

Frequently Asked Questions and Answers (FAQs) on Ohio's HIV/AIDS Surveillance Data

What is the difference between the terms “diagnosis of HIV infection” and “persons living with a diagnosis of HIV infection?”

A *diagnosis of HIV infection* refers to persons newly diagnosed and reported with an HIV infection in a particular year, regardless of the stage of disease at initial diagnosis. This includes persons newly diagnosed with HIV (not AIDS), persons previously diagnosed with HIV who are now newly diagnosed with AIDS, and persons concurrently diagnosed with HIV and AIDS at initial diagnosis.

Persons living with an HIV infection represent all persons ever diagnosed and reported with an HIV infection since the beginning of the epidemic living in Ohio who have not been reported as having died.

Can the term “persons living with a diagnosis of HIV infection” also be referred to as HIV prevalence?

Yes. HIV prevalence is all persons living with an HIV infection. Prevalence is recalculated annually to factor in deaths that occurred in the population the previous year. It is often expressed as a rate per 100,000 population to demonstrate the disease burden in a population (e.g. 145.6 cases per 100,000 population).

Why isn't HIV incidence data produced or available for Ohio?

HIV incidence is a measure of *recent infectivity*. States monitor the number of *new diagnoses* of HIV. A diagnosis of HIV is not an indication of when a person became infected with HIV (i.e. incidence); it indicates the earliest known date of diagnosis with HIV. The U.S. Centers for Disease Control and Prevention (CDC) uses complex statistical methodology to estimate HIV incidence at the national level. The CDC estimates 20 percent of persons infected with HIV in the U.S. are unaware of their HIV status. At this time, the national methodology cannot be applied to estimate a state level HIV incidence.

What is meant by HIV transmission category or mode of HIV transmission?

HIV is known to be transmitted through the exchange of bodily fluids (e.g. blood, semen, breast milk), sharing of contaminated needles, transfusion of infected blood and other blood products, and transplants of infected tissue and organs. A transmission category is the classification of a case of HIV into the risk factor most likely to have been responsible for HIV transmission (e.g. sexual relations, injection drug use, mother-to-child during birth). The Ohio Department of Health (ODH) HIV/AIDS Surveillance Program summarizes the transmission information reported on cases of HIV/AIDS in Ohio to identify trends in transmission patterns in populations. This important information is used by state and local HIV prevention specialists to target effective prevention strategies and interventions accordingly.

Can a person be classified into more than one HIV transmission category?

Cases are counted only once in a hierarchy of transmission categories. The six common HIV transmission categories are male-to-male sexual contact, injection drug use, male-to-male sexual contact and injection drug use, heterosexual contact, mother-to-child (perinatal) transmission, and other (includes blood transfusions and unknown cause). Persons with more than one reported risk factor for HIV infection are classified in the transmission category listed first in the hierarchy. The exception is men who report sexual contact with other men and injection drug use; this group makes up a separate transmission category.

Why do such a large proportion of HIV cases in Ohio have an unknown mode of HIV transmission?

The information ODH analyzes and publishes on modes of HIV transmission for Ohio cases comes from individual HIV and AIDS diagnoses reported by physicians, hospitals and/or outpatient health care facilities to the HIV/AIDS Surveillance Program. The ODH HIV Surveillance Program performs follow-up with health care providers on every newly diagnosed HIV infection reported without a risk factor for HIV. Behavioral risk factor information is also obtained from local disease intervention specialists performing HIV counseling, testing and partner referral services.

Real or perceived stigma and fear of discrimination in discussing sexual and/or drug use history with health care providers contributes to the many cases of HIV infection reported without a mode of HIV transmission. In addition, a patient's medical records may not document the mode of HIV transmission for various reasons. For example, patients may be asked about their drug use history, including history of using/abusing alcohol and other illegal substances, but may not specify injection drug use.

Persons newly diagnosed with an HIV infection with multiple sexual partners may not know the HIV status of their sex partners. In these instances, unless the diagnosing/treating physician documents and reports to ODH that a newly infected person had heterosexual relations with a known HIV positive person, the mode of HIV transmission remains unknown indefinitely according to CDC's risk ascertainment technical guidance. This unfortunately leaves the mode of HIV transmission category as "unknown" for a high proportion of cases, especially among females.

Why are HIV rates for persons newly diagnosed and/or living with a diagnosis of HIV infection not calculated by mode of HIV transmission category?

The calculation of a rate requires a numerator and denominator and is generally expressed per 100,000 population. The numerator is the number of persons in a population with the characteristic of interest (e.g. number of injection drug users with HIV in Ohio) while the denominator is the total number of persons in that population (e.g. total number of injection drug users in Ohio). So while the numerator may be known, the denominator is not. At this time there is no nationally recognizable or accepted data source or method for estimating the number of injection drug users, men who have sex with men, and/or persons who engage in heterosexual relations with multiple sex partners for the general U.S. population. CDC is currently exploring options to produce scientifically sound estimates.

What does the death data analyzed by the ODH HIV/AIDS Surveillance Program represent?

Death information represents deaths from any cause among persons reported with a diagnosis of HIV infection in Ohio. Death data attributing HIV/AIDS as an underlying or contributing cause of death is collected and available from the Office of Vital Statistics within the ODH Center for Public Health Informatics and Statistics.

Can you describe the representativeness and limitations of HIV/AIDS surveillance data?

HIV/AIDS surveillance data represents persons diagnosed with HIV and AIDS reported to the ODH HIV/AIDS Surveillance Program. It does not represent all persons infected with HIV. HIV/AIDS surveillance data may underestimate the level of recently infected persons because some HIV-infected persons have not been tested to learn their serostatus. The earliest date a case of HIV is reported to ODH may not be the earliest date an individual first became aware of their HIV infection. Individuals may have previously tested anonymously and/or were diagnosed out-of-state prior to being confidentially tested and reported to Ohio.

As previously mentioned, a limitation of HIV surveillance data is behavioral risk information is often unreported to ODH. This may lead to an inaccurate description of risk behaviors to target for public health intervention. The reasons for this vary including the real or perceived stigma of patients in sharing their sexual and drug use history with their health care provider or person offering patient counseling and testing services, patient embarrassment in not knowing the HIV serostatus of sexual and/or needle sharing partners, health care providers not accurately asking or documenting risk factors for HIV in the patient medical record, and/or a patient's risk is known by the health care provider but not reported to the public health jurisdiction.

Due to the long and variable period from initial HIV infection to the development of AIDS; trends in AIDS surveillance do not represent recent HIV infections. Asymptomatic HIV-infected persons are not represented by AIDS case data. In addition, incomplete HIV or CD4+ t-cell testing may interfere with the representativeness of reporting. Widespread use of HAART complicates the interpretation of AIDS case surveillance data and estimation of the HIV/AIDS epidemic in an area. Newly reported AIDS cases may reflect treatment failures or the failure of the health care system to halt progression of HIV infection to AIDS. AIDS cases represent late-stage HIV infection.

What practical user guidance and considerations can you share with someone requesting HIV/AIDS surveillance data to improve their understanding of the data when using it for planning, evaluation, grants and/or policy considerations?

- 1) Read all table and graph titles and footnotes, and any accompanying technical notes to improve your understanding of surveillance data;
- 2) View and use surveillance data as the starting point and not the ending point. Use it to guide your decision-making. Surveillance data is less effective when used to answer or support conclusions and decisions already pre-determined;
- 3) Appreciate and accept surveillance data may not be able to answer your question(s) and/or be the appropriate data source to meet all of your needs;

- 4) Recognize the HIV/AIDS Surveillance Program is not the sole source of HIV-related data collected at ODH. HIV-related testing, treatment and patient care data is not collected through HIV surveillance activities. You may need to be referred to other ODH programs for this data so that you may examine and consider all relevant data related to persons living with HIV/AIDS; and
- 5) Recognize the importance of data stewardship. In addition to providing high quality HIV/AIDS surveillance data to its customers; the ODH HIV/AIDS Surveillance Program must also serve as responsible data stewards. In this role, surveillance staff is required to adhere to data confidentiality standards that may limit the availability and detail of data that can be released to protect against real or perceived threats to patient confidentiality.