

HIV Surveillance Supported by the Division of HIV/AIDS Prevention

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Over the years, the Division of HIV/AIDS Prevention (DHAP) at the Centers for Disease Control and Prevention (CDC) has developed a comprehensive program of HIV surveillance to collect, analyze, and disseminate data on HIV infection and infection classified as stage 3 (AIDS). Through HIV surveillance, DHAP monitors many facets of the trends in HIV infection in the United States.

This fact sheet contains information on the HIV surveillance systems that DHAP currently supports. The data inform and guide the critical decisions that ensure HIV prevention funds are directed to those populations most affected by the disease.

HIV Case Surveillance

In 1981, CDC first reported cases of a rare pneumonia in young gay men. This condition was subsequently determined to be acquired immunodeficiency syndrome (AIDS), which was a result of infection with the human immunodeficiency virus (HIV).

AIDS reporting started in 1981; by 1986, all 50 states, the District of Columbia, and several US dependent areas had implemented AIDS case reporting. Beginning in 1985, many states implemented HIV case reporting as part of an integrated HIV and AIDS surveillance system. As of 2008, all states had implemented confidential, name-based HIV infection reporting.

Beginning in 2013, CDC began referring to AIDS as HIV infection, stage 3 (AIDS) in all HIV surveillance products.

Process:

Using a uniform surveillance case definition and report form, all 50 states, the District of Columbia, and 6 US dependent areas (American Samoa, Guam, Northern Mariana Islands, Puerto Rico, Republic of Palau, and the US Virgin Islands) report confirmed diagnoses of HIV infection and infection classified as stage 3 (AIDS) to CDC. Case reports from these jurisdictions are sent to CDC after personal identifying information is removed.

Which jurisdictions participate:

As of April 2008, all jurisdictions had implemented confidential name-based HIV infection reporting. However, jurisdictions needed to have reported 4 years of name-based surveillance data to CDC before the data could be statistically adjusted to account for reporting delays and missing risk-factor information.

The 2011 HIV Surveillance Report (published in 2013) was the first report to contain estimated data on diagnosed HIV infection from all 50 states and 6 US dependent areas. Because states implemented confidential name-based HIV reporting at different times, trend data on diagnosed HIV infection begin with data from 2008, the first year that all areas had name-based reporting.

What data are collected:

HIV case surveillance data include information on demographic characteristics (i.e., sex, race/ethnicity, age, and place of diagnosis), transmission category (mode of exposure), initial immune status, and viral load.

In addition, HIV case surveillance activities allow jurisdictions to monitor HIV disease progression and utilization of care services through the ongoing collection of data on laboratory test results (viral load and CD4 counts), opportunistic infections and illnesses, and vital status.

The national HIV Surveillance Report is published annually.

How this surveillance contributes to HIV prevention:

Case surveillance data provide the basis for our understanding of the burden of disease and are used to guide public health action at the federal, state, and local levels. Knowing how many people are diagnosed with HIV infection each year—and their stage of disease at diagnosis—is important for planning and resource allocation and for monitoring trends and disparities between groups.

Laboratory data (e.g., viral load and CD4 counts) are essential for monitoring whether people are receiving the vital HIV medical care services they need to live long, healthy lives and reduce transmission to others. With these data, state and local level staff can identify people with HIV who may not be receiving care and help them to return to care.

HIV Incidence Surveillance

HIV incidence surveillance is a component of the National HIV Surveillance System, CDC funds selected state and local health departments to conduct HIV incidence surveillance activities.

Process:

State and local health departments that conduct HIV incidence surveillance collect HIV testing and antiretroviral use history as a part of routine HIV surveillance activities. These data are sent to CDC after personal identifying information is removed. In addition, incidence surveillance staff at state and local health departments work closely with commercial/private, public, and hospital-based laboratories to acquire leftover diagnostic blood specimens to test for recent infection. By applying a statistical approach that uses the test results indicating recent HIV infection, combined with HIV testing and antiretroviral use history information, CDC is able to identify the trends of new HIV infections at the national level.

Which jurisdictions participate:

Since 2008, HIV incidence surveillance areas have included 25 jurisdictions¹.

What data are collected:

In addition to data collected through case surveillance, data on HIV testing behaviors, use of antiretroviral medications, and results from tests for recent HIV infection collected from the jurisdictions participating in HIV incidence surveillance are used to estimate HIV incidence. HIV incidence estimates, which are stratified by age, race/ethnicity, sex, and transmission category, describe new HIV infections in the United States.

The data from the jurisdictions that conduct incidence surveillance are extrapolated to yield a national estimate.

How this surveillance contributes to HIV prevention:

Annual HIV incidence estimates can be used to monitor trends of new infections in the United States. Monitoring HIV incidence is critical for allocating resources and evaluating the effectiveness of HIV testing and other prevention programs. Improved surveillance methods allow us to better direct our programs and resources to the populations most affected.

National HIV Behavioral Surveillance (NHBS)

In 2003, CDC created NHBS for conducting behavioral surveillance among persons at high risk for HIV infection.

Process:

Surveillance is conducted in rotating annual cycles in three different populations at high risk for HIV: men who have sex with men (MSM), injection drug users (IDUs), and heterosexuals at increased risk for HIV infection (HET). Before each NHBS cycle, formative research is conducted to learn more about the populations and collect data to help with sampling procedures. MSM are sampled using venue-based, time-space sampling methods. Health department staff members first identify venues frequented by MSM (e.g., bars, clubs, and organizations) and days and times when men frequent those venues. Venues (and specific day/time periods) for recruitment are chosen randomly each month. IDUs and heterosexuals are recruited using respondent-driven sampling, a type of chain referral sampling. Health department staff members select a small number of initial participants, or “seeds,” who complete the survey and recruit their peers to participate. Recruitment and interviewing continue until the target sample size is reached.

Trained interviewers in all NHBS jurisdictions use a standardized anonymous questionnaire to collect information on HIV-related risk behaviors, HIV testing, and use of HIV prevention services. HIV testing is also offered to all participants. During each cycle, a minimum of 450 (for heterosexuals) to 500 (for MSM and IDUs) eligible persons from each participating jurisdiction are interviewed and tested for HIV infection. The first full round of NHBS, which comprised all three cycles (MSM, IDU, and HET), was conducted during 2003–2007. The second round was conducted during 2008–2010 and the third round was conducted during 2011–2013. The fourth round began in January 2014.

Which jurisdictions participate:

As of 2011, 20 jurisdictions² with high AIDS prevalence are funded to conduct NHBS. Many of the health department grantees subcontract with local health departments, universities, or community-based organizations to implement NHBS activities.

¹ Incidence surveillance: Alabama; Arizona; California; Chicago; Colorado; Connecticut; District of Columbia; Florida; Houston; Indiana; Los Angeles County; Louisiana; Massachusetts; Michigan; Mississippi; New Jersey; New York; New York City; North Carolina; Philadelphia; San Francisco; South Carolina; Texas; Virginia; and Washington.

² NHBS: Atlanta, GA; Baltimore, MD; Boston MA; Chicago, IL; Dallas, TX; Denver, CO; Detroit, MI; Houston, TX; Los Angeles, CA; Miami, FL; Nassau, NY; New Orleans, LA; New York, NY; Newark, NY; Philadelphia, PA; San Diego, CA; San Francisco, CA; San Juan, PR; Seattle, WA; and Washington, DC.

What data are collected:

Data on behavioral risks for HIV, HIV testing behaviors, access to and use of prevention services, and HIV testing results are collected.

Findings from NHBS have been published in several issues of CDC's Morbidity and Mortality Weekly Report (MMWR).

How this surveillance contributes to HIV prevention:

NHBS data are used to provide a behavioral context for trends seen in HIV surveillance data. They also describe populations at increased risk for HIV infection and thus provide an indication of the leading edge of the epidemic. Through systematic surveillance in groups at high risk for HIV infection, NHBS is critical for monitoring the impact of the National HIV/AIDS Strategy, which focuses on decreasing HIV incidence, improving linkage to care, and reducing disparities.

Additional Resources

CDC-INFO
1-800-CDC-INFO (232-4636)
www.cdc.gov/info

CDC HIV Website
www.cdc.gov/hiv

CDC Act Against AIDS Campaign
www.cdc.gov/actagainstaids

Medical Monitoring Project (MMP)

In 2005, CDC implemented MMP, a supplemental surveillance system designed to produce nationally representative data on clinical and behavioral outcomes among adults receiving medical care for HIV infection in the United States and Puerto Rico.

Process:

MMP uses a 3-stage sampling design to select an appropriate sample of persons from which locally and nationally representative data can be derived. The first stage is selecting geographic areas to participate; the second stage is selecting outpatient facilities providing HIV medical care within those participating project areas; and the third stage is selecting patients at least 18 years of age who are receiving care at those selected facilities. The annual sample of facilities participating in MMP ranges from 600 to 800 health care facilities. Approximately 9,000 patients from these facilities are sampled annually. Trained MMP interviewers and abstractors collect data through interviews and medical record abstraction.

Which jurisdictions participate:

Since 2009, 23 jurisdictions have been conducting MMP activities³. The MMP jurisdictions include over 70% of the total cases of HIV infection and AIDS in the United States.

What data are collected:

The 45-minute interview includes questions about demographics (i.e., gender, age, and health insurance or medical coverage), access to care, HIV treatment and adherence to medications, drug and alcohol use, sexual behavior, met and unmet needs for social services, and receipt of prevention counseling in a clinical setting. MMP abstractors then collect additional information on clinical outcomes, prescription of antiretroviral therapy, and other health care services provided from patients' medical charts.

How this surveillance contributes to HIV prevention:

MMP data provide national estimates of the clinical and behavioral characteristics of persons receiving HIV care. MMP data are used to monitor the US National HIV/AIDS Strategy goal of increasing access to care and optimizing health outcomes among persons living with HIV. Prevention planning groups, policy leaders, health care providers, and people living with HIV infection can use the data to inform HIV prevention activities, highlight disparities in care and services, identify unmet needs, and evaluate services. The data are also used to guide policy and funding decisions aimed at reducing the spread of HIV and improving the quality of care for people living with HIV infection throughout the United States.

³ MMP: California; Chicago, Illinois; Delaware; Florida; Georgia; Houston, Texas; Illinois; Indiana; Los Angeles County, California; Michigan; Mississippi; New Jersey; the state of New York; New York City, New York; North Carolina; Oregon; Pennsylvania; Philadelphia, Pennsylvania; Puerto Rico; San Francisco, California; Texas; Virginia; and Washington.