



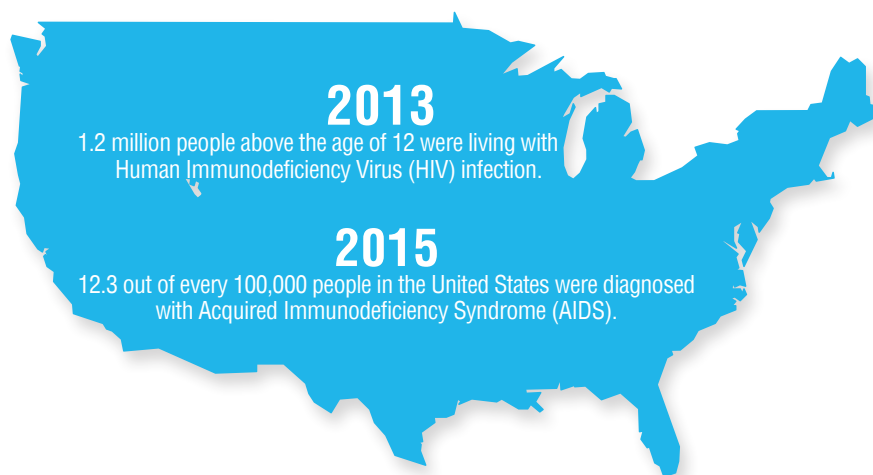
HIV PREVENTION THROUGH SURVEILLANCE AND PRIMARY CARE

Overview and History of HIV/AIDS Surveillance in the United States

Public health surveillance is the process in which health data is continuously and systematically collected. This data is then analyzed and used to make decisions to prevent or control disease.¹ It is through surveillance that the Centers for Disease Control and Prevention (CDC) was able to estimate in 2013 that 1.2 million people above the age of 12 were living with Human Immunodeficiency Virus (HIV) infection in the United States², and that in 2015, 12.3 out of every 100,000 people in the United States were diagnosed with Acquired Immunodeficiency Syndrome (AIDS).³

HIV/AIDS surveillance began in 1981 when the CDC first reported cases of AIDS.⁴ Shortly after, state health departments required name-based reporting for each new case of AIDS from physicians and hospitals.⁵ In the following decades, surveillance efforts have expanded significantly to include all stages of HIV infection. As of April 2008, all 50 states, the District of Columbia, and 6 U.S. territories have integrated confidential name-based reporting using a standard case definition and report form in their HIV infection surveillance systems.^{6, 8} Additionally, as of January 2013, 36 states, Puerto Rico, Guam, and the cities of Philadelphia (PA) and Washington (DC) have required name-based reporting of CD4 T-lymphocyte and HIV viral load lab tests to their health departments. These tests are routinely ordered by providers.⁹ Over time, the HIV/AIDS case definitions have also been periodically updated by the CDC. The most recent update was released in 2014.¹⁰

As HIV/AIDS surveillance evolved, the focus of the system and its uses has also changed. When HIV/AIDS was first reported, surveillance was focused on monitoring the end stages of HIV infection, which included opportunistic infections resulting from severe immunosuppression and death from AIDS.¹¹ The advancement of HIV/AIDS treatment and further knowledge of the condition have allowed surveillance programs to shift their focus from monitoring AIDS cases to better understanding the epidemic through information collected on all stages of HIV infection.¹¹



In collaboration with



HIV/AIDS Surveillance Information Flow

Data for HIV/AIDS Surveillance is generated when a patient visits a provider and has laboratory tests performed. The sources of HIV/AIDS surveillance data fall into four major categories:



Reportable cases from these sources are then sent to the local and state health departments using standard confidential case reports. The health departments remove identifiable information and submit the data to CDC.^{3,12} The CDC then analyzes, interprets, and disseminates the data and publishes national estimates.⁸ Some examples of dissemination include the CDC's Morbidity and Mortality Weekly Report (MMWR), as well as annual HIV surveillance reports.

Effective surveillance requires the successful cooperation of everyone, from individual practitioners to large public health entities. While reporting to the federal government is voluntary, states receive federal funding for HIV/AIDS surveillance.¹³ In turn, state and local regulations mandate providers and laboratories to report case information for HIV/AIDS.¹

From Primary Care to Surveillance

Monitoring Trends & Outbreak Detection

Providers are at the forefront in linking HIV surveillance and primary care through identifying HIV cases and reporting them in a timely manner.¹⁴ This reported data can be used to characterize the burden of disease and can inform resource allocation and other public health decision making. The CDC's Case Surveillance system collects information from anyone with a confirmed HIV infection. This information includes demographics, mode of exposure, initial immune status, and viral load.⁴ In addition, the HIV Incidence Surveillance system collects information on HIV testing and antiretroviral use history.⁴ Using these systems, estimates are made on the number of people living with HIV at a given time and on the number of new infections each year, and allows at risk populations to be characterized.⁸

Timely detection of any outbreak, including HIV, depends on rapid communication between health care providers and public health officials.¹⁴ Information from surveillance programs can detect potential threats to public health early on. For example, public health officials can use surveillance programs to perform contact tracing for those with acute HIV infection, which can lead to the diagnosis of others who may also be infected. By figuring out the path of transmission during an outbreak, surveillance measures allow for the strategic design and implementation of prevention strategies.⁸

Monitoring HIV Risk Behavior

The CDC also collects information on HIV risk behavior. National HIV Behavioral Surveillance (NHBS) monitors behaviors in high risk HIV groups including: men who have sex with men, injection drug users, and heterosexuals at increased risk for HIV infection.⁸

The Medical Monitoring Project (MMP) collects information on clinical and behavioral outcomes in adults who receive HIV medical care.⁸ Both of these systems provide a behavioral context to track the successes of the National HIV/AIDS strategy and highlights disparities in HIV care and treatment.¹⁴

Identifying Out-of-Care Patients and Linking them to Care

The evolution of current understanding on HIV/AIDS has allowed for the focus of surveillance to be shifted from the end stage of the disease, to monitoring new infections and preventing disease progression.¹¹ The CDC's Data to Care strategy aims to utilize HIV surveillance data to identify HIV-diagnosed individuals currently out-of-care and link them to care.¹⁵ The two goals of the Data to Care strategy are to increase the number of HIV-diagnosed individuals who are engaged in HIV care, and to increase the number of HIV-diagnosed persons with an undetectable viral load. Individuals who were never linked to care after diagnosis or did not continue to receive care could be identified using CD4 and viral load lab results that were reported to the health departments.¹⁵

Increase the number of HIV-diagnosed individuals who are engaged in HIV care.



Increase the number of HIV-diagnosed persons with an undetectable viral load who were never linked to care.

2 Goals of the Data to Care Strategy

The Data to Care strategy is implemented by state and local health departments, alongside healthcare providers and community based organizations.⁸ According to the CDC, one model of implementing this strategy is through the Healthcare Provider Model. Under this model, health departments might assist providers in contacting individuals who are out of care, by sharing information on whether or not the out-of-care patient is receiving treatment somewhere else.¹⁵ Another model is through the Health Department Model, where health departments can use HIV surveillance data to directly reach out to HIV-diagnosed individuals who are not in care. Alternatively, a combination of the two models can be used under the Data to Care strategy. This strategy could help healthcare providers prioritize who to contact in re-engagement to care.¹⁵

The Data to Care strategy is relatively new, as states are trying to use HIV surveillance data to better inform programmatic operations and interventions.¹⁶ Some states have already tried implementing the Data to Care strategy into their workflow. One example is a year-long pilot conducted in New York State, where Data to Care was worked into its existing Partner Services. Under this program, disease intervention specialists received extra training to serve as Expanded Partner Services advocates.¹⁷

The Expanded Partner Services advocates then tried to locate out-of-care patients by searching through databases, and tried to engage these individuals by conducting phone calls, going on field visits, and sending letters to the out-of-care patients' last known residences. These individuals were also trained in nationally standardized Partner Services training and in motivational interviewing.¹⁷ From this pilot, 71.2% of the located out-of-care patients were successfully relinked to care. This pilot is currently being expanded to a state-wide level due to its potential effectiveness in successfully relinking individuals to care.¹⁷

While the Data to Care strategy still needs to be refined to be more efficient in relinking out-of-care individuals. A qualitative study of Seattle-King County, Washington's Data to Care program showed that while health departments can use surveillance data to contact out-of-care individuals, obtaining key stakeholder input, such as that of HIV positive patients, health providers, and social services providers, is essential in making the use of this strategy more efficient and acceptable.¹⁶ The CDC's Effective Interventions currently offers a toolkit to assist in the implementation of the Data to Care strategy (<https://effectiveinterventions.cdc.gov/en/HighImpactPrevention/PublicHealthStrategies/DatatoCare.aspx>).

Using Surveillance Data to Alert Providers

Surveillance data can also be used to alert providers on persons who may have fallen out of care. This is an area where the future of HIV surveillance may be expanded in which there is a bidirectional system of data exchange between state health surveillance systems and a health center's electronic medical record system.^{1, 15} This flow of information would alert providers if an HIV-diagnosed individual has not received care, and would check through the state surveillance system to see if they have been receiving care elsewhere. Providers could use this information to offer help in relinking a patient to HIV care, including HIV screening services, care interventions such as antiretroviral treatment and access to services, as well as other case management and peer-based interventions.¹

HIV/AIDS surveillance is a multifaceted system that engages a range of stakeholders from the individual provider to the federal public health agency. As the understanding of HIV/AIDS progression and treatment options has evolved, providers and public health professionals have found new partnership opportunities to integrate surveillance into their practices to promote more effective HIV prevention.

Building Organizational Capacity

The CDC-funded HIV CBA center at CAI can help your organization conduct needs assessment, identify resources, plan for implementation, and provide you with training and capacity building technical assistance that leads to a robust and successful program for high-impact HIV prevention.

The HIV CBA center is able to shape trainings and technical assistance to the specific needs of your healthcare organization. For more information on how to obtain our capacity building services, visit www.hivcbacenter.org.

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