example, if a person living with AIDS died in a car collision, CIDPC may be less likely to receive an update than if the person died directly as a result of AIDS.

CIDPC is able to report information on deaths of AIDS cases only when they are linked to a previous AIDS case report. Without active follow-up, the health care provider completing the AIDS case report may not know whether a person has died, moved or just changed health care providers.

Duplicate Reports

The removal of duplicate positive HIV test reports is difficult because of the non-identifying nature of some positive HIV test results. However, all provinces and territories rule out duplicate reports as much as possible. If duplicate reports are missed, surveillance data may overestimate the number of positive HIV test reports.

For additional information on duplicate reports, please refer to FAQ 11.

HIV Reporting among Children under Two Years of Age (Infants)

Infants who are **seropositive** at the time of their first HIV test may, in fact, be **seronegative** on subsequent HIV tests. As any positive HIV test report for an infant has historically been included in the data for children, this may have resulted in an overestimate of HIV infection among children. However, CIDPC monitors any reported changes in the **serostatus** of infants, and the surveillance data for children are updated to reflect this change.

See FAQ 12 for further information on HIV infection reporting among children under two years of age.

15. What methods are used by the Centre for Infectious Disease Prevention and Control (CIDPC) to take account of data limitations?

(See also FAQ 14)

There are some common statistical methods used by CIDPC to take account of data limitations and improve the accuracy of reported data.

For example, statistical methods are used to estimate and adjust for underreporting and to estimate and adjust for reporting delays. These adjusted numbers take into account regional variations in reporting delay.

As HIV and AIDS **surveillance** data do not provide the entire picture of people living with HIV infection, CIDPC also produces estimates of **prevalence** and **incidence**. For additional information on the methods used to estimate HIV prevalence and incidence, please refer to FAQ 20.

16. The definition of AIDS has changed over time. How does the Centre for Infectious Disease Prevention and Control (CIDPC) account for these changes when reporting AIDS data?

The definition of AIDS has changed only slightly since AIDS **surveillance** began. However, the national AIDS surveillance database has not been adjusted to take account of these changes. All reports of AIDS fall under the definition of AIDS that was current at the time of the **AIDS diagnosis**. Once in the database, the **AIDS case report** remains in the database. Information recorded on the reporting form also does not change.

The definition of the Canadian AIDS diagnosis has changed over time as more information has been gathered on the disease. In general, the definition has expanded to include additional diseases indicative of AIDS. This means that some **cases** that now fit the criteria for an AIDS diagnosis may not have fit the narrower criteria used in the past. For example, before 1993, AIDS *would not* have been diagnosed in an HIV positive individual who also had tuberculosis disease. Yet, this same person would *now* be considered to have AIDS, as the current definition for AIDS includes a diagnosis of tuberculosis disease in an HIV positive individual.

CIDPC considers this a limitation to the AIDS database. However, as the definition of AIDS has changed only slightly since surveillance began, the effects are considered to be minimal. For more information on data limitations, please see FAQ 14.

17. Are comparisons of AIDS statistics between countries limited by different definitions of AIDS?

Comparisons of AIDS statistics between countries are difficult because of the differences in the definition of AIDS and the different **surveillance** methods used between countries.

The definition of AIDS used in Canada is based on guidelines set by the Centers for Disease Control and Prevention in the United States. However, it is important to note that in contrast to the U.S. **AIDS case** definition, the list of specific disease indicators required for a Canadian **AIDS diagnosis** does not include a CD4 T-lymphocyte count less than 200 cells per cubic millimetre of blood ($< 200/\mu\text{L}$).

The definitions of AIDS used in other countries are based on different guidelines. Although global differences between guidelines and therefore the definition of AIDS exist, these differences are small.

The methods used to collect, analyze and report HIV/AIDS surveillance data may also vary from country to country.

Positive HIV Test Reports, HIV Incidence and New HIV Diagnoses

18. a) Is there a difference between positive HIV test reports and HIV incidence?

Yes. HIV **incidence** refers to the number of people who recently contracted HIV and is reported for a specific period of time – that is, the number of new HIV infections in that time period. **Positive HIV test reports**, on the other hand, are a reflection of the number of positive HIV tests that have been reported to public health authorities. They also apply to a specific period of time – that is, in documents produced by the Centre for Infectious Disease Prevention and Control (CIDPC), positive HIV test reports include only those people who have been tested (positive) and, of those, only the people for whom a report was received at CIDPC. It is also important to note that positive HIV test reports refer to the time of diagnosis of HIV infection, not to the time of infection with HIV, which may have been much earlier.

It is important not to confuse these two terms. HIV incidence refers to the number of *new HIV infections* per year. However, positive HIV test reports refer to the number of *new diagnoses* of HIV infection that are *reported* per year.

For example, in 1999, there were an estimated 4,190 Canadians newly infected with HIV (HIV incidence). There were 2,239 new diagnoses of HIV infection reported in Canada (positive HIV test reports) in 1999.

b) Is there a difference between positive HIV test reports and new HIV diagnoses?

As not all new HIV diagnoses will be reported to public health authorities, the number of positive HIV test reports will be an underestimate of the actual number of new diagnoses of HIV infection.

HIV Incidence and HIV Prevalence

19. What is the difference between HIV incidence and HIV prevalence?

HIV **incidence** is the number of *new* HIV infections occurring during a specified period of time while HIV **prevalence** is the *total* number of cases of HIV infection at a particular point in time. HIV prevalence can also be described as the total number of people living with HIV infection (including those living with AIDS) at a particular point in time.

In the area of HIV/AIDS research, prevalence gives us an idea of how many people are currently living with HIV infection, and incidence gives us a sense of how many people are newly infected, that is, how fast the HIV **epidemic** is growing.

20. How does the Centre for Infectious Disease Prevention and Control (CIDPC) estimate national HIV incidence and HIV prevalence? (See also FAQ 19)

Surveillance data relate only to HIV positive individuals who seek testing or medical care and whose positive HIV test was reported to public health authorities. Therefore, these data do not represent the total number of people who become infected with HIV each year (**incidence**) or the total number of people living with HIV infection (**prevalence**).

To take account of this, national HIV incidence and prevalence are estimated using direct and indirect methods. These methods use data from a wide variety of sources, such as provincial HIV testing databases, population-based surveys, targeted epidemiological studies, and census data.

The *direct method* estimates incidence and prevalence using epidemiological studies among specific population groups. These estimates are then multiplied by the estimated **population at risk**. Sizes for estimated populations at risk are obtained through a variety of methods, including projected population estimates, population-based surveys, and census data.

Two *indirect methods* are used together to estimate HIV prevalence. They are both based on the number of positive HIV diagnoses obtained from provincial HIV testing databases, and on information relating to HIV testing behaviour obtained from population surveys.

HIV incidence is also estimated using another *indirect method*. This method estimates HIV incidence by taking the difference between the two most recent prevalence estimates and adding the number of AIDS deaths that occurred between the two prevalence estimates. The result is an estimate of the number of new infections.

For further information on the national estimates for HIV prevalence and incidence, please refer to the reference listed for the Bureau of HIV/AIDS, STD and TB, Centre for Infectious Disease Prevention and Control, Health Canada, 2001a, at the back of the guide.

21. How accurate are the national incidence and prevalence estimates of Canadians living with HIV infection?

The methods used to estimate HIV **prevalence** and **incidence** among Canadians make maximum use of a wide variety of data sources, **including AIDS case reports**, provincial HIV testing databases, population-based surveys, epidemiological studies, and census data. The estimates are inevitably imprecise, but using several methods of estimation in a combined approach improves their accuracy. The advantages of the approach are its flexibility, and its ability to incorporate new data and to highlight gaps in existing knowledge.

The fact that the methods used to estimate national **trends** in HIV infection are largely determined by data collected from large cities is a limitation. These estimates may not therefore necessarily reflect local trends of HIV **incidence** and **prevalence** in Canada.

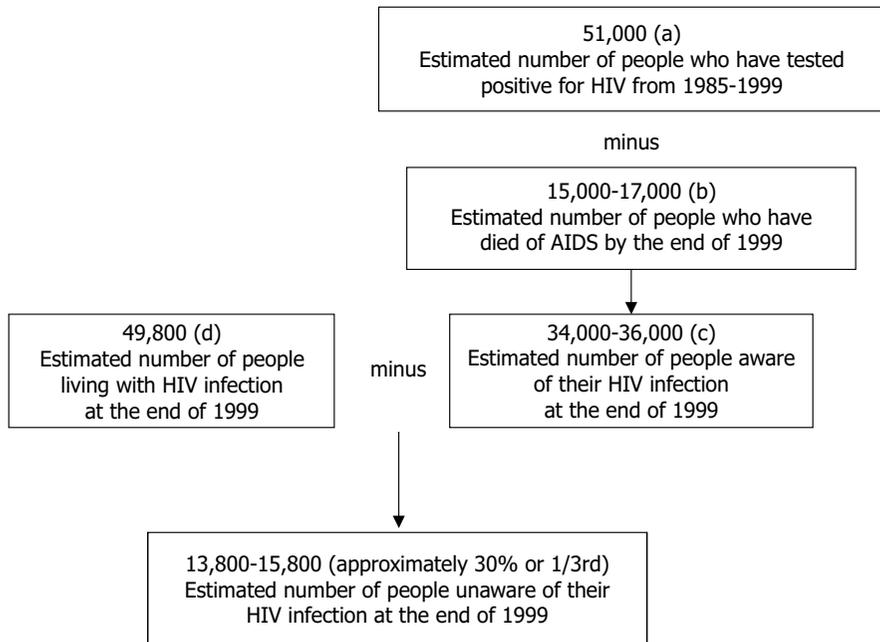
22. How do you know that up to one-third of prevalent HIV infections may be undiagnosed?

(See also **FAQ 20**)

The Centre for Infectious Disease Prevention and Control (CIDPC) has estimated the number of people who may be infected with HIV but are unaware of their infection – that is, the number of people who are living with HIV infection but whose infection has not been diagnosed.

Several steps are involved in estimating the number of HIV infections that may be undiagnosed. The steps follow and are also represented in an example given in the diagram below.

1. The total number of Canadians (a) who tested positive for HIV and (b) who died from AIDS are first estimated. This is done by adjusting the numbers reported to CIDPC to take account of underreporting and delayed reporting. (Underreporting and delayed reporting are explained in FAQ 14.)
2. The estimated number of people who have died from AIDS (b) is subtracted from the number of people who have tested positive for HIV (a). The result is the total number of people who are aware of their HIV infection and are living (c). That is, their HIV infection has been diagnosed.
3. The total number of people living with HIV infection, *either* aware/diagnosed or unaware/undiagnosed (d) is then estimated. This is done by using a combination of different sources and methods. These are described in FAQ 20.
4. The total number of people who are aware of their HIV infection and are living (c) is then subtracted from the estimated total number of people living with HIV infection (d) – that is, both those aware/diagnosed and unaware/undiagnosed.



This results in an estimated number of undiagnosed HIV infections (those living with HIV infection but who have not yet been tested).

Epidemiology and Surveillance

23. What is the difference between the terms epidemiology and surveillance?

Epidemiology refers to the study of the occurrence, distribution and determining factors associated with the health and disease of a population – that is, the study of how often diseases or health events occur in different groups and why.

Surveillance is a key component of epidemiology. It can be defined as the ongoing collection, analysis, interpretation and dissemination of health related data such as data about HIV infection. In simpler terms, surveillance is “counting” the who and where of disease and “looking” at the patterns of disease. Surveillance is one of a number of methods used by epidemiologists to gather information on a disease such as HIV infection.

For example, an epidemiological study might examine behaviours that place people at risk of HIV infection (**risk factors**) or might investigate the people who display these risk behaviours. If researchers first wanted to determine the group of people that accounts for the greatest number of **positive HIV test reports**, they would look to surveillance data.

Website Resources

Additional information on HIV/AIDS, epidemiology or surveillance can be obtained on the following websites.

The B.C Centre for Excellence in HIV/AIDS

<http://cfeweb.hivnet.ubc.ca/cfe.html>

Canadian Aboriginal AIDS Network

www.caan.ca

Canadian AIDS Society

www.cdn aids.ca

Canadian AIDS Treatment Information and Exchange (CATIE)

www.catie.ca

The Canadian Foundation for AIDS Research

www.canfar.com

Canadian HIV/AIDS Clearinghouse

www.clearinghouse.cpha.ca

Canadian HIV/AIDS Legal Network

www.aidslaw.ca

Canadian HIV Trials Network

www.hivnet.ubc.ca/ctn.html

Canadian Institutes of Health Research

www.cihr.ca/index.shtml

The Canadian Strategy on HIV/AIDS

www.hc-sc.gc.ca/hppb/hiv_aids/can_strat/partners/can_partners.html

Canadian Treatment Action Council (CTAC)

www.ctac.ca

The Centre for Infectious Disease Prevention and Control, Division of HIV/AIDS Epidemiology and Surveillance (Health Canada)

www.hc-sc.gc.ca/pphb-dgspssp/hast-vsmt/index.html

Centers for Disease Control and Prevention (U.S.A.)

www.cdc.gov

Harvard AIDS Review

www.aids.harvard.edu/publications/har/index.html

Joint United Nations Programme on HIV/AIDS (UNAIDS)

www.unaids.org

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