

# 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 AIDS. Through HIV surveillance, DHAP monitors many facets of the trends in HIV in the United States.

This fact sheet contains information on the HIV surveillance 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 AIDS, which in turn 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 U.S. dependent areas had instituted 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 reporting.

### Process:

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

### Which jurisdictions participate:

As of April 2008, all jurisdictions had implemented confidential name-based HIV infection reporting. However, jurisdictions need to report 4 years of name-based surveillance data to CDC before the data can be statistically adjusted for reporting delays and missing risk-factor information. The 2010 HIV Surveillance Report contains adjusted data on diagnoses of HIV infection, regardless of the stage of disease, from 46 states<sup>1</sup> and 5 U.S. dependent areas (all but the Republic of Palau). It contains AIDS diagnosis data from 50 states, the District of Columbia, and 6 U.S. dependent areas.

### What data are collected:

HIV reporting provides 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. (<http://www.cdc.gov/hiv/surveillance/resources/reports/2010report/index.htm>)

### 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.

<sup>1</sup>HIV case surveillance for at least 4 years: Alabama; Alaska; Arizona; Arkansas; California; Colorado; Connecticut; Delaware; Florida; Georgia; Idaho; Illinois; Indiana; Iowa; Kansas; Kentucky; Louisiana; Maine; Michigan; Minnesota; Mississippi; Missouri; Montana; Nebraska; New Hampshire; New Jersey; New Mexico; New York; Nevada; North Carolina; North Dakota; Ohio; Oklahoma; Oregon; Pennsylvania; Rhode Island; South Carolina; South Dakota; Tennessee; Texas; Utah; Virginia; Washington; West Virginia; Wisconsin; and Wyoming.

## HIV Incidence Surveillance

In 2004, as an extension of HIV case surveillance activities, CDC first funded selected state and local health departments to begin data collection for HIV incidence surveillance.

### Process:

State and local health departments that conduct HIV incidence surveillance collect testing and treatment history information as a part of routine surveillance activities. These data are sent to CDC after removal of personally identifying information. In addition, incidence surveillance coordinators 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 additional tests to leftover blood specimens from persons newly diagnosed with HIV infection in the funded jurisdictions, CDC is able to identify the number of new HIV infections in a given year.

### Which jurisdictions participate:

Since 2008, HIV incidence surveillance areas have included 25 jurisdictions.<sup>2</sup>

### What data are collected:

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

The data from the jurisdictions that conduct incidence surveillance are extrapolated to yield a national estimate. In 2011, CDC published estimates indicating that HIV incidence has remained essentially stable over the period 2006–2009. Read more about the HIV incidence estimates (<http://www.cdc.gov/hiv/topics/surveillance/incidence.htm>).

### How this surveillance contributes to HIV prevention:

Annual estimates of the number of new infections in the U.S. can be used to monitor current transmission patterns. 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.

## Variant, Atypical, and Resistant HIV Surveillance (VARHS)

Since 2004, as an extension of HIV case surveillance activities, selected state and local health departments have been funded to collect HIV genetic sequence data to identify HIV subtypes and the presence of drug resistance mutations among persons newly diagnosed with HIV infection who have never taken antiretroviral medications.

### Process:

Health department surveillance staff partner with commercial/private, public, and hospital-based laboratories to obtain electronic genetic sequence data from genotype testing that has been done as a part of HIV care. Case reports from these jurisdictions are sent to CDC after removal of personally identifying information.

### Which jurisdictions participate:

Currently, 11 jurisdictions<sup>3</sup> are funded to collect genetic sequence data to determine HIV-1 drug resistance and subtypes.

### What data are collected:

In addition to data collected through case surveillance, genetic sequence data are reported to the state or local health department from genotype testing conducted as a routine part of HIV care.

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<sup>2</sup>**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.

<sup>3</sup>**VARHS:** Chicago; Colorado; Connecticut; Florida; Los Angeles County; Louisiana; Michigan; New York City; South Carolina; Texas; and Washington.

VARHS data are published periodically. The 2006 data were published in the May 2010 issue of *AIDS* (read the abstract: <http://www.ncbi.nlm.nih.gov/pubmed?term=VARHS%202010>). The 2007 data were presented in February 2010 at the 17<sup>th</sup> Conference on Retroviruses and Opportunistic Infections (read the abstract: <http://www.retroconference.org/2010/Abstracts/38109.htm>).

### **How this surveillance contributes to HIV prevention:**

Data from VARHS are used to monitor the frequency of transmitted drug-resistance-associated mutations and HIV subtypes among persons for whom HIV infection is newly diagnosed. These data provide information on the variance of the transmitted strains of HIV and the emergence of resistant strains. To effectively monitor HIV drug resistance, state and local surveillance systems must work with laboratories in their jurisdictions to expand their surveillance activities to include reporting of HIV genomic data.

## **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, organizations, and street locations) 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 began in January 2011.

### **Which jurisdictions participate:**

As of 2011, 20 jurisdictions<sup>4</sup> 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.

### **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 the first NHBS round have been published in several issues of CDC’s *Morbidity and Mortality Weekly Report* (*MMWR*). Additionally:

- In 2010, findings from the second cycle of NHBS for MSM (NHBS-MSM) were published in the September 24 issue of *MMWR* (<http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5937a2.htm>).
- In 2011, findings from the NHBS-MSM2 were published in the June 2011 *MMWR* issue commemorating the 30<sup>th</sup> year since the first HIV cases were reported (<http://www.cdc.gov/mmwr/pdf/wk/mm6021.pdf>) and in a surveillance summary published in October 2011 (<http://www.cdc.gov/mmwr/pdf/ss/ss6014.pdf>).

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<sup>4</sup>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.

## 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 will be critical for monitoring the impact of the National HIV/AIDS Strategy, which focuses on decreasing HIV incidence, improving linkage to care, and reducing disparities.

## 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 U.S. 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 600–800 health-care facilities. Approximately 9,000 patients from these facilities are sampled annually. Trained MMP interviewers and abstractors collect data through face-to-face interviews and medical record abstraction.

### Which jurisdictions participate:

Since 2009, 23 jurisdictions have been conducting MMP activities.<sup>5</sup> The MMP jurisdictions include over 80% 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.

The current 5-year MMP cycle extends through May 31, 2013. MMP publications include the following.

- Data from the 2005 MMP pilot cycle were published in a 2010 surveillance report ([http://www.cdc.gov/hiv/topics/surveillance/resources/reports/pdf/MMP\\_2005\\_Report\\_6.pdf](http://www.cdc.gov/hiv/topics/surveillance/resources/reports/pdf/MMP_2005_Report_6.pdf)).
- Data from the 2007 cycle were published in a September 2011 *MMWR* surveillance summary (<http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6011a1.htm>).
- Nationally representative data from the 2009 MMP cycle were featured in a November 2012 Vital Signs *MMWR* ([http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6047a4.htm?s\\_cid=mm6047a4\\_w](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6047a4.htm?s_cid=mm6047a4_w)).

## 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 U.S. 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.

<sup>5</sup>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.

### Additional Resources:

**CDC-INFO**  
1-800-CDC-INFO (232-4636)  
[cdcinfo@cdc.gov](mailto:cdcinfo@cdc.gov)  
*Get answers to questions  
and locate HIV testing sites.*

**CDC HIV Web Site**  
[www.cdc.gov/hiv](http://www.cdc.gov/hiv)

**Locate an HIV Testing Site**  
[www.hivtest.org](http://www.hivtest.org)

**CDC National Prevention  
Information Network (NPIN)**  
1-800-458-5231  
[www.cdcpin.org](http://www.cdcpin.org)  
*Technical assistance and  
resources.*

**AIDSInfo**  
1-800-448-0440  
[www.aidsinfo.nih.gov](http://www.aidsinfo.nih.gov)  
*Treatment and clinical trials.*

**AIDS.gov**  
[www.aids.gov](http://www.aids.gov)  
*Comprehensive government  
HIV resources.*