OVERVIEW
The National Alliance of State and Territorial AIDS Directors (NASTAD) represents the nation’s chief state health agency staff with programmatic responsibility for administering HIV and hepatitis programs. Approximately 75% of state AIDS directors oversee HIV surveillance activities. HIV surveillance monitors the HIV epidemic in the United States and provides data that are critical to targeting the delivery of HIV prevention activities and care and treatment services where they are needed most. Health departments are uniquely able to conduct surveillance because of the expertise, statutory authority and the confidentiality protection of existing public health disease surveillance and reporting systems.

HIV surveillance collects data at all stages of HIV infection, including stage 0, when viral levels are high and the person may not be aware of their status through stage 3 (AIDS), the most advanced stage of HIV infection. Therefore, the data that surveillance collects can be analyzed to understand how well we are doing at early diagnosis and prevention of advanced disease all the way through what needs to be done to achieve viral suppression and prevent death. Reporting of HIV cases also alerts public health departments and providers to local HIV outbreaks and emerging trends in communities.

Diagnosis of HIV infection is a notifiable condition in all 50 states, the District of Columbia and six U.S. dependent areas (American Samoa, Guam, Northern Mariana Islands, Puerto Rico, Republic of Palau and the U.S. Virgin Islands). The Centers for Disease Control and Prevention (CDC) funds these areas and six local jurisdictions (Chicago, Houston, Los Angeles County, New York, Philadelphia and San Francisco) for HIV surveillance activities. These funds are used to conduct a uniform, confidential, name-based HIV infection reporting system for collecting, evaluating and analyzing HIV infection data.

TYPES OF SURVEILLANCE
CASE SURVEILLANCE
HIV Case (sometimes referred to as Core) Surveillance is the primary source of population-based data on persons living with HIV. Reporting began in 1981 with the reporting of AIDS cases, and has since grown to include all stages of HIV infection, including stage 3 (AIDS). Since April 2008, all jurisdictions have conducted confidential, name-based HIV infection reporting using a uniform surveillance case definition and report form. This case definition was last updated in April 2014 and, for the first time, combined definitions for HIV infection into a single case definition for persons of all ages. After personal identifiers are removed by the jurisdiction, confirmed HIV infection diagnoses are reported to the CDC. Other information collected and reported to CDC includes: sex, age, race/ethnicity and transmission category/risk factor.¹

INCIDENCE SURVEILLANCE
HIV Incidence Surveillance was developed to provide reliable and scientifically valid estimates of the number of new HIV infections in a given time period at the local, state, territorial and national level. This system is a part of the National HIV Surveillance System. Twenty-five jurisdictions receive funding from CDC during the current funding cycle to conduct HIV incidence surveillance. Funded jurisdictions collect the following information from newly reported HIV cases: demographics and clinical indicators, supplemental HIV testing information and blood test to indicate a recent HIV infection. Using these data and a statistical methodology, CDC produces a national HIV incidence estimate that includes undiagnosed and unreported cases.²

KEY SURVEILLANCE TERMS
- **Incidence**: The number or proportion of persons estimated to be newly infected with HIV in a specific area during a specific time.
- **Prevalence**: The number or proportion of persons living with HIV at a given time regardless of the time of infection, whether the person has been diagnosed or the stage of HIV disease.

¹ Incidence:
² Prevalence:
NATIONAL HIV BEHAVIORAL SURVEILLANCE
The National HIV Behavioral Surveillance (NHBS) system was developed in 2003 by the CDC to conduct behavioral surveillance among populations at high risk for HIV infection. This cross-sectional, community-based study 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). The objectives of the NHBS are to collect information on risk behaviors, HIV testing history, seroprevalence and exposure to and uses of HIV prevention services. Since 2011, CDC has funded 20 jurisdictions with high AIDS prevalence to conduct NHBS. Local health departments are directly funded to conduct the NHBS, but they are encouraged to partner with local community-based organizations (CBOs) and universities that receive federal or state HIV prevention funds.

MEDICAL MONITORING PROJECT
The Medical Monitoring Project (MMP) was developed by the CDC to obtain a nationally representative sample of HIV-infected adults that are receiving medical care. Currently, there are 23 participating projects areas, including 16 states, 6 separately funded cities and one U.S. territory, and these project areas are estimated to include over 80% of the total HIV/AIDS cases in the U.S. MMP provides critical state and national information about the behaviors, medical care and health status of people living with HIV infection. This information helps highlight disparities that exist in care and treatment services and can be used for care and prevention planning purposes. MMP is a multilateral collaboration with the National Institutes of Health (NIH), Health Resources and Services Administration (HRSA), Community and Provider Advisory Boards, state and local health departments, CDC and various other national agencies.

KEY SURVEILLANCE TERMS

**Year of Infection**: The year in which a person becomes infected with HIV. This is usually difficult to determine because it depends on a previous negative test which may have never been done or, when done, is not uniformly reported. For a person infected with HIV in 2014, the year of infection is 2014.

**Year of Diagnosis**: The year in which the health provider or laboratory diagnoses the case, regardless of when the person was infected. For a person who is infected with HIV in 2014 but not diagnosed until the end of the 2015, the year of diagnosis is 2015.

**Year of Report**: The year in which the report was officially made to state/federal health officials, regardless of when the person became infected or when the case was diagnosed. For a person who is infected with HIV in 2010, diagnosed at the end of 2014, but whose case is not reported to the state or CDC until 2015, the year of report is 2015.

HOW IS HIV SURVEILLANCE BEING USED?

FEDERAL FUNDING
The federal government uses HIV surveillance data to determine and allocate funding for various federal and state HIV programs, including the Ryan White HIV Program, high-impact prevention and surveillance programs and Housing Opportunities for Persons With AIDS (HOPWA).

HRSA is responsible for administering the five parts of the Ryan White Program—the largest federal program specifically serving people living with HIV (PLWH). Two parts of the program, Part A and B, rely on surveillance data to determine formula allocations in federal grants. Part A funds are provided to Eligible Metropolitan Areas (EMAs)—areas with a cumulative total of more than 2,000 reported AIDS cases over the most recent five-year period and a population of at least 50,000. Additional funding is provided to Transitional Grant Areas (TGAs)—areas with 1,000-1,999 cumulative reported AIDS cases and a population of at least 50,000. Two-thirds of Part A funds are allocated based on the number of reported living HIV/AIDS cases; the remainder is allocated based on demonstrated need.

Part B base funds are distributed using a formula based on a state’s share of living HIV and living AIDS cases (prevalence), weighted to reflect the presence or absence of EMAs/TGAs. A portion of Part B base funds are set aside for grants to metropolitan areas that do not yet qualify as EMAs or TGAs, but have 500-999 cumulative reported AIDS cases over the most recent five years. Part B AIDS Drug Assistance Program (ADAP) funds are awarded to states and territories using a formula based on the number of reported living HIV/AIDS cases.
cases in the state or territory for the most recent calendar year. Additionally, five percent of the ADAP base funds are earmarked as supplemental grants for states with “demonstrated need.”

CDC’s Division of HIV/AIDS Prevention (DHAP) uses HIV surveillance data to allocate funding for health departments to conduct high-impact prevention and surveillance programs.

High-impact prevention originated in the PS12-1201 Funding Opportunity Announcement (FOA). This funding aligned resources with the National HIV/AIDS Strategy and with HIV burden in jurisdictions. Category A of PS12-1201 provides funding to state health departments and also to “county or city health departments that serve ten specific MSAs or specified Metropolitan Divisions that have the highest unadjusted number of persons living with a diagnosis of HIV infection as of year-end 2008.” Category B provides funding for expanded HIV testing initiatives targeting disproportionately affected populations. Eligibility for Category B funding is limited to jurisdictions with at least 3,000 HIV cases among Blacks and Hispanics at the end 2008.

More information on PS12-1201 and HIV prevention funding can be found in NASTAD’s 2013 National HIV Prevention Inventory.

In 2013, like high-impact prevention, HIV surveillance funding was realigned to areas and jurisdictions with high HIV burden. Through the PS13-1302 FOA, jurisdictions were awarded a base amount to conduct HIV case surveillance, and additional funding was then awarded to each jurisdiction based on the number of PLWH at the end of 2009.

HOPWA, administered by the Department of Housing and Urban Development, is the only federal program dedicated to the housing needs of PLWH. Ninety percent of grants are awarded to metropolitan statistical areas (MSA) with more than 500,000 people and at least 1,500 cumulative AIDS cases and states with more than 1,500 cumulative AIDS cases outside of eligible MSA.

DISPROPORTIONATELY IMPACTED COMMUNITIES
HIV surveillance systems are used to find and highlight communities that are being disproportionately impacted by the HIV epidemic. The NHBS, specifically, looks at the communities that are being impacted and face a

HEPATITIS SURVEILLANCE
In the United States, there are an estimated 5.3 million people living with chronic hepatitis B (HBV) and/or hepatitis C (HCV), with up to one third of HIV-infected persons in the U.S. co-infected with HCV. In 2012 alone, 40,599 cases of HBV and 145,762 cases of HCV were reported to the CDC. Unfortunately, due to the lack of an adequate surveillance system, these estimates are likely only the tip of the iceberg. Additionally, hepatitis disproportionately impacts several communities, particularly people who inject drugs (PWID), MSM, African Americans, Asian Americans, Latinos, residents of rural and remote areas and PLWH—many of the same communities that are also disproportionately impacted by HIV.

The CDC currently funds only five state and two local health departments to conduct minimal hepatitis surveillance in their jurisdictions. With support for the creation of a national surveillance system, states, health departments, policy makers and providers would be equipped with information that is critical to understanding the impact of the hepatitis epidemics, identifies and averts outbreaks, and that will allow for improved targeting of resources to the most impacted communities. As a core public health activity, effective surveillance is needed to ensure accurate reporting of all cases and to support and evaluate prevention activities.
disproportionate share of the new HIV cases. From the NHBS, researchers have found that, among MSM, young black MSM face a disproportionate share of HIV infection and are more likely to be unaware of their HIV infection.

The MMP highlights areas of improvement in the delivery of HIV care, treatment and prevention interventions, and more importantly, highlights the needs of persons living with HIV that are not being met, particularly among disproportionately impacted communities. Using the data produced by the MMP, CDC, HRSA and state and local governments are able to identify disproportionately impacted communities and thus influence policy and funding decisions aimed at improving the quality of care for PLWH in the U.S.

THE NATIONAL HIV/AIDS STRATEGY
The National HIV/AIDS Strategy (NHAS), released in 2010 by President Obama, is the nation’s guide towards taking measurable steps to end the HIV epidemic. State and local health departments play a critical role in collecting, organizing, analyzing and reporting surveillance data to the Administration. These data are then used to establish national HIV incidence and prevalence and are critical for measuring progress towards the goals of the NHAS. Most, if not all, of the indicators developed to measure progress towards the NHAS will be based upon HIV surveillance data.

The HIV Care Continuum Initiative (HCCI), released in 2013 to accelerate developments in HIV prevention and care, provides a tool to measure progress towards increased access to and retention in medical care and antiretroviral treatment as a primary means to prevent new HIV infections. This encompasses diagnosing HIV and linking individuals to care, engaging, re-engaging and retaining individuals in care and successfully treating individuals and achieving viral suppression. HIV surveillance data play a central role in strategically targeting public health action along the HCCI, and to more effectively locate and reach individuals and communities in need.

DATA TO CARE
To help achieve the goals of the HCCI, CDC has begun promoting Data to Care programs. Data to Care activities involve the use of HIV surveillance data to determine individuals who may need linkage-to-care or re-engagement services, and they are a key step to supporting individuals along the HCCI and ultimately achieving viral suppression. Data to Care strategies are implemented by state and local health departments in partnership with clinical providers and community based organizations. To have sufficient data and for health departments officials to effectively do their jobs, Data to Care programs must rely on robust surveillance programs. Data to Care programs have begun relying on both sexually transmitted disease (STD) and HIV surveillance data and increasingly utilizing Disease Intervention Specialists to reach individuals who have dropped out of care. This allows health departments to intervene directly in disease control and broaden the typical descriptive and monitoring purposes of HIV surveillance.

WHERE DO GAPS EXIST?
FUNDING
HIV surveillance has been chronically underfunded. As a result, many states and directly funded cities fund their HIV surveillance programs with resources leveraged from other programs, including other HIV surveillance activities and HIV prevention and care. When faced with cuts or continued flat funding for surveillance programming, health departments are often forced to reduce or eliminate staff positions or hours, threatening the completeness and timeliness of the data used to measure our progress toward ending the epidemic. Funding cuts damage the effectiveness of programs, decreasing the time available to 1) analyze the data to identify people who are not in care, 2) find missing data by matching with other databases to find critical information, including

INCLUSIVE THE TRANSGENDER COMMUNITY IN SURVEILLANCE DATA
There is no uniform collection of data on transgender individuals living with HIV in the U.S. Often, transgender individuals are misidentified or miscounted (e.g., trans women counted as MSM). Even without national surveillance data on trans individuals, there are increased data that show the trans community is disproportionately impacted by HIV, particularly black trans women.

CDC has made efforts to revise and improve the national surveillance systems to include assigned gender at birth and current gender identity. Additionally, in 2011, the Institute of Medicine (IOM) released recommendations that called for behavioral and surveillance data on transgender persons to be collected and analyzed separately from MSM. This type of collection increases the likelihood that trans individuals will be accurately identified.

This allows health departments to intervene directly in disease control and broaden the typical descriptive and monitoring purposes of HIV surveillance.
dates of deaths or births to HIV-positive women, allowing less analysis of trends and/or to find unreported cases.

REPORTING DELAY
HIV incidence statistics are often adjusted to account for reporting delays—the difference between the dates of diagnosis and report. Federal and state partners expect the delay to eventually decrease as an increasing number of sources are implementing electronic medical records (EMR). However, the time and effort needed to transition from health department reporting based on paper medical records to the unstandardized and variable EMR systems is substantial.

REPORTING BURDEN
Health departments are increasingly required to report additional information to federal agencies. Despite the fourth goal of the NHAS to simplify grant administration activities, standardization of data collection and streamline reporting requirements, between 2011 and December 2014, there were increases in the number of federal reporting requirements. A recent NASTAD analysis found that health departments face 238 federal reporting requirements, with 41 states required to meet at least 125 annual reporting requirements associated with federally-funded HIV, hepatitis, STD and tuberculosis (TB) programs.

Over the past two years, there has been progress to streamline and reduce data reporting requirements on the part of federal agencies. Even with these reductions, health departments have not seen substantial reductions in the overall administrative effort or burden related to grant or cooperative agreements, and new administrative and reporting requirements continue to be added.

RECOMMENDATIONS
In order to improve surveillance systems in the U.S., NASTAD recommends the following:

1. Robust funding for the surveillance branches of the CDC’s DHAP
   › Additional resources will allow improvements in core surveillance and expand surveillance for HIV incidence, behavioral risk and receipt of point of care information, including electronically reported CD4 and viral load results. This will, in turn, contribute to improved testing and linkage to care, retention and re-engagement in care and reducing risk behaviors.

2. Invest in the creation of a national hepatitis surveillance system
   › A national hepatitis surveillance system will allow states to develop monitoring systems and prevention strategies to stop any emerging hepatitis epidemics. Additionally, it will strengthen state and local capacity to detect new infections, coordinate prevention activities and provide feedback to providers for quality improvement and track progress toward prevention goals.

3. Align data reporting requirements related with STD, hepatitis and TB funding streams
   › Continue to provide specific recommendations to CDC and HRSA on a joint guidance that will inform the development of a singular health department HIV plan that meets the requirements of HRSA’s Comprehensive Plan and Statewide Coordinated Statement of Need, as well as CDC’s Jurisdictional Plan.
   › Encourage the linkage of surveillance systems, particularly STD/HIV systems. This will further Data to Care programs and provide health departments with the necessary information to engage PLWH who are lost to care.

THE ROLE OF SURVEILLANCE IN DISEASE OUTBREAKS
Surveillance programs serve as an early warning for potential threats to public health. Specifically, HIV surveillance programs identify unusual patterns of transmission of disease. This can help public health officials determine if there is an outbreak. During an outbreak, HIV surveillance programs identify modes of transmission (i.e., IDU, MSM) and target testing initiatives. Public health officials identify prevention practices that can be targeted by interventions to reduce future transmissions.

Surveillance programs also allow public health officials to perform contact tracing. Contact tracing for individuals with acute HIV infection can effectively lead to the diagnosis of other PLWH. Using the path of transmissions during an outbreak, public health officials can design prevention strategies to avert future outbreaks.
FOOTNOTES

i. 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.

ii. 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.

iii. California; Chicago, IL; Delaware; Florida; Georgia; Houston, TX; Illinois; Indiana; Los Angeles County, CA; Michigan; Mississippi; New Jersey; New York; New York City, NY; North Carolina; Oregon; Pennsylvania; Philadelphia, PA; Puerto Rico; San Francisco, CA; Texas; Virginia; and Washington.

REFERENCES


