



Accurate, Complete, Timely HIV Surveillance Data
for Public Health Action

Technical Guidance for HIV Surveillance Programs

Overview of HIV Surveillance and Technical Guidance Files

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Acknowledgments

The *Technical Guidance for HIV Surveillance Programs* is a series of Technical Guidance files that are part of a portfolio of resources to guide HIV surveillance programs at health departments in U.S. states, cities, and territories on the implementation of HIV surveillance systems in accordance with state, local, and territorial laws, regulations, and practices.

These files are living documents and the updates include adaptations and adjustments from previous iterations. We acknowledge previous contributors from the Centers for Disease Control and Prevention (CDC), other federal agencies, academic partners, and state, local, and territorial health departments.

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Contents

Introduction	5
Overview of HIV Surveillance Activities	7
CDC HIV Surveillance Portfolio: Monitoring the Spectrum of HIV Infection	7
National HIV Surveillance System (NHSS).....	7
National HIV Behavioral Surveillance System (NHBS).....	8
Injection Drug Use Surveillance Project (IDU-SP).....	9
Medical Monitoring Project (MMP).....	9
Surveillance of HIV-Related Service Barriers Among Individuals with Early or Late HIV Diagnoses (SHIELD).....	10
Conducting HIV Surveillance	10
Data for Public Health Action	11
Policies and Procedures	11
HIV Surveillance Case Definition.....	12
Security and Confidentiality (S&C) Standards.....	12
Document-based Data Management	13
Evaluation and Data Quality	13
Uses of HIV Surveillance Data: Analysis and Dissemination	14
Surveillance Standards	14
Process Standard	14
Description of Technical Guidance Files	15
Data Collection and Reporting	15
Adult HIV Confidential Case Report Form.....	15
Date and Place of Residence.....	15
Death Ascertainment	15
Pediatric HIV Confidential Case Report Form.....	15
Pediatric HIV Surveillance	16
Reporting	16
Risk Factor Ascertainment	16
Data Systems and Management	16
Data Management.....	16
Duplicate Review.....	16
Record Linkage.....	17
Data Analysis, Dissemination, and Evaluation.....	17
Data Analysis and Dissemination.....	17
Evaluation and Data Quality.....	17
Data for Action and Special Considerations.....	17
Cases of Public Health Importance (COPHI).....	17
Data to Care Reporting	18

Detecting HIV Clusters..... 18
Early HIV Infection, HIV-2, and Other Diagnostic Considerations 18
Geocoding and Data Linkage 18
Integrated Guidance for Developing Epidemiologic Profiles 19
CSTE Position Statements 19
Recommended Readings 20
References 21
Appendix 22
 Dear Colleague Letter About HIPAA, Public Health Disease Surveillance and Data Protections ..22

Introduction

The goals of HIV surveillance are to describe the burden and epidemiology of HIV, monitor HIV trends, identify HIV clusters and outbreaks, and guide public health action at the federal, state, local, and territorial levels.

The *Technical Guidance for HIV Surveillance Programs* is a series of Technical Guidance files that are part of a portfolio of resources to guide HIV surveillance programs at health departments on the implementation of HIV surveillance systems in accordance with state, local, and territorial laws, regulations, and practices. These files are prepared by the Centers for Disease Control and Prevention (CDC) in collaboration with the Council of State and Territorial Epidemiologists (CSTE), with contributions from state, local, and territorial HIV surveillance programs. These files are living documents and the updates include adaptations and adjustments from previous iterations.

State, local, and territorial HIV surveillance programs at health departments are responsible for their HIV surveillance system, which encompasses surveillance activities, reporting sources, surveillance information systems (including the enhanced HIV/AIDS Reporting System [eHARS]), and other supporting tools (like ATra Blackbox, Secure HIV-TRACE). All HIV surveillance systems together contribute to the National HIV Surveillance System (NHSS).

CDC provides technical assistance and support to HIV surveillance programs to ensure that HIV surveillance systems have complete, accurate, and timely data for public health action. The HIV Surveillance Branch (HSB) of the Division of HIV Prevention (DHP), National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) is responsible for NHSS.

The Technical Guidance files, periodically, will include examples of how eHARS can be used for collecting and managing HIV surveillance data. Note that the same demonstrated concepts should also apply if another surveillance information system is used by the HIV surveillance program.

Technical Guidance file *Overview of HIV Surveillance and Technical Guidance Files* provides an overview of HIV surveillance, reflects CDC and CSTE current guidance for standards and best practices, and briefly describes each of the Technical Guidance files.

HIV surveillance programs should ensure that their policies and procedures include the activities described in this Technical Guidance file and relevant public health actions; policies and procedures should be reviewed at least annually and updated as needed. Ensure that staff are trained on the policies and procedures with a focus on changes to procedures or areas needing improvement. Contact the HIV surveillance program's CDC surveillance project officer with any questions or feedback about this Technical Guidance file. If needed, call the HSB main phone number at 404-639-2050 for assistance with identifying the HIV surveillance program's CDC surveillance project officer.

Background and Purpose of HIV Surveillance

AIDS (now HIV infection, stage 3) reporting was initiated at the national level in 1981 to help monitor the scope and impact of the epidemic. After the Food and Drug Administration (FDA) approved the first HIV antibody test in 1985, several states expanded their AIDS surveillance systems to include surveillance of HIV infection. Since 2008, all 50 states, the District of Columbia, Puerto Rico, and the U.S. dependent areas conduct HIV reporting, in addition to stage 3 reporting.

For HIV surveillance data to be comparable and valuable on a national level, all participating HIV surveillance programs need to collect data with a high level of accuracy and consistency. The *Technical Guidance for HIV Surveillance Programs* files

- address the importance of maintaining a standardized framework for data collection by all HIV surveillance programs,
- describe the required components of an effective HIV surveillance system, and
- suggest methods and techniques designed to optimize productivity.

Public health surveillance is defined as the ongoing systematic collection, analysis, and interpretation of health data for public health purposes, and the timely dissemination of public health information for assessment and public health response to reduce morbidity and mortality [1].

HIV surveillance aims for more equitable public health action by making HIV surveillance data more complete, accurate and timely.

The primary functions of HIV surveillance are to:

- collect epidemiologic data to monitor HIV trends
- detect HIV clusters and outbreaks
- monitor HIV prevention and care outcomes
- disseminate findings and support data interpretation

HIV surveillance has been used for one or more of the following purposes:

- measure numbers and rates of new diagnoses and prevalence of HIV infection and HIV-related morbidity and mortality
- estimate HIV incidence and prevalence
- identify rapid HIV transmission
- guide planning, implementation, and evaluation of prevention programs and health-care services
- inform HIV policies and resource allocation for prevention and care
- identify HIV disparities

- support status neutral and syndemic approaches for prevention and care
- support equitable individual- and population-level public health action

The release of the 2010 National HIV/AIDS Strategy (NHAS), the 2019 plan to end the HIV epidemic in the United States (EHE), and the updated NHAS 2022–2025 [2–4] provides stakeholders across the United States a way to accelerate efforts to end HIV in the United States and has served to highlight the need for complete, accurate, and timely HIV surveillance data in order to monitor progress toward meeting NHAS and EHE goals and objectives.

Overview of HIV Surveillance Activities

CDC HIV Surveillance Portfolio: Monitoring the Spectrum of HIV Infection

CDC and public health partners promote the health of all Americans by preventing HIV infection and reducing HIV-related illness and death. To be most effective, information and data about persons who engage in behaviors that increase their chances of getting HIV, those with HIV but who are unaware of their HIV status, those who do know and are not receiving treatment, and those with HIV who need support staying in care and adherent to their medications is needed. Given the infectious and chronic disease characteristics of HIV, CDC established an HIV surveillance approach that begins by assessing certain behavioral risk factors for HIV and continues to monitor events across the spectrum of disease from behavioral risk factors to testing, diagnosis, stage of HIV disease, linkage to care, treatment, and death. This approach requires gathering different types of information using different methods and systems tailored to the populations and type of data needed. DHP-supported HIV surveillance systems and surveillance-related projects (for more information, see [CDC’s HIV Surveillance and Monitoring systems page](#)) are used to describe behaviors of persons disproportionately affected by HIV so that intended populations receive HIV prevention and care efforts, monitor patterns of HIV infection, identify individuals in need of engagement or re-engagement in care, monitor clinical outcomes of persons with HIV, monitor population-level HIV drug resistance patterns, and detect and respond to HIV transmission clusters. These data are used and relied upon by organizations and government agencies at all levels to allocate medical care resources and services, guide prevention and disease control activities, and monitor progress toward achieving national prevention goals of ending the HIV epidemic in the United States (for more information, see CDC’s Ending the HIV Epidemic in the U.S. (EHE) page, available at <https://www.cdc.gov/endhiv/index.html>).

The CDC HIV Surveillance Portfolio to monitor the spectrum of HIV infection includes:

National HIV Surveillance System (NHSS)

NHSS is the primary source for monitoring trends in HIV infection and deaths in the United States. NHSS data are used for calculating core indicators for monitoring progress for both EHE and National HIV/AIDS Strategy (NHAS) including HIV incidence, knowledge of HIV status, HIV diagnoses, linkage to HIV medical care, and HIV viral suppression. The fifty states, the District of Columbia, and 6 U.S. dependent areas have regulatory authority and confidentiality

protections to collect information on persons with diagnosed HIV infection. Data are secondary data collected from medical records and laboratory reports using standard confidential case reports and are reported to CDC without personal identifiers. The data collected include adult/adolescent and pediatric case reports of persons with diagnosed HIV infection and reports of perinatally exposed infants. While data are not collected from individuals living with HIV, these reports together with clinical and laboratory data provide information on stage of HIV disease among individuals and are used to monitor basic care outcomes. HIV surveillance collects information from initial diagnosis of HIV infection to death. This includes information on numerous HIV-related sentinel events, such as the date of initial diagnosis; first and subsequent measurements of CD4, HIV viral loads, and HIV nucleotide sequences from drug resistance tests; HIV negative test results for persons with diagnosed HIV infection, immunologic and clinical diagnosis of stage 3 HIV infection (or AIDS); and death. Infants born to persons with HIV infection are followed up to determine the infant's diagnostic status and provide critical information to evaluate prevention efforts to eliminate perinatal transmission and improve health of infants. Programs routinely collect information on deaths among persons reported with HIV from vital statistics or matching to the Social Security Death Master File and National Death Index. CDC estimates HIV incidence, prevalence (diagnosed and undiagnosed) and percent of undiagnosed HIV infections. HIV surveillance data are used for classifying HIV infection in one of five stages, detecting rapid HIV transmission, and monitoring prevention and care outcomes.

National HIV Behavioral Surveillance System (NHBS)

HIV bio-behavioral surveillance data are collected from populations that are disproportionately affected by HIV. Bio-behavioral surveillance data are used to monitor prevalence and trends in sexual behaviors, drug use, HIV testing, and use of HIV prevention and care services. NHBS ([National HIV Behavioral Surveillance \(NHBS\) | HIV Data | CDC](#)) is CDC's comprehensive system for conducting surveillance among persons with behavioral risk factors for HIV infection living in Metropolitan Statistical Areas (MSAs) with the highest HIV prevalence. Interviews, HIV testing, and other testing (e.g., hepatitis or STD testing) are conducted among populations disproportionately affected by HIV including, but not limited to, gay, bisexual, and other men who have sex with men, persons who inject drugs, and heterosexual persons with risk factors for HIV infection. Data on additional priority populations are collected in participating bio-behavioral surveillance programs as funding permits. NHBS focuses on monitoring prevalence and trends in behavioral risk factors for HIV, HIV testing, exposure to and use of prevention services, and other HIV-associated outcomes, and it includes a Brief HIV Bio-behavioral Assessment component (NHBS-BHBA) designed to collect data in populations with specific behavioral risk factors or in areas that are outside of MSAs. NHBS data are electronically collected by trained interviewers via portable computers and are submitted to and managed by a CDC-funded Data Coordinating Center (DCC). NHBS data on a national level are reported in annual surveillance summaries and other reports and are used to monitor national HIV prevention strategies. On a local level, NHBS data are used to prioritize and evaluate HIV-related prevention activities.

Injection Drug Use Surveillance Project (IDU-SP)

IDU-SP is a national HIV behavioral surveillance system to monitor local drug use among Syringe Services Program (SSP) participants in the U.S. While DHP conducts NHBS among PWID in 20 U.S. cities with high burden of HIV every 3 years, yielding critical information, the NHBS mechanism does not allow for data collection outside of major metropolitan areas specifically for PWID. IDU-SP sentinel surveillance expands PWID surveillance to these unreached areas and establishes community partnerships across multiple levels of services that locally address social determinants of health (i.e., medical, behavioral, and housing service providers). Outcomes of the project will contribute to: (1) improved health outcomes for PWID; (2) reduced incidence of infectious disease resulting from injection drug use; and (3) reduced injection drug use and other substance use. The system includes a bio-behavioral survey of PWID and their peers who use drugs to monitor risk factors among people who inject drugs and their peers, access to and use of prevention services, prevalence of HIV and HCV infections, and prevalence of other health outcomes related to injection drug use. The main data collection components include the eligibility screening tool, behavioral survey, and specimen collection for HIV and HCV testing, all conducted by trained project staff. SSPs are recruited from the North American Syringe Exchange Network (NASEN) list of SSPs. PWID and their peers are recruited directly from the SSPs using a respondent-driven sampling method.

Medical Monitoring Project (MMP)

MMP ([Medical Monitoring Project \(MMP\) | HIV Data | CDC](#)) is a surveillance system that draws a representative sample of adults with diagnosed HIV reported to NHSS and collects additional information on behaviors, clinical outcomes, social determinants of health, and quality of care. Data are collected through respondent interviews and medical chart abstractions and are weighted to provide representative estimates at the national level and for each of the 23 project areas (<https://www.cdc.gov/hiv/statistics/systems/mmp/projectareas.html>) that report to MMP. MMP data are used to monitor progress towards meeting National HIV/AIDS Strategy (NHAS) (<https://www.hiv.gov/federal-response/national-hiv-aids-strategy/national-hiv-aids-strategy-2022-2025/>) goals and objectives related to HIV stigma and domains of quality of life, including physical health, mental/emotional health, and structural/subsistence factors for all people with HIV, including among priority populations outlined in NHAS: gay, bisexual, and other men who have sex with men (including Black, Latino, and American Indian/Alaska Native men); Black women; transgender women; youths; and people who inject drugs. By combining interview and medical record abstraction data with periodically collected data on facilities that provide care to people with HIV (through the MMP Facility Survey) MMP describes services associated with these care and prevention outcomes. MMP data are electronically collected via portable computers and are submitted to and managed by CDC staff or a CDC-funded Data Coordinating Center (DCC). MMP data on a national level are reported in annual surveillance summaries ([Behavioral and Clinical Characteristics of Persons with Diagnosed HIV | HIV Data | CDC](#)) and other reports. MMP data are used by state and local health departments, other government agencies, prevention and care planning groups, health care providers, people with HIV, and others to guide program, policy, and funding decisions aimed to improve engagement in care and quality of life, and decrease disparities experienced among people with HIV in the United States.

Surveillance of HIV-Related Service Barriers Among Individuals with Early or Late HIV Diagnoses (SHIELD)

Project SHIELD focuses on persons with early and late HIV diagnosis to understand system- and individual-level factors associated with new infection and delayed testing. Using NHSS surveillance data, health departments identify persons with recent HIV diagnosis at stage 0 or at stage 3 (AIDS) in the United States to characterize barriers, gaps, and failure in existing HIV prevention and testing services. Quantitative and qualitative data are collected to identify actionable missed opportunities for early HIV diagnosis and prevention.

Together, these complementary systems provide the primary population-based data on persons disproportionately affected by HIV, those with diagnosed HIV infection, those who are unaware of their HIV infection, those in treatment and virally suppressed, and those no longer in treatment who need to be re-engaged in care. Each system plays a unique role and contributes information essential to address different aspects of HIV disease along the spectrum.

Conducting HIV Surveillance

HIV is a *reportable* infection that is governed by state, local, and territorial reporting laws and regulations. HIV surveillance programs are responsible for identifying and collecting data on individuals diagnosed with HIV in accordance with the laws of each jurisdiction. HIV is also a *notifiable* infection. The list of notifiable diseases and conditions is maintained by CSTE and CDC. Because HIV infection is also a notifiable infection, HIV surveillance programs voluntarily inform CDC when certain criteria defining a case are met (<https://www.cdc.gov/nndss/about/index.html>). Currently, HIV surveillance programs use document-based surveillance methods, which allow programs to monitor cases longitudinally. Data collected include demographic, clinical, laboratory test results, vital status, and behavioral data. These data are stored and managed in a data platform supported by CDC called the enhanced HIV/AIDS Reporting System (eHARS). eHARS and supporting tools for conducting surveillance activities (i.e., Secure Online Soundex Match Application, ATra Blackbox, and Secure HIV-TRACE) provide a platform for collecting case information and for reporting to CDC securely and confidentially. HIV surveillance programs are at liberty to use ancillary databases in support of surveillance efforts, but end-of-month transfers to CDC are conducted via eHARS. Currently, 55 eHARS installations exist to support the National HIV Surveillance System. De-identified data are transferred from each of these installations monthly to CDC through a secure data network. In addition, CDC is leading a public health data modernization initiative that includes developing maximally efficient and sustainable ways of accessing data, sharing data, and using the data in a timely manner. For more information about the data modernization initiative, see <https://www.cdc.gov/surveillance/index.html>. For additional information about data management, see Technical Guidance file *Data Management*; see Technical Guidance file *Record Linkage* for additional information about specific initiatives to make the data more interoperable.

Many HIV surveillance activities described above are dependent upon state, local, and territorial laws and regulations. The laws and regulations include specifications on activities such as the reporting of all HIV-related laboratory test results, specifically mentioning CD4 results (counts and percentages), viral load results (detectable and undetectable), HIV nucleotide sequence data

and all laboratory tests conducted as part of the HIV diagnostic testing algorithm including any negative tests when part of the algorithm contains a positive or reactive result; HIV perinatal exposure reporting; HIV testing during pregnancy; reporting of pregnant persons with diagnosed HIV infection; and HIV criminalization and data protection laws. As such, HIV surveillance programs should periodically review state, local, or territorial laws and regulations regarding requirements for communicable disease reporting, specifically those for HIV, and update as needed. Refer to CSTE position statements for recommendations regarding these activities <https://www.cste.org/page/PositionStatements>.

Data for Public Health Action

Individual-level public health action involves immediate interventions for priority cases, including epidemiologic follow-up, linkage to care, and partner services activities. Population-level public health action include programmatic activities, such as HIV surveillance program coordination with prevention services, review of comorbid infections, identification of unusual or special cases requiring additional follow-up and cluster detection and response activities. Population-level public health action also includes coordination with other HIV surveillance programs and with CDC to identify recent and ongoing HIV transmission clusters and to describe trends in transmission of drug resistance and the geographic distribution of subtypes in the United States. It also includes ascertaining persons who may not be in care and linking those individuals to needed medical care and services.

Policies and Procedures

CDC supports the CSTE recommendation of implementing standardized case definitions for HIV infection and the classification of stages of HIV disease as outlined in the Public Health Reporting and National Notification for HIV Infection position statement and ongoing revisions to support complete, accurate, and timely reporting of the earliest diagnosis of HIV infection (exclusive of anonymous tests), the results of all HIV-associated laboratory tests, the earliest classification of stage 3 (AIDS) in persons of all ages, deaths among persons with HIV infection, and all cases of perinatal HIV exposure in infants [5].

Recommended practices represent guidance for best public health practices based on scientific data. A single set of policies and procedures cannot address all of the diversity among, and the needs of, individual surveillance systems; therefore, state, local, and territorial HIV surveillance programs must develop their own policies and procedures in accordance with *Technical Guidance for HIV Surveillance Programs* but should tailor them to their specific situations. HIV surveillance programs must ensure their policies and procedures are comprehensive and describe any public health action required for priority cases (e.g., responding to identification of acute or stage 0 HIV infection, cases of public health importance).

Throughout *Technical Guidance for HIV Surveillance Programs*, the use of the word *must* denotes a required action, and use of the word *should* denotes a recommended action.

HIV surveillance programs must protect patients' privacy by adhering to CDC's *Data Security and Confidentiality Guidelines* [6] and adapting them to a Security and Confidentiality (S&C) policy tailored to their jurisdiction.

HIV Surveillance Case Definition

Public health surveillance requires specific case definitions. The definition of a diagnosis of HIV infection for surveillance purposes has changed over time. Reports of diagnoses of HIV infection must satisfy laboratory and clinical criteria included in *Revised Surveillance Case Definition for HIV Infection—United States, 2014*, available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr6303a1.htm>. The case definition will continue to be updated, as needed, to ensure the most accurate monitoring of HIV disease.

Security and Confidentiality (S&C) Standards

A guiding principle of NCHHSTP is to enhance cross-sector collaboration through partnerships, coordination, and community engagement work across disease areas, recognizing the value of syndemic approaches for prevention of HIV, viral hepatitis, other sexually transmitted diseases (STDs), and tuberculosis (TB). Maintaining confidentiality and security of public health data remains a priority across all public health programs and will be a key component of data modernization initiatives. Adoption of common practices for securing and protecting data across programs is critical for ensuring the appropriate sharing and maximizing use and sharing of data for public health purposes and responding to public health emergencies. CDC's *Data Security and Confidentiality Guidelines* provides a strong framework for ensuring data are protected and outlines standards for all NCHHSTP programs to facilitate the secure collection, storage, and use of data while maintaining confidentiality [6]. Maintaining strong data protections as outlined in the guidelines should be a priority for HIV surveillance programs and be considered at every stage of data collection, sharing and use. HIV surveillance programs must protect patients' privacy by adhering to these standards and adapting them to a S&C policy tailored to their jurisdiction. Having written data security policies and procedures help ensure data are protected and staff are aware of their responsibilities to protect the data and is a recommended standard. Breaches of the S&C protocol can result in inadvertent disclosure of protected data. Actual breaches of S&C (e.g., release of patient names to an unauthorized party) can negatively affect people whose information is reported to HIV surveillance programs. Moreover, breaches can compromise the ability of public health officials to sustain surveillance and intervention activities. The NCHHSTP standards include investigating breaches to ensure they are followed up appropriately and policies revised if necessary. Refer to the [Appendix](#) for a Dear Colleague Letter that HIV surveillance programs may use to inform and educate providers about the Health Insurance Portability and Accountability Act (HIPAA), public health disease surveillance and data protections.

Along with CDC's public health data modernization initiative, the authority that governs how, what, and when public health data are collected and shared will also be modernized. Data authority will enable information to travel more seamlessly to everyone who needs it, eliminating duplication and making data sharing less complex. Any new data authority will not change CDC's legal responsibility to strictly adhere to existing privacy standards and laws, including the Privacy Act (<https://www.cdc.gov/surveillance/policy-standards/how-data-authority-works.html>).

Document-based Data Management

To monitor trends in HIV, surveillance staff need to collect accurate information on key events during the time from diagnosis of HIV infection until death. Information collected after diagnosis for select, previous events includes prior negative HIV test results and antiretroviral (ARV) use history (e.g., PrEP, PEP). This information is collected from many sources and documents, including health care providers (adult and pediatric case report forms), laboratories (laboratory reports), and vital records offices (birth and death certificates). Increased use of diagnostic laboratory testing and the growth of electronic reporting have led to an increased number of documents. Historically, consolidated information from all documents had been used to create a single case record for each person with diagnosed HIV infection. Currently, instead of completing one Adult or Pediatric HIV Confidential Case Report Form for a reported case, applicable parts of the form should be completed for each data source contributing information to that HIV case or perinatal HIV exposure.

Unlike case-based data management, document-based data management allows all documents to be stored and retained electronically with their original contents. Staff can refer not only to case report records but also to original source documents. In document-based data management, an algorithm is used to select the most appropriate values from incoming documents to create and update case records for analysis while allowing for review of the overall case information. This approach to data processing requires a shift from storing data in flat, rectangular data files to storing data in relational databases. A relational database is one in which data are stored in several tables that are linked by specific key fields or variables, such as a case identifier.

This approach requires a surveillance information system that supports document-based data management by linkage and retention of individual documents. Document-based surveillance requires that all documents received by the HIV surveillance program and containing case surveillance information on HIV cases be retained. Linking all the documents regarding each patient in one database makes it easier to maintain and process the information, from collection through analysis and dissemination. For additional information about data management, see Technical Guidance file *Data Management* and the most recent eHARS Technical Reference Guide (available at the HSB SharePoint site, <https://cdcpartners.sharepoint.com/sites/NCHHSTP/HSB/default.aspx>).

Evaluation and Data Quality

HIV surveillance programs must evaluate their HIV surveillance systems to monitor data quality and identify possible sources of underreporting and delays in reporting. Evaluation of the National HIV Surveillance System and HIV surveillance systems at state, local, and territorial levels are incorporated into routine surveillance activities at all levels to ensure that it provides complete, accurate, and timely data for public health action. CDC requires that HIV surveillance programs routinely assess their HIV surveillance system on an annual basis, at a minimum, by using both the process and outcome standards. In addition to annual process and outcome measure evaluation, routine monitoring of the quality of the surveillance data is required. For additional information including a list of all evaluation measures, refer to Technical Guidance file *Evaluation and Data Quality*.

HIV surveillance programs should also use their data to assess trends in HIV care outcomes to track progress towards meeting national goals and to inform public health action at the local level. Care outcomes of interest include linkage to HIV medical care within one month of diagnosis, receipt of care among persons living with HIV, and viral suppression among persons living with HIV. For guidance on conducting these calculations, refer to the SAS program *Monitoring HIV Care Outcomes Using Surveillance Data: Updated December 2020* (see Table 3; available at the HSB SharePoint site, <https://cdcpartners.sharepoint.com/sites/NCHHSTP/HSB/default.aspx> in the CDC Developed SAS Programs—Monitoring HIV Care Outcomes folder).

Uses of HIV Surveillance Data: Analysis and Dissemination

All HIV surveillance programs are required to:

- Publish and disseminate an HIV surveillance report annually.
- Publish and disseminate analyses on health equity annually.
- Develop an integrated epidemiologic profile (IEP) at least once every 5 years, to be published at least 6 months before the deadline for submission of the CDC/HRSA Integrated Prevention and Care Plan.
- Annually, update the executive summary and core epidemiologic data of the IEP—including tables and figures. The annual update can be in the form of fact sheets, supplemental reports, slide sets, or any standardized reports utilized by the state. The annual update should include analyses on co-morbidities, as needed for public health action.

These analyses aim to address all questions that may reasonably be expected from users of surveillance data, such as prevention partners, HIV planning groups, and health care providers. These analyses complement each other and are used at the state, local, and territorial levels to allocate HIV prevention and care resources, plan and evaluate programs and policies, and monitor the goals of the National HIV/AIDS Strategy (<https://www.hiv.gov/federal-response/national-hiv-aids-strategy/national-hiv-aids-strategy-2022-2025>). For additional information about analysis and dissemination, see Technical Guidance file *Data Analysis and Dissemination*.

Surveillance Standards

Process Standard

HIV surveillance policies and procedures: At least annually, review the HIV surveillance program’s policies and procedures, and update documents and train staff as needed.

Description of Technical Guidance Files

In total, there are 19 *Technical Guidance for HIV Surveillance Programs* files, including the *Overview of HIV Surveillance and Technical Guidance* file. The remaining Technical Guidance files are divided into 4 categories to support navigating the files. For new HIV surveillance program staff, Technical Guidance file *Overview of HIV Surveillance Technical Guidance Files* should be the first file to review. However, the order to review the remaining Technical Guidance files will depend on the roles of the HIV surveillance program staff and the areas in need of improvement. Contact your CDC surveillance project officer if you need assistance determining the order to review the Technical Guidance files.

Data Collection and Reporting

Adult HIV Confidential Case Report Form

Technical Guidance file *Adult HIV Confidential Case Report Form (ACRF)* describes the purpose and indicators for use of the ACRF and instructions for completing the ACRF, which is designed to collect information for persons with diagnosed HIV 13 years of age or older. The ACRF Technical Guidance file supports standard data collection, which is important for ensuring accurate HIV surveillance data that can guide public health action.

Date and Place of Residence

Technical Guidance file *Date and Place of Residence* describes requirements, standards, policies, and procedures for HIV surveillance programs to determine the date of diagnosis of HIV infection and a person's residence at date of diagnosis and to maintain current address information. Accurate and complete information about the date and place of residence is critical for using HIV surveillance data for public health action.

Death Ascertainment

Technical Guidance file *Death Ascertainment* describes the policies and procedures for collecting data on the deaths of persons with HIV infection. HIV surveillance programs should use death ascertainment activities to update vital status (from alive or unknown to deceased), ascertain cause(s) of death among persons with HIV, and identify persons with HIV infection not previously reported to HIV surveillance programs. These activities are essential for providing the most accurate calculation of HIV infection prevalence (i.e., persons living with diagnosed HIV infection), evaluating efforts to prevent and treat HIV infection, and assessing syndemics.

Pediatric HIV Confidential Case Report Form

Technical Guidance file *Pediatric HIV Confidential Case Report Form (PCRF)* describes the purpose and indicators for use of the PCRF and instructions for completing the PCRF, which is designed to collect information for persons less than 13 years of age who are perinatally exposed to HIV or diagnosed with HIV. The PCRF Technical Guidance file supports standard data collection, which is important for ensuring accurate HIV surveillance data that can guide public health action.

Pediatric HIV Surveillance

Technical Guidance file ***Pediatric HIV Surveillance*** serves as a guide for collecting and managing pediatric HIV surveillance data in the United States and dependent areas including data collection for children <13 years of age with diagnosed HIV infection, infants perinatally exposed to HIV (who may or may not be infected with HIV), and pregnant persons with diagnosed HIV infection.

Reporting

Technical Guidance file ***Reporting*** describes the policies and procedures that health departments should have in place for successful reporting of high-quality HIV laboratory and case reports. The file also describes the components of reporting systems as well as processes and activities that all HIV surveillance programs should have in place to collect and maintain high-quality laboratory and case reports. High-quality case and laboratory reports result in accurately identifying if a person has met the case definition, the stage of HIV infection, the progression of HIV infection, molecular clusters, and care related outcomes.

Risk Factor Ascertainment

Technical Guidance file ***Risk Factor Ascertainment*** describes the risk factors for HIV infection as defined by HIV surveillance that are collected through the patient history variables, and how to summarize this information to convey the risk factor most likely responsible for transmission (transmission category) or all the known ways a person could have been exposed to HIV (exposure category).

Data Systems and Management

Data Management

Technical Guidance file ***Data Management*** focuses on data management activities for all data sources required for state, local, and territorial HIV surveillance programs without regard for whether the program is integrated with other disease surveillance programs. The activities described in this file include the management of paper and electronic documents, record linkage, and documentation of procedures. These practices are supplemented by the technical manual for eHARS, the eHARS Technical Reference Guide.

Duplicate Review

Technical Guidance file ***Duplicate Review*** describes requirements, standards, policies, and procedures for HIV surveillance programs to conduct activities to identify and correct duplicate case reports within a state (intrastate) or between states (interstate). HIV surveillance encourages ongoing and redundant reporting from a variety of sources. HIV surveillance systems must provide a reliable measure of the number of persons in need of HIV prevention and care services at the national, state, local, and territorial levels. An accurate HIV surveillance system is one that minimizes the degree to which it overcounts or undercounts reported cases of HIV infection and maximizes the reliability with which data for a given person are linked over time. Failing to

properly link an incoming surveillance report to an existing case leads to overcounting and incomplete case information, or incorrectly linking an incoming surveillance report to an existing case may lead to undercounting and data contamination.

Record Linkage

Technical Guidance file ***Record Linkage*** describes requirements, standards, policies, and procedures for HIV surveillance programs to conduct record linkage between the HIV surveillance data file and other (“external”) data files, such as a state death certificate data file or data files of laboratory test results (e.g., HIV antibodies, CD4 T-lymphocyte counts, nucleotide sequences). Complete, accurate and timely HIV surveillance data supports equitable public health action.

Data Analysis, Dissemination, and Evaluation

Data Analysis and Dissemination

Technical Guidance file ***Data Analysis and Dissemination*** describes requirements, standards, policies, and procedures for HIV surveillance programs to analyze and disseminate data.

Evaluation and Data Quality

Technical Guidance File ***Evaluation and Data Quality*** describes the evaluation process for HIV surveillance systems and recommendations for routine data quality assessments. Information collected by HIV surveillance programs is the cornerstone for monitoring and characterizing the burden of HIV infection and for planning and evaluating HIV-related prevention and care programs at the national, state, local, and territorial level in the United States. Therefore, it is imperative that systematic and scientific evaluation of HIV surveillance systems at all levels are incorporated into routine surveillance activities to ensure that they provide complete, accurate and timely data for public health action.

Data for Action and Special Considerations

Cases of Public Health Importance (COPHI)

Technical Guidance file ***Cases of Public Health Importance (COPHI)*** describes COPHI, which consist of the following general categories: (1) Cases involving reported unusual transmission circumstances that should be brought to the attention of CDC; (2) Persons with unusual strains of HIV, including HIV-2; and (3) Special diagnostic situations (e.g., persons with false-positive or false-negative test results) that should be communicated with CDC. COPHI may reveal issues related to quality of care, occupational risk factors or transmission risk factors. Due to their public health implications and to accurately reflect the current trends in the transmission of HIV in the United States, COPHI should be a priority for reporting to CDC, investigation, follow-up, and ensuring the collection of high-quality information. Due to the sensitive nature of COPHI information, maintaining security and confidentiality is paramount. Programs are required to collect, maintain, and share data securely and confidentially according to CDC’s *Data Security*

and Confidentiality Guidelines (available at <https://www.cdc.gov/nchhstp/programintegration/Data-Security.htm>)

Data to Care Reporting

Technical Guidance file ***Data to Care Reporting*** describes reporting and evaluation of Data to Care (D2C) Not in Care (NIC) programs. D2C programs use HIV surveillance data to identify people who might not be in care and relink them to HIV medical care and other needed services. D2C efforts also have the added benefit of improving HIV surveillance data quality, such as identifying previously unknown deaths, updating address information, and discovering unreported laboratory results.

Detecting HIV Clusters

Technical Guidance file ***Detecting HIV Clusters*** describes the use of HIV surveillance data to detect clusters through the identification of persons with HIV diagnoses clustered in time and space (i.e., time-space clusters) and clusters of persons with HIV infections with closely related sequences (i.e., molecular clusters). It also describes the mechanisms behind detecting molecular clusters by using HIV nucleotide sequence data and the relationship of a molecular cluster to the larger network experiencing rapid transmission. A brief introduction to the methodology behind time-space cluster detection is also presented.

Early HIV Infection, HIV-2, and Other Diagnostic Considerations

Technical Guidance file ***Early HIV Infection, HIV-2, and Other Diagnostic Considerations*** provides guidance on the detection of stage 0, inferred from a negative or indeterminate HIV test result within 6 months of a confirmed positive result, which indicates early HIV infection (i.e., acute and recent HIV infection). This file also offers guidance on several other topics related to how HIV infection is diagnosed, including rare types of HIV (particularly HIV-2) and special diagnostic considerations (e.g., false-positive results, false-negative results). These diverse topics have in common a negative (nonreactive) HIV-1 test results for persons who have HIV infection. Early infection HIV infection is a **sentinel health event**. Clinicians and laboratories should report immediately, and thorough case investigation and data collection (including previous negative HIV test results) should be the standard of response.

Geocoding and Data Linkage

Technical Guidance file ***Geocoding and Data Linkage*** assists HIV surveillance programs with capturing, storing, analyzing, and displaying geocoded HIV surveillance data along with social determinants of health (SDOH) indicators that may affect health outcomes and quality of life of persons living with HIV infection. The Geocoding and Data Linkage activity (GDL) requires that HIV surveillance data be geocoded to the census tract level (for addresses of residence at the time of diagnosis and addresses at the end of each year for persons living with HIV) and linked at the census tract level to SDOH indicator data from the U.S. Census Bureau's American Community Survey (ACS). Using census tract-level surveillance data at the state, local, or territorial level increases the ability to assess the geographic distribution of HIV, the social determinants associated with HIV, and the relationship of HIV to other diseases and health care

resources in a defined area. These data can help to inform and guide public health actions, decision making, and resource allocation.

Integrated Guidance for Developing Epidemiologic Profiles

Technical Guidance file ***Integrated Guidance for Developing Epidemiologic Profiles*** provides guidance on compiling and interpreting HIV prevention, surveillance, and care data for state, local or territorial HIV epidemiologic profiles. The document provides one set of guidance to help profile writers develop integrated epidemiologic profiles and to advise them how to interpret epidemiologic data in ways that are consistent with, and useful in, meeting the planning and evaluation needs of both HIV prevention and care programs. Integrating data for HIV prevention and care planning helps to streamline the work of health department staff and HIV planning groups (HPGs) by reducing duplicated efforts and by promoting consistency and comparability of data.

CSTE Position Statements

CSTE position statements seek to standardize surveillance case definitions, maintain the Nationally Notifiable Condition List, and address policy issues affecting state, local, and territorial laws, rules, and regulations. HIV-specific position statements are important for implementation of standardized case definitions for HIV infection and the classification of stages of HIV disease; see, for example, the Public Health Reporting and National Notification for HIV Infection position statement, available at <https://cdn.ymaws.com/www.cste.org/resource/resmgr/PS/09-ID-01.pdf>. Ongoing revisions help to support complete, accurate, and timely reporting.

The following list is a sample of helpful position statements; however, it is not a comprehensive list. To view the details of the position statements listed below, as well as all archived statements, visit <https://www.cste.org/page/PositionStatements>.

Year	Title	ID
2021	CSTE recommendations for modernization of laws to prevent HIV	21-ID-03
2017	Surveillance for perinatal HIV exposure: Update	17-ID-05
2017	Transgender HIV Surveillance	17-ID-06
2012	Revisions Recommended for the Surveillance Case Definition for HIV Infection	12-ID-05
2010	Increased Emphasis on Perinatal HIV Surveillance and Prevention	10-ID-02
2009	Public Health Reporting and National Notification for HIV Infection	09-ID-01
2007	Use of HIV/AIDS surveillance data in future Ryan White HIV/AIDS Treatment Modernization Act funding formulas	07-ID-08
2007	Heterosexual HIV Transmission Classification	07-ID-09
2007	Revision of CSTE 06-ID-01: Surveillance Case Definition for HIV Infection among Children age <18 months	07-ID-10
2006	Revision of the Surveillance Case Definition for HIV Infection Among Children age <18 months	06-ID-01

Year	Title	ID
2006	Revision of the Surveillance Case Definition for HIV Infection and AIDS among children age ≥ 18 months but < 13 years	06-ID-02
2006	HIV Incidence Surveillance	06-ID-08
2005	Revision of Surveillance Case Definition for AIDS among adults and adolescents ≥ 13 years of age	05-ID-04
2004	Development of population-based HIV/AIDS clinical surveillance	04-ID-05
2004	Laboratory reporting of clinical test results indicative of HIV infection: new standards for a new era of surveillance and prevention	04-ID-07
2004	Support for “Guiding Principles for HIV Prevention”	04-ID-10
2004	Development of population-based HIV/AIDS clinical surveillance	04-ID-05
2003	The impact of new technologies and therapies on HIV/AIDS surveillance: surveillance of antiretroviral resistance	03-ID-09
2002	Surveillance for perinatal HIV exposure	02-ID-04
2002	Surveillance for HIV Incidence	02-ID-07
2001	Reciprocal (Inter-state) Notification of HIV cases	01-ID-04
2001	Improved laboratory surveillance for HIV	01-ID-03
1999	Revised Surveillance Case Definition of HIV Infection	99-ID-14
1999	Funding for HIV/AIDS Surveillance	99-ID-12
1995	Pediatric HIV Infection: Addition to the National Notifiable Diseases Surveillance System (NNDSS)	1995-6
1995	Reporting of HIV and TB Comorbidity	1995-2

Note. Web address access date: January 2022.

Recommended Readings

Karch DL, Chen M, Tang T. Evaluation of the National Human Immunodeficiency Virus Surveillance System for the 2011 diagnosis year. *J Public Health Manag Pract* 2014;20(6):598–607. <https://pubmed.ncbi.nlm.nih.gov/24253405/>

Birkhead GS, Maylahn CM. State and local public health surveillance. In *Principles & Practice of Public Health Surveillance* (3rd ed). Published August 2010. <https://doi.org/10.1093/acprof:oso/9780195372922.003.0018>

Cohen SM, Gray KM, Ocfemia MC, Johnson AS, Hall HI. The status of the National HIV Surveillance System, United States, 2013. *Public Health Rep* 2014;129(4):335–341. doi:10.1177/003335491412900408

Guidelines Working Group. Updated guidelines for evaluating public health surveillance systems: Recommendations from the Guidelines Working Group. *MMWR* 2001;50(RR13):1–35. <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5013a1.htm>

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1. Thacker SB, Berkelman RL. Chapter 1. History of public health surveillance. In: Halperin W, Baker EL, editors. *Public Health Surveillance*. New York, NY, USA: Van Nostrand Reinhold; 1992:1–15.
2. The White House Office of National AIDS Policy. National HIV/AIDS strategy for the United States. <https://d15z5zmc2jt7n3.cloudfront.net/s3fs-public/nhas.pdf>. Published July 2010. Accessed July 26, 2023.
3. Fauci AS, Redfield RR, Sigounas G, Weahkee MD, Giroir BP. Ending the HIV Epidemic: a plan for the United States. *JAMA* 2019;321(9):844–845. doi:10.1001/jama.2019.1343
4. The White House Office of National AIDS Policy. National HIV/AIDS strategy for the United States 2022–2025. <https://www.hiv.gov/federal-response/national-hiv-aids-strategy/national-hiv-aids-strategy-2022-2025>. Published 2021. Accessed May 2, 2023.
5. CSTE. Public health reporting and national notification for HIV infection. <https://cdn.ymaws.com/www.cste.org/resource/resmgr/PS/09-ID-01.pdf>. Published 2009. Accessed July 31, 2023.
6. CDC. Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Programs: Standards to Facilitate Sharing and Use of Surveillance Data for Public Health Action. <https://www.cdc.gov/nchhstp/programintegration/Data-Security.htm>. Published 2011. Accessed May 2, 2023.

Appendix

Dear Colleague Letter About HIPAA, Public Health Disease Surveillance and Data Protections

September 19, 2023

Dear Colleague,

Balancing the protection of individual health information with the need to protect public health, the HIPAA Privacy Rule expressly permits disclosures without individual authorization to public health authorities authorized by law to collect or receive the information for the purpose of preventing or controlling disease, injury, or disability, including but not limited to public health surveillance, investigation, and intervention. HIV infection is a reportable condition in all 50 U.S. states, the District of Columbia, and 6 U.S. dependent areas, HIPAA does not supersede that requirement. Please refer to the HIPAA Privacy Rule and Public Health Guidance from CDC and the U.S. Department of Health and Human Services for additional information (available at <https://www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.htm>).

HIV is a nationally notifiable condition (see <https://ndc.services.cdc.gov>). CDC collaborates with the Council of State and Territorial Epidemiologists (CSTE) to set standards for HIV data collection and national notification. Under these standards, states and territories voluntarily report HIV case data to CDC; case records do not contain personally identifiable information. CDC provides support, guidance, and technical assistance on the collection, protections, and use of HIV surveillance data. CDC National HIV Surveillance System (NHSS) data are used to monitor HIV trends, alert communities or the nation to HIV clusters and outbreaks, inform HIV prevention and care efforts and policy. CDC publishes aggregate level data according to data re-release agreements with each state and territory (see <https://www.cdc.gov/nchhstp/atlas/index.htm>).

CDC is committed to protecting individuals' privacy. HIV data received at CDC are strongly protected by an Assurance of Confidentiality Statement (AoC) under Section 308(d) of the Public Health Service Act. The AoC guarantees that all information is held in strict confidence; used only for the purposes stated in the AoC; not disclosed or released without the consent of the individual or institution; and protected forever, including after a person's death.

As a condition of receiving funding from CDC's National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), state and territorial health departments must comply with CDC's Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Programs: Standards to Facilitate Sharing and Use of Surveillance Data for Public Health Action (see <https://www.cdc.gov/nchhstp/programintegration/Data-Security.htm>). These standards require that any personal or confidential information collected as part of public health activities is held securely and confidentially and used for legitimate public health purposes. To ensure this guidance is followed, CDC requires states and territories to specifically assess protections in

place to prevent the release of public health data for any non-public health purpose (including for use in criminal cases) and to develop action plans to address any gaps in data protection.

Thank you for your efforts to collect HIV case information and forward it to your state, local, or territorial health department. Please contact the HIV surveillance coordinator at the health department for more information.

Sincerely,

/Angela L. Hernandez/

Angela L. Hernandez, MD, MPH
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National Center for HIV, Viral Hepatitis, STD, and TB Prevention