

Integrated Guidance for Developing Epidemiologic Profiles

*HIV Prevention and Ryan White HIV/AIDS
Program Planning*

Updated March 2022



All material contained in this document is in the public domain and may be used and copied without permission; citation of the source is, however, appreciated.

Suggested citation

Centers for Disease Control and Prevention and Health Resources and Services Administration. *Integrated Guidance for Developing Epidemiologic Profiles: HIV Prevention and Ryan White HIV/AIDS Program Planning*. Atlanta, Georgia: Centers for Disease Control and Prevention; 2022.

The guidance is available at <http://www.cdc.gov/hiv/guidelines/> and at <http://hab.hrsa.gov/>.

Contents

Contributors	5
Executive Summary	6
Introduction	9
Overview	10
Goals and Benefits of Integrated Guidance	11
Core Concepts	12
Starting the Process	14
CDC and HRSA Requirements for Developing a Comprehensive Update or Full HIV Epidemiologic Profile	15
Determining the Scope	15
Determining the Content and Organization of the Profile	17
Development Process	19
Obtaining Profile Data	20
Analysis and Interpretation	23
Confidentiality	26
Core Epidemiologic Questions and Content	28
Overview	29
Points to Consider During Epidemiologic Profile Development	30
Domain 1—Characteristics of General Population in Your Service Area	31
Domain 2—Epidemiology of HIV in Your Service Area	35
Domain 3—HIV Care and Treatment among People with HIV in Your Service Area	55
Domain 4—Prevention of HIV in Your Service Area	63
Completing the Epidemiologic Profile	75
Overview	76
Making Your Profile User-Friendly	77
Writing Your Narrative	79
Disseminating Your Profile	85
Special Considerations	86
Additional Populations	87
Areas with Low Morbidity and Minimal Data	88
Pediatric HIV Surveillance	88

Appendices.....90

- A. Sample Data Tables and Charts with Interpretation Associated with Chapter 3.....91**
- B. Use of Tables, Charts, and Maps to Illustrate Data 122**
- C. Primary Data Sources 130**
- D. Ryan White HIV/AIDS Programs..... 159**
- E. Preparing Oral Presentations of Your Profile 161**
- F. Epidemiologic Profile Feedback Form for Planning Groups 165**
- G. Terms, Definitions, and Calculations 168**

References and Suggested Readings..... 175

Contributors

The original guidance was developed by the Centers for Disease Control and Prevention (CDC) and Health Resources and Services Administration (HRSA) Community Risk Profile Work Group with assistance from state, territorial, and local health departments, and the Academy for Educational Development.

Members of the CDC/HRSA work group that produced the current document: Stacy Cohen, André Dailey, Sharoda Dasgupta, Kevin Delaney, Erica Dunbar, Anne Marie France, Michael Friend, Zanetta Gant, Yvonne Greene, Anna Satcher Johnson, Tonya Joyner, Dafna Kanny, Pamela Klein, Shacara Johnson Lyons, Tebitha Mawokomatanda, Stacy Muckleroy, and Amanda Okello.

Executive Summary

The Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) developed *the Integrated Guidance for Developing Epidemiologic Profiles: HIV Prevention and Ryan White HIV/AIDS Program Planning* to assist with compiling and interpreting HIV prevention, surveillance, and care data for state, territorial, or local 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.

This update builds upon the previous version issued in 2014. Key changes reflect new data sources and new core questions that align with the [National HIV/AIDS Strategy \(2022–2025\)](#) (NHAS) and the [Ending the HIV Epidemic in the U.S.](#) (EHE) initiative.

The U.S. Department of Health and Human Services (HHS), in collaboration with local, state, and federal partners, works toward achieving national goals, such as reducing new HIV infections by 90% by 2030. To reach these goals, the NHAS and EHE initiative are closely aligned and complementary.

The NHAS is a roadmap for ending HIV in the U.S. by 2030 and focuses on four goals:

- Prevent new HIV infections
- Improve HIV-related health outcomes of people with HIV
- Reduce HIV-related disparities and health inequities
- Achieve integrated and coordinated efforts that address HIV among all partners and stakeholders.

The EHE initiative focuses on four key strategies: Diagnose, Treat, Prevent, and Respond to achieve the goal of reducing new HIV infections in the United States by 75% by 2025 and 90% by 2030.

Both the NHAS and EHE initiative include efforts to prioritize reducing HIV-related disparities, including racial, ethnic, and geographic disparities, to address social determinants of health (SDH) that exacerbate disparities, and to reduce gaps in HIV prevention and care. Although there have been significant recent developments in HIV prevention and treatment tools, new infections continue to be highly concentrated among certain communities impacted by SDH, including men who have sex with men, as well as Black/African American, Hispanic/Latino, and American Indian/Alaska Native persons, and persons who live in the southern United States. To support efforts to reduce these health disparities, this updated Epi Profile guidance includes recommendations and examples for incorporating data on the SDH that act as barriers to HIV prevention, testing, and care.

The guidance document is organized into 5 chapters that (1) provide an overview of an integrated HIV epidemiologic profile, (2) outline what writers need to do to start creating a comprehensive profile, (3) list the core epidemiologic questions and describe recommended analyses and data sources, (4) address how to complete a profile that is accessible and user-friendly, and (5) consider special issues that may arise during the writing of the profile. Each chapter is organized into sections. Specific data and core elements to meet the requirements of CDC and HRSA are also addressed. Highlights of each chapter are as follows:

- **Chapter 1**
 - Describes the purpose of the guidance, identifies the audience for the document, and outlines what end users will learn
- **Chapter 2**
 - Describes how to determine the scope, content, and organization of the profile; describes development process and how to obtain and analyze data
- **Chapter 3**
 - Describes 4 domains containing a total of 9 core epidemiologic questions that help to describe the general population and the population of persons with HIV in a jurisdiction
 - Domain 1: Characteristics of general population in your service area
 - Core question 1.1: What are the demographic characteristics and social determinants of health among the general population in your service area?
 - Domain 2: Epidemiology of HIV in your service area
 - Core question 2.1: What is the epidemiology of HIV and HIV-related disparities or health inequities in your service area?
 - Core question 2.2: What is the distribution of social determinants of health that exacerbate HIV-related disparities among people with HIV in your service area?
 - Domain 3: HIV care and treatment among people with HIV in your service area
 - Core question 3.1: What HIV care and treatment services are available in your service area?
 - Core question 3.2: What is the HIV care continuum in your service area for the overall population and for priority populations in your service area (e.g., demographic characteristics, social determinants of health, disparities)?
 - Domain 4: Prevention of HIV in your service area
 - Core question 4.1: What is the landscape of HIV prevention and testing services in your service area, including gaps in prevention?
 - Core question 4.2: What are the indicators of risk for acquiring and transmitting HIV infection in your service area?
- **Chapter 4**
 - Describes how to make the profile user-friendly, write the narrative, and disseminate the profile
- **Chapter 5**
 - Addresses special-needs populations, comorbidities, and areas with low morbidity and minimal data

The guidance also includes appendices, terms, definitions, and calculations common to HIV epidemiologic profiles, and a list of references and suggested readings. The appendices consist of the following:

- Appendix A: Additional Sample Data Tables and Charts with Interpretation Associated with Chapter 3
- Appendix B: Use of Tables, Charts, and Maps to Illustrate Data
- Appendix C: Data Sources
- Appendix D: HRSA Ryan White HIV/AIDS Program
- Appendix E: Preparing Oral Presentations of Your Profile
- Appendix F: Planning Group Epidemiologic Profile Feedback Form
- Appendix G: Terms, Definitions, and Calculations

The data in an integrated HIV epidemiologic profile may be used for several purposes, including HIV planning, designing, and implementing prevention and care activities and the evaluation of those activities, and informing policy decisions and documenting prevention and care needs for underserved groups. Diverse stakeholders including providers, national HIV partners, researchers, consumers, legislators, and the media also use the data. Data presentations and data sources recommended in the guidance should be a starting point in the development of your profile. Recommended analyses represent the minimum data for an integrated profile. Depending on the need for HIV prevention and care services in a jurisdiction, additional analyses may be required, and additional data sources may be available. Technical assistance with analyzing, interpreting, and presenting prevention-related data and care-related data is available from CDC and HRSA.

Epidemiologic profiles should be compiled, interpreted, and summarized by epidemiologists in the state or local health department in collaboration with interested planning group members. Planning group members should, at a minimum, assist in framing the questions to be addressed by the profile. Although input from planning group members is a valuable component of profile development, final editorial control should rest with the state or local health department.

Chapter 1.

Introduction

Section 1 Overview

Section 2 Goals and Benefits of Integrated Guidance

Section 3 Core Concepts

Section 1: Overview

The epidemiologic profile is a document that describes the demographic, social determinants, geographic, behavioral, and clinical characteristics of persons with HIV and other persons who could benefit from HIV prevention in a specific area. The profile is a valuable tool that is used at the state, territorial, and local levels by those who make recommendations for allocating HIV prevention and care resources, planning programs, and evaluating programs and policies.

The Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) are two federal agencies that use HIV epidemiologic and surveillance data. Both agencies provide guidance and funding for programs for persons with, or disproportionately affected by, HIV. The goals of these programs are to prevent HIV infection and promote HIV testing, care, and treatment.

Purpose of the guidance

The *Integrated Guidance for Developing Epidemiologic Profiles* is a joint project of CDC and HRSA. The purpose of the document is to provide guidance to help writers create integrated epidemiologic profiles and advice on how to interpret the data in consistent and useful ways to meet the planning needs of both HIV prevention and care programs. Integrating prevention and care data should help streamline the work of health department staff, HIV planning groups (HPGs), and Ryan White planning councils/advisory groups by reducing duplicated effort and promoting consistency and comparability of data and terms in prevention and care planning.

HIV planning

HIV planning is a process through which people from different walks of life, interests, responsibilities, and involvement with HIV come together as a group to inform and support the development and implementation of an Integrated HIV Prevention and Care Plan, including the Statewide Coordinated Statement of Need. HIV planning is based on the belief that local planning is the best way to respond to local HIV prevention and care needs and priorities and is built on the tenets of Parity, Inclusion, and Representation (PIR). HIV planning is organized by the health department jurisdiction in which HIV prevention and care planning and priority setting (e.g., programs and services provided, resource allocations) within the jurisdiction are decided via a formal concurrence process by the Integrated Planning Group (IPG). The epidemiologic profile is an essential document, in that it informs the following:

- **Integrated HIV Prevention and Care Plan, including the Statewide Coordinated Statement of Need**—The IPG is responsible for developing a comprehensive HIV prevention and care plan. To develop the plan, the IPG should review and discuss information presented in the epidemiologic profile, such as geographical and demographic patterns of HIV cases in the jurisdiction. In addition, data for populations experiencing rapid HIV transmission should be discussed.
- **Composition of Integrated Planning Group**—The IPG should be diverse and include representatives of persons with HIV in the jurisdiction. Members should also be representative of varying races and ethnicities, genders, sexual orientations, ages, and other characteristics such as varying educational backgrounds, professions, and expertise. The demographic

breakdown of HIV prevalence and diagnoses presented in the epidemiologic profile is used to determine the composition of the IPG to create parity in the planning body. These statistics help to ensure that the health department meets this fundamental component of the cooperative agreement. Please refer to CDC’s most recent HIV Planning Guidance (<https://www.cdc.gov/hiv/pdf/p/cdc-hiv-planning-guidance.pdf>) and the RWHAP Part A (<https://hab.hrsa.gov/sites/default/files/hab/Global/happartamanual2013.pdf>) and Part B manuals (<https://hab.hrsa.gov/sites/default/files/hab/Global/habpartbmanual2013.pdf>) for more details about HIV planning processes.

Health departments that have produced profiles using methods that they find effective, but which may differ from the procedures presented here, should feel free to adapt the recommendations in this document based on their own experience, community needs, and priorities.

Section 2: Goals and Benefits of Integrated Guidance

Recognizing that epidemiologic profiles for HIV prevention and care share common purposes, data needs, and staff demands, CDC and HRSA agreed to create common guidance that will contribute to the following goals and benefits:

Goal	Benefit
<ul style="list-style-type: none"> ● Consistent epidemiologic profiles <ul style="list-style-type: none"> ○ common time frame ○ common data ○ core elements with specific sections to meet the individual requirements of CDC and HRSA ○ common data elements, definitions, categories, time frames 	<ul style="list-style-type: none"> ● Increased usefulness and application ● Enhanced sharing of information at all levels (federal, state, regional, territorial, and local) and in all organizations ● Increased quality ● Increased confidence in data validity because the data are being used for two processes
<ul style="list-style-type: none"> ● User-friendly epidemiologic profiles 	<ul style="list-style-type: none"> ● Easy interpretation and application to local needs ● Enhanced possibility that data will be used in planning
<ul style="list-style-type: none"> ● Flexibility to customize profiles to meet local needs 	<ul style="list-style-type: none"> ● Enhanced quality and sharing of information while meeting local requirements
<ul style="list-style-type: none"> ● Shared resources for prevention and care 	<ul style="list-style-type: none"> ● Reduced strain on local capacity ● Reduced duplication of effort

Section 3: Core Concepts

HIV epidemiologic profile goals

An epidemiologic profile should

- provide a thorough description of the overall population in a service area in terms of demographic, SDH, geographic, behavioral, and clinical characteristics
- provide a thorough description of people with HIV in a service area (overall and subpopulations) in terms of demographic, SDH, geographic, behavioral, and clinical characteristics
- describe clinical outcomes for people with HIV in the service area and identify disparities, needs, and barriers to accessing care and treatment among people with HIV
- provide overview of populations/networks experiencing rapid HIV transmission in the area (i.e., networks with multiple new infections occurring within months of one another)
- identify characteristics and inequities of the general population and of populations who are at increased risk for, HIV in defined geographic areas
- provide information required to conduct needs assessments and gap analyses
- provide data for monitoring progress in meeting the goals of federal and state initiatives

Users and uses of an epidemiologic profile

Epidemiologic profiles have many users. The primary users are prevention and care planning groups, recipients, and applicants for funding. As you develop the profile, keep these end users in mind. Make the profile user-friendly to all planning group members, regardless of their experience with epidemiological and statistical data.

Planning groups use the HIV epidemiologic profile to

- identify gaps and set priorities for populations who need prevention and care services
- provide a basis for determining or projecting future needs
- prioritize and allocate funding resources
- develop requests for proposals to providers and subcontractors
- increase general community awareness of HIV
- disseminate data for providers
- frame research and evaluation questions
- apply for, and receive, funding
- respond to public needs (e.g., educators, funding agencies, media, policymakers)

Profile end user	Focus	Specific uses
CDC <ul style="list-style-type: none"> • HIV planning groups (HPGs) • State and local health departments • Community-based organizations 	<ul style="list-style-type: none"> • Preventing and intervening to reduce transmission of HIV 	<ul style="list-style-type: none"> • Prioritize populations and identify appropriate interventions for each priority population • Develop CDC and HRSA Integrated HIV Prevention and Care Plan, including the Statewide Coordinated Statement of Need
HRSA <ul style="list-style-type: none"> • Ryan White HIV/AIDS Program grant recipients • Ryan White HIV/AIDS Program planning bodies • Community-based organizations 	<ul style="list-style-type: none"> • Providing care, treatment, and support services for people with HIV 	<ul style="list-style-type: none"> • Set priorities and allocate resources for care • Develop CDC and HRSA Integrated HIV Prevention and Care Plan, including the Statewide Coordinated Statement of Need • Serve as source document for applications to HRSA's HIV/AIDS Bureau

The profile should also meet the program requirements of the end users. For example, if the planning group using the profile must address emerging communities at risk, ensure that the profile provides data on this topic.

Using the profile to meet CDC HIV prevention guidelines

CDC prevention guidelines state that the HIV planning process should be used to develop a comprehensive HIV prevention plan. The plan is jointly developed by the health department and the HPGs to focus on priority settings and populations for which HIV prevention will have the greatest impact. The first step in HIV prevention planning is the development of an epidemiologic profile. State, local, and territorial health departments are responsible for providing an epidemiologic profile that describes HIV in the HPG's service area.

Using the profile to meet the Ryan White HIV/AIDS Program legislative requirements

As part of needs assessment, an epidemiologic profile is also an important component of Ryan White HIV/AIDS Program planning as found in the Ryan White HIV/AIDS Treatment Extension Act of 2009 ([Public Law 111-87, October 30, 2009](#)). Legislative requirements and the expectations of HRSA's HIV/AIDS Bureau differ by Part (A, B, C, and D). In general, each Part calls for profile preparers to:

- determine the size and demographics of the population with HIV
- determine the service needs of these populations, with particular attention to those who know they have HIV but are not receiving HIV-related services and to historically underserved persons and communities that are experiencing difficulties in obtaining services
- identify populations with urgent needs and substantial comorbidities

Chapter 2.

Starting the Process

Section 1 Determining the Scope

Section 2 Determining the Content and Organization of the Profile

Section 3 Development Process

Section 4 Obtaining Profile Data

Section 5 Analysis and Interpretation

Section 6 Confidentiality

CDC and HRSA Requirements for Developing a Comprehensive Update or Full HIV Epidemiologic Profile

CDC and HRSA have different requirements for producing and updating the HIV epidemiologic profile. Below are several suggestions:

- The health department should produce at least one comprehensive epidemiologic profile in a funding cycle (3–5 years). RWHAP planning consortia and councils should follow their program guidance from HRSA HAB.
- Annually, the health department should update the executive summary and core epidemiologic data—including tables and figures—to ensure that planning groups can identify and set priorities among populations and their prevention and care needs. The annual update can also be in the form of fact sheets, supplemental reports, slide sets, or any standardized reports utilized by the state.

Section 1: Determining the Scope

The first step in preparing an HIV epidemiologic profile is to determine its scope. Scope refers to the boundaries, such as the time frame and geographic area, that define the extent of information in your profile. The scope should be broad enough to provide planning groups with the information and background data they need to identify and set priorities among HIV prevention and care services. At the same time, the scope needs to be narrow enough to meet specific requirements of prevention and care programs. Determining the scope of your epidemiologic profile is a **collaborative** effort that requires consultation **with your planning groups and with other potentially interested parties**.

Checklist for Determining the Scope of an Epidemiologic Profile

- ✓ Is the profile a comprehensive epidemiologic profile or an annual update?
- ✓ What planning jurisdiction(s) or service area(s) should be included?
- ✓ What years of data will be presented in the profile?
- ✓ What specific questions for prevention and care planning should be addressed by this profile?

Examples

- Do the populations at higher risk of acquiring HIV have special needs?
 - What are the trends that can be identified?
 - What are the priorities for prevention and care services among prioritized populations?
 - What are the differences among populations (regarding SDH and health outcomes) that are leading to health disparities in your service area(s)?
- ✓ What resources—time, personnel, and funds—are available to develop the profile?
 - ✓ What sources of information are needed to answer the profile’s epidemiologic questions?
 - ✓ What data are available to supplement the HIV surveillance data that describe HIV in the population?
 - ✓ What information is already available? Additional information, which may be readily available, may allow for a broader scope.

Section 2: Determining the Content and Organization of the Profile

To be useful for prevention and care planning, a full epidemiologic profile should answer several core epidemiologic questions:

- Domain 1: Characteristics of general population in your service area
 - Core question 1.1: What are the demographic characteristics and social determinants of health among the general population in your service area?
- Domain 2: Epidemiology of HIV in your service area
 - Core question 2.1: What is the epidemiology of HIV and the distribution of HIV-related disparities or health inequities in your service area?
 - Core question 2.2: What is the distribution of social determinants of health that exacerbate HIV-related disparities among people with HIV in your service area?
- Domain 3: HIV care and treatment among people with HIV in your service area
 - Core question 3.1: What HIV care and treatment services are available in your service area?
 - Core question 3.2: What is the HIV care continuum in your service area for the overall population and for priority populations in your service area?
- Domain 4: Prevention of HIV in your service area
 - Core question 4.1: What is the landscape of HIV prevention and testing services in your service area, including gaps in prevention?
 - Core question 4.2: What are the indicators of risk for acquiring and transmitting HIV infection in your service area?

Profile sections and organization

A well-organized profile is divided into logical sections:

- Front matter
- Introduction
- Body
- Appendices
- Other back matter

Front matter

The front matter should consist of the following:

- **Contributors**, a list that includes the names of writers and others who worked on the profile
- **Guide to Acronyms and Initialisms**, a list of the shortened names for terms and organizations that appear in the profile
- **Executive summary**, a synopsis of the profile's content. Although the executive summary is at the beginning of the profile, it is one of the last elements you should write
- **Table of contents**, a listing of, and page numbers for, topics, tables, and figures

Introduction

The introduction should include the following:

- **Background** about the history and purpose of the profile
- **General description** of data sources and their strengths and limitations to ensure that users understand what the profile can and cannot explain
- **Overall description** of the profile's strengths and limitations
- **Other sources of information beyond the profile**. Links to MMWR articles, other reports, published work that includes data from your jurisdiction.

Body

The body of the profile includes the epidemiologic questions and the data that answer the questions.

Data are typically presented in tables, graphs, pie charts, or maps. These presentations should be accompanied by a narrative that explains and expands upon the data.

Appendices and other back matter

The back matter should consist of the following:

- **Appendices** contain information on data sources, supporting documentation, and a feedback form for end users to complete and return to the authors.
- **Other back matter (in addition to the appendices)** includes items such as a glossary and a list of references or suggested readings.

Section 3: Development Process

Recommended development process

1. In collaboration with state and local surveillance staff and prevention and care planning groups, determine the specific and unique needs and priorities of the planning group. Determine the boundaries and the scope of the profile. Establish mechanisms to ensure collaboration throughout the process.
2. Obtain core and supplemental data. Determine which of these data to include in the analysis. Suggested data sources are listed below in Section 4.
3. Analyze and interpret data.
4. Present data in user-friendly formats using plain and non-stigmatizing language.
5. Draw overall conclusions, including areas that might benefit from improvement, and write an effective, useful narrative.
6. Write remaining sections and compile complete epidemiologic profile.
7. Prepare clear presentations for appropriate audiences.

Here are some additional tips to help ensure a successful profile development process:

- Realize that the process is a group effort; it cannot be done by one person
- Expect that a full-time equivalent staff person will need at least several months to complete the profile
- Have a knowledgeable person with technical expertise on local data sources review and proofread the document
- Create a dissemination plan well before your profile is complete and ready for distribution

Section 4: Obtaining Profile Data

General data considerations

The following are considerations for reviewing data and data sources that you may use in the epidemiologic profile:

- **Completeness of the data:** How well does the number of reported HIV cases reflect the true number of people with HIV and are thus eligible to be reported? For example, how well does the prevalence of HIV represent the true number of people with HIV in your service area?
- **Timeliness of the data:** How long is the reporting delay between the diagnosis of HIV and the report to the health department?
- **Representativeness of the data:** How well do the characteristics from a data source correspond to the characteristics of the overall population? For example, data from a hospital-based sample may not represent all people with HIV or all people with HIV in care in the area covered by the survey.
- **Age of the data:** How old are the data that will be used for analysis? For example, a behavioral survey conducted in 2010 might not provide data that are sufficiently up to date for current prevention activities.
- **Surrogate, or proxy, markers:** A proxy measure is used as a marker for other variables when what we really want to measure is too difficult to measure directly. For example, some areas may use sexually transmitted disease (STD) data as a proxy when data on sexual behaviors are not available.
- **Small numbers:** When presenting HIV case surveillance data, small numbers of cases need to be interpreted with caution because small absolute changes in the number of cases can produce large relative or proportionate changes in rates that may be misinterpreted by end users. Rates calculated using NHSS data from numerators smaller than 12 should be denoted in a footnote as unreliable. This case threshold was chosen to keep the relative standard error (RSE) below 30% (consistent with surveys). Suggested footnote may read “Reported numbers less than 12, as well as estimated numbers (and accompanying rates and trends) based on these numbers, should be interpreted with caution because the numbers have underlying relative standard errors greater than 30% and are considered unreliable.” Other data sources (e.g., MMP, NHBS) may have different standards for reporting small numbers.
- **Reliability of estimated data:** CDC’s Division of HIV Prevention recommends aligning with the reliability standards the [National Center for Health Statistics \(NCHS\)](#) uses in many of its statistical reports. When presenting estimates of HIV incidence, prevalence, and undiagnosed infection, estimates with RSE < 30% can be considered reliable. Estimates with RSEs of 30%–50% should be interpreted with caution. Estimates with RSEs of > 50% are statistically unreliable and display is not recommended.

Types and sources of data for epidemiologic profiles

This section includes a description of commonly available data and their sources. Several of these sources directly report HIV cases and clinical conditions of persons with a diagnosis of HIV infection.

Other sources are used to round out the picture of HIV in your service area. Other sources also are used if no HIV data are available. See [Appendix C](#) for additional details and data sources.

Type of Data	Sources	Description
HIV case surveillance	enhanced HIV/AIDS reporting system (eHARS)	Used by state and local health departments to collect data on all persons with confirmed diagnoses of HIV infection
Surveillance data on behavioral and clinical characteristics of persons with diagnosed HIV infection	Medical Monitoring Project (MMP)	Annual, cross-sectional complex sample survey that reports nationally and locally representative estimates of behavioral and clinical characteristics among adults with diagnosed HIV in the United States (<i>as applicable</i>)
Surveillance data on behavioral characteristics of people at risk for HIV	National HIV Behavioral Surveillance (NHBS)	Conducted in rotating, annual cycles in three different populations at increased risk for HIV in U.S. urban areas with high HIV prevalence to collect information on HIV-related risk behaviors, HIV testing, and the use of HIV prevention services (<i>as applicable</i>)
Demographic data	U.S. Census Bureau	Used to describe social characteristics (e.g., gender, age, race/ethnicity, and transmission category) of persons in the service area
HIV testing data	National HIV Prevention Program Monitoring and Evaluation (NHM&E)	Collects standardized HIV prevention program evaluation data from health departments and community-based organizations who receive funding from CDC for HIV prevention activities
Ryan White HIV/AIDS Program (RWHAP)	Health Resources and Services Administration (HRSA): RWHAP Services Report (RSR), AIDS Drug Assistance Program Data Report (ADR); other HRSA HIV/AIDS Bureau data reporting systems	Provides a comprehensive system of HIV primary medical care, essential support services, and medications for low-income people with HIV. The program funds grants to states, cities, counties, and local community-based organizations to provide care and treatment services to people with HIV to improve health outcomes and reduce HIV transmission among hard-to-reach populations

Type of Data	Sources	Description
Social determinants of health (SDH)	<i>Community-level</i> eHARS	Used to describe the complex, integrated, and overlapping social structures and economic systems that include the social environment, physical environment, and health services; and structural and societal factors that are responsible for most health inequities. eHARS data are linked to census tract or county level data from the U.S. Census Bureau on characteristics among the general population in the service area (community-level; data are not based on the characteristics of persons with HIV but rather the characteristics of the population where persons with HIV live in the service area).
	<i>Person-level</i> MMP (people with HIV) and NHBS (people at risk for HIV)	MMP/NHBS data are presented in aggregate from participant interviews (person-level) and are based on the characteristics of persons with HIV in the area.
STD, TB, hepatitis B and C surveillance data	National Centers for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) AtlasPlus and local service areas	Provides data on HIV, viral hepatitis, sexually transmitted diseases (STDs), and tuberculosis (TB)
Preexposure prophylaxis (PrEP) coverage	NCHHSTP AtlasPlus	Reporting of persons prescribed PrEP in the service area
Substance abuse data	Substance Abuse and Mental Health Services Administration (SAMHSA) programs	Collect nationally representative data on use of tobacco, alcohol, and illicit drugs; substance use disorders (SUDs); receipt of substance use treatment; mental health issues; and use of mental health services among the civilian, noninstitutionalized population aged 12 or older
Qualitative data, special studies, and surveys at the local level	Service area; local clinics, researchers, and universities	Used to obtain data through observations, interviews, discussion groups, focus groups, and analysis of social networks
Vital statistics	State Vital Records Registrar	Provides information on all births and deaths

Section 5: Analysis and Interpretation

Collecting and presenting HIV data are only part of the task. To be useful to planning groups and others, the data must be analyzed and interpreted.

Analysis is the application of logic to understand and find meaning in the data. It involves identifying consistent patterns and summarizing the relevant details.

The purposes of analysis in an HIV epidemiologic profile are to:

- identify populations affected by HIV and describe their key characteristics and associated SDH
- describe the epidemiology of HIV in the service area; identify emerging populations and their needs
- describe HIV care and treatment outcomes and services available in the service area
- identify groups or populations at higher risk of acquiring or transmitting HIV and identify their prevention needs

The following are a few general guidelines for analyzing and interpreting data for the HIV epidemiologic profile. Also see [Appendix G](#), Terms, Definitions, and Calculations.

Descriptive analysis

Descriptive analysis involves organizing and summarizing health-related data according to time, place, and person. An example of descriptive analysis might be “The transmission category (based on sex at birth) for X% of men with diagnosed HIV infection in the United States in 2010 was male-to-male sexual contact.”

To conduct an effective descriptive analysis, become familiar with the data before applying analytic techniques. This initial examination should progress to summarizing the data with descriptive statistics, such as frequencies and percentages, in a table to explain the distribution of HIV in your service area.

As you analyze and interpret your data, keep the following cautions in mind:

- Be aware of the strengths and limitations of the data source. For example, HIV diagnosis data can include persons who have had HIV for a long time and may not adequately represent persons who recently acquired HIV.
- Surveillance data reflect where a person lived when the diagnosis of HIV was made, which may or may not be where the person currently lives.
- Confidentiality of public health data is a special concern when dealing with small numbers of cases because of the potential that a person can be identified.
- Interpret surrogate or proxy data with caution (e.g., using STD data as a marker for HIV exposure or infection).

- Concerns about lack of reliability mean that you should be careful about misinterpreting large percentage changes (increases or decreases) based on small numbers.

Example: You observe a 200% increase in cases in one group versus a 5% increase in another. However, the 200% increase represents a change from 2 cases in 2010 to 6 cases in 2011; the 5% increase represents a change from 1,000 cases to 1,050 cases. This is an absolute difference of 4 versus an absolute difference of 50. The 200% increase could be due to fluctuations typical of small numbers. Or perhaps 2 of the 6 cases in 2011 should have been reported in 2010. If so, then 4 cases would have been diagnosed in each of the 2 years, and there would have been no increase.

Also see [Appendix G](#), Terms, Definitions, and Calculations.

Where to get technical assistance

The person preparing the profile may want to seek the assistance of the HIV surveillance coordinator if the coordinator is not part of the team preparing the profile. The surveillance coordinator will be able to provide technical assistance in acquiring, analyzing, and interpreting core HIV surveillance data. Also consult with the HIV prevention or care programs in the health department about remaining questions or needs for technical assistance.

If your technical needs cannot be addressed at the local level, technical assistance is available both from HRSA and CDC.

RWHAP grant requirements

For technical assistance needs that relate directly to RWHAP grant requirements, contact HRSA. All technical assistance requests must go through your project officer:

Part A

Division of Metropolitan HIV/AIDS Programs
HIV/AIDS Bureau
Health Resources & Services Administration

Part B

Division of State HIV/AIDS Programs
HIV/AIDS Bureau
Health Resources & Services Administration

For prevention grant requirements

For technical assistance needs that relate to prevention cooperative agreement requirements, contact the Prevention Program Branch at CDC:

Chief, Prevention Development and Implementation Branch
Division of HIV Prevention
National Center for HIV, Viral Hepatitis, STD, and TB Prevention
Centers for Disease Control and Prevention

For developing epidemiologic profiles for HIV prevention planning

For technical assistance needs that relate to developing epidemiologic profiles for HIV prevention planning, contact the HIV Surveillance Branch at CDC:

Chief, HIV Surveillance Branch
Division of HIV Prevention
National Center for HIV, Viral Hepatitis, STD, and TB Prevention
Centers for Disease Control and Prevention
HIVsurveillance@cdc.gov

Other sources

Other sources of technical assistance include researchers at local universities (such as those at schools of public health, programs in community health and education, and social science departments) and organizational entities, such as the American Psychological Association's Behavioral and Social Scientist Volunteers Program.

Section 6: Confidentiality

Confidentiality can be defined as the protection of personal information collected by public health organizations. The right to such protection is based on the principle that personal information should not be released without the consent of the person involved except as necessary to protect public health.

It is important for health departments and service providers to maintain the confidentiality of HIV surveillance data and information about clients and services because people at risk for, and that have, HIV infection have the right to know that information about them is kept confidential by everyone involved, including prevention and care program planners, service providers, and funders. Ensuring the confidentiality of information on individuals is a fundamental requirement.

A breach in confidentiality

A breach in confidentiality is a security infraction that results in the release of private information with or without harm to one or more persons. A breach in confidentiality may cause a person to be subject to harassment and discrimination because their HIV status or other confidential information became publicly linked to that person. Even the erroneous appearance of a link (e.g., someone believed to be HIV-positive because of the release of personal identifying information) can lead to these problems. Therefore, protection of confidentiality is essential to surveillance and the use of data from surveillance and other public health programs.

The relationship of the community, the health department, and care services providers hinges on trust. One way that officials and providers maintain trust is through ensuring the confidentiality of surveillance information. A breach can erode the community's confidence in public health and care systems.

Confidentiality and the use of data

Most states have laws and policies to protect the confidentiality of HIV surveillance data and other information and to protect the privacy of persons with HIV. These laws are supported by several federal statutes. HIV surveillance data reported to CDC are protected by federal assurance of confidentiality. HIV surveillance programs should remind providers that the Health Insurance Portability and Accountability Act (HIPAA) permits public health reporting requirements and that providers are still subject to relevant laws, regulations, and public health practices, as described in "HIPAA Privacy Rule and Public Health: Guidance from CDC and the U.S. Department of Health and Human Services" (<http://www.cdc.gov/mmwr/PDF/wk/mm52SU01.pdf>). Surveillance staff can also find answers to many frequently asked questions regarding HIPAA and public health at the Office of Civil Rights Web site (<http://www.hhs.gov/ocr/hipaa>). In addition, CDC requires, as a condition of funding, that states ensure that security and confidentiality procedures/policies are in place and all policies, procedures and data sharing agreements comply with standards described in CDC/NCHHSTP'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, 2011](#). These standards cover health department responsibilities for the ways in which HIV data are collected, analyzed, maintained, transmitted to CDC or other state agencies, and released, as well as how to dispose of them. These guidelines also recommend that HDs also have data release policies that outline rules for how data may be released and disseminated to the public.

Confidentiality and epidemiologic profiles

Keep confidentiality concerns regarding the data in mind when developing your epidemiologic profile. Use aggregate—rather than individual—reporting of data throughout, including tables and figures. Aggregate data include summary statistics compiled from personal information that have been grouped to prevent the identification of individuals.

For your epidemiologic profile, observe local data release policies and restrictions on small cell size. Many areas suppress data with small cells (e.g., <5) to prevent the inadvertent disclosure of confidential information. These rules may be applicable to certain geographic areas and cross tabulations of data. In addition, some areas may suppress data when populations denominators are small (e.g., population subgroups <100). Areas may also have rules about when to interpret results with caution, based on the stability of rates, when working with a small number of cases. For example, a rule that will be applied when rates are calculated where any numerator in a series is fewer than XX cases (e.g., <12 cases). Under these circumstances, a cautionary note should be included when the data are provided; in some instances, the data should not be released. The following is an example of a cautionary note:

“Note. Please use caution when interpreting numbers less than 12, and rates and trends based on these numbers.”

All health department staff, including all local/state/tribal personnel and contractors, should be informed of the standards and familiar with the local data release policies. When preparing the profile, writers should indicate when data were suppressed because of small cell size.

Analyses by geographic area should be completed within strict guidelines for the confidentiality and release of HIV surveillance data, as specified by the health department. Do not include any personally identifiable information (PII) (e.g., name, address, month and day of birth, or Social Security number) that could identify an individual in the profile, summary data, or presentations to the planning group.

Reference: 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. Published 2011. Available at <http://www.cdc.gov/nchhstp/programintegration/docs/PCSIDataSecurityGuidelines.pdf>.

Chapter 3.

Core Epidemiologic Questions and Content

Section 1 Domain 1: Characteristics of general population in your service area

Section 2 Domain 2: Epidemiology of HIV in your service area

Section 3 Domain 3: HIV care and treatment among people with HIV in your service area

Section 4 Domain 4: Prevention of HIV in your service area

Overview

This chapter discusses the core epidemiologic questions and content that should be included in HIV profiles. It describes the types of supporting data you can use to answer each question and where to find the data, presents recommended analyses, and provides caveats and explanatory notes, as appropriate. The topics are divided into 4 domains with 7 core questions:

- **Domain 1:** Characteristics of general population in your service area
 - Core question 1.1: What are the demographic characteristics and social determinants of health among the general population in your service area?
- **Domain 2:** Epidemiology of HIV in your service area
 - Core question 2.1: What is the epidemiology of HIV and the distribution of HIV-related disparities or health inequities in your service area?
 - Core question 2.2: What is the distribution of social determinants of health that exacerbate HIV-related disparities among people with HIV in your service area?
- **Domain 3:** HIV care and treatment among people with HIV in your service area
 - Core question 3.1: What HIV care and treatment services are available in your service area?
 - Core question 3.2: What is the HIV care continuum in your service area for the overall population and for priority populations in your service area?
- **Domain 4:** Prevention of HIV in your service area
 - Core question 4.1: What is the landscape of HIV prevention and testing services in your service area, including gaps in prevention?
 - Core question 4.2: What are the indicators of risk for acquiring and transmitting HIV infection in your service area?

Describing HIV in the United States relies heavily on surveillance data collected through the coordinated efforts of public health officials and private and public health care professionals throughout the country. States and territories collect data locally and share it with CDC. State, territory, and local health departments and CDC analyze and disseminate the data in a variety of formats for use by public health, prevention and care planning, and health communications and news organizations.

Examining groups at higher risk for HIV infection and answering these core questions will help you understand the characteristics of the population in your service area and the distribution of HIV. The answers provide the basis for setting priorities for populations and then identifying appropriate interventions and services. Answering these core questions is the first step in developing a comprehensive Integrated HIV Prevention and Care Plan for your jurisdiction. Answer the questions as completely as possible, basing your answers on the needs, available data, and resources in your area.

Conducting additional analyses based on the circumstances within your service area may supplement your epi profile. If you choose to conduct additional analyses, be sure to state in the text that you have done so. You may also conduct analyses different from the ones recommended here if you still answer the core questions and provide an interpretation of your tables in the accompanying text.

Supplementing surveillance data with other sources of data will help provide a more comprehensive and in-depth picture of HIV in your service area, but be aware of the caveats and limitations of HIV surveillance data and the strengths and limitations of your data sources.

The remainder of this chapter presents the core questions and the recommended analyses that will help you answer the questions. First, however, the chapter briefly describes the importance of changes in HIV trends in the service area and in HIV surveillance data and the potential effect of these changes on epidemiologic profiles.

Points to Consider During Epidemiologic Profile Development

Because of the successful effects of treatment and the expansion of surveillance data, you may see changes in the trends in HIV in your service area. Keep the following points in mind as you develop your epidemiologic profile.

- The number of persons reported as living with diagnosed HIV infection does not include persons who were not tested, or persons who were tested anonymously or completed self-testing. CDC estimates that at the end of 2019, 1.2 million adults and adolescents were living with HIV infection; of these, 13.3% (158,500) were unaware of their infection. Persons unaware of their HIV infection are not benefiting from improved health and survival associated with antiretroviral therapy and HIV-related care and services.
- Of the persons with diagnosed HIV infection reported in 2019 in the United States and 6 U.S. dependent areas less than a quarter (20.4%) received a stage 3 (AIDS) classification at the same time as their HIV diagnosis. These persons represent those who are tested late in the disease process. Increasing early testing and programs to link persons with HIV to ongoing care and prevention services are essential to reducing the number of new infections and to supporting the health of people with HIV.
- Surveillance data on new HIV diagnoses provide counts of persons known to have received an HIV diagnosis. HIV diagnosis data may not reflect trends in HIV incidence (new infections), because the data are affected by when a person seeks or is offered HIV testing.
- A trend in the number of new HIV diagnoses that is stable, increasing, or decreasing may reflect current or historical patterns in HIV incidence or changes in testing behaviors in the geographic area.

Section 1: Domain 1—Characteristics of General Population in Your Service Area

Core Question 1.1: What are the demographic characteristics and social determinants of health among the general population in your service area?

The general characteristics of the population in your service area provide an essential context. Supporting data will help you examine these characteristics from 2 perspectives:

- Demographic characteristics
- Social determinants of health (SDH)

The information you develop will help you identify the risk factors associated with HIV infection, such as poverty level and lack of health care coverage, and may indicate a greater need for providing prevention and care services. Compile and analyze demographic and SDH data for the populations in your service area to determine trends during the past 5 years. Data should be current based on what is available through the U.S. Census Bureau and other sources providing population-based data. Present substantial changes; if no substantial changes have occurred, state that.

Demographic characteristics

Gender identity (if data available)

Gender identity refers to a person’s internal understanding of their own gender, or the gender with which a person identifies.

- Male: persons assigned “male” sex at birth and gender identity is “male.”
- Female: persons assigned “female” sex at birth and current gender identity is “female.”
- Transgender woman: persons assigned “male” sex at birth and current gender identity is “female.”
- Transgender man: persons assigned “female” sex at birth and current gender identity is “male.”
- Additional gender identity (AGI): persons assigned “male” or “female” sex at birth and current gender identity is not “man,” “woman,” “transgender woman,” or “transgender man.”

Sex

Sex designations are based on a person’s sex at birth.

- Male
- Female

Age

The following age groups are recommended as they align with standard presentations of national-level data:

- <13 years
- 13–14
- 15–24
- 25–34
- 35–44
- 45–54
- 55–64
- ≥65

Other age groupings can also be used in the epidemiologic profile. Although the above age groups are recommended to allow for comparisons with national data, profile writers should consider your local needs when deciding on the age groups to use.

Race and ethnicity

Race and ethnicity are based on categories defined by the Office of Management and Budget (OMB); ethnicity (Hispanic/Latino or Not Hispanic/Latino) is often shown in tables with six categories of race: American Indian/Alaska Native, Asian, Black/African American, Native Hawaiian/other Pacific Islander, White, or a multiracial category (e.g., Black/African American and White). Hispanic/Latino persons may be of any race. For surveillance purposes, Hispanic/Latino ethnicity is shown with race categories regardless of any specific race information entered for the person.

Race and ethnicity are not risk factors but are instead markers for many underlying factors of greater relevance to health, including socioeconomic status and cultural and behavioral characteristics, which are social and not biological. Racial and ethnic differences in health are more likely to reflect profound differences in people’s experiences based on the relatively advantaged or disadvantaged position in society into which they are born. SDH, shaped by economic stability, education access and quality, health care access, neighborhood and built environment, and social and community context, vary systematically by race and ethnicity and are important in explaining differences in health outcomes.

Nativity

Nativity status refers to whether a person is native or foreign-born. The native-born population includes anyone who was a U.S. citizen or U.S. national at birth (born in the United States, Puerto Rico, a U.S. Island Area [U.S. Virgin Islands, Guam, American Samoa, or the Commonwealth of the Northern Mariana Islands], or born abroad of a U.S. citizen parent). Foreign-born is anyone who is not a U.S. citizen at birth (naturalized U.S. citizens, legal permanent residents, temporary migrants, humanitarian migrants, and people with unauthorized status). In recent years, the foreign-born population has come to represent a greater share of the total U.S. population. Areas with a large foreign-born population are encouraged to include presentation of nativity data in the epi profile. Nativity data by state can be acquired from the U.S. Census Bureau’s American Community Survey.

Recommended analyses

- Number and percentage distribution of the general population by
 - age group and sex at birth
 - race/ethnicity and sex at birth

- race/ethnicity and nativity and sex at birth
- race/ethnicity and geographic subunit (e.g., planning region, county, Eligible Metropolitan Area [EMA])

Social determinants of health (SDH)

Social determinants of health are conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks. Stratifying public health data by key SDH is useful in monitoring health inequities. Addressing the SDH that adversely affect health outcomes may advance efforts in reducing disparities in HIV diagnosis rates between populations. Addressing SDH also helps to quantify health differences between populations or geographic areas and can provide insight for identifying populations or areas that may benefit from HIV testing, prevention, and treatment initiatives.

Recommended analyses

- Poverty
- Homelessness/unstable housing
- Uninsured
- CDC Social Vulnerability Index
- Employment

Data sources for demographic characteristics on the general population and social determinants of health

- U.S. Census Bureau (age, sex at birth, race/ethnicity, nativity) (<https://www.census.gov/programs-surveys/popest.html>)
- U.S. Census Bureau's American Community Survey (<https://www.census.gov/programs-surveys/acs/data.html>)
- U.S. Department of Housing and Urban Development (HUD) (homelessness, unstable housing) (<https://www.hudexchange.info/resource/6291/2020-ahar-part-1-pit-estimates-of-homelessness-in-the-us/>)
- United States Interagency Council on Homelessness (USICH) (homelessness, unstable housing) ([https://www.usich.gov/tools-for-action/map/#fn\[\]=1300&fn\[\]=2900&fn\[\]=6400&fn\[\]=10200&fn\[\]=13400](https://www.usich.gov/tools-for-action/map/#fn[]=1300&fn[]=2900&fn[]=6400&fn[]=10200&fn[]=13400))
- CDC Social Vulnerability Index (<https://www.atsdr.cdc.gov/placeandhealth/svi/index.html>)

Section 2: Domain 2—Epidemiology of HIV in Your Service Area

Core Question 2.1: What is the epidemiology of HIV and the distribution of HIV-related disparities or health inequities in your service area?

Using enhanced HIV/AIDS Reporting System (eHARS) data

eHARS is a software application installed at state/local health departments to enter, store, manage and report data collected by HIV surveillance programs. Data on demographic characteristics, geographic locations, risk factors for HIV infection, HIV-related laboratory results, clinical events, prophylaxis and treatment, and deaths among persons with diagnosed HIV infection are collected and stored. eHARS should serve as the primary source for acquiring data to describe the demographic characteristics of people with HIV and epidemiology of HIV in the service area.

Demographic characteristics

In addition to the demographic categories (presented above) used to describe the characteristics of the general population in the service area (sex at birth, age, and race/ethnicity for persons with diagnosed HIV), data on gender identity and HIV transmission/exposure category are collected in eHARS and should be included when describing the demographic characteristics of persons with diagnosed HIV in the service area.

Gender identity

Gender identity refers to a person’s internal understanding of their own gender, or the gender with which a person identifies. HIV surveillance personnel collect data on gender identity, when available, from sources such as case report forms submitted by health care or HIV testing providers and medical records, or by matching with other health department databases (e.g., RWHAP data). CDC routinely provides state and local surveillance programs with guidance on methods for collecting data on transgender persons and working with transgender-specific data. Include a note that transgender men, women, and persons of additional gender identity are adults and adolescents aged ≥ 13 years whenever data are not limited to adults (age 18 years and older).

- Male: persons assigned “male” sex at birth and gender identity is “male.”
- Female: persons assigned “female” sex at birth and current gender identity is “female.”
- Transgender woman: persons assigned “male” sex at birth and current gender identity is “female.”
- Transgender man: persons assigned “female” sex at birth and current gender identity is “male.”
- Additional gender identity (AGI): persons assigned “male” or “female” sex at birth and current gender identity is not “man,” “woman,” “transgender woman,” or “transgender man.”

Transmission category

Transmission category is the term for the classification of cases that summarizes a person's possible HIV risk factors based on their assigned sex at birth; the summary classification results from selecting, from the presumed hierarchical order of probability, the 1 (single) risk factor most likely to have been responsible for transmission. For surveillance purposes, a diagnosis of HIV infection is counted only once in the following hierarchy of transmission categories:

- Male-to-male sexual contact (MMSC): includes individuals assigned male sex at birth, regardless of current gender identity, males who have had sexual contact with other males, and individuals assigned male sex at birth who have had sexual contact with both males and females (i.e., bisexual contact).
- Injection drug use (IDU): includes persons who injected nonprescription drugs or who injected prescription drugs for nonmedical purposes.
- Male-to-male sexual contact *and* injection drug use (MMSC/IDU): includes individuals assigned male sex at birth, regardless of current gender identity, who have had sexual contact with other males (or with both males and females [i.e., bisexual contact]) *and* injected nonprescription drugs or injected prescription drugs for nonmedical purposes.
- Heterosexual contact: includes persons who have ever had heterosexual contact with a person known to have, or with a risk factor for, HIV infection.
- Perinatal: includes persons who acquired HIV through mother-to-child transmission
- Other: includes persons with other risk factors (e.g., blood transfusion, hemophilia) or whose risk factor was not reported or not identified.

HIV indicators

Over the last decade there has been an increased effort to track progress in HIV. Routine presentation of data on the HIV indicators listed in this section will aid HIV planning groups in monitoring progress in HIV prevention and care outcomes as required by the Integrated HIV Prevention and Care Plan. Indicators designated as “NHAS indicator” in this guidance are used to monitor progress in NHAS and should be prioritized for inclusion in epi profiles when feasible. Although HIV affects more than a million people in the United States from all social, economic, and racial and ethnic groups, it disproportionately affects certain populations. In the HNSP, state/local prevention programs are encouraged to focus efforts on selected populations that have been over-represented in the HIV epidemic. Presentation of data on the following priority populations should be included in HIV profiles when sufficient data for their display are available for the service area:

- gay, bisexual, and other men who have sex with men (particularly, Black/African American, Hispanic/Latino, and American Indian/Alaska Native men)
- Black/African American women
- transgender women
- youth aged 13–24 years
- people who inject drugs

HIV incidence (NHAS indicator)

HIV incidence is the estimated number of new HIV infections in a calendar year. New HIV infections among persons aged ≥ 13 years are estimated using surveillance data (HIV diagnoses, the first CD4+ T-lymphocyte [CD4] test result after HIV diagnosis) and a CD4-depletion model indicating disease progression or duration after infection. Epi profile writers should work with local staff experienced with the CD4-based model for estimating HIV incidence in deriving and including HIV incidence estimates in the epidemiologic profile. Consulting with these staff is essential for the appropriate interpretation of HIV incidence data and understanding the factors that may affect incidence estimates produced using the CD4 model (e.g., increases/decreases in HIV testing, completeness of CD4 data, proportion of cases with indications of viral suppression before their first CD4 test, etc.).

HIV incidence data are expressed either as an estimated number of persons newly infected with HIV during a defined period (e.g., a year) or as a rate calculated from the number of estimated persons with new HIV infections divided by the number of persons at risk for HIV infection during the specified period. The relative standard error (RSE) is used to assess the reliability of each point estimate of HIV incidence. CDC's National Center for Health Statistics (NCHS) encourages caution when using estimates with an RSE of $> 30\%$ because they are subject to high estimation error. Estimates that do not meet NCHS's requirement for a minimum degree of reliability are typically not published.

Recommended analyses (assess trends for most recent 5 years):

- Estimated number, percentage distribution, and estimated rates (per 100,000 population) by:
 - sex at birth
 - age group
 - race/ethnicity
 - transmission category (based on sex at birth)
- Estimated numbers and rates by race/ethnicity for each sex

Note. Gender identity not included as estimates, even at the national level, are unreliable due to small numbers.

Incidence estimates produced for jurisdictions without laws requiring reporting of laboratory data, or with incomplete reporting of laboratory data to the HIV surveillance program should also be interpreted with caution.

CDC has provided guidance and SAS programs to state/local HIV surveillance programs for estimating new HIV infections in the jurisdictions using the CD4-based model. State/local surveillance staff should be contacted for the latest estimates.

For examples of data displays, see [Appendix A](#) (Sample Data Tables and Charts with Interpretation Associated with Chapter 3) and [Appendix B](#) (Use of Tables, Charts, and Maps to Illustrate Data). More information on estimating new HIV infections and the limitations and assumptions of the CD4-based method can be found in the Technical Notes of CDC's *HIV Surveillance Supplemental Report*, "Estimated HIV Incidence and Prevalence in the United States," at <https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>.

Estimated HIV prevalence (estimates of diagnosed and undiagnosed infection)

HIV prevalence is the estimated number of persons with HIV, including persons with diagnosed and undiagnosed infection, at the end of a specified year. HIV prevalence among persons aged ≥ 13 years is estimated using CD4-based model estimates and surveillance data (HIV diagnoses and deaths). Epi profile writers should work with local staff experienced with the CD4-based model for estimating HIV incidence and prevalence in deriving and including HIV prevalence estimates in the epidemiologic profile. Consulting with these staff is essential for the appropriate interpretation of HIV prevalence data and understanding the factors that may affect prevalence estimates produced using the CD4 model.

Recommended analyses

- Estimated number, percentage distribution, and estimated rates (per 100,000 population) by:
 - sex at birth
 - age group
 - race/ethnicity
 - transmission category (based on sex at birth)
- Estimated numbers and rates by race/ethnicity for each sex

Note. Gender identity not included as estimates, even at the national level, are unreliable due to small numbers.

Knowledge of HIV status (NHAS indicator)

Knowledge of HIV status is the estimated percentage of persons aged ≥ 13 with HIV who have received a diagnosis. For this measure the numerator (data reported to CDC) is the number of persons aged ≥ 13 years living with diagnosed HIV infection at the end of the year. The denominator, estimated HIV prevalence (discussed above), is the estimated number of persons aged ≥ 13 years living with HIV infection (diagnosed or undiagnosed) at the end of the year.

Recommended analyses

- Estimated percentage with diagnosed HIV by:
 - sex at birth
 - age group
 - race/ethnicity
 - transmission category (based on sex at birth)
- Numbers and rates by race/ethnicity for each sex

Note. Gender identity not included as estimates, even at the national level, are unreliable due to small numbers. CDC has provided guidance and SAS programs to state surveillance programs for estimating HIV prevalence and knowledge of HIV status in the jurisdictions using the CD4-based model. State/local surveillance staff should be contacted for the latest estimates.

Prevalence and knowledge of status estimates produced for jurisdictions without laws requiring reporting of laboratory data, or with incomplete reporting of laboratory data to the HIV surveillance

program, should be interpreted with caution. Accurate estimation of prevalence and knowledge of status is dependent upon complete death ascertainment.

For recommended data displays, see [Appendix A](#) (Sample Data Tables and Charts with Interpretation Associated with Chapter 3) and [Appendix B](#) (Use of Tables, Charts, and Maps to Illustrate Data).

More information on estimating HIV prevalence and knowledge of status can be found in the Technical Notes of CDC's *HIV Surveillance Supplemental Report*, "Estimated HIV Incidence and Prevalence in the United States," at <https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>.

Data sources for HIV indicators

- HIV surveillance data (eHARS)
- Vital statistics data
- National Center for Health Statistics mortality dataset
- National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) AtlasPlus
- America's HIV Epidemic Analysis Dashboard (AHEAD)

HIV diagnoses (NHAS indicator)

HIV diagnoses are the number of HIV infections confirmed by laboratory or clinical evidence in a calendar year. Counts include persons with a diagnosis regardless of the stage of disease (stage 0, 1, 2, 3 [AIDS], or unknown). HIV diagnoses data are expressed as either the number of persons with newly diagnosed HIV during a defined period (e.g., a year) or as a rate calculated from the number of persons with newly diagnosed HIV divided by the number of persons in the population during the specified period.

Recommended analyses (assess trends for most recent 5 years)

- Number, percentage distribution, and rates (per 100,000 population) by:
 - sex at birth and gender
 - age group
 - race/ethnicity
 - transmission category (based on sex at birth; rates not available)
 - exposure category (for transgender and AGI persons; rates not available)
- Numbers and rates by race/ethnicity for each sex

When presenting data on diagnoses, profile developers should keep in mind (and remind users) that data on diagnoses of HIV infection may not be representative of all persons with HIV because not all persons with HIV have been (1) tested or (2) tested at a time when the infection could be detected and diagnosed. Also, your service area may offer anonymous HIV testing or people may complete self-testing at home; the results of anonymous and self-tests are not reported to the confidential, name-based HIV registries of state and local health departments. Therefore, reports of confidential test results may not represent all persons who tested positive for HIV infection in your service area.

Data on HIV diagnoses can also be displayed by stage of disease. Stage of disease at time of HIV diagnosis (i.e., HIV infection, stage 0, 1, 2, 3 [AIDS], or unknown) is determined by using the first CD4 test result or documentation of an AIDS-defining condition ≤ 3 months after the HIV diagnosis date, unless documentation indicated disease stage 0. For stage of disease at time of diagnosis, infections should be classified as “stage unknown” if the month of HIV diagnosis is missing, or if, ≥ 3 months after HIV diagnosis, neither a CD4 count nor a CD4 percentage had been determined and no AIDS-defining condition has been documented.

For recommended data displays, see [Appendix A](#) (Sample Data Tables and Charts with Interpretation Associated with Chapter 3) and [Appendix B](#) (Use of Tables, Charts, and Maps to Illustrate Data).

More information on counting diagnoses of HIV infection can be found in the Technical Notes of CDC’s annual *HIV Surveillance Report* at <https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. More information on calculating and presenting data stage of disease at diagnosis can be found in the Technical Notes of CDC’s *HIV Surveillance Supplemental Report*, “Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas,” at <https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>.

Linkage to HIV medical care within 1 month of diagnosis (NHAS indicator)

Linkage to HIV medical care is the percentage of persons who have received a diagnosis of HIV infection in a calendar year and were linked to HIV medical care within 1 month. The numerator is the number of persons aged ≥ 13 years whose HIV infection was diagnosed during the specified period, and who had ≥ 1 CD4 or viral load (VL) tests within 1 month of HIV diagnosis. The denominator is the number of persons aged ≥ 13 years whose HIV infection was diagnosed during the specified period. Reporting of linkage to HIV medical care data requires a minimum 3-month reporting lag to account for delays in reporting of laboratory results to the state/local health department.

Recommended analyses

- Number and percentage distribution by:
 - sex at birth and gender
 - age group
 - race/ethnicity
 - transmission category (based on sex at birth)
 - exposure category (for transgender and AGI persons; rates not available)
- Numbers and percentages by race/ethnicity for each sex

Linkage to care data for jurisdictions without laws requiring reporting of laboratory data, or with incomplete reporting of laboratory data to the HIV surveillance program, should be interpreted with caution.

For recommended data displays, see [Appendix A](#) (Sample Data Tables and Charts with Interpretation Associated with Chapter 3) and [Appendix B](#) (Use of Tables, Charts, and Maps to Illustrate Data). CDC has provided guidance and SAS programs to state/local HIV surveillance programs for calculating care outcomes.

More information on calculating and presenting data on linkage to HIV medical care can be found in the Technical Notes of CDC's *HIV Surveillance Supplemental Report*, "Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas," at <https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>.

Receipt of HIV medical care

Receipt of HIV medical care is the percentage of persons with diagnosed HIV who received care at any time during the calendar year. Receipt of any HIV medical care should be measured by documentation of ≥ 1 CD4 or viral load tests performed during the specified year. Retention in care (receipt of continuous HIV medical care) is measured by documentation of ≥ 2 CD4 or viral load tests performed ≥ 3 months apart during the specified year.

Recommended analyses (for receipt and retention in HIV medical care)

- Number and percentage distribution by:
 - sex at birth and gender
 - age group
 - race/ethnicity
 - transmission category (based on sex at birth)
 - exposure category (for transgender and AGI persons; rates not available)
- Numbers and percentages by race/ethnicity for each sex

Receipt of care data for jurisdictions without laws requiring reporting of laboratory data, or with incomplete reporting of laboratory data to the HIV surveillance program, should be interpreted with caution. Accurate monitoring of receipt of HIV medical care is also dependent upon complete reporting of deaths.

For recommended data displays, see [Appendix A](#) (Sample Data Tables and Charts with Interpretation Associated with Chapter 3) and [Appendix B](#) (Use of Tables, Charts, and Maps to Illustrate Data). CDC has provided guidance and SAS programs to state/local HIV surveillance programs for calculating care outcomes.

More information on calculating and presenting data on linkage to HIV medical care can be found in the Technical Notes of CDC's *HIV Surveillance Supplemental Report*, "Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas," at <https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>.

Viral suppression (NHAS indicator)

HIV viral suppression is the percentage of persons with diagnosed HIV who have a suppressed viral load at the most recent test in a calendar year. Data on viral suppression at most recent test during the specified year should be measured for persons aged ≥ 13 years who resided in the jurisdiction during the specified year, and who were alive at the end of the specified year. The numerator is the number of persons aged ≥ 13 years with HIV infection diagnosed by the end of the prior year, and who had a VL < 200 copies/mL at the most recent test in the specified year. The denominator is the number of persons

aged ≥ 13 years with HIV diagnosed by the end of the prior year, and who were alive at the end of the specified year.

Recommended analyses

- Number and percentage distribution by:
 - sex at birth and gender
 - age group
 - race/ethnicity
 - transmission category (based on sex at birth)
 - exposure category (for transgender and AGI persons; rates not available)
- Numbers and percentages by race/ethnicity for each sex

Accurate monitoring of HIV viral suppression at most recent test among persons with diagnosed infection is dependent upon complete reporting of deaths.

A suggested secondary measure is *viral suppression within 6 months of diagnosis*. This indicator is measured for persons whose infection was diagnosed during a given year. Viral suppression for this indicator is defined as a viral load result of < 200 copies/mL at any viral load test within 6 months of an HIV diagnosis made during the specified year.

Viral suppression data for jurisdictions without laws requiring reporting of laboratory data, or with incomplete reporting of laboratory data to the HIV surveillance program, should be interpreted with caution.

For recommended data displays, see [Appendix A](#) (Sample Data Tables and Charts with Interpretation Associated with Chapter 3) and [Appendix B](#) (Use of Tables, Charts, and Maps to Illustrate Data). CDC has provided guidance and SAS programs to state/local HIV surveillance programs for calculating care outcomes.

More information on calculating and presenting data on viral suppression can be found in the Technical Notes of CDC's *HIV Surveillance Supplemental Report*, "Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas," at <https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>.

HIV prevalence (diagnosed)

Prevalence is the number/rate of persons with diagnosed HIV that are alive at the end of a specified year. Prevalence trends and data reflect persons with diagnosed HIV infection, regardless of stage of disease at the end of a given year and are based on cases reported to the state/local health department (not an estimate). Because of delays in the reporting of deaths, a 12-month reporting lag should be applied to allow data to be reported to the state/local health department and surveillance program. For tables presenting prevalence data, area of residence should be based on a person's most recent known address as of the end of the specified year.

Recommended analyses (assess trends for most recent 5 years)

- Number, percentage distribution, and rates (per 100,000 population) by:
 - sex at birth and gender
 - age group
 - race/ethnicity
 - transmission category (based on sex at birth; rates not available)
 - exposure category (for transgender persons; rates not available)
- Numbers and rates by race/ethnicity for each sex

For recommended data displays, see [Appendix A](#) (Sample Data Tables and Charts with Interpretation Associated with Chapter 3) and [Appendix B](#) (Use of Tables, Charts, and Maps to Illustrate Data).

More information on analyzing and presenting data on HIV prevalence can be found in the Technical Notes of CDC's annual *HIV Surveillance Report* at <https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>.

Deaths

Persons with diagnosed HIV infection reported to state/local surveillance programs are assumed alive unless their deaths have been reported to state/local vital statistics programs or the program has received information on their death by matching to the Social Security Administration's Death Master File or the National Death Index. Death data from eHARS will include deaths of persons with diagnosed HIV infection regardless of the cause of death. Persons reported to eHARS are assumed alive unless their deaths have been reported to the state/local health department. Death data should always be based on a 12-month reporting delay to allow time for deaths to be reported to the state/local health department and surveillance program.

Recommended analyses (assess trends for most recent 5 years)

- Number, percentage distribution, and rates (per 100,000 population) by:
 - sex at birth and gender
 - age group
 - race/ethnicity
 - transmission category (based on sex at birth; rates not available)
 - exposure category (for transgender and AGI persons; rates not available)
- Numbers and rates by race/ethnicity for each sex at birth

For recommended data displays, see [Appendix A](#) (Sample Data Tables and Charts with Interpretation Associated with Chapter 3) and [Appendix B](#) (Use of Tables, Charts, and Maps to Illustrate Data).

More information on analyzing and presenting data on deaths among persons with diagnosed HIV infection can be found in the Technical Notes of CDC's annual *HIV Surveillance Report* at <https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>.

Impact of COVID-19 on HIV surveillance data

Caution should be used when analyzing, presenting, and interpreting HIV surveillance data for the year 2020 due to the impact of COVID-19 on access to HIV testing and care services, and case surveillance activities in state/local jurisdictions. Significant declines in HIV testing (and diagnoses) occurred during the COVID-19 pandemic that are likely attributed to interruptions in the availability of clinical services, patient hesitancy in accessing face-to-face clinical services, and shortages in HIV testing reagents/materials.

Important note: Estimates of new HIV infections and prevalence should not be produced for the year 2020 using the CD4 model SAS programs. The CD4-based model for estimating incidence and prevalence does not produce reliable estimates for the year 2020 due to the significant declines in HIV testing and diagnoses that occurred in the United States during the COVID-19 pandemic.

National Center for Health Statistics mortality data

If HIV infection is among the 10 leading causes of death in your area, you may also wish to present mortality data from the National Center for Health Statistics:

1. Number of deaths by underlying cause among persons 25 to 44 years of age, based on vital statistics mortality data (see Table 3–4)
2. Number and rates of death (per 100,000 population) by race/ethnicity and sex at birth, based on vital statistics mortality data

These analyses will enable you to determine the rank of HIV infection among underlying causes of death for the most recent year for which data are available.

HIV clusters and outbreaks

Detecting and responding to HIV clusters and outbreaks is an important step toward bringing the nation closer to the goal of ending the HIV epidemic. HIV clusters or outbreaks refer to groups of people that are experiencing rapid HIV transmission. Clusters can be identified through multiple approaches, including partner services, providers and community members, and surveillance. Surveillance-based cluster detection methods include molecular cluster detection, using HIV nucleotide sequence data reported as part of HIV surveillance, as well as time-space cluster detection, based on analysis of diagnosis data. Evidence shows that HIV surveillance can identify clusters of rapid transmission that may otherwise go unrecognized. HIV clusters may indicate gaps in HIV prevention or care, with populations and areas that are not effectively being reached by existing resources. Understanding these clusters can help focus proven HIV prevention tools where they are needed most. In this way, expanded use of HIV surveillance data has the potential to substantially improve HIV prevention efforts.

Identifying HIV clusters and outbreaks

Clusters and outbreaks of HIV can be identified through multiple mechanisms, including molecular analysis, time-space analysis, provider reporting, and through partner services. Cluster detection methods and tools are described in detail in the Technical Guidance for HIV Surveillance Programs chapter titled ‘Detecting HIV Transmission Clusters.’

Describing HIV clusters and outbreaks

Characteristics of individual clusters and outbreaks of HIV often vary across clusters in a single jurisdiction, and aggregating data across clusters can obscure characteristics of individual clusters of concern. For this reason, it is recommended that clusters be described at an individual cluster level, with a focus on cluster-level characteristics. These descriptions, including those in epidemiological profiles, should adhere to all local, state, and federal security and confidentiality guidelines with care taken to mitigate the risk of unintentionally identifying individuals or small groups of individuals.

An important caveat in describing clusters is that detection of clusters through surveillance-based methods is reliant on routinely conducting cluster detection analyses, as well as complete and timely surveillance data. For this reason, including information on data completeness and timeliness and frequency of analysis alongside descriptions of cluster information is important.

Recommended information and data for inclusion

- Describe routine cluster detection activities conducted in your jurisdiction (including the methods [i.e., molecular and time-space], and the frequency of analysis). Additionally, describe the completeness* of HIV nucleotide sequence data, and timeliness of HIV case and laboratory reporting.
- Describe any concerning HIV clusters identified in your jurisdiction in the past one-year period or from the latest year of data available. Include newly detected clusters, as well as previously detected clusters that continue to be of high concern (for example, clusters with persistent growth that continue to meet national priority criteria). For these clusters, describe the:
 - Number of concerning clusters in the year of interest, including
 - Molecular clusters meeting national priority criteria[†]
 - Other clusters of high concern, including clusters identified through time-space analysis, provider notification, and/or partner services
 - Size of clusters identified (including size at detection and current size)
 - Key characteristics of clusters and people linked to these clusters. Characteristics may include demographic, geographic, behavioral, and clinical characteristics.
 - Gaps in HIV prevention, care and/or treatment programs identified through cluster response activities.
 - Number of clusters with response efforts conducted and description of response activities and lessons learned

* *Nucleotide sequence completeness* is defined as the percent of cases diagnosed in the year or time period of interest for which an analyzable nucleotide sequence is available; in the Standards Evaluation Report, this is measured 12 months following the end of the period of interest.

[†] *National priority criteria*: A molecular cluster that has met certain criteria and which should be flagged for preliminary investigation. Currently, CDC-defined national priority clusters for high and medium morbidity jurisdictions are clusters identified at a 0.5% genetic distance threshold with ≥ 5 cases in the most recent 12-month period. For low morbidity jurisdictions, CDC-defined priority clusters are those identified at a 0.5% genetic distance threshold with ≥ 3 cases in the most recent 12-month period. Analyses of clusters meeting the abovementioned criteria indicates similar transmission rates that are approximately 11 times that of the transmission rate among people living with HIV in the United States. In addition to using criteria for CDC-defined priority clusters, jurisdictions may also develop criteria to identify additional, locally defined priority clusters.

- Incorporation of strategies from EHE Diagnose, Treat, and Prevent pillars into responses to clusters (e.g., testing, HIV treatment, PrEP or syringe services program [SSP] referral, linkage, or provision).
- Gaps identified and addressed in HIV prevention and care programs as a result of cluster response

Data sources

- Results of routine cluster detection analyses using NHSS data (i.e., molecular cluster detection using Secure HIV-TRACE and Time-Space cluster detection programs)
- HIV surveillance data, including output from Standards Evaluation Reports
- HIV Cluster Report Forms, and local HIV cluster data tools and repositories
- eHARS cluster variables

Comorbidities

Comorbidity is defined as the coexistence of a condition, disease, or illness and HIV infection in one person (e.g., a person with HIV who also has TB). In setting service priorities, planning groups must consider epidemiologic data on comorbid conditions. It is also important to provide information on increases or decreases in comorbid conditions among people within the HIV care system. A useful epidemiologic profile provides information on HIV prevalence among populations identified by a comorbid condition, such as sexually transmitted infections (STIs), hepatitis B or C, TB, substance use, severe mental illness, or other conditions prevalent in the service area.

Sexually transmitted infections

Sexually transmitted infections (STIs) are infections that spread from person to person through sexual activity, including anal, vaginal, or oral sex. Persons with an STI have an increased risk of acquiring HIV because the risk behaviors are similar. STIs are often more prevalent among persons with HIV compared to the general population. Comparing rates of STIs in the service area can highlight health disparities. Some of the most prevalent STIs among persons with HIV are chlamydia, genital herpes, gonorrhea, and syphilis. Most cases of syphilis in the United States are among gay, bisexual, and other men who have sex with men with increases in recent years. Epi profile writers should discuss STI diagnoses among priority populations and highlight the most common STIs in the service area in the profile document.

Data sources

- State/local STD surveillance programs
- National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) AtlasPlus
- CDC's Division of STD Prevention <https://www.cdc.gov/std/statistics/default.htm>

Viral hepatitis

Hepatitis B virus (HBV) is a bloodborne virus transmitted primarily through sexual contact and injection-drug use. Because of these shared modes of transmission, a high proportion of adults at risk

for HIV infection are also at risk for HBV infection. People with HIV who become infected with HBV are at increased risk for liver-related morbidity and mortality. As hepatitis C virus (HCV) is also a bloodborne virus transmitted through direct contact with the blood of an infected person, coinfection with HIV and HCV is common (62%–80%) among persons with HIV who inject drugs. Although transmission via injection-drug use remains the most common mode of HCV acquisition in the United States, sexual transmission is an important mode of acquisition among MSM with HIV who also have risk factors, including those who participate in unprotected anal intercourse and use of non-injection drugs. HCV is one of the primary causes of chronic liver disease in the United States, and HCV-related liver injury progresses more rapidly among people coinfecting with HIV. HCV infection may also affect the management of HIV infection.

Data sources

- State/local Hepatitis surveillance program
- National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) AtlasPlus
- CDC’s Division of Viral Hepatitis Prevention <https://www.cdc.gov/hepatitis/statistics/index.htm>

Tuberculosis

Tuberculosis (TB) is one of the leading causes of death among people with HIV. TB is an AIDS-defining condition among people with HIV. Without treatment, as with other opportunistic infections, HIV and TB can work together to shorten lifespan. Untreated latent TB infection can quickly progress to TB disease in people with HIV, and without treatment, TB disease can progress from sickness to death.

Data sources

- State/local TB surveillance program
- National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) AtlasPlus
- CDC’s Division of TB Prevention <https://www.cdc.gov/tb/statistics/default.htm>

Substance use

Use of substances, such as excessive alcohol use or use of other substances, such as crack cocaine, methamphetamine (“meth”), amyl nitrite (“poppers”), prescription opioids, and heroin, are associated with transmission of HIV and other sexually transmitted diseases. Injection drug use (IDU) can be a direct route of HIV transmission if people share needles, syringes, or other injection materials that are contaminated with HIV. Excessive alcohol use and ingesting, smoking, or inhaling drugs are also associated with increased risk for HIV. These substances alter judgment, which can lead to sexual behaviors that can make people more likely to get and transmit HIV (e.g., having sex without a condom, having multiple partners, etc.). Among people with HIV, substance use is associated with more rapid disease progression, barriers to accessing and receiving HIV care and treatment, lower adherence to antiretroviral therapy, and worse clinical outcomes.

Data sources

- Medical Monitoring Project (MMP) (*as applicable*)
- National HIV Behavioral Surveillance (NHBS) (*as applicable*)
- Substance Abuse and Mental Health Services Administration <https://www.samhsa.gov/data/>

Mental health

Research has found persons with HIV may be at risk for mental health conditions, such as depression and anxiety. These conditions can be associated with substance use and greater HIV transmission risk. Additionally, mental health conditions may impede access to and receipt of HIV care and treatment and contribute to treatment non-adherence and higher viral load.

Data sources

- Medical Monitoring Project (MMP) (*as applicable*)
- National HIV Behavioral Surveillance (NHBS) (*as applicable*)
- Ryan White HIV/AIDS Program Services Report <https://akaprod-hab.hrsa.gov/program-grants-management/ryan-white-hiv-aids-program-services-report-rsr>
- Substance Abuse and Mental Health Services Administration <https://www.samhsa.gov/data/>
- NIH National Institute of Mental Health <https://www.nimh.nih.gov/health/statistics/mental-illness>

For recommended data displays for comorbidities, see [Appendix A](#) (Sample Data Tables and Charts with Interpretation Associated with Chapter 3) and [Appendix B](#) (Use of Tables, Charts, and Maps to Illustrate Data).

Core Question 2.2: What is the distribution of social determinants of health (SDH) that exacerbate HIV-related disparities among people with HIV in your service area?

HIV-related disparities and SDH

Health disparities are avoidable differences in the incidence, prevalence, mortality, and causes of a disease and the related adverse health conditions that exist among specific population groups, with most health disparities being related to SDH. Identification and awareness of differences among populations regarding health determinants and health outcomes are essential steps toward reducing health disparities.

SDH are the conditions in the environments where people are born, live, learn, work, play, worship, and age. SDH can have a major impact on people's health, well-being, and quality of life. HHS's Healthy People 2030 initiative groups SDH measures into five domains, including economic stability (e.g., poverty, employment, food insecurity), education access and quality (e.g., educational attainment, health literacy), health care access and quality (e.g., health care coverage and lack of insurance; use of non-routine healthcare, such as emergency room visits), neighborhood and built environment (e.g., available public transit, housing structures), and social and community context (e.g., stigma and discrimination, forms of social and community support and cohesion)[‡].

Using eHARS data (community-level data)

Measuring health disparities

Disparities can be expressed in two types of measures—absolute and relative.

- **Absolute disparity:** Simple difference between two proportions, means, rates, or risks
 - Also referred to as rate difference, absolute difference, or range
 - The ***maximal rate difference*** is the difference between the highest and lowest group rates
 - An absolute difference gives the magnitude of the difference, and some indication of how many infections could be prevented if the difference were reduced or eliminated
- **Relative disparity:** Disparities measured relative to another group, best rate, mean, or target rate
 - Examples include percent differences between rates or the ratio between rates
 - A relative difference indicates by how many times or by what percent one group differs from another group or standard
 - Unlike absolute differences a relative difference does not depend on the prevalence of the indicator and is usually more stable between populations.
 - It is frequently preferred for assessing change over time and across indicators of health.

[‡] Department of Health and Human Services. Healthy People 2030. <https://health.gov/healthypeople/objectives-and-data/social-determinants-health>

To understand the magnitude and direction of disparities, it is important to use both absolute and relative disparity measures. Also, absolute, and relative disparities can go in opposite directions depending on the simultaneous increase or decrease of diagnosed HIV in each subpopulation. For further explanation on disparity measures, see the article, *Measuring health disparities: a comparison of absolute and relative disparities* at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4662578/>.

Measuring Disparities: Example (Baseline)

Table 1a. Diagnoses of HIV infection, by year of diagnosis and selected characteristics.

	2015	2016	2017	2018	2019
	Rate ^a				
Race/ethnicity					
American Indian/Alaska Native	7.3	9.1	8.6	7.5	8.6
Asian	5.3	5.2	5.1	4.6	3.9
Black/African American	42.0	41.2	39.4	37.9	37.3
Hispanic/Latino ^d	18.4	18.5	17.9	17.7	16.7
Native Hawaiian/other Pacific Islander	11.9	7.1	9.0	10.9	11.1
White	5.1	4.9	4.8	4.7	4.6
Multiracial	23.4	20.9	17.1	14.5	12.6

The **absolute difference (or range)** between the lowest and highest group rates was 36.9 HIV diagnoses per 100,000 persons.

$$42.0 - 5.1 = 36.9$$

The highest group rate was 8.2 times the lowest group rate (**relative disparity**).

$$42.0 \div 5.1 = 8.2$$

The average rate for all other race/ethnicity groups (excluding the lowest rate) was 3.5 times the lowest group rate (**summary rate ratio**).

$$((7.3 + 5.3 + 42.0 + 18.4 + 11.9 + 23.4) \div 6) \div 5.1 = 3.5$$

Measuring Disparities: Example (Most Recent)

Table 1a. Diagnoses of HIV infection, by year of diagnosis and selected characteristics.

	2015	2016	2017	2018	2019
	Rate ^a				
Race/ethnicity					
American Indian/Alaska Native	7.3	9.1	8.6	7.5	8.6
Asian	5.3	5.2	5.1	4.6	3.9
Black/African American	42.0	41.2	39.4	37.9	37.3
Hispanic/Latino ^d	18.4	18.5	17.9	17.7	16.7
Native Hawaiian/other Pacific Islander	11.9	7.1	9.0	10.9	11.1
White	5.1	4.9	4.8	4.7	4.6
Multiracial	23.4	20.9	17.1	14.5	12.6

The **absolute difference (or range)** between the lowest and highest group rates was 33.4 HIV diagnoses per 100,000 persons.

$$37.3 - 3.9 = 33.4$$

The highest group rate was 9.6 times the lowest group rate (**relative disparity**).

$$37.3 / 3.9 = 9.6$$

The average rate for all other race/ethnicity groups (excluding the lowest rate) was 3.9 times the lowest group rate (**summary rate ratio**).

$$((8.6 + 37.3 + 16.7 + 11.1 + 4.6 + 12.6) \div 6) \div 3.9 = 3.9$$

Measuring Disparities: Example (Changes over Time)

The change in **maximal rate difference** over time was -3.5 HIV diagnoses per 100,000 persons, which means the disparity decreased by 3.5 on an absolute scale.

$$33.4 - 36.9 = -3.5$$

The change in **maximal rate ratio** was 1.4, which means the disparity increased by 1.4 (or 40%) on a relative scale.

$$9.6 - 8.2 = 1.4$$

The change in **summary rate ratio** was 0.4, which is an increase in disparity.

$$3.9 - 3.5 = 0.4$$

Measuring Disparities: Example (Summary)

In 2019, diagnosed HIV infections for Black persons was 37.3 per 100,000 (the highest group rate) and for Asian persons was 3.9 per 100,000 (the lowest group rate). The difference in diagnosed HIV (absolute difference) is 37.3 per 100,000 minus 3.9 per 100,000, which equals 33.4 per 100,000. Thus, for every 100,000 Black persons with diagnosed HIV, 33.4 diagnoses would be prevented if Black persons had the same health experience as Asian persons. This compares to a relative risk (relative disparity) for Black persons receiving HIV diagnosis at a rate that is 9.6 times the rate of Asian persons (i.e., for every HIV diagnosis among Asian persons, 9.6 diagnoses occur among Black persons).

Geocoding and Data Linkage (GDL)/Social Determinants of Health (SDH)

The Geocoding and Data Linkage (GDL) activity enables the state/local surveillance program in the service area to capture, store, analyze, and display geocoded HIV surveillance data along with SDH indicators that may affect HIV transmission. HIV surveillance data are geocoded to the census tract level for addresses of residence at the time of diagnosis and linked at the census tract level to SDH indicator variable data from the U.S. Census Bureau's American Community Survey (ACS). Using census tract-level surveillance data at the state or local 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.

Data sources

- eHARS/Geocoding and data linkage (GDL)
- U.S. Census Bureau's American Community Survey
Note. See [Appendix C](#) for a description of the U.S. Census Bureau American Community Survey.
- CDC Social Vulnerability Index (<https://www.atsdr.cdc.gov/placeandhealth/svi/index.html>)

Recommended analyses:

- *Federal poverty status:* proportion of residents in the census tract who were living below the U.S. poverty level (i.e., below a specified threshold) during the 12 months before the survey response (individuals aged 18 years and older)

- *Education level*: proportion of residents in the census tract with less than a high school diploma (individuals aged 18 years and older)
- *Median household income*: median income for a household within the census tract during the 12 months before the survey response
- *Health care coverage*: proportion of residents in the census tract without health insurance or health coverage plan (individuals aged 18 years and older)
- *Gini index*: proportion of income inequality (i.e., the distribution of household income) within a census tract
- *Disparities and SDH*: The absolute rate difference and the relative disparities between SDH variable levels.

Geographic distribution of HIV

If the number of cases is large enough (>20) to stratify by geographic region (see [Chapter 5](#) on how to handle areas with low morbidity and a small number of cases), consider developing geographic tables stratified by region.

Recommended analyses for areas with large case numbers

- Number and percentage distribution of cases by:
 - sex at birth or gender
 - race/ethnicity
 - age group
 - transmission category (based on sex at birth)
 - exposure category (for transgender and AGI persons)
- Case rates (cases per 100,000 population) by race/ethnicity for each geographic region
- Case rates by race/ethnicity for each sex

These analyses will be somewhat directed by the planning jurisdiction. For example, a regional HPG will need a regional profile. However, areas with a state planning group should stratify by geographic or public health area, whichever makes sense at the local level.

Using MMP/NHBS Data (Person-level Data) (if applicable)

For jurisdictions participating in MMP, estimates of person-level SDH factors among people with HIV—including health care coverage, poverty level, homelessness, and HIV-related stigma—can be reported. Other sources of data, including NIH-funded studies, could be used to describe SDH among the local population in your service area in the absence of MMP data. Similar SDH can also be reported by using NHBS data for MSM, PWID, and heterosexually active adults who may be at high risk for HIV.

The following table displays the elements of person-level SDH that are available through CDC surveillance systems. MMP/NHBS data are presented in aggregate from participant interviews (person-level) and are based on the characteristics of persons with HIV in the area.

NHBS	MMP
<ul style="list-style-type: none"> • Nativity • Language • Educational attainment • Employment status • Household income and corresponding poverty level • Health care access and utilization • Disability status • Homelessness • Discrimination due to sexual orientation • Perceived community intolerance of gay, bisexual, and other MSM • Experiences with sexual and physical violence 	<ul style="list-style-type: none"> • Health care coverage • Receipt of RWHAP assistance • Household income and corresponding poverty level • Employment • Educational attainment • Country of birth • Housing stability, including homelessness* • HIV-related stigma* and HIV healthcare discrimination • Experiences with sexual and physical violence • History of incarceration • English proficiency

*National indicators used to assess progress towards meeting HIV prevention and care goals outlined in NHAS.

Recommended analyses

- Examples of SDH that could be assessed among people with diagnosed HIV in your local service area include English proficiency, educational attainment, household income and poverty level, housing stability (e.g., homelessness), history of incarceration, health care coverage, receipt of assistance through the RWHAP, and HIV-related stigma.
- Stratifications of SDH that may be useful include:
 - By gender, race/ethnicity, poverty level
 - By race/ethnicity among MSM, as MSM of color are a priority population in NHAS
 - By HIV clinical outcomes, including retention in care in the past 12 months, ART dose adherence in the past 30 days, and viral suppression in the past 12 months
 - By other clinical outcomes, including unmet needs for HIV ancillary care services, emergency room visits, and hospitalizations in the past 12 months
- HIV-related stigma: If MMP data are used to describe HIV-related stigma in your local service area, data cycles on or after 2018 should be used due to changes made to the stigma scale.[§] Recommended analyses that directly contribute to the core questions include:
 - Likert scale responses describing experiences with HIV-related stigma for components in each of the 4 stigma domains:
 - personalized stigma in the past 12 months (e.g., feeling hurt by others' reactions to, or losing friends due to, one's HIV status)
 - disclosure concerns (e.g., being careful about who one tells about one's HIV status or fearing others will disclose one's status)

[§] The modified HIV-related stigma scale now assesses personalized stigma over the past 12 months to better capture current experiences with stigma; Wright et al.'s original personalized stigma statement asked about experiences at any time in the past.

- negative self-image (e.g., feeling that one is not as good as others or is a bad person due to one's status)
- perceived public attitudes about people with HIV (e.g., feeling that most people think that a person with HIV is disgusting or that most people with HIV are rejected when people become aware of their status)
- HIV-related stigma score (median, 95% CI), overall and by selected characteristics, including demographic characteristics and social determinants of health.

Note: HIV-related stigma score ranges from 0–100, with 0 representing low stigma and 100 representing high stigma.

Section 3: Domain 3—HIV Care and Treatment among People with HIV in Your Service Area

Core Question 3.1: What HIV care and treatment services are available in your service area?

- Describe HIV care and treatment resources in your service areas including:
 - HRSA Ryan White HIV/AIDS Program, Centers for Medicare and Medicaid Services, and other federally funded programs
 - Other locally funded programs and care facilities
- Describe gaps in HIV care and treatment resources and other barriers to HIV care engagement.
- Describe any evidence-based interventions or other public health strategies currently implemented to link, retain, or re-engage people with diagnosed HIV in care and treatment.

Describing HIV care and treatment services allows jurisdictions to evaluate current efforts being implemented in the service area and identify gaps in care access among the local population of people with HIV. We recommend jurisdictions briefly describe (or present in a table) currently available care and treatment services, including federally, locally, and privately funded programs, and identify gaps in and other barriers to HIV care engagement in the service area. This information allows jurisdictions to prioritize and allocate resources and project future needs in the service area to meet goals of federal, state, and local initiatives.

CDC and HRSA support the use of evidence-based, evidence-informed, and emerging behavioral, biomedical, and structural interventions, public health strategies, and social marketing campaigns to improve the delivery of HIV prevention and care. We recommend jurisdictions briefly describe (or present in a table) any public health strategies and/or evidence-based, evidence-informed, or emerging interventions implemented for persons with HIV in the service area. This information allows jurisdictions to identify areas to mobilize community action, implement innovative and integrated service models, and strengthen strategic partnerships to scale-up high impact HIV care and treatment strategies to close gaps and advance health equity goals.

HIV care and treatment resources

HIV care and treatment services are crucial for attaining optimal HIV health outcomes among people with HIV, preventing further transmission of the virus, and ultimately, ending the HIV epidemic. People with HIV who reach and maintain an undetectable viral load can live a close to average lifespan and have effectively no risk of sexually transmitting the virus to a partner without HIV. Understanding the landscape of HIV care provision in the jurisdiction provides staff with a complete picture of local resources available for people with HIV and assists with the ability to link people to the services they

need. Jurisdictions can also identify gaps in services or service areas based on geographic coverage of providers and needs identified through local needs assessments.

Recommended analyses

- HIV care and treatment service providers and characteristics of those providers within your local service areas. Characteristics of interest may include the number of clients, provider specialty (e.g., youth-focused clinic), size of clinic, number of locations, or services delivered. Consider including HIV care, treatment, and support providers funded through the following mechanisms:
 - HRSA Ryan White HIV/AIDS Program Parts A–D
 - HRSA HAB EHE funding
 - HRSA Bureau of Primary Health Care funding (i.e., Community Health Center program)
 - Centers for Medicare and Medicaid Services funding
 - Other federally funded programs
 - Other locally funded programs and care facilities
 - Private care, treatment, and/or HIV support services facilities
- Geographic coverage of HIV care and treatment services across your local service area. Describe what geographic areas and priority populations are reached by the existing HIV care and treatment resources. Describe the reach of HIV care and treatment resources in medically underserved areas, rural areas, and other special geographic areas.
- Specific services available within your local service area. State and local jurisdictions use planning processes to inform which services are funded and, therefore, available within their local jurisdiction. These decisions are informed by needs assessments and community engagement processes to best respond to the needs of the local jurisdiction. Describe which specific services are available within the local service area, especially those funded through the HRSA RWHAP and HAB EHE funding. Refer to Policy Clarification Notice #16-02 for definitions of RWHAP service categories (<https://hab.hrsa.gov/program-grants-management/policy-notice-and-program-letters>).

Recommended data sources

- HIV Surveillance data. Because HIV is a mandatory reportable condition, the jurisdictional/local HIV surveillance database may be a source of HIV care provider location data.
- RWHAP Services Report (RSR) data. These data contain information about all providers funded by the RWHAP recipient. It is important to note that all RWHAP service providers in the jurisdiction are not funded by Part B (State) or Part A (metropolitan) RWHAP recipients; therefore, the data contained in a Part A or B RSR database would be only a subset of RWHAP service providers. A more complete picture could be accomplished by coordinating across all Parts A, B, C, and D recipients and subrecipients.
- RWHAP AIDS Drug Assistance Program Data Report (ADR). These data contain information about clients receiving ADAP-funded medication and health care coverage assistance. Each Part B (State) RWHAP program also has an ADAP.

- RWHAP “Find a Provider” Tool (<https://findhivcare.hrsa.gov/>). The Find a RWHAP Medical Provider locator tool allows users to search for RWHAP medical providers. Users may search for providers by allowing the tool to detect their location automatically or by entering search criteria such as an address or place name. The information used to populate the Find a RWHAP Medical Provider locator tool originates from the RWHAP Services Report (RSR) Provider Report.
- RWHAP Allocations & Expenditure Reports: These reports serve as a reference to determine how recipients allocate and subsequently expend funds each budget period. It is important to note that the Ryan White HIV/AIDS Program annual allocation and expenditure reports do not serve as a source for determining the total amount of funds awarded and unspent by recipients.
- The American Academy of HIV Medicine’s Referral Link (<https://providers.aahivm.org/referral-link-search>) is a directory of healthcare providers specializing in HIV management and prevention across the country. The doctors and clinicians represented in this database practice in a variety of care settings including health centers, RWHAP-funded providers, and private practices.

Gaps in HIV care and treatment resources and barriers to care engagement

HIV care engagement is strongly associated with viral suppression among people with HIV. In addition, use of HIV ancillary care services supports medical care engagement; these may include non-HIV medical services (e.g., medical case management, mental health care, substance use disorder treatment), and HIV care support services (e.g., non-medical case management, food assistance, housing services). Unmet needs for ancillary care services are associated with adverse HIV clinical outcomes, including lower retention in HIV care, poorer ART adherence, and being virally unsuppressed. A large percentage of people with HIV experience comorbidities and co-occurring social and medical conditions and often rely on HIV ancillary care services.

Disparities in HIV care engagement and viral suppression may be attributed to differing levels of care access and other barriers to care among selected populations. Identifying and addressing barriers to care and unmet needs among people with HIV—particularly among priority populations who may be at higher risk for adverse outcomes—may help improve HIV care engagement and viral suppression, and is a national priority outlined in NHAS.

Recommended analyses

- Barriers to care
 - Using internal resources and/or through relationships with local community-based organizations, universities, community planning groups, partner advocacy organizations, etc., describe barriers to accessing care and treatment by people with HIV in the jurisdiction. These partner organizations may collect data for their own work within the communities they serve.

Data sources

- Partner organizations, local planning groups, university partners, etc.
- RWHAP RSR and ADR data
- RWHAP Part A unmet needs analyses
- Medical Monitoring Project (MMP)
(<https://www.cdc.gov/hiv/statistics/systems/mmp/index.html>)

Using Medical Monitoring Project data (if applicable)

Representative data on barriers to HIV care and receipt of and unmet needs for HIV ancillary care services are available through the CDC Medical Monitoring Project (MMP) for reporting jurisdictions and should be used when available.

Recommended analyses

- Barriers to HIV care
 - Recommend estimates be reported by using MMP data cycles from 2018 onwards, due to changes to the structure of this section of the questionnaire in 2018. Note that data on barriers to HIV care are not comparable between data collected prior to 2018 and to 2018 onwards.
- Availability of, receipt of, and unmet needs for ancillary care services
 - Ancillary care services can be categorized into three groups, including HIV support services, non-HIV medical services, and non-HIV subsistence services. HIV support services include HIV case management, adherence counseling, peer group, patient navigation services. Non-HIV medical services include dental, mental health, drug/alcohol counseling or treatment services. Subsistence services include Supplemental Nutrition Assistance Program (SNAP) or Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) services; meal or food services; transportation assistance; or shelter or housing services.
 - Consider also reporting associations between unmet needs for ancillary care services and HIV clinical outcomes, including retention in HIV care, ART dose adherence, and viral suppression.
 - When sample size is sufficient, recommend also reporting reasons for unmet needs for HIV ancillary care services to help direct local public health action to reduce barriers to care.

Data source

- Medical Monitoring Project (MMP)
(<https://www.cdc.gov/hiv/statistics/systems/mmp/index.html>)

Evidence-based, evidence-informed, and emerging interventions or other public health strategies for HIV in care and treatment

CDC and HRSA strongly encourage the implementation of evidence-based, evidence-informed, and emerging interventions in local jurisdictions to reduce HIV-related health disparities and improve health outcomes, including increasing retention in care, improving treatment adherence, and improving viral suppression for people with HIV.

HRSA HAB, in collaboration with the CDC and the National Institutes of Mental Health (NIMH), developed three categories of intervention strategies that have demonstrated effectiveness at improving the care and treatment of people with HIV.

- Evidence-based interventions: Published research evidence supporting these interventions meets CDC criteria for being evidence-based.
- Evidence-informed interventions: Published research evidence meets HRSA evidence-informed criteria but does not meet CDC criteria for evidence-based interventions. It may also meet CDC criteria for evidence-informed interventions.
- Emerging interventions: Innovative strategies that address emerging priorities for improving the care and treatment of people with HIV. Real world validity and effectiveness have been demonstrated, but emerging strategies do not yet have sufficient published research evidence.

Intervention strategies are activities or practices that improve outcomes along the HIV care continuum. Intervention strategies may be simple tools (e.g., alcohol screening and brief intervention) or they may be complex, involving multiple components (e.g., implementation of a system-wide, trauma-informed approach). Finally, intervention strategies may occur at any level of healthcare, including the system/environment, organizational, group/learning, supervisory, and individual (provider/client) levels.

Recommended analyses

- Describe evidence-based, evidence-informed, and emerging interventions recently, currently, or planned to be implemented in your local area. If known, provide the following information about each intervention:
 - Purpose of the intervention and intended outcomes
 - Focus population: Population(s) that are the primary focus for or benefit from this intervention.
 - Setting: Organizational setting where intervention is implemented.

Data sources

- [Compendium of Evidence-based Interventions and Best Practices for HIV Prevention](#)
- RWHAP Best Practices Compilation (<https://targethiv.org/bestpractices>) gathers and disseminates intervention strategies that have been implemented in RWHAP funded settings and improve outcomes along the HIV care continuum.

Core Question 3.2: What is the HIV care continuum for the overall population and for priority populations in your service area?

- What is the diagnosis-based care continuum (among persons with diagnosed HIV) in your service area?
- What is the prevalence-based care continuum (among the estimated number of persons with HIV) in your service area?

HIV care continuum

The HIV care continuum is a public health model that outlines the steps or stages that people with HIV go through from diagnosis to viral suppression.

The steps are:

- diagnosis of HIV infection
- linkage to HIV medical care
- receipt of HIV medical care
- retention in medical care
- viral suppression

The HIV care continuum is useful as a population-level framework to analyze the proportion of people with HIV in the service area who are engaged in each step. This helps pinpoint where gaps in services might exist and develop strategies to better support viral suppression among people with HIV. These focused analyses of HIV care outcome data allow service areas to strengthen infrastructure, monitor and evaluate progress toward achieving care goals and objectives.

Using enhanced HIV/AIDS Reporting System (eHARS) data

Two different approaches are available when using surveillance data to monitor the HIV care continuum. The two approaches are used for different purposes, and both are essential to monitoring progress and identify key HIV prevention and care needs. The major difference between the two approaches is that they have different denominators. All people with HIV (includes persons with diagnosed and undiagnosed infection) are used as the denominator for the prevalence-based continuum. People with diagnosed HIV is the denominator used for the diagnosis-based continuum.

Recommended analyses

Diagnosis-based HIV care continuum

The diagnosis-based HIV care continuum describes each step of the continuum as a percentage of the number of people living with diagnosed HIV. The denominator is the number of persons aged ≥ 13 years living with diagnosed HIV infection at year-end in the service area. Please note the denominator for linkage to care and viral suppression within 6 months of diagnosis is limited to people with HIV diagnosed in a single year and cannot be directly compared to other steps in the continuum (e.g., receipt

or retention in care, viral suppression). The numerator is the number of persons with diagnosed HIV at each step of the continuum in the service area.

Single year tables

For the most recent available calendar year:

1. % distribution among persons with HIV diagnosed by indicator (e.g., stage of disease at diagnosis of HIV infection, linkage to HIV medical care ≤ 1 month of diagnosis, viral suppression ≤ 6 months of diagnosis) overall and for priority populations by selected characteristics (e.g., demographics, transmission/exposure category, geographic area, social determinants of health)
2. % distribution among persons with diagnosed HIV by indicator (e.g., diagnosed HIV cases, receipt of HIV medical care, retention in HIV medical care, viral suppression) overall and for priority populations by selected characteristics

Prevalence-based HIV care continuum

State/local jurisdictions able to produce estimates of HIV incidence and prevalence by using the CD4-based model can monitor the prevalence-based HIV Care Continuum in their service area. The prevalence-based HIV Care Continuum describes each step of the continuum as a percentage of the total number of people living with HIV (diagnosed or undiagnosed). The denominator is the estimated number of persons aged ≥ 13 years living with diagnosed or undiagnosed HIV infection at year-end in the service area (calculated by using the first CD4 test after HIV diagnosis and a CD4 depletion model indicating disease progression). The numerator is extrapolated from the number of persons at each step of the continuum in the service area (apply the percentage to the total number of people with HIV).

Single year tables

For the most recent available calendar year:

1. % distribution among persons with HIV infection (diagnosed or undiagnosed) by indicator (e.g., diagnosed HIV cases, receipt of HIV medical care, retention in HIV medical care, viral suppression) overall and for priority populations by selected characteristics (e.g., demographics, transmission category, geographic area)

HIV care continuum data should be presented for the overall population and for priority populations in the service area. Profile writers should be aware that monitoring HIV care outcomes in the service area by using eHARS data is typically dependent upon complete reporting of HIV-related laboratory results (including CD4+ T-lymphocyte [CD4], viral load, and genotype sequences) and deaths to HIV surveillance programs. Caution should be used when interpreting data for jurisdictions that do not have laws and regulations that require the reporting of all laboratory results or had incomplete death ascertainment.

CDC has developed and provided SAS programs for analyzing HIV care outcomes by using jurisdictional-level surveillance data in eHARS (refer to *Monitoring HIV Care Outcomes Using Surveillance Data User Guide, version 1.5*) to state/local programs. The SAS programs produce data tables on two (of the eight) of NHAS core indicators (1) linkage to HIV Medical Care within one month of HIV diagnosis and (2) viral suppression among persons with diagnosed HIV. The SAS program also provides data tables on three secondary indicators, which are, (1) stage of disease at the time of HIV diagnosis, (2) viral suppression within 6 months of HIV diagnosis, and (3) receipt of and retention in HIV medical care (discussed in section 2 of Chapter 3).

For estimating HIV prevalence for the denominator of the prevalence-based continuum, state/local programs should refer to the CDC-supplied SAS program for *Estimating HIV Incidence and Prevalence using CD4-Based Model, version 4.0*.

For recommended data displays, see [Appendix A](#) (Sample Data Tables and Charts with Interpretation Associated with Chapter 3) and [Appendix B](#) (Use of Tables, Charts, and Maps to Illustrate Data).

More information on calculating and presenting care outcome data can be found in the Technical Notes of CDC's *HIV Surveillance Supplemental Report*, "Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas," at <https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>.

Data sources

- HIV surveillance data (eHARS)
- National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) AtlasPlus (<https://www.cdc.gov/nchhstp/atlas/index.html>)
- America's HIV Epidemic Analysis Dashboard (www.AHEAD.hiv.gov)

Section 4: Domain 4—Prevention of HIV in Your Service Area

Core Question 4.1: What is the landscape of HIV testing and prevention services in your service area, including gaps in prevention?

- Discuss and provide population-level data on PrEP coverage, condom use, harm reduction, and syringe services programs.

HIV testing

CDC receives, analyzes, and disseminates data on CDC-funded HIV testing and prevention activities reported through the National HIV Prevention Program Monitoring and Evaluation (NHM&E) data reporting system, EvaluationWeb®. Test-level data are reported through NHM&E and represent a portion of all HIV testing done in the United States, Puerto Rico, and the U.S. Virgin Islands. These data are used to assess the impact of CDC-funded HIV testing efforts, inform programmatic activities, and document the progress of programs toward local, state, and national HIV prevention goals. These data can be used to provide insight into the demographics of persons tested, and receiving HIV diagnoses, programmatic activities (e.g., linkage to HIV medical care and referral to partner and prevention services) and can be used in conjunction with other relevant information (e.g., progress reports, surveillance data, census data). Because identifying information is not submitted with HIV testing data to CDC, it is not possible to deduplicate multiple HIV tests conducted with the same person. Therefore, these data are “test-level” rather than “client-level” estimates. To minimize this limitation, calculate newly identified HIV cases by excluding records for which there is a current HIV-positive test result and a self-report of a previous HIV-positive test result. Examples of HIV test-level data from 60 state and local health departments (HDs) and 100 community-based organizations (CBOs) reported to CDC through EvaluationWeb® can be found in the following CDC report updated annually:

CDC. CDC-funded HIV testing in the United States, Puerto Rico, and the U.S. Virgin Islands, 2019. <https://www.cdc.gov/hiv/pdf/library/reports/cdc-hiv-annual-HIV-testing-report-2019.pdf>. Published March 2021. Accessed [Date].

Recommended analyses

- HIV testing by demographics (age, gender, race/ethnicity, population group)
- HIV testing by health care setting
- HIV testing and outcomes
 - Number of persons with newly diagnosed HIV
 - Percentage of persons with newly diagnosed HIV linked to HIV medical care within 30 days
 - Percentage of persons with newly diagnosed HIV interviewed for partner services

Data source

- National HIV Prevention Program Monitoring and Evaluation (NHM&E) data reporting system, EvaluationWeb®

HIV testing data available from the Behavioral Risk Factor Surveillance System (BRFSS)

The Behavioral Risk Factor Surveillance System (BRFSS) is the nation’s premier system of health-related telephone surveys that collect state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. Established in 1984 with 15 states, BRFSS now collects data in all 50 states as well as the District of Columbia and three U.S. territories. BRFSS completes more than 400,000 adult interviews each year, making it the largest continuously conducted health survey system in the world. Since 1994, the BRFSS questionnaire has included questions related to HIV for respondents aged 18 to 49 years. The BRFSS questionnaire currently includes questions about history of ever testing for HIV, and if ever tested, month and year of the most recent test. The questionnaire also includes a measure of self-reported past-year HIV risk on the rotating (biannual) core survey, as well as demographic information, including sexual orientation and gender identity for a subset of states. The BRFSS survey sample is large enough to produce stable estimates of the proportion ever tested at both state and local level, as well as estimates of testing in the past year in most jurisdictions. Examples of such data output are included in the following reference:

Pitasi MA, Delaney KP, Brooks JT, DiNenno EA, Johnson SD, Prejean J. HIV testing in 50 local jurisdictions accounting for the majority of new HIV diagnoses and seven states with disproportionate occurrence of HIV in rural areas, 2016–2017. *MMWR* 2019;68(25):561–567. Published 2019 Jun 28. doi:10.15585/mmwr.mm6825a2

Recommended analyses

- HIV Testing at State and County levels
 - Ever tested
 - Tested in past 12 months

Data source

- Behavioral Risk Factor Surveillance System (BRFSS) <https://www.cdc.gov/brfss/index.html>

Note. As of 2020, BRFSS will only ask about self-reported HIV risk every other year, and only about 3% of the sample reports past year risk. Because of these smaller sample sizes, estimates of the proportion tested in the past year and time since last test are only stable for some of the larger state and local jurisdictions using BRFSS. Other data sources (such as NHBS described below) may be needed to produce stable estimates of past year HIV testing at the jurisdictional level among persons at high risk for HIV infection.

Optional analyses for HIV testing

Planning groups may find it useful to review testing data for their communities to help focus testing campaigns and other efforts.

Data sources

- Available everywhere
 - School health profiles
- Available in some areas
 - National Health Interview Survey

- Youth Risk Behavior Survey (YRBS). These project area surveys, along with a national YRBS, constitute CDC's Youth Risk Behavioral Surveillance System (YRBSS) (may not include testing questions).
- National HIV Behavioral Surveillance (NHBS)
- Pregnancy Risk Assessment Monitoring System (PRAMS)

Note. See [Appendix C](#) for a description of some of the data sources mentioned above.

Other indicators of HIV testing

Knowledge of status is a proximal indicator of HIV testing. Knowledge of HIV status (diagnosed infections among persons with HIV infection) is measured as the percentage of persons aged ≥ 13 years with diagnosed HIV infection out of all persons estimated to be living with HIV infection (prevalence) at the end of a given year. Estimates for states and EHE counties are produced and published annually in the NCHHSTP AtlasPlus (<https://www.cdc.gov/nchhstp/atlas/index.htm>).

Data Sources

- NCHHSTP AtlasPlus
- America's HIV Epidemic Analysis Dashboard (www.AHEAD.hiv.gov)

Preexposure prophylaxis (PrEP)

PrEP (preexposure prophylaxis) is medicine people at risk for HIV take to prevent getting HIV from sex or injection drug use. When taken as prescribed, PrEP is highly effective for preventing HIV. An essential goal of national HIV prevention is that PrEP reaches the populations who can benefit from it. As part of NHAS, state and local communities should scale-up PrEP awareness and employ innovative strategies to increase access to and use of PrEP among people for whom it is indicated.

PrEP data available from the NCHHSTP AtlasPlus

PrEP coverage is not a reportable disease or condition and is not reported to HIV surveillance programs. For informing the Integrated HIV Prevention and Care Plan, profile writers should acquire and use state/county-level PrEP data from CDC's NCHHSTP AtlasPlus.

Recommended analyses

- PrEP prescriptions: Number of persons prescribed PrEP in the service area during a given year, defined as the number of persons aged ≥ 16 years classified as having been prescribed PrEP during the given year.
- PrEP indications: Estimated number of persons aged ≥ 16 years in the service area with indications for PrEP during a given year.
- PrEP coverage: Reported as a percentage and calculated as the number of persons aged ≥ 16 years prescribed PrEP during a given year divided by the estimated number of persons aged ≥ 16 years who had indications for PrEP in a specified year. Profile writers should use caution when interpreting the percentage of PrEP coverage for the service area because different data sources are used to produce the numerator and denominator.

National pharmacy data from the IQVIA Real World Data-Longitudinal Prescriptions database are used to classify persons aged ≥ 16 years who have been prescribed PrEP in a specific year. The number of persons aged ≥ 16 years with indications for PrEP is estimated by using data from U.S. Census American Community Survey (ACS), the National Health and Nutrition Examination Survey (NHANES), and the National HIV Surveillance System (NHSS). Caution should be used when interpreting PrEP data. Different data sources are used in the numerator and denominator to calculate PrEP coverage. For an in-depth description of how PrEP measures are calculated, see the Technical Notes of CDC's *HIV Surveillance Supplemental Report*, "Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas," at <https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>.

Data source

- NCHHSTP AtlasPlus (<https://www.cdc.gov/nchhstp/atlas/index.htm>)

PrEP data available from the Health Resources and Services Administration (HRSA)

As part of the EHE initiative, the HRSA-funded Health Center Program is focusing on key geographic areas and expanding HIV prevention interventions, including education, access to PrEP services, and care coordination for individuals with substantial risk of acquiring HIV infection.

Recommended analysis

- Preexposure Prophylaxis (PrEP)-associated management of all PrEP patients

Data sources

- 2020 Uniform Data System (UDS) for the national Health Center Program (HCP) and HCP look-alikes (unfunded health centers that receive many FQHC benefits) aggregated data <https://data.hrsa.gov/tools/data-reporting/program-data/national>
 - Table 6A: Selected Diagnoses and Services Rendered includes PrEP measure
- UDS Manuals/Resources, by calendar year: <https://bphc.hrsa.gov/datareporting/reporting/index.html>
 - Each individual HRSA-supported health center submits their own patient population UDS data annually to HRSA. The data are later displayed on [data.hrsa.gov Home Page](https://data.hrsa.gov) geographically—nationwide, as well as by HHS region, state, county, congressional district and by individual health center.
- Academic, clinical, and other organizations conducting PrEP surveys and studies that have locally useful data.
- Evaluation and performance PrEP measures required for jurisdictions funded by PS20-2010 (see [Appendix A](#)).

Additional PrEP Measures (from the PS20-2010 Evaluation and Performance Measurement Plan [EPMP])

The following are additional recommended indicators for PrEP eligibility, access, and use.

Indicators

1. Percentage of persons testing negative for HIV who are screened for PrEP eligibility
 - a. Numerator: Number of persons who tested negative for HIV who are screened for PrEP eligibility
 - b. Denominator: Total number of persons who tested negative for HIV
2. Percentage of persons who are referred and linked to a PrEP provider
 - a. Numerator: Number of persons who tested negative for HIV who are linked to a PrEP provider
 - b. Denominator: Total number of persons who tested negative for HIV
3. Percent of persons using PrEP (defined as classified as having been prescribed PrEP) among those with indications for PrEP (EHE target: at least 50% by 2025)
 - a. Numerator: Number of persons ≥ 16 years who were classified as having been prescribed PrEP in a calendar year
 - b. Denominator: Estimated number of persons with indications for PrEP in a calendar year

Notes:

- *PrEP eligibility* refers to a person's status with regard to whether or not the person meets appropriate criteria for using PrEP; specifically, whether or not the person is HIV-negative and at risk for HIV, as defined locally or by CDC guidelines for PrEP (<https://www.cdc.gov/hiv/pdf/risk/prep/cdc-hiv-prep-guidelines-2017.pdf>).
- A *PrEP provider* is a health care professional (e.g., physician, advanced practice nurse, physician assistant) who conducts evaluations for preexposure prophylaxis (PrEP) eligibility and clinical appropriateness, prescribes PrEP, and provides comprehensive management of persons taking PrEP. Refer to aggregate data tables for Linkage to a PrEP Provider for additional reporting guidance.

Other PrEP Data Sources

- America's HIV Epidemic Analysis Dashboard (www.AHEAD.hiv.gov)
- Locally generated estimates of number of persons with indications for PrEP in any jurisdiction are available at (<http://tinyurl.com/PrEPWebtool>)

Condom use

Correct and consistent condom use is one of the most effective methods to reduce the risk of HIV transmission during sexual activity. Condom distribution programs are an HIV and sexually transmitted infection (STI) prevention strategy that helps increase the availability and accessibility of condoms to prevent the spread of HIV. Free and accessible condoms are an integral, structural component of HIV prevention services.

Recommended analyses

- To what extent are condoms distributed to persons with HIV and persons at risk for HIV across the service area?

Data source

- Local data collection method and system.

Harm reduction

Harm reduction strategies aim to lessen harms associated with drug use and related behaviors that increase the risk of HIV infection. The sharing of needles and other injection equipment increases the risk for HIV and other blood-borne infections such as viral hepatitis. Drug use is associated with risky sexual behaviors including unprotected sex and the exchange of sex for drugs or money, which are linked to an increased risk of HIV infection. Harm reduction is key in the prevention of HIV infection among people who inject drugs (PWIDs) and their sexual partners.

Syringe services programs

Syringe services programs (SSPs) are community-based prevention programs. Comprehensive SSPs offer patients vaccinations and testing for diseases, referrals to treatment for substance use disorder and other diseases (such as viral hepatitis and HIV), and sterile injection equipment to prevent the transmission of infectious diseases, and provide Naloxone for opioid overdose prevention.

Recommended indicators for SSP coverage

1. Explicit authorization of SSPs by state law: The law explicitly authorized the establishment of SSPs.
2. Number of SSPs in the state/jurisdiction: Population-level indicator and should reflect data from all SSPs, regardless of funding source.
3. Proportion of SSPs which report providing needs-based syringe exchange model in state/jurisdiction: Numerator is the number of SSPs that offer anything but 1:1 exchange; denominator is all SSPs, regardless of funding source.

Data sources

- [Syringe service program laws \(lawatlas.org\)](http://lawatlas.org)
- SSP locations: <https://nasen.org/map/>
- National HIV Behavioral Surveillance (NHBS) (<https://www.cdc.gov/hiv/statistics/systems/nhbs/index.html>)

Core Question 4.2: What are the indicators of risk for acquiring and transmitting HIV infection in your service area?

- Discuss and provide individual-level data on risk behaviors for priority populations and populations of special interest (if available).

HIV risk behaviors

In this section of your profile, examine data on risk behaviors and markers from 2 perspectives:

- Factors that affect the risk of acquiring HIV infection among persons without HIV
- Factors that affect the risk of transmitting HIV infection among persons with HIV

Use the data sources listed in “Types and Sources of Data for Epidemiologic Profiles” (Chapter 2, Section 4) to examine the risk for HIV infection by transmission category (based on sex at birth), including the following:

- Male-to-male sexual contact
- Injection drug use
- Heterosexual contact

The populations described in the answers to Core Question 2.1 as most affected by HIV are the groups for which data should be presented as well as populations deemed to be at greatest risk for HIV infection in the service area. You may also want to examine the risk for HIV infection among populations of special interest, including incarcerated persons, homeless persons, migrant laborers, people who exchange sex for money or drugs, persons with mental illness, persons with disabilities, perinatally exposed persons, transgender and AGI persons (using HIV exposure category data), immigrant or refugee residents and any other populations in your local area at increased risk for HIV infection.

Conduct stratified analyses of these exposure categories by gender, race/ethnicity, age group, and other available SDH. Because of incomplete reporting on the variable to capture country of birth in routine surveillance, it is recommended that sites explore locally conducted studies involving immigrant or refugee residents to characterize HIV in these populations. However, where completeness on this variable in routine surveillance data is adequate, jurisdictions may use this variable to describe HIV in immigrant or refugee populations.

Direct and indirect measures of risk behavior

Direct measures of risk provide information about risk behavior that is directly associated with HIV transmission. Indirect measures do not directly describe HIV risk behaviors. Rather, they are indicators of *possible* HIV risk that may need further investigation. For example, an increase in STI or teen pregnancy rates does not directly indicate that HIV exposure is increasing but may indicate an increase in unprotected sex.

Recommended analyses for data on men who have sex with men (MSM): Direct measures

- Factors that may affect the risk of acquiring or transmitting HIV, such as
 - number of sex partners
 - frequency of condom use
 - substance use (including injection drug use)
 - previous or current primary or secondary syphilis infection
 - information about other HIV prevention measures taken, including use of preexposure prophylaxis (PrEP) or condoms, or having sex with a sex partner based on their HIV status/viral suppression status, and/or use of sterile injection equipment without sharing

Conduct stratified analyses by race/ethnicity and age group (include adolescents).

Data sources

In some areas, the following survey data are available:

- At-risk populations
 - Youth Risk Behavioral Survey (YRBS). These project area surveys, along with a national YRBS, constitute CDC's Youth Risk Behavioral Surveillance System (YRBSS).
 - National HIV Behavioral Surveillance (NHBS)
 - In addition, seek results from locally conducted studies funded by the National Institutes of Health (NIH), CDC, and other government agencies or nongovernmental organizations.
- Persons with HIV
 - Medical Monitoring Project (MMP)
 - In addition, seek results from locally conducted studies funded by NIH, CDC, and other government agencies or nongovernmental organizations.

Note. See [Appendix C](#) for a description of some of the data sources mentioned above.

Recommended analyses for gay, bisexual, other men who have sex with men, and transgender women: Indirect measures

- Trends in a service area in the male-to-female ratio for gonorrhea, syphilis, hepatitis A, and hepatitis B (an increase in this ratio may indicate increasing infections among MSM)
- For STD data available in some areas, trends in
 - gonorrhea, chlamydia (rectal), and syphilis among men and transgender women
 - rectal gonorrhea among men and transgender women
 - proportion of Gonococcal Isolate Surveillance Project (GISP) isolates from MSM
- Methamphetamine use

Conduct stratified analyses by race/ethnicity and age group (include adolescents).

Data sources

- STD notifiable disease surveillance data
- Gonococcal Isolate Surveillance Project
- HIV surveillance registry matches to STD registry to monitor trends in STD incidence among persons with HIV
- National HIV Behavioral Surveillance (NHBS)
- Medical Monitoring Project (MMP)
- Local SSP data

Recommended analyses for people who inject drugs (PWID): Direct measures

- Factors that may affect risk of acquiring or transmitting HIV, such as
 - injection drug use and other substance use
 - needle sharing
 - sharing of injection equipment (cookers, cottons, water, drug solution)
 - exchanging sex for money or drugs
 - number of sex partners
 - frequency of condom use or condomless sex
 - PrEP coverage

Conduct stratified analyses by gender, race/ethnicity, and age group (include adolescents).

Data sources

- Available everywhere for persons at risk
 - Behavioral Risk Factor Surveillance System (BRFSS)
 - Youth Risk Behavior Survey (YRBS). These project area surveys, along with a national YRBS, constitute CDC's Youth Risk Behavioral Surveillance System (YRBSS)
 - HIV Testing Data
 - National Household Survey of Drug Abuse
- Available in some areas for persons at risk
 - National HIV Behavioral Surveillance (NHBS)
 - Monitoring the Future Study (National Institute on Drug Abuse—survey of drug abuse among youth in high school)
 - In addition, seek results from locally conducted cross-sectional studies funded by NIH, CDC, and other government agencies or nongovernmental organizations.

- Persons with HIV
 - Medical Monitoring Project (MMP)
 - In addition, seek results from locally conducted cross-sectional studies funded by NIH, CDC, and other government agencies or nongovernmental organizations.

Note. See [Appendix C](#) for a description of the some of the data sources mentioned above.

Potential local data sources

Additional data sources useful in characterizing the population of persons who inject drugs and specific sub-populations at greatest risk for HIV infection (e.g., young persons who inject drugs) include syringe exchange programs, pharmacies, substance abuse treatment programs, recovery groups, harm reduction coalitions, the city/county medical examiner's office, and local law enforcement. Data on opioid overdose deaths, collected through local review and/or surveillance systems (e.g., data from the national violent death reporting system [NVDRS] where available), dashboards and reports may serve as additional indicators of injection drug use patterns. Other sources of data include published journal articles and reports from public and private researchers and organizations.

Recommended analyses for people who inject drugs (PWIDs): Indirect measures

- Trends in the rate of hepatitis C infection
- Rates of mortality due to substance abuse
- Trends in injection drug use
- Trends in non-injection drug use (alcohol, poppers)
- Trends in recent STI history

Conduct stratified analyses by gender, race/ethnicity, and age group (include adolescents).

Data sources

- Available in every state
 - National Notifiable Diseases Surveillance System
- Available in some areas
 - Drug Abuse Warning Network
 - National Household Survey on Drug Abuse (NHSDA)
 - Treatment episode data set
 - Community epidemiology work group reports

Note. Use these sources to glean data on which drugs are prevalent in your service area, among which groups, and whether the pattern is changing. All these factors can affect HIV risk. See [Appendix C](#) for a description of some of the data sources mentioned above.

Recommended analyses for data on heterosexual populations: Direct measures

- Number of sex partners
- Frequency of condom use or condomless sex
- Substance use (including injection drug use)
- Exchanging sex for money or drugs
- Information about discordant sex partners (i.e., one partner has HIV and the other does not)
- PrEP coverage

Conduct stratified analyses by sex at birth, race/ethnicity, and age group (include adolescents).

Data sources

- Available in all areas for persons at risk
 - Behavioral Risk Factor Surveillance System (BRFSS)
 - Kaiser Family Foundation—State Health Facts
 - HIV testing data
- Available in some areas for persons at risk
 - Youth Risk Behavior Survey (YRBS). These project area surveys, along with a national YRBS, constitute CDC’s Youth Risk Behavioral Surveillance System (YRBSS).
 - National HIV Behavioral Surveillance (NHBS)
 - National Health Interview Survey
 - National Survey of Family Growth
- Available in some areas for persons with HIV
 - Medical Monitoring Project (MMP)
 - In addition to routine surveillance data, seek results from locally conducted cross-sectional studies funded by NIH, CDC, other government agencies, or nongovernmental organizations.

Note. See [Appendix C](#) for a description of some of the data sources mentioned above.

Recommended analyses for heterosexual populations: Indirect measures

- Trends in
 - teen pregnancy rates
 - gonorrhea rates
 - primary, secondary, and congenital syphilis*
 - recent STD diagnoses

Conduct stratified analyses by gender, race/ethnicity, and age group (include adolescents).

**Note.* This analysis might be appropriate in an area that has a large number of syphilis cases. If your area has a small number of syphilis cases (<20), use this analysis with caution: sporadic outbreaks do not necessarily indicate changes in risk behavior in the community.

Data sources

- Available in every state
 - Vital statistics
- Available in some areas for persons with HIV
 - HIV surveillance registry matches to STD registry to monitor trends in STD incidence among persons with HIV
 - STD programs

Note. See [Appendix C](#) for a description of some of the data sources mentioned above.

Data available from the National HIV Behavioral Surveillance (NHBS)

NHBS conducts behavioral surveillance among persons at high risk for HIV infection. Surveillance is conducted in rotating, annual cycles in three different populations at increased risk for HIV: (1) Gay, bisexual and other men who have sex with men (MSM cycle); (2) Persons who inject drugs (PWID cycle); and (3) Heterosexually active persons at increased risk for HIV infection (HET cycle).

Recommended analyses

- Sexual behaviors among HIV-negative persons
 - Ever tested
 - Tested in past 12 months
 - Condomless sex with an HIV-discordant partner at last sex
 - Exchange sex
- PrEP awareness
 - Percentage of NHBS participants who had ever heard of PrEP
- Discussion of PrEP with a health care provider in the past 12 months
 - Percentage of NHBS participants who reported having a discussion with a health care provider about taking PrEP in the past 12 months
- PrEP use in the past 12 months
 - Percentage of NHBS participants who reported taking PrEP in the past 12 months

Recommended analyses for data on additional populations of special interest

You may wish to include additional populations in your profile because their members may belong to the groups already listed or because of unique factors that increase their risk. Data may be available from a variety of sources, including some of those already listed and others that are local. Analyses of case data may also suggest the need for additional studies of these populations. When routine surveillance data are not available, seek results from locally conducted cross-sectional studies funded by NIH, CDC, other government agencies, or nongovernmental organizations.

Chapter 4.

Completing the Epidemiologic Profile

Section 1 Making Your Profile User-Friendly

Section 2 Writing Your Narrative

Section 3 Disseminating Your Profile

Overview

Once you have gathered and analyzed all your data, making your profile user-friendly will help ensure that prevention and care planning groups appropriately use the information to make decisions about prevention and care programs and resources.

This chapter provides suggestions for ensuring that your profile is accessible and useful. It focuses first on ways to ensure that the body of your epidemiologic profile—your data and accompanying narrative—is clear and effective. It then provides guidance on preparing the remaining sections. The chapter concludes with some suggestions for preparing oral presentations of your data and analyses and for disseminating your profile.

Section 1: Making Your Profile User-Friendly

- Organize the profile in a logical sequence, using the sections described in Chapter 2, Section 2
- Present your data in clear, easy-to-understand tables and figures (graphs, charts, maps).
- Explain your data in a well-organized narrative, using straightforward and easy-to-understand language.

Organization of the profile

Presenting your data: Tables and figures

Summarizing your data and presenting them in tables or figures are key to an effective profile and to better understanding, visualizing, and detecting trends in data.

When used appropriately, tables and figures can be used to summarize and display complex data clearly and effectively and can emphasize specific points. These tools let you identify and present distributions, trends, and relationships among the data. They help make sense of the data in the profile and communicate findings to HIV planning groups (HPGs).

However, poorly designed or executed tables and figures can mislead users or distract them from your message.

Tables may be the only presentation format needed when the data are few and relationships are straightforward (tables are the best choice when the display of exact values is important). Figures (e.g., line and bar graphs, pie charts) make more sense for trends and for comparing populations, especially when you wish to show populations broken into subsets, such as males and females or age groups. The key points of tables and figures should always be explained in the accompanying narrative.

As you develop the profile and determine which kind of display to use, ask yourself these questions:

- Can the HPG determine what I want to convey by looking at this type of display, or would another type be better?
- Given the needs of the HPG, is this presentation of the data logical?
- Will the data displayed provide the HPG with the accurate information needed to make informed decisions?

Important considerations for presenting data

The following guidelines apply to all graphic aids:

- The table or figure should be an integral part of the text but should also be able to stand alone (i.e., the reader should understand the table or figure without reference to the text). Ideally, a table or figure should convey one main point.
- Write clear and concise titles for figures and tables. Name the source of your data. Discuss key points of the figure or table in your text.

- For tables, write clear and consistent column headings and row entries (use consistent terms). For figures, write clear and consistent labels, and label all elements to avoid misunderstanding.
- The table or figure should explain the who, what, when, and where of your data. For example, a figure (perhaps a line or bar graph) is useful for showing gender or racial/ethnic differences, geographic differences, or trends.
- Consider the number of tables and figures in the profile. You should have enough to clearly summarize and display your data, but not so many that they are confusing and difficult to understand in terms of the text, regardless of the user’s technical background.
- Avoid clutter. Include only what you need to communicate the point. Eliminate unnecessary words and avoid unnecessarily large words that can detract from the message (e.g., footnotes to tables, and notes to figures, need not be expressed in complete sentences).
- Maintain scale and balance by keeping the width and height of the table or figure in proportion (i.e., for a figure, the length of the vertical [y] axis should be approximately two-thirds the length of the horizontal [x] axis; in general, tables are longer than they are wide).
- Consider how copies of the profile will be produced. Often, epidemiologic profiles are photocopied rather than professionally printed. If a color document is photocopied in black and white, the data elements (e.g., bars in a chart or slices of a pie chart) will probably be difficult to distinguish. Consider using patterns (e.g., dots, wavy lines, solid black). Shades of gray must differ at least 30%, or the gray elements will not be clearly distinguished in the original or in the copies (even if the document is professionally printed).
- Consider the preferences of your HPG. If you have an opportunity, find out how they would like to see the data presented. That will help you determine the types of presentation that are easiest for them to understand and use.
- Consider the best way to present your data:
 - Ensure that your presentation of epidemiologic data does not inadvertently stigmatize the demographic groups to which the data refer. Work with your HPG to avoid this problem.
 - In situations in which the presentation of data on larger groups would overwhelm the presentation of data on smaller groups, you can present the data on the smaller groups separately. In the explanation below the figure, point out the differences between the larger and smaller groups. For additional information on how to present data, see:

Edward R. Tufte. *The Visual Display of Quantitative Information*. Cheshire, CT: Graphics Press; 2nd edition, 2009.
 - When the numbers for a group are small, observe restrictions on cell size to protect confidentiality.

See [Appendix B](#) (Use of Tables, Charts, and Maps to Illustrate Data) for examples of table and figure presentations suitable for your epidemiologic profile.

Section 2: Writing Your Narrative

Presenting data without effective explanation and interpretation often limits the clarity and user-friendliness of an epidemiologic profile. Your narrative is crucial in helping users understand and interpret the data you present about HIV in your service area and in helping them use the data appropriately to plan prevention and care programs.

Effective writing has many elements. This section concentrates on 3 elements that can significantly affect your profile:

- Know your audience—who they are, their level of familiarity with epidemiologic issues and terminology, and their perspectives as end users of your profile.
- Focus your narrative on findings so that its purpose is clear, and it addresses specific questions and the needs of specific end users.
- Write clearly, using concrete, familiar words and strong, active language.
 - Use readability indices and grammar tools (e.g., spelling and grammar checks in Microsoft Word) to improve clarity and/or to identify sentences that may need improvement.
 - Avoid stigmatizing language

See [Appendix A](#) (Sample Data Tables and Charts with Interpretation Associated with Chapter 3) for examples of narrative interpretations of epidemiologic data.

Know your audience

Good writing is reader-centered, not writer-centered. Start by assessing your audience—the end users of the profile. Remember, your profile should be a document that planning group members can use to make decisions about prevention and care programs and resources. To help you bring your users into focus, ask yourself:

- Who will read the profile?
- What are their professions, their viewpoints on and/or lived experiences with HIV, and their familiarity with epidemiology?
- How much do they already know about HIV?
- What are the most important things they will be looking for in the profile?
- How will they use the information in the profile?

Knowing the backgrounds of HPG members, their experience and expertise with epidemiology, and how they will use the information can help you ensure that the profile meets their needs and capabilities. Planning groups may be diverse (e.g., community advocates; paraprofessionals, such as outreach workers; health care professionals, such as nurses, social workers, counselors, physicians, or psychologists; and program managers with differing educational backgrounds). Some members may have had formal training in epidemiology or statistics, while others may have had no formal training but may be able to easily assimilate epidemiologic concepts and the implications of those concepts for

prevention and care programs. Additionally, some members may know their communities well but have little or no experience working with data.

Members will also have varying levels of experience and expertise with HIV, which will influence what you include in your profile and how you frame the information. For example, consider questions that deal with changing demographics or clinical patterns that service providers and advocates in the planning group may have observed. Think about how your data may or may not be able to address these kinds of changes.

In addition, members of HPGs and Ryan White planning councils/advisory groups may differ in their ability to read and comprehend English. When you prepare slides for oral presentations, remember that persons who are color-blind cannot distinguish red and green when they are close together, and that persons who are visually impaired may have difficulty with graduated colors (sometimes called color sweeps).

Work closely with members of the HPG in developing the profile. In doing so, keep the following in mind:

- Understand the perspectives of the HPG; the members are the primary end users. This will help you to:
 - address populations that group members serve and will also help you address those populations specifically, in terms of risk, reported cases, and testing or other service patterns
 - address policies that affect the data and that may also affect service delivery (e.g., changes in case reporting resulting from named reporting)
- Recognize and respect different perspectives of end users. For example, service providers and advocates tend to think in terms of individuals and trends among the individuals that they serve rather than in terms of grouped data (e.g., population-level measurements, such as mean and median).

Focus your narrative on the needs of users

Although the profile is not the only resource that HPGs use, it is a principal contributor to the planning process. Therefore, your profile needs to focus on the uses of data as spelled out in CDC and HRSA guidance. You also need to explain your conclusions carefully and clearly to minimize the possibility that users will misinterpret them. Here are some suggestions for how to respond to these uses. Craft your profile so that it allows planning groups to:

- set priorities among populations by:
 - describing differences in the financial burden, socioeconomic burden, and incidence and prevalence of HIV (geographically and by population)
 - describing social determinants of health and HIV-related disparities (by population)
 - presenting findings from cluster detection analyses
- prepare for needs assessments and for analysis of gaps in care and prevention by:
 - describing access to care and treatment services (by population)
 - describing the HIV care continuum (by population)
 - describing differences in HIV risk (geographically and by population)

- detailing changes in policy, diagnostics, and treatment strategies that may affect risk, financial burden, socioeconomic burden, and incidence and prevalence of HIV or care and prevention needs
- presenting findings on gaps in services from cluster and outbreak response activities
- identify questions that cannot be answered from the epidemiologic data
 - set priorities for implementing interventions by:
 - defining populations who need prevention or care services
 - identifying and describing areas that need prevention or care services
 - describing whether current services match the population and geographic distribution of HIV and relevant risk behaviors

Write clearly

Good writing is straightforward and easy to follow. The ideas flow logically from one to another. Readers should not have to stop and ask, “Now, what did that mean?” They should come to the end of a document with a clear sense of the author’s main points and conclusions from the information presented.

These concepts are vital in an epidemiologic profile because HPG members must understand the narrative and the data presentations if they are to make sound decisions about prevention and care services.

Below are suggestions for avoiding several common pitfalls in scientific or technical documents. Skirting these pitfalls will make your profile clearer, more explicit, and more accessible to your users, and therefore more useful. These suggestions include:

- Avoid jargon and overly technical terms
- Spell out abbreviations at first use in the document
- Use active, not passive, voice
- Uncover smothered verbs
- Avoid “there is” and “there are” constructions
- Be explicit

Avoid jargon and overly technical terms

Jargon is the specialized vocabulary and idioms of a particular field or profession. Jargon works against clarity because it is often composed of long, or unfamiliar, words or phrases. The use of jargon and technical terms can be seen as a way of talking above a group or avoiding direct discussion of controversial issues and can be perceived as pretentious. Avoiding jargon and overly technical terms *does not* mean that you write down to the audience or that you eliminate all technical terms related to epidemiology. In fact, many technical terms are necessary to describe HIV in the service area (e.g., prevalence, incidence, rates). However, avoiding jargon *does* mean that you explain the technical term and how it relates to the data. The following example demonstrates how to translate epidemiologic jargon into useful information.

Jargon: The data show an increase in the prevalence of persons with HIV in 2019. Data show an increase in adolescent drinking and unprotected sex; thus, there is an increased risk of exposure for adolescents.

Useful information: In 2019, compared with earlier years, adolescents in County X were at increased risk for exposure to HIV. Data show an increased prevalence (*prevalence* is the total number of persons with HIV, whether their infection is diagnosed or undiagnosed, at a particular point in time) of HIV in 2019. At the same time, the frequency of high-risk behavior among adolescents—drinking and unprotected sex—also increased. When the prevalence of HIV infection in the community and the frequency with which adolescents practice high-risk behavior increase, the risk for exposure may also increase.

Spell out abbreviations

Abbreviations (used here to include acronyms and initialisms) can be especially confusing to people who are not familiar with them. Be sure to write out the term or proper name at first use. Include in your profile a list of abbreviations and the written-out forms for which they stand.

Use active, not passive, voice

Voice is the relation of a subject to its verb; that is, whether the subject acts or is acted upon. In the passive voice, the subject receives the action (is acted upon). It is formed by adding the past participle of a verb to the proper form of the verb *to be*.

Many authors use the passive voice in scientific documents because they believe that it contributes to an impersonal, more formal style. However, it requires more words and forces the reader to work harder. Active voice, in which the subject acts, is usually better than passive voice because it:

- is easier to understand and sentences are often shorter
- gives more information
- is often more direct
- is closer to spoken language and therefore is more natural
- names the doer of the action

Here are two examples of the passive voice:

An additional seroprevalence study was conducted by the HIV Epidemiology Program. The plan of the XYZ Prevention Planning Group was submitted to the committee.

Here are the same two sentences in the active voice:

The HIV Epidemiology Program conducted an additional seroprevalence study. The XYZ Prevention Planning Group submitted its plan to the committee.

Uncover smothered verbs

Verbs are action words. Burying them in a group of other words robs them of their power. Smothered verbs often end in *ion*—as in *collection of*—and may accompany the passive voice. Getting rid of one sometimes helps you get rid of the other.

Smothered: Collection of data occurs throughout the year.

Uncovered: The health department collects data throughout the year.

Avoid “there is” and “there are” constructions

Beginning a sentence with these phrases often leads to a wordy, weak sentence. You can almost always rework your sentence to avoid this construction by beginning with the word that is the subject of the sentence. Your writing will be shorter and more direct as a result.

Before: There is very limited information available on the risk behaviors among transgender persons.

After: Information on the risk behaviors of transgender persons is very limited.

Before: There are hundreds of Native American tribes in the United States.

After: Hundreds of Native American tribes live in the United States.

Be explicit

As the writer of the profile, you cannot assume that your readers know everything about the subject or can infer your meaning. When you write explicitly, you anticipate readers’ questions. For example,

- Have you raised a question or issue but not answered it?
- Have you come to a conclusion in your paragraph but not stated it?
- Have you assumed important information in coming to a conclusion but not stated it?
- Are 2 points related in some way that is not evident to a reader who is unfamiliar with the subject matter?

If you can answer yes to any of these questions, you should revise your text.

Additional suggestions and reminders for clear writing and user-friendly formats

- The word *data* is plural, not singular. For example, “Data show that injection drug use increases a person’s risk for HIV.”
- Consider using the reading-level feature built into word processing software to determine readability.
- Ask another person to read your draft profile. If he or she has trouble understanding what you have written or stumbles into the pitfalls already described, you should revise. Having another person read your draft is particularly helpful for catching writing that assumes knowledge that a reader may not have or writing that is not explicit.

- Use consistent formats for headings in the overall profile, within sections, and for tables and figures.
- Use bullets to highlight key information and to break up a long series of items listed in a single sentence.

Section 3: Disseminating Your Profile

Writers of epidemiologic profiles should ensure that the state health department disseminates the completed profile to members of HIV prevention planning groups, RWHAP grant recipients, and planning councils and consortia as part of the comprehensive needs assessment.

The epidemiologic profile is the first step in the planning process for both prevention and care groups, and each process includes other key elements. Prevention planning groups use the community needs assessment to build on the epidemiologic profile and thus examine resource needs of the populations described in the profile. The comprehensive needs assessment conducted by care planning groups consists of 5 components:

- Epidemiologic profile
- Description of service needs of the affected population
- Resource inventory
- Profile of provider capacity and capability
- Description of unmet needs for primary health care and of other gaps in services

Both prevention and care groups use these elements to identify gaps in the coverage of prevention services, set priorities among populations, and conduct interventions for populations at higher risk. In addition, care planning groups use these elements to identify gaps in the coverage of RWHAP services and to set priorities that address the care needs of persons with HIV and affected populations.

Disseminating your profile for other purposes

You may wish to distribute your profile to other key stakeholders. Here are some suggestions for doing this successfully:

- Develop a dissemination plan well in advance of the final publication.
- Distribute the profile widely, under the name of, or with a cover letter from a well-known official at the top of the health department.
- Post the profile on the health department website. This is recommended as the primary method of distribution.
- Draw the attention of relevant individuals and agencies to the online availability of the profile: executive directors of local CBOs; major providers of HIV care, including physicians, nurses, and physician assistants; sister government agencies or departments (e.g., STI and TB program directors); community activists; local academic HIV researchers; and local government officials.
- Make presentations to HPGs, RWHAP planning councils and planning bodies, CBOs, provider groups, university audiences, and others.
- Put copies in the reception areas of your offices for visitors.
- When inquiries are made about data on a specific population, refer the inquirer to the profile.

See [Appendix E](#) (Preparing Oral Presentations of Your Profile).

Chapter 5.

Special Considerations

Section 1 Additional Populations

Section 2 Areas with Low Morbidity and Minimal Data

Section 3 Pediatric HIV Surveillance

Section 1: Additional Populations

The Ryan White HIV/AIDS Treatment Extension Act of 2009 (Public Law 111-87, October 30, 2009; aka the RWHAP law) requires that applicants for program funds demonstrate the need for RWHAP funds. Furthermore, the law requires that needs assessments and comprehensive plans used by RWHAP planning councils or consortia in setting priorities and allocating funds identify and address the unmet service needs of additional populations. RWHAP Part A and B recipients should be familiar with the 2021 update to the [methodology for estimating unmet need](#). The manual includes background on the unmet need requirement and a summary of how changes to the methodology were determined, and provides instructions for RWHAP Parts A and Part B recipients on how to calculate unmet need by using the updated methodology.

In planning for additional populations, unmet needs may refer to the service needs of persons not currently in the system of HIV care. It may also refer to persons in the system of HIV care whose needs are being only partially met. Determining unmet needs among additional populations, which should be carried out during needs assessment, is important in determining how to direct resources to people with HIV who may be disenfranchised from HIV care services.

NHAS identifies the following populations as priorities for efforts to reduce disparities and improve HIV outcomes:

- gay, bisexual, and other men who have sex with men, in particular Black/African American, Hispanic/Latino, and American Indian/Alaska Native men
- Black/African American women
- transgender women
- youth aged 13–24 years
- people who inject drugs

In addition, RWHAP grant recipients are encouraged to identify other populations that have been significantly or disproportionately affected by HIV. Evidence indicating that a population has been significantly affected should be provided by the data included for underserved populations. These data should come from epidemiologic profiles and needs assessments and may also include other national and local data. Some underserved populations include the following:

Rural populations

In recent years, people in rural communities have been experiencing notable increases in diagnoses of HIV infections, at least in part because of the opioid epidemic and associated HIV outbreaks. Many rural communities lack drug use/addiction treatment centers and syringe services programs (SSPs). Increasing rates of injection drug use in rural communities has led to an increase in rates of HIV, hepatitis C, and other infectious diseases in rural communities. Historically, HIV was centralized in major cities, which meant that resources and research attention were heavily concentrated in urban areas contributing to HIV disparities in rural communities. In addition, social factors, HIV criminalization laws, and the lack of public health infrastructure investment led to barriers and challenges complicating access to HIV prevention and treatment efforts in rural communities. The [HRSA Federal Office of Rural Health Policy](#) can serve as a resource for identifying and working with rural communities.

Transgender women

Data from the [NHBS HIV Surveillance Special Report](#) among transgender women found 4 in 10 surveyed in seven major U.S. cities have HIV. Also, nearly two-thirds of Black/African American and more than one-third of Hispanic/Latina transgender women surveyed have HIV. Transgender women face numerous prevention and care challenges, including medical mistrust due to experiences of transphobia, lack of trans-inclusive marketing, and concerns about drug interactions between hormones and PrEP. HIV prevention and care efforts that are culturally informed and responsive to community needs are essential to eliminate socioeconomic barriers to care, including systemic racism, poverty, and stigma, and to address unequal access to health care, educational inequity, housing instability, and employment circumstances.

Section 2: Areas with Low Morbidity and Minimal Data

For areas with a small number of cases, data may need to be aggregated or suppressed to avoid disclosure of data and to protect confidentiality. Aggregation/collapsing balances the need to protect individual privacy with the goal of maximizing data presentation. The epidemiologists providing data for the profile should determine when aggregating or suppressing data is appropriate. Aggregation is most useful when aggregating across years or demographic groups. For data re-release, CDC suppresses cells 1–4 for tabulations in areas with less than 500,000 population. A suppression rule is also applied for analyses when population denominators are <100. See “Data Analysis and Dissemination” in CDC’s *Technical Guidance for HIV Surveillance Programs: Policies and Procedures*, which can be obtained from the HIV surveillance program in your service area.

For areas with low morbidity, geographic analysis may be particularly difficult and, in some instances, inappropriate. For example, analysis at the county level may be inappropriate because of the small number of cases. Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs) often consist of multiple counties or other jurisdictions of which one (the “dominant” county) typically has most of the cases, and the boundaries of the EMA/TGA may cross state lines (e.g., Washington D.C., Kansas City). The numbers of cases in the nondominant or less populous counties may be too small for comparison with those in the dominant county or for analysis of other variables within individual nondominant counties. Consequently, the suggested analyses by “geographic area” should generally pertain only to EMAs/TGAs within states and not to counties or other smaller areas within an EMA or TGA. Apply the same rationale when examining rural and urban data.

If the distribution of HIV has remained stable in your service area, explain the data and possible reasons for this stability in your epidemiologic profile and in presentations to your community planning group. If data are available from supplemental data sources or local studies that may help explain the distribution of HIV in your service area, be sure to include those results in your epidemiologic profile. For service areas in which data are not available, note this lack of data in the profile.

Section 3: Pediatric HIV Surveillance

Pediatric HIV Surveillance serves as a guide for collecting and managing pediatric HIV surveillance in the United States, including data collection for children <13 years of age with diagnosed HIV infection, infants perinatally exposed to HIV, and pregnant women with diagnosed HIV infection.

Surveillance for perinatal HIV exposure and HIV infection enables timely and complete monitoring of the effectiveness of perinatal HIV prevention efforts. Perinatal exposure data can be used to monitor HIV incidence trends, identify groups in which prevention strategies are less successful, evaluate the impact of antiretroviral therapy on perinatal HIV incidence, assess resources required to provide care for children exposed to HIV, examine the timeliness of receipt of HIV-related care, and evaluate potential short- or long-term adverse effects of in utero exposure to antiretroviral therapy.

Perinatal HIV surveillance and prevention programs, including the testing of pregnant women and treatment for those who have HIV, are needed to continue the declines in the number of children with HIV. A large proportion of pregnancies among women with HIV infection now occur after HIV has been diagnosed, emphasizing the importance of considering linking to and retention in care of women with HIV as a priority in HIV planning. There continues to be perinatal HIV transmission in the United States each year. These infections are due to missed opportunities for prevention, most often a lack of detection of HIV infection in pregnant women or a lack of adequate preconception care (e.g., adequate therapy and pregnancy planning for adult women with HIV infection).

Appendices

Appendix A Sample Data Tables and Charts with Interpretation Associated with Chapter 3

Appendix B Use of Tables, Charts, and Maps to Illustrate Data

Appendix C Data Sources

Appendix D Ryan White HIV/AIDS Programs

Appendix E Preparing Oral Presentations of Your Profile

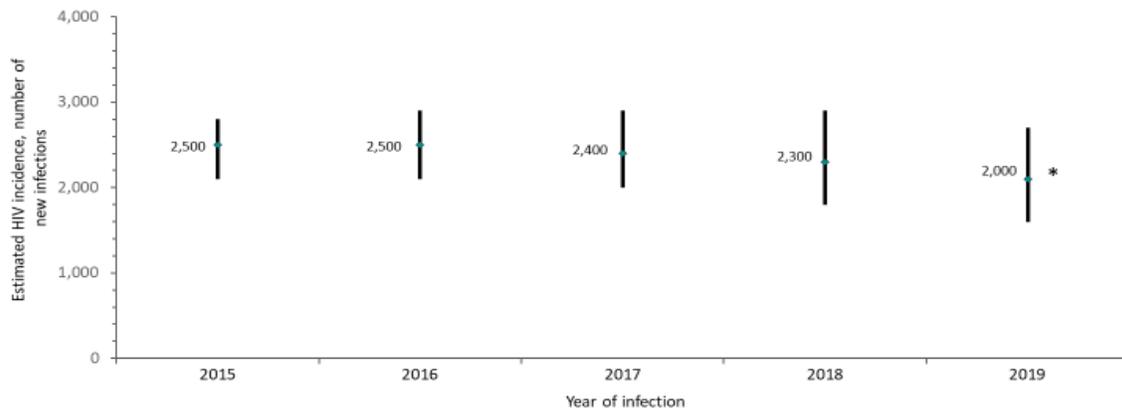
Appendix F Planning Group Epidemiologic Profile Feedback Form

Appendix G Terms, Definitions, and Calculations

Appendix A.

Sample Data Tables and Charts with Interpretation Associated with Chapter 3

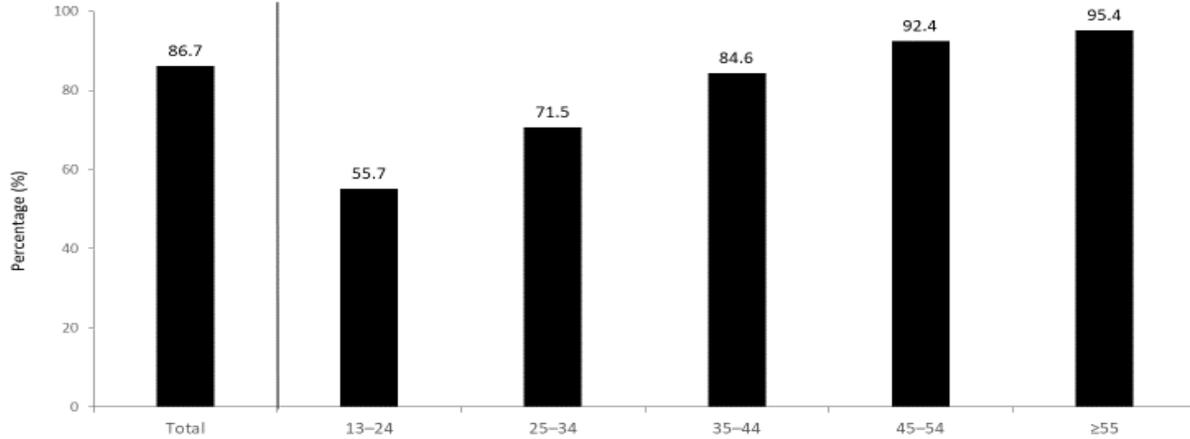
Figure A1. Estimated HIV incidence among persons aged ≥13 years, 2015–2019—State X



Note. Estimates were derived from a CD4 depletion model using HIV surveillance data. Bars indicate the range of the lower and upper bounds of the 95% confidence intervals for the point estimate.

* Difference from the 2015 estimate was deemed statistically significant ($P < .05$).

Interpretation: HIV incidence decreased in 2019, compared with 2015. In 2019, the estimated number of HIV infections was 32,000.

Figure A2. Knowledge of HIV status among persons aged ≥ 13 years

Note. Estimates were derived from a CD4 depletion model using HIV surveillance data.

Interpretation: The estimated percentage of persons with diagnosed HIV (aware of their HIV status) increased with age. Only 55.7% of persons aged 13–24 years had received a diagnosis, while 95.4% of persons aged ≥ 55 years had received a diagnosis.

Table A-1. HIV diagnoses among persons in State X, by age group and sex at birth, 2019

Age (yr)	Male		Female		Total	
	No.	%	No.	%	No.	%
<13	—	—	—	—	—	—
13–14	—	—	—	—	—	—
15–24	172	22.7	41	18.1	213	21.6
25–34	290	38.3	74	32.6	364	37.0
35–44	136	18.0	35	15.4	171	17.4
45–54	83	11.0	45	19.8	128	13.0
55–64	61	8.1	24	10.6	85	8.6
≥65	14	1.8	8	3.5	22	2.2
Total	757	100.0	227	100.0	984	100.0

Source: enhanced HIV/AIDS Reporting System (eHARS)

Dash indicates cell size of ≤3.

Interpretation: In 2019, a diagnosis of HIV was made for 984 persons in State X. Among all persons, a high proportion of the diagnoses (43.3%) were for males aged 25–44 years.

Table A-2. HIV diagnoses and rates among persons in State X, by race/ethnicity and sex at birth, 2019

Race/ethnicity	Male			Female			Total		
	No.	%	Rate ^a	No.	%	Rate ^a	No.	%	Rate ^a
American Indian/Alaska Native	—	—	—	—	—	—	—	—	—
Asian	14	1.8	6.1	—	—	—	14	1.4	3.0
Black/African American	338	44.6	50.3	130	57.3	18.0	468	47.6	33.6
Hispanic/Latino ^b	139	18.4	27.4	40	17.6	8.1	179	18.2	17.9
Native Hawaiian/other Pacific Islander	—	—	—	—	—	—	—	—	—
White	242	30	5.1	53	23.3	1.1	295	30.0	3.0
Multiracial	23	3	21.4	4	1.8	3.6	27	2.7	12.3
Total	757	100.0	12.1	227	100.0	3.5	984	100.0	7.7

Source: enhanced HIV/AIDS Reporting System (eHARS)

^a Rates are per 100,000 population.

^b Hispanic/Latino persons can be of any race.

Dash indicates cell size of ≤3.

Interpretation: In 2019, HIV was diagnosed for 984 persons of whom 757 (76.9%) were male and 227 (23.1%) were female. By race/ethnicity, 468 (47.6%) were Black, 295 (30.0%) were White, 179 (18.2%) were Hispanic/Latino, 14 (1.4%) were Asian persons, and 27 (2.7%) were multiracial. American Indian/Alaska Native persons and Native Hawaiian/other Pacific Islander persons constituted less than 1.0% each.

The rate of diagnosed cases of HIV was 7.7 per 100,000 in State X. The rate for males was 3 times that for females (12/100,000 compared with 4/100,000). By race/ethnicity, the rate was highest for Black persons (34/100,000) compared with Hispanic/Latino (18/100,000), Asian and White (3/100,000) persons. The rates for Black/African American and Hispanic/Latino males were higher than those for all other groups (50/100,000 and 27/100,000, respectively). The third highest rate was that for multiracial males (21/100,000).

Table A-3. HIV diagnoses among persons in State X, by transmission category and sex at birth, 2019

Transmission category (based on sex at birth)	Male		Female		Total	
	No.	%	No.	%	No.	%
Male-to-male sexual contact	552	72.9	—	—	552	56.1
Injection drug use	67	8.9	39	17.2	106	10.8
Male-to-male sexual contact and injection drug use	31	4.1	—	—	31	3.2
Heterosexual contact ^a	94	12.4	153	67.4	247	25.1
Perinatal ^b	—	—	—	—	—	—
Other ^c	13	1.7	35	15.4	48	4.8
Total	757	100.0	227	100.0	984	100.0

Source: enhanced HIV/AIDS Reporting System (eHARS)

^a Heterosexual contact with a person known to have, or with a risk factor for, HIV infection.

^b Individuals were ≥13 years of age at time of diagnosis of HIV infection.

^c Includes hemophilia, blood transfusion, and risk factor not reported or not identified.

Interpretation: By transmission category (based on sex at birth), 552 (56.1%) persons had HIV attributed to male-to-male sexual contact, 247 (25.1%) to heterosexual contact, and 106 (10.8%) to injection drug use. Among the 757 males with diagnosed HIV infection, the predominant transmission category was male-to-male sexual contact (72.9%), followed by heterosexual contact (12.4%) and injection drug use (8.9%). Among the 227 females with diagnosed HIV infection, the primary transmission category was heterosexual contact (67.4%), followed by injection drug use (17.2%).

Table A-4. HIV diagnoses among persons in State X, by transmission category and race/ethnicity, 2019

Transmission category (based on sex at birth)	American Indian/Alaska Native		Asian		Black/African American		Hispanic/Latino ^a		Native Hawaiian/other Pacific Islander		White		Multiracial		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Male-to-male sexual contact	—		10	71.4	241	51.5	101	56.4	—		153	51.9	16	59.3	522	53.0
Injection drug use	—		—		32	6.8	13	7.3	—		60	20.3	—		106	10.8
Male-to-male sexual contact and injection drug use	—		—		5	1.1	5	2.8	—		20	6.8	—		31	3.2
Heterosexual contact ^b	—		—		100	21.4	44	24.6	—		51	17.3	9	33.3	207	21.0
Perinatal ^c	—		—		—		—		—		—		—		—	
Other/unknown ^d	—		—		90	19.2	16	8.9	—		11	3.7	—		118	12.0
Total	—		14	100.0	468	100.0	179	100.0	—		295	100.0	27	100.0	984	100.0

Source: enhanced HIV/AIDS Reporting System (eHARS)

^a Hispanic/Latino persons can be of any race.^b Heterosexual contact with a person known to have, or with a risk factor for, HIV infection.^c Individuals were ≥13 years of age at time of diagnosis of HIV infection.^d Includes hemophilia, blood transfusion, and risk factor not reported or not identified.

Dash indicates cell size of ≤3.

Interpretation: The percentage of persons with HIV attributed to male-to-male sexual contact (based on sex at birth) was higher among Black/African persons than other racial/ethnic groups; injection drug use was higher for White and Black/African American persons. The percentage of Hispanic/Latino persons with HIV attributed to heterosexual contact was similar to the percentage for Black/African American persons and 1.4 times the percentage for White persons.

Table A-5. HIV diagnoses among persons in State X, by gender and race/ethnicity, 2019

Race/ethnicity	Male		Female		Transgender woman ^a		Transgender man ^b		Additional gender identity ^c		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Hispanic/Latino ^d	139	18.6	39	17.3	—	—	—	—	—	—	179	18.2
American Indian/Alaska Native	—	—	—	—	—	—	—	—	—	—	—	—
Asian	14	1.9	—	—	—	—	—	—	—	—	14	1.4
Black/African American	330	44.2	130	57.5	8	80.0	—	—	—	—	468	47.6
Native Hawaiian/other Pacific Islander	—	—	—	—	—	—	—	—	—	—	—	—
White	241	32.3	53	23.5	1	10.0	—	—	—	—	295	30.0
Multiracial	22	2.9	4	1.8	1	10.0	—	—	—	—	27	2.7
Total	747	100.0	226	100.0	10	100.0	—	—	—	—	984	100.0

Source: enhanced HIV/AIDS Reporting System (eHARS)

^a “Transgender woman” includes individuals who were assigned “male” sex at birth but have ever identified as “female” gender.

^b “Transgender man” includes individuals who were assigned “female” sex at birth but have ever identified as “male” gender.

^c “Additional gender identity” examples include “bigender,” “gender queer,” and “two spirit.”

^d Hispanic/Latino persons can be of any race.

Dash indicates cell size of ≤3.

Interpretation: The percentage of Black/African American persons with HIV diagnosed in 2019 in State X was 1.6 times higher than the percentage of White persons and 2.6 times higher than the percentage of Hispanic/Latino persons with diagnosed HIV. Of the 747 (76.7% of all diagnoses) males with diagnosed HIV in 2019, Black/African males accounted for 44.2%, compared to White males accounting for 32.3% and Hispanic/Latino males accounting for 18.6% of HIV diagnoses among males.

Table A-6. HIV diagnoses among transgender persons in State X, by exposure category and gender, 2019

Exposure category ^c	Transgender woman ^a		Transgender man ^a		Additional gender identity ^b		Total	
	No.	%	No.	%	No.	%	No.	%
Sexual contact ^d	571	88.8	15	31.9	19	82.6	605	84.9
Injection drug use	2	0.3	3	6.4	0	0.0	5	0.7
Sexual contact ^d and injection drug use	52	8.1	1	2.1	1	4.3	54	7.6
Perinatal ^e	0	0.0	0	0.0	0	0.0	0	0.0
Other ^f	18	2.8	28	59.6	3	13.0	49	6.9
Total	643	100	47	100	23	100	713	100

Source: enhanced HIV/AIDS Reporting System (eHARS)

^a “Transgender woman” includes individuals who were assigned “male” sex at birth but have ever identified as “female” gender. “Transgender man” includes individuals who were assigned “female” sex at birth but have ever identified as “male” gender.

^b Additional gender identity examples include “bigender,” “gender queer,” and “two-spirit.”

^c Data presented for transgender persons aged ≥ 13 years only. Categories are mutually exclusive but are not hierarchical. Data were not statistically adjusted for missing exposure category.

^d Sexual contact with a person known to have, or with a risk factor for, HIV infection.

^e Individuals were aged ≥ 13 years at time of diagnosis of HIV infection.

^f Includes hemophilia, blood transfusion, and risk factor not reported or not identified. Data were not statistically adjusted to account for missing exposure category.

Interpretation: By exposure category, 605 (84.9%) transgender persons had HIV infection attributed to sexual contact, 54 (7.6%) to sexual contact *and* injection drug use, and 5 (0.7%) to injection drug use. Among the 713 transgender persons, transgender women accounted for 90.1% of persons with diagnosed HIV infection. Among the 643 transgender women with diagnosed HIV infection, the predominant exposure category was sexual contact (88.8%), followed by sexual contact *and* injection drug use (8.1%).

Table A-7. HIV diagnoses among persons in State X, by year of diagnosis and age at diagnosis, 2015–2019 and cumulative

Age at diagnosis (yr)	2015 No.	2016 No.	2017 No.	2018 No.	2019 No.	Cumulative cases through 2019 (Total) No.
<13	6	—	—	—	—	741
13–14	—	—	—	—	—	90
15–24	268	259	256	232	213	8,168
25–34	347	379	352	353	364	19,859
35–44	218	206	216	172	171	18,699
45–54	212	183	155	145	128	9,760
55–64	103	89	81	92	85	3,249
≥65	26	24	33	21	22	891
Total	1,181	1,143	1,094	1,016	984	61,457

Source: enhanced HIV/AIDS Reporting System (eHARS)

Dash indicates cell size of ≤3.

Interpretation: There was a steady decrease of the number of HIV diagnoses each year from 2015 to 2019. In 2019, of the 984 diagnoses of HIV, the largest percentage (36.9%) was for persons aged 25–34 years, followed by 21.6% for persons aged 15–24, 17.4% for persons aged 35–44, 13.0% for persons aged 45–54, 8.6% for persons aged 55–64, 2.2% for persons aged 65 and older, and less than 1.0% for persons aged 13–14 years and 13 years and younger.

Table A-8. Deaths of persons with diagnosed HIV infection in State X, by year of death and race/ethnicity, 2015–2019 and cumulative

	2015	2016	2017	2018	2019	Cumulative deaths through 2019
Race/ethnicity	No.	No.	No.	No.	No.	No.
Hispanic/Latino ^a	60	79	87	72	68	2,891
American Indian/Alaska Native	—	—	—	—	—	18
Asian	—	—	5	—	—	76
Black/African American	292	300	292	274	266	13,224
Native Hawaiian/other Pacific Islander	—	—	—	—	—	—
White	199	184	203	167	170	10,468
Multiracial	23	30	28	35	32	512
Total	577	593	615	549	540	27,193

Source: enhanced HIV/AIDS Reporting System (eHARS)

^a Hispanic/Latino persons can be of any race.

Dash indicates cell size of ≤ 3 .

Interpretation: From 2015 through 2019 in State X, the number of deaths of persons with diagnosed HIV remained stable. In 2019, the highest number of deaths of persons with diagnosed HIV was 266 Black/African American persons (49.3%), followed by 170 White persons (31.5%) and 68 Hispanic/Latino persons (12.6%).

Table A-9. Linkage to HIV medical care after HIV diagnosis during 2019 among persons aged ≥13 years in State X, by selected characteristics

Characteristics	Persons diagnosed with HIV infection No.	Within 30 days ^a			
		≥1 care visits		No care visits	
		No.	%	No.	%
Sex at birth					
Male	500	373	74.6	127	25.4
Female	135	97	71.9	38	28.1
Gender					
Male	497	370	74.4	127	25.6
Female	135	97	71.9	38	28.1
Transgender woman ^b	—	—	—	—	—
Transgender man ^b	—	—	—	—	—
Additional gender identity ^c	—	—	—	—	—
Age at diagnosis (yr)					
13–24	166	111	66.9	55	33.1
25–34	219	172	78.5	47	21.5
35–44	117	87	74.4	30	25.6
45–54	75	55	73.3	20	26.7
≥55	58	45	77.6	13	22.4
Race/ethnicity					
American Indian/Alaska Native	—	—	—	—	—
Asian	—	—	—	—	—
Black/African American	456	332	72.8	124	27.2
Hispanic/Latino ^d	14	12	85.7	2	14.3
Native Hawaiian/other Pacific Islander	—	—	—	—	—
White	151	113	74.8	38	25.2
Multiracial	12	11	91.7	1	8.3
Unknown races	—	—	—	—	—
Transmission category (based on sex at birth)^e					
Male-to-male sexual contact	268	212	79.1	56	20.9
Injection drug use					
Male	7	7	100.0	0	0.0
Female	6	3	50.0	3	50.0
Male-to-male sexual contact and injection drug use	9	7	77.8	2	22.2
Heterosexual contact ^f					
Male	13	11	84.6	2	15.4
Female	29	22	75.9	7	24.1
Other ^g					
Male	203	136	67.0	67	33.0
Female	100	72	72.0	28	28.0
Total	635	470	74.0	165	26.0

Source: enhanced HIV/AIDS Reporting System (eHARS)

^a Linkage to HIV medical care was measured by documentation of ≥1 CD4 or VL or genotype test ≤30 days after HIV diagnosis.^b “Transgender male-to-female” includes individuals who were assigned “male” sex at birth but have ever identified as “female” gender. “Transgender female-to-male” includes individuals who were assigned “female” sex at birth but have ever identified as “male” gender.^c Additional gender identity examples include “bigender,” “gender queer,” and “two-spirit.”^d Hispanic/Latino persons can be of any race.^e Transmission category data presented based on sex at birth and include transgender persons.^f Heterosexual contact with a person known to have, or to be at high risk for, HIV infection.^g Other transmission category includes persons whose infection was attributed to hemophilia, blood transfusion, perinatal exposure or whose risk factor was not reported or not identified. Data not displayed because the numbers were too small to be meaningful.

Interpretation: By transmission category (based on sex at birth), the highest linkage to care group percentage was for males with infection attributed to male-to-male sexual contact (79.1%) and the lowest linkage to care group percentage was among females with infection attributed to IDU (50.0%).

Table A-10. Receipt of HIV medical care among persons aged ≥13 years with infection diagnosed by year-end 2018 and alive at year-end 2019 in State X, by selected characteristics

Characteristics	Persons alive at year-end 2019 No.	≥1 care visits ^a		≥2 care visits ^a	
		No.	%	No.	%
Sex at birth					
Male	9,873	7,559	76.6	5,670	57.4
Female	3,680	2,873	78.1	2,261	61.4
Gender					
Male	9,810	7,500	76.5	5,629	57.4
Female	3,679	2,872	78.1	2,260	61.4
Transgender woman ^b	63	59	93.7	41	65.1
Transgender man ^b	—	—	—	—	—
Additional gender identity ^c	—	—	—	—	—
Age at year-end 2018 (yr)					
13–24	722	568	78.7	419	58.0
25–34	2,781	2,113	76.0	1,578	56.7
35–44	2,762	2,128	77.0	1,576	57.1
45–54	3,668	2,861	78.0	2,182	59.5
≥55	3,620	2,762	76.3	2,176	60.1
Race/ethnicity					
American Indian/Alaska Native	5	—	—	—	—
Asian	39	22	56.4	21	53.8
Black/African American	8,550	6,577	76.9	4,969	58.1
Hispanic/Latino ^d	449	293	65.3	228	50.8
Native Hawaiian/other Pacific Islander	—	—	—	—	—
White	3,727	2,889	77.5	2,193	58.8
Multiracial	741	647	87.3	517	69.8
Unknown race	39	—	—	—	—
Transmission category (based on sex at birth)^e					
Male-to-male sexual contact	6,342	5,055	79.7	3,800	59.9
Injection drug use					
Male	389	270	69.4	214	55.0
Female	329	251	76.3	199	60.5
Male-to-male sexual contact and injection drug use	451	361	80.0	266	59.0
Heterosexual contact ^f					
Male	811	582	71.8	447	55.1
Female	1,892	1,553	82.1	1,204	63.6
Other ^g					
Male	1,880	1,291	68.7	943	50.2
Female	1,459	1,069	73.3	858	58.8
Total	13,553	10,432	77.0	7,931	58.5

Source: enhanced HIV/AIDS Reporting System (eHARS)

^a Receipt of care any care is defined as at least one care visit during the calendar year. Retention in care is defined as two or more visits at least 3 months (≤91 days) apart in the calendar year.^b “Transgender male-to-female” includes individuals who were assigned “male” sex at birth but have ever identified as “female” gender. “Transgender female-to-male” includes individuals who were assigned “female” sex at birth but have ever identified as “male” gender.^c Additional gender identity examples include “bigender,” “gender queer,” and “two-spirit.”^d Hispanic/Latino persons can be of any race.^e Transmission category data presented based on sex at birth and include transgender persons.^f Heterosexual contact with a person known to have, or to be at high risk for, HIV infection.^g Other transmission category includes persons whose infection was attributed to hemophilia, blood transfusion, perinatal exposure or whose risk factor was not reported or not identified.

Dash indicates cell size of ≤3.

Interpretation: By age group, the highest receipt of HIV medical care percentage was for persons 13–24 years of age (78.7%) and the lowest receipt of HIV medical care percentage was among persons 25–34 years of age (76.0%).

Table A-11. HIV viral suppression during 2019 among persons aged ≥13 years with HIV infection diagnosed by year-end 2018 and alive at year-end 2019 in State X, by selected characteristics.

Characteristics	Persons alive at year-end 2019		Persons with ≥1 care visits		Persons with ≥1 VL tests		VL of <200 copies/ml ^a			
	No.	%	No.	%	No.	%	Among persons alive at year-end 2019	Among persons with ≥1 care visits	Among persons with ≥1 VL tests	%
Sex at birth										
Male	9,873	72.8	7,559	76.6	7,305	74.0	6,475	65.6	85.7	88.6
Female	3,680	27.2	2,873	78.1	2,816	76.5	2,435	66.2	84.8	86.5
Gender										
Male	9,810	72.4	7,500	76.5	7,247	73.9	6,428	65.5	85.7	88.7
Female	3,679	27.1	2,872	78.1	2,815	76.5	2,434	66.2	84.7	86.5
Transgender woman ^b	63	0.5	59	93.7	58	92.1	47	74.6	79.7	81.0
Transgender man ^b	—	—	—	—	—	—	—	—	—	—
Additional gender identity ^c	—	—	—	—	—	—	—	—	—	—
Age at year-end 2018 (yr)										
13–24	722	5.3	568	78.7	562	77.8	453	62.7	79.8	80.6
25–34	2,781	20.5	2,113	76.0	2,075	74.6	1,753	63.0	83.0	84.5
35–44	2,762	20.4	2,128	77.0	2,073	75.1	1,777	64.3	83.5	85.7
45–54	3,668	27.1	2,861	78.0	2,792	76.1	2,496	68.0	87.2	89.4
≥55	3,620	26.7	2,762	76.3	2,619	72.3	2,431	67.2	88.0	92.8
Race/ethnicity										
American Indian/ Alaska Native	5	0.0	—	—	—	—	—	—	—	—
Asian	39	0.3	22	56.4	22	56.4	21	53.8	95.5	95.5
Black/African American	8,550	63.1	6,577	76.9	6,356	74.3	5,458	63.8	83.0	85.9
Hispanic/Latino ^d	449	3.3	293	65.3	287	63.9	261	58.1	89.1	90.9
Native Hawaiian/other Pacific Islander	—	—	—	—	—	—	—	—	—	—
White	3,727	27.5	2,889	77.5	2,814	75.5	2,598	69.7	89.9	92.3
Multiracial	741	5.5	647	87.3	638	86.1	568	76.7	87.8	89.0
Transmission category (based on sex at birth)^e										
Male-to-male sexual contact	6,342	46.8	5,055	79.7	4,912	77.5	4,404	69.4	87.1	89.7
Injection drug use										
Male	389	2.9	270	69.4	263	67.6	241	62.0	89.3	91.6
Female	329	2.4	251	76.3	246	74.8	207	62.9	82.5	84.1
Male-to-male sexual contact and injection drug use	451	3.3	361	80.0	350	77.6	302	67.0	83.7	86.3
Heterosexual contact ^f										
Male	811	6.0	582	71.8	557	68.7	478	58.9	82.1	85.8
Female	1,892	14.0	1,553	82.1	1,525	80.6	1,333	70.5	85.8	87.4
Other^g										
Male	1,880	13.9	1,291	68.7	1,223	65.1	1,050	55.9	81.3	85.9
Female	1,459	10.8	1,069	73.3	1,045	71.6	895	61.3	83.7	85.6
Total	13,553	100.0	10,432	77.0	10,121	74.7	8,910	65.7	85.4	88.0

Source: enhanced HIV/AIDS Reporting System (eHARS)

^a VL test result of <200 copies/mL indicates HIV viral suppression. VL test results are from the most recent test during the specified year.^b “Transgender woman” includes individuals who were assigned “male” sex at birth but have ever identified as “female” gender. “Transgender man” includes individuals who were assigned “female” sex at birth but have ever identified as “male” gender.^c Additional gender identity examples include “bigender,” “gender queer,” and “two-spirit.”^d Hispanic/Latino persons can be of any race.^e Transmission category data presented based on sex at birth and include transgender persons.^f Heterosexual contact with a person known to have, or to be at high risk for, HIV infection.^g Other transmission category includes persons whose infection was attributed to hemophilia, blood transfusion, perinatal exposure or whose risk factor was not reported or not identified. Data not displayed because the numbers were too small to be meaningful.**Interpretation:** By race/ethnicity, the highest viral suppression group percentage was for multiracial persons (76.7%) and the lowest viral suppression group percentage was for Asian persons (53.8%).

Table A-12. Persons living with diagnosed HIV in State X, by year and transmission category, 2015–2019

Transmission category (based on sex at birth)	2015	2016	2017	2018	2019
	No.	No.	No.	No.	No.
Male-to-male sexual contact	14,688	15,474	15,964	15,992	16,215
Injection drug use	7,557	7,508	7,372	7,152	6,988
Male-to-male sexual contact and injection drug use	1,834	1,864	1,859	1,826	1,813
Heterosexual contact ^a	11,750	12,200	12,234	12,177	12,132
Perinatal ^b	566	578	575	564	565
Other ^c	2,341	2,379	2,557	2,690	2,786
Total	38,736	40,003	40,561	40,401	40,499

Source: enhanced HIV/AIDS Reporting System (eHARS)

^a Heterosexual contact with a person known to have, or with a risk factor for, HIV infection.

^b Individuals were ≥ 13 years of age at time of diagnosis of HIV infection.

^c Includes hemophilia, blood transfusion, and risk factor not reported or not identified.

Interpretation: At year-end 2019 in State X, of the 40,499 adults and adolescents living with diagnosed HIV, 40.0% of infections were attributed to male-to-male sexual contact, 30.0% to heterosexual contact, 17.3% to IDU, 4.5% to male-to-male sexual contact and injection drug use, and 1.4% to perinatal transmission.

Table A-13. Number of deaths of persons with diagnosed HIV infection and death rates per 100,000 population in State X, by race/ethnicity, 2019

Race/ethnicity	Male			Female			Total		
	No.	%	Rate ^a	No.	%	Rate ^a	No.	%	Rate ^a
Hispanic/Latino ^b	51	12.4	10.0	16	10.8	3.3	67	12.0	6.7
American Indian/Alaska Native	—	—	—	—	—	—	—	—	—
Asian	—	—	—	—	—	—	—	—	—
Black/African American	193	46.8	28.7	87	58.8	12.0	280	50.0	20.1
Native Hawaiian/other Pacific Islander	—	—	—	—	—	—	—	—	—
White	142	34.5	3.0	36	24.3	0.7	178	31.8	1.8
Multiracial	24	5.8	22.4	6	4.1	5.4	30	5.4	13.7
Total	412	100.0	6.6	148	100.0	2.3	560	100.0	4.4

Source: enhanced HIV/AIDS Reporting System (eHARS)

Note. Deaths may be due to any cause.

^a Rates are per 100,000 population.

^b Hispanic/Latino persons can be of any race.

Dash indicates cell size of ≤3.

Interpretation: The rate of death of persons with diagnosed HIV infection was greater among males than among females and much greater among Black persons than among White persons. The rate for Hispanic/Latino persons was intermediate between the rate for White persons and the rate for Black persons.

Note. The denominator used in calculating death rates is the population of interest in a service area. For example, in Table A-13, since the numbers and overall rates of deaths are being calculated for persons with a diagnosis of HIV infection, the denominator is the entire population in the service area. If you wanted to calculate the rate of deaths among persons with diagnosed HIV aged 25–44, the denominator would be limited to the population in this age group.

Table A-14. Ranking of 10 leading underlying causes of death among persons 25–44 years of age in State X, 2019

Cause	Ranking	Deaths, No.	Total deaths, % (N=723)
Unintentional injury	1	238	32.9
Suicide	2	139	19.2
Malignant neoplasms	3	115	15.9
Heart disease	4	86	12.0
Homicide	5	80	11.1
Diabetes mellitus	6	23	4.8
HIV disease	7	17	0.2
Chronic liver disease	8	14	0.7
Cerebrovascular disease	9	6	0.8
Pneumonia and influenza	10	5	0.7

Source: X

Note. HIV disease not listed if it either was not among the top 10 causes or caused 3 or fewer deaths per group.

Interpretation: HIV disease was the sixth leading cause of death in 2019 among persons 25–44 years old in State X, accounting for less than 1.0% of all deaths in this age group.

Table A-15. HIV diagnoses among persons in State X, by sex at birth and tuberculosis comorbidity, 2019

Tuberculous diagnosis	Male		Female		Total	
	No.	%	No.	%	No.	%
Not diagnosed	752	99.4	227	100.0	979	99.5
Definitive case	5	0.6	—	—	5	0.5
Presumptive case	—	—	—	—	—	—
Total	757	100.0	227	100.0	984	100.0

Source: enhanced HIV/AIDS Reporting System (eHARS)

Interpretation: Of the 757 males with HIV diagnosed in 2019 in State X, less than 1.0% had received a tuberculosis diagnosis. Of the 227 females with HIV diagnosed in 2019, none had a tuberculosis diagnosis in State X.

Table A-16. Diagnoses of HIV infection among adults, by race/ethnicity, sex at birth, and federal poverty status, 2019—census tract level, United States and Puerto Rico

Percent (%) below federal poverty level	American Indian/Alaska Native		Asian		Black/African American		Hispanic/Latino ^a		Native Hawaiian/ other Pacific Islander		White		Multiracial	
	No.	Rate	No.	Rate	No.	Rate	No.	Rate	No.	Rate	No.	Rate	No.	Rate
Male														
<6	13	10.8	112	4.6	998	46.5	778	24.8	12	22.9	1,303	5.2	91	12.8
6.00–10.99	19	9.0	131	6.7	1,788	58.5	1,471	28.9	7	10.3	1,773	7.1	177	21.2
11.00–17.99	21	8.0	114	8.8	2,390	64.2	1,931	33.1	12	21.0	1,453	8.4	186	26.4
≥18	45	11.5	103	9.9	4,269	76.0	2,524	35.0	11	25.0	1,415	13.5	212	31.3
Subtotal^b	105	10.6	471	7.0	9,784	66.8	6,897	32.3	43	19.3	6,184	7.9	688	23.4
Female														
<6	1	0.8	16	0.6	319	14.1	93	2.9	0	0	167	0.6	16	2.2
6.00–10.99	7	3.2	16	0.7	550	16.3	181	3.6	2	2.8	322	1.2	32	3.7
11.00–17.99	7	2.6	21	1.4	762	18.0	258	4.5	1	1.7	288	1.6	48	6.5
≥18	12	2.9	13	1.2	1,535	22.8	434	5.9	3	6.7	373	3.4	73	10.0
Subtotal^b	29	2.8	69	0.9	3,253	19.6	1,004	4.7	6	2.6	1,180	1.4	175	5.7
Total^c	134	6.6	540	3.7	13,037	41.7	7,901	18.5	49	10.9	7,364	4.6	863	14.4

Source: X

Abbreviations: SDH, social determinants of health [footnotes only]; ACS, American Community Survey [footnotes only].

Note. Rates are per 100,000 population. Row entries indicate categories based on census tracts; data reflect the census tract of the person's residential address at the time they received an HIV diagnosis. Reported numbers less than 12, and rates based on these numbers, should be interpreted with caution. The ACS does not provide age- and sex-specific SDH variables stratified by race and ethnicity for racial groups except whites (i.e., white, not Hispanic/Latino). Therefore, the denominators used for computing race-specific rates may include Hispanic/Latino persons and should be interpreted with caution; see Technical Notes for more details. For the definitions of SDH indicator variables used in this report, see http://www2.census.gov/programs-surveys/acs/tech_docs/subject_definitions/2019_ACSSubjectDefinitions.pdf.

^a Hispanic/Latino persons can be of any race.^b Because column subtotals were calculated independently of the values for the subpopulations, the values in each column may not sum to the column subtotals.^c Totals do not represent all adults whose HIV infection was diagnosed during 2019 in these areas.

Interpretation: In 2019, among adults who lived in census tracts with the highest level of poverty (i.e., lowest level of wealth; where 18% or more of the residents lived below the federal poverty level), the highest HIV diagnosis rates were for both sexes in all racial/ethnic groups.

For additional SDH variables and interpretations (e.g., education level, income), see the annual HIV supplemental surveillance report, *Social Determinants of Health among Adults with Diagnosed HIV Infection* (<https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>).

PROPOSED SSP MEASURES

Recommended for all states/jurisdictions

The following are core recommended indicators for SSP coverage. Note that state and local jurisdictions may have more and/or more recent information.

Indicators

1. Explicit authorization of SSPs by state law: The law explicitly authorized the establishment of SSPs.
2. Number of SSPs in the state/jurisdiction: Population-level indicator and should reflect data from all SSPs, regardless of funding source.
3. Proportion of SSPs which report providing needs-based syringe exchange model in state/jurisdiction: Numerator is the number of SSPs that offer anything but 1:1 exchange, denominator is all SSPs regardless, of funding source.

SSP Measure Tables Addressing Core Question 4.1

Table A-17. Status of state laws which impact Syringe Service Program (SSP) operations

	Yes	No
Does state law explicitly authorize SSPs?		
Does state law allow for possession of syringes by SSP participants?		
Does the state require one-for-one exchanges?		
Does the law require direct exchange?		

Data source: The Policy Surveillance Program, A Law Atlas Project. (2019, August 1). *Syringe Service Program Laws*. [Syringe Service Program Laws \(lawatlas.org\)](https://lawatlas.org)

Table A-18. State Syringe Services Program (SSP) reported characteristics and services

	N	%
Total SSPs in the state		
Needs-based syringe exchange model		
HIV testing/Education		
Case management/Coordinated care		
PEP		
PrEP		
MAT Education/Referrals		
Provides HCV testing/education		
Naloxone distribution		
Safe sex items		
STI Testing Treatment		

Data source: NASEN, A Dave Purchase Initiative. (n.d.). *SSP Locations*. <https://nasen.org/map/>.

Table A-19. State Syringe Services Program (SSP) outputs *[If available]*

	N	%
Number of SSPs operating in the jurisdiction		
Number of encounters related to at least one standard service by an SSP		
Percentage of SSPs that directly provide or actively refer to key services		
Number of encounters served by SSPs		

Data source: PS20-2010: Integrated HIV Programs for Health Departments to Support Ending the HIV Epidemic in the United States: Evaluation and Performance Measurement Plan (EPMP) for Component A

Table A-20. Reported use of SSPs and related services among people who inject drugs *[If available]*

	N	%
Accessed sterile syringes at SSP, past 12 months		
Tested for HIV, past 12 months		
HCV testing, ever		
Participated in substance use disorder treatment, past 12 months		
Used MOUD past 12 months		
Unmet need for MAT, past 12 months		
Total		

Source: Description of NHBS methods and measures are in the technical notes of the NHBS-PWID report at [HIV Infection, Risk, Prevention, and Testing Behaviors among Persons Who Inject Drugs \(cdc.gov\)](#). The MSAs that participate in NHBS-PWID have local data available at their health department. MSAs that participate in NHBS-PWID often ask additional questions for local use that may be specific to this population. The data for these measures can be obtained by contacting the local NHBS project coordinator in the respective project area: [Project Areas | NHBS | Surveillance Systems | Statistics Center | HIV/AIDS | CDC](#).

SSP Measure Table Addressing Core Question 4.2**Table A-21. Reported injections risk behaviors among people who inject drugs *[If available]***

	N	%
Receptive syringe sharing, past 12 months		
Any receptive sharing, past 12 months		
Distributive syringe sharing, past 12 months		
Condomless sex with an HIV-discordant partner at last sex		
Exchange sex, past 12 months		
PrEP awareness		
PrEP use		
Total		

Source: Description of NHBS methods and measures are in the technical notes of the NHBS-PWID report at [HIV Infection, Risk, Prevention, and Testing Behaviors among Persons Who Inject Drugs \(cdc.gov\)](#). The MSAs that participate in NHBS-PWID have local data available at their health department. MSAs that participate in NHBS-PWID often ask additional questions for local use that may be specific to this population. The data for these measures can be obtained by contacting the local NHBS project coordinator in the respective project area: [Project Areas | NHBS | Surveillance Systems | Statistics Center | HIV/AIDS | CDC](#).

Proposed tables for NHBS data

Note. The following sets of tables are proposed for inclusion for jurisdictions that conduct NHBS.

Table A-22. HIV testing and sexual behaviors among HIV-negative men who have sex with men—National HIV Behavioral Surveillance, [U.S. City], 2017

	Ever tested		Tested in past 12 months ^a		Exchange sex ^b		Condomless sex with an HIV-discordant partner at last sex ^c	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Age at interview (yr)								
18–29								
30–49								
≥50								
Race/ethnicity								
American Indian/Alaska Native								
Asian								
Black/African American								
Hispanic/Latino ^d								
Native Hawaiian/other Pacific Islander								
White								
Multiple races								
Education								
Less than high school								
High school diploma or equivalent								
More than high school								
Household income^e								
At or below the federal poverty level								
Above the federal poverty level								
Health insurance								
Yes								
No								
Visited a health care provider, past 12 months								
Yes								
No								
Homeless^f, past 12 months								
Yes								
No								
Incarcerated^g, past 12 months								
Yes								
No								
Total								

Note. For HIV testing measures: Data include all participants who did not report a previous HIV-positive test result and participants who received their first HIV-positive test result less than 12 months before interview. For sexual behavior measures: Participants with a valid negative NHBS HIV test result. Outcomes are reported for the 12 months before interview.

^aPast 12 months refers to the 12 months before interview.

^b“Exchange sex” refers to giving or receiving money or drugs from a male casual partner in exchange for sex.

^c“HIV-discordant partner” refers to a sex partner of different or unknown HIV status. “Condomless sex” refers to whether the participant reported engaging in vaginal or anal sex without a condom during his most recent sexual encounter. Partner viral load is unknown and participant PrEP use at most recent sexual encounter is unknown.

^dHispanic/Latino persons can be of any race.

^ePoverty level is based on household income and household size.

^fLiving on the street, in a shelter, in a single room occupancy hotel, or in a car.

^gHaving been held in a detention center, jail, or prison, for more than 24 hours.

Source: <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-special-report-number-22.pdf>

Table A-23. HIV testing and sexual behaviors among HIV-negative persons who inject drugs—National HIV Behavioral Surveillance, [U.S. City], 2018

	Ever tested		Tested in past 12 months ^a		Exchange sex ^b		Condomless sex with an HIV-discordant partner at last sex ^c	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Gender								
Male								
Female								
Transgender					N/A	N/A	N/A	N/A
Age at interview (yr)								
18–29								
30–49								
≥50								
Race/ethnicity								
American Indian/Alaska Native								
Asian								
Black/African American								
Hispanic/Latino ^d								
Native Hawaiian/other Pacific Islander								
White								
Multiple races								
Education								
Less than high school								
High school diploma or equivalent								
More than high school								
Household income^e								
At or below the federal poverty level								
Above the federal poverty level								
Health insurance								
Yes								
No								
Visited a health care provider, past 12 months								
Yes								
No								
Homeless^f, past 12 months								
Yes								
No								
Incarcerated^g, past 12 months								
Yes								
No								
Total								

Note. For testing measures: CDC recommends that all persons who inject drugs be tested for HIV at least annually. Data include all participants who did not report a previous HIV-positive test result and participants who received their first HIV-positive test result less than 12 months before interview. For sexual behavior measures: Participants with a valid negative NHBS HIV test result. NHBS sexual behavior questions assume anatomy based on reported gender (male or female). These questions are not asked of transgender participants. Consequently, transgender participants are not included in calculation of sexual behavior outcomes in this table.

^a“Past 12 months” refers to the 12 months before interview.

^b For females, “exchange sex” refers to receiving money or drugs from a male casual partner in exchange for sex. For males, “exchange sex” refers to giving money or drugs to a female casual partner in exchange for sex or giving or receiving money or drugs to or from a male casual partner in exchange for sex.

^c“Condomless sex” refers to whether the participant reported engaging in vaginal or anal sex without a condom at any time during his or her most recent sexual encounter with an opposite sex partner. “HIV-discordant partner” refers to a partner of different or unknown HIV status. Partner viral load is unknown and participant PrEP use at most recent sexual encounter is unknown.

^d Hispanic/Latino persons can be of any race.

^e Poverty level is based on household income and household size.

^f Living on the street, in a shelter, in a single room occupancy hotel, or in a car.

^g Having been held in a detention center, jail, or prison, for more than 24 hours.

Source: <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-special-report-number-24.pdf>

Table A-24. HIV testing among HIV-negative heterosexually active men and women—National HIV Behavioral Surveillance, [U.S. City], 2019

	Ever tested		Tested in past 12 months ^a		Exchange sex ^b		Condomless sex with an HIV-discordant partner at last sex ^c	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Gender								
Male								
Female								
Age at interview (yr)								
18–29								
30–49								
≥50								
Race/ethnicity								
American Indian/Alaska Native								
Asian								
Black/African American								
Hispanic/Latino ^d								
Native Hawaiian/other Pacific Islander								
White								
Multiple races								
Education								
Less than high school								
High school diploma or equivalent								
More than high school								
Household income^e								
At or below the federal poverty level								
Above the federal poverty level								
Health insurance								
Yes								
No								
Visited a health care provider, past 12 months								
Yes								
No								
Homeless^f, past 12 months								
Yes								
No								
Incarcerated^g, past 12 months								
Yes								
No								
Total								

Note. For testing measures: Data include all participants who did not report a previous HIV-positive test result and participants who received their first HIV-positive test result less than 12 months before interview. For sexual behavior measures: Participant with a valid negative NHBS HIV test result. Outcomes are reported for the 12 months before interview.

^aPast 12 months refers to the 12 months before interview.

^bFor females, “exchange sex” refers to receiving money or drugs from a male casual partner in exchange for sex. For males, “exchange sex” refers to giving money or drugs to a female casual partner in exchange for sex.

^c“Condomless sex” refers to engaging in vaginal or anal sex without a condom at any time during his or her most recent sexual encounter with an opposite-sex partner. “HIV-discordant partner” refers to a partner of different or unknown HIV status. Partner viral load is unknown and participant PrEP use at most recent sexual encounter is unknown.

^dHispanic/Latino persons can be of any race.

^ePoverty level is based on household income and household size.

^fLiving on the street, in a shelter, in a single room occupancy hotel, or in a car.

^gHaving been held in a detention center, jail, or prison, for more than 24 hours.

Source: <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-special-report-number-26.pdf>

Table A-25. HIV testing and sexual behaviors among HIV-negative transgender women—National HIV Behavioral Surveillance, [U.S. City], 2019–2020

	Ever tested		Tested in past 12 months ^a		Exchange sex ^b		Condomless sex with an HIV-discordant partner at last sex ^c	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Age at interview (yr)								
18–29								
30–49								
≥50								
Race/ethnicity								
American Indian/Alaska Native								
Asian								
Black/African American								
Hispanic/Latino ^d								
Native Hawaiian/other Pacific Islander								
White								
Multiple races								
Education								
Less than high school								
High school diploma or equivalent								
More than high school								
Household income^e								
At or below the federal poverty level								
Above the federal poverty level								
Health insurance								
Yes								
No								
Visited a health care provider, past 12 months								
Yes								
No								
Homeless^f, past 12 months								
Yes								
No								
Incarcerated^g, past 12 months								
Yes								
No								
Total								

Note. For testing measures: Data include all participants who did not report a previous HIV-positive test result and participants who received their first HIV-positive test result less than 12 months before interview. For sexual behavior measures: Participants with a valid negative NHBS HIV test result. Outcomes are reported for the 12 months before interview.

^a “Past 12 months” refers to the 12 months before interview.

^b “Exchange sex” refers to receiving money or drugs from a sex partner in exchange for sex.

^c “Condomless sex” refers to whether the participant reported engaging in vaginal or anal sex without a condom during their most recent sexual encounter (“last sex”). “HIV-discordant partner” refers to a sex partner of different or unknown HIV status. Partner viral load is unknown and participant PrEP use at most recent sexual encounter is unknown.

^d Hispanic/Latino persons can be of any race.

^e Poverty level is based on household income and household size.

^f Living on the street, in a shelter, in a single room occupancy hotel, or in a car.

^g Having been held in a detention center, jail, or prison, for more than 24 hours.

Source: <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-special-report-number-27.pdf>

Proposed tables for MMP data

Note. The following sets of tables are proposed for inclusion for jurisdictions that conduct MMP.

Table A-26. Demographic characteristics and social determinants of health among adults with diagnosed HIV—Medical Monitoring Project, United States, 2017–2020.

Note. Jurisdictions could also stratify this table by household poverty, gender, and race/ethnicity, and also examine among MSM, if helpful.

	n	col% (95% CI)
Overall	12,372	100
Age at time of interview, in years		
18–29	1,045	8.6 (7.8–9.4)
30–39	1,971	17.2 (16.3–18.0)
40–49	2,630	21.9 (20.9–22.8)
≥50	6,726	52.4 (51.1–53.7)
Race/ethnicity†		
Black/African American	5,186	41.2 (35.9–46.5)
Hispanic/Latino	2,773	22.3 (18.0–26.6)
White	3,526	29.0 (25.8–32.3)
Other	887	7.4 (6.4–8.5)
Gender		
Male	8,999	74.7 (73.2–76.2)
Female	3,127	23.4 (22.0–24.9)
Transgender‡	233	1.9 (1.6–2.2)
Sexual behavior by current gender identity/sexual behavior		
MSM	6,090	49.9 (47.8–52.1)
MSW	2,719	23.0 (21.8–24.2)
WSM	3,045	22.8 (21.4–24.3)
Other	516	4.3 (3.8–4.7)
Country of birth		
United States	10,472	85.1 (84.0–86.2)
Country outside United States	1,806	14.9 (13.8–16.0)
English proficiency		
Speaks English well	11,488	93.5 (91.2–95.7)
Does not speak English well	844	6.5 (4.3–8.8)
Educational attainment		
<High school	2,094	16.6 (15.6–17.5)
High school diploma or equivalent	3,307	27.0 (25.9–28.2)
>High school	6,929	56.4 (54.8–57.9)
Combined yearly household income (US\$)		
\$0–\$19,999	6,009	51.9 (50.0–53.8)
\$20,000–\$39,999	2,482	22.4 (21.2–23.5)
\$40,000–\$74,999	1,615	14.9 (13.9–15.8)
≥\$75,000	1,269	10.9 (9.7–12.1)
Household at or below federal poverty level, past 12 months§		
Yes	4,905	42.0 (39.9–44.2)
No	6,466	58.0 (55.8–60.1)
Homeless, past 12 months¶		
Yes	1,163	9.3 (8.6–10.0)
No	11,173	90.7 (90.0–91.4)
History of incarceration, past 12 months		
Yes	542	4.7 (4.1–5.2)
No	11,784	95.3 (94.8–95.9)

	n	col% (95% CI)
Attendance at a RWHAP-funded facility for HIV care		
Yes	8,109	68.8 (63.5–74.2)
No	3,601	31.2 (25.8–36.5)
Type of health insurance or coverage for care or medications, past 12 months**		
RWHAP or ADAP		
Yes	5,863	45.9 (44.4–47.3)
No	6,153	54.1 (52.7–55.6)
Medicaid		
Yes	5,700	45.6 (44.1–47.1)
No	6,429	54.4 (52.9–55.9)
Medicare		
Yes	3,497	27.8 (26.8–28.9)
No	8,526	72.2 (71.1–73.2)
Private health insurance		
Yes	4,254	35.2 (33.4–36.9)
No	7,786	64.8 (63.1–66.6)
Other publicly funded insurance		
Yes	1,682	13.8 (10.0–17.6)
No	10,370	86.2 (82.4–90.0)

Note. All numbers are unweighted and all percentages are weighted percentages; CIs incorporate weighted percentages.

MSM=men who had sex with men; MSW=men who had sex with only women; WSM=women who had sex with men; RWHAP=Ryan White HIV/AIDS Program; ADAP=AIDS Drug Assistance Program.

Excluded are estimates with a coefficient of variation ≥ 0.30 , estimates based on a denominator sample size < 30 , "don't know" responses, and skipped (missing) responses. Estimates with an absolute CI width ≥ 0.30 , estimates with an absolute CI width between 5 and 30 and a relative CI width $> 130\%$, and estimates of 0% or 100% are marked with an asterisk (*) and should be interpreted with caution.

† Hispanic or Latino persons might be of any race. Persons are classified in only 1 race/ethnicity category.

‡ Persons were classified as transgender if sex at birth and gender reported by the person were different, or if the person chose transgender in response to the question about self-identified gender.

§ Poverty guidelines as defined by HHS; the 2016 guidelines were used for persons interviewed in 2017, the 2017 guidelines were used for persons interviewed in 2018, the 2018 guidelines were used for persons interviewed in 2019, the 2019 guidelines were used for persons interviewed in 2020. More information regarding HHS poverty guidelines can be found at <https://aspe.hhs.gov/frequently-askedquestions-related-poverty-guidelines-and-poverty>.

¶ Living on the street, in a shelter, in a single-room-occupancy hotel, or in a car.

** Persons could select more than 1 response for health insurance or coverage for antiretroviral medications or care. Other publicly funded insurance included coverage through Tricare/CHAMPUS, the VA, or other publicly funded insurance. Unknown insurance type means that the person had insurance or coverage for antiretroviral medications or care, but the type of insurance or coverage could not be determined.

Table A-27. Experiences with HIV-related stigma among adults with diagnosed HIV, by domain—Medical Monitoring Project, United States, 2018–2020.

	Strongly disagree		Somewhat disagree		Neutral		Somewhat agree		Strongly agree	
	n	row%	n	row%	n	row%	n	row%	n	row%
		(95% CI)		(95% CI)		(95% CI)		(95% CI)		
Personalized stigma										
I have been hurt by how people reacted to learning I have HIV	5,630	71.3 (69.2–73.4)	348	4.7 (4.0–5.5)	704	8.4 (7.4–9.4)	460	5.9 (5.3–6.4)	801	9.7 (8.8–10.6)
I have stopped socializing with some people because of their reactions to my HIV status	5,823	73.7 (71.7–75.6)	318	4.2 (3.4–4.9)	591	7.1 (6.3–8.0)	415	5.2 (4.7–5.8)	798	9.8 (8.9–10.7)
I have lost friends by telling them I have HIV	6,193	78.2 (76.5–79.9)	308	4.1 (3.4–4.8)	563	6.9 (6.0–7.8)	300	3.7 (3.2–4.1)	582	7.2 (6.5–7.9)
Disclosure stigma										
I am very careful who I tell that I have HIV	782	9.2 (8.4–10.1)	192	2.1 (1.7–2.5)	376	4.4 (3.9–5.0)	630	7.6 (6.7–8.4)	6,056	76.6 (74.9–78.4)
I worry that people who know I have HIV will tell others	2,291	28.3 (27.0–29.7)	450	5.8 (4.7–6.8)	695	8.3 (7.3–9.3)	1,062	13.1 (12.3–14.0)	3,534	44.5 (42.2–46.7)
Negative self-image										
I feel that I am not as good a person as others because I have HIV	5,614	70.0 (68.3–71.6)	356	4.5 (3.6–5.4)	480	6.0 (5.3–6.7)	772	9.6 (8.6–10.6)	821	10.0 (9.2–10.8)
Having HIV makes me feel unclean	5,473	67.9 (65.9–69.8)	422	5.4 (4.3–6.5)	482	5.7 (5.1–6.3)	840	10.6 (9.6–11.6)	822	10.4 (9.5–11.2)
Having HIV makes me feel that I am a bad person	6,527	81.0 (79.7–82.4)	339	4.2 (3.5–4.9)	371	4.5 (4.0–5.1)	452	5.9 (5.1–6.7)	351	4.3 (3.8–4.9)
Public attitudes										
Most people think that a person with HIV is disgusting	2,945	36.4 (34.1–38.7)	647	7.8 (6.9–8.8)	998	12.9 (11.7–14.1)	1,629	21.1 (19.6–22.6)	1,728	21.8 (20.1–23.5)
Most people with HIV are rejected when others find out	1,648	20.5 (18.5–22.4)	759	9.6 (8.2–11.0)	1,111	13.8 (12.8–14.8)	2,119	27.5 (25.8–29.3)	2,330	28.6 (26.4–30.8)

Note. All numbers are unweighted and all percentages are weighted percentages; CIs incorporate weighted percentages.

HIV stigma during the past 12 months was based a ten-item scale that measures 4 dimensions of HIV stigma: personalized stigma during the past 12 months, current disclosure concerns, current negative self-image, and current perceived public attitudes about people living with HIV.

Excluded are estimates with a coefficient of variation ≥ 0.30 , estimates based on a denominator sample size < 30 , "don't know" responses, and skipped (missing) responses. Estimates with an absolute CI width ≥ 0.30 , estimates with an absolute CI width between 5 and 30 and a relative CI width $> 130\%$, and estimates of 0% or 100% are marked with an asterisk (*) and should be interpreted with caution.

Table A-28. HIV clinical outcomes among adults with diagnosed HIV, overall and by demographic characteristics and social determinants of health—Medical Monitoring Project, United States, 2017–2020.

**Note:* Please use Table A-26 as a model for social determinants of health to include as rows. Example variables included here.

	Retained in HIV care, past 12 months				ART dose adherent, past 30 days				Had sustained viral suppression, past 12 months			
	Yes		No		Yes		No		Yes		No	
	n	row% (95% CI)	n	row% (95% CI)	n	row% (95% CI)	n	row% (95% CI)	n	row% (95% CI)	n	row% (95% CI)
Overall	9,930	78.5 (77.1–79.9)	1,860	21.5 (20.1–22.9)	7,060	56.2 (55.0–57.5)	5,187	43.8 (42.5–45.0)	8,271	62.1 (60.0–64.2)	4,101	37.9 (35.8–40.0)
Race/ethnicity†												
Black/African American	4,074	75.1 (73.3–76.9)	887	24.9 (23.1–26.7)	2,771	52.1 (49.8–54.4)	2,350	47.9 (45.6–50.2)	3,169	56.2 (54.1–58.3)	2,017	43.8 (41.7–45.9)
Hispanic/Latino	2,350	85.1 (82.6–87.7)	303	14.9 (12.3–17.4)	1,584	56.7 (54.6–58.8)	1,164	43.3 (41.2–45.4)	1,956	67.4 (64.4–70.3)	817	32.6 (29.7–35.6)
White	2,818	79.1 (77.4–80.8)	518	20.9 (19.2–22.6)	2,234	63.0 (60.6–65.5)	1,266	37.0 (34.5–39.4)	2,574	67.4 (63.9–71.0)	952	32.6 (29.0–36.1)
Other	688	75.1 (71.8–78.3)	152	24.9 (21.7–28.2)	471	51.1 (47.3–54.9)	407	48.9 (45.1–52.7)	572	58.1 (52.6–63.5)	315	41.9 (36.5–47.4)
Gender												
Male	7,216	78.5 (77.0–80.0)	1,338	21.5 (20.0–23.0)	5,172	56.9 (55.5–58.2)	3,735	43.1 (41.8–44.5)	6,123	63.0 (60.6–65.4)	2,876	37.0 (34.6–39.4)
Female	2,523	78.8 (76.6–81.0)	481	21.2 (19.0–23.4)	1,774	54.9 (52.8–57.1)	1,325	45.1 (42.9–47.2)	1,999	59.9 (57.7–62.1)	1,128	40.1 (37.9–42.3)
Transgender‡	181	75.4 (68.0–82.7)	41	24.6 (17.3–32.0)	108	46.7 (39.7–53.7)	122	53.3 (46.3–60.3)	143	56.9 (50.0–63.8)	90	43.1 (36.2–50.0)
Household at or below federal poverty level, past 12 months§												
Yes	4,040	79.8 (77.8–81.8)	686	20.2 (18.2–22.2)	2,688	53.2 (51.4–55.0)	2,188	46.8 (45.0–48.6)	3,114	59.3 (57.1–61.5)	1,791	40.7 (38.5–42.9)
No	5,109	77.7 (75.9–79.5)	1,008	22.3 (20.5–24.1)	3,816	58.2 (56.5–59.9)	2,629	41.8 (40.1–43.5)	4,546	65.0 (62.0–68.0)	1,920	35.0 (32.0–38.0)

Note. All numbers are unweighted and all percentages are weighted percentages; CIs incorporate weighted percentages.

Retention in care was defined as having ≥ 2 elements of outpatient HIV care at least 90 days apart in each 12-month period.

ART dose adherent was defined as not missing any ART doses in the past 30 days.

Sustained viral suppression was defined as having all viral load measurements documented during the past 12 months being undetectable or < 200 copies/mL.

Excluded are estimates with a coefficient of variation ≥ 0.30 , estimates based on a denominator sample size < 30 , “don’t know” responses, and skipped (missing) responses. Estimates with an absolute CI width ≥ 0.30 , estimates with an absolute CI width between 5 and 30 and a relative CI width $> 130\%$, and estimates of 0% or 100% are marked with an asterisk (*) and should be interpreted with caution.

† Hispanic or Latino persons can be of any race. Persons are classified in only 1 race/ethnicity category.

‡ Persons were classified as transgender if sex at birth and gender reported by the person were different, or if the person chose transgender in response to the question about self-identified gender.

§ Poverty guidelines as defined by HHS; the 2016 guidelines were used for persons interviewed in 2017, the 2017 guidelines were used for persons interviewed in 2018, the 2018 guidelines were used for persons interviewed in 2019, the 2019 guidelines were used for persons interviewed in 2020. More information regarding HHS poverty guidelines can be found at <https://aspe.hhs.gov/frequently-askedquestions-related-poverty-guidelines-and-poverty>.

Table A-29. Barriers to receiving HIV care among adults with diagnosed HIV—Medical Monitoring Project, United States, 2018–2020.

	n	col% (95% CI)
Overall	8,150	100
<i>Barriers to HIV care</i>		
Problems with money or health insurance		
Yes	1,129	15.2 (13.9–16.4)
No	6,964	84.8 (83.6–86.1)
Mental health issues		
Yes	1,140	14.6 (13.6–15.7)
No	6,949	85.4 (84.3–86.4)
Felt well and did not need HIV care		
Yes	721	9.7 (8.9–10.6)
No	7,373	90.3 (89.4–91.1)
Doctor’s office or HIV clinic was hard to get to		
Yes	786	10.2 (9.4–10.9)
No	7,307	89.8 (89.1–90.6)
Too busy with personal things, such as family or work		
Yes	1,500	19.1 (17.9–20.3)
No	6,593	80.9 (79.7–82.1)
<i>Accessibility of HIV care</i>		
There was a doctor’s office or HIV clinic that was easy to get to		
Yes	6,824	83.8 (81.8–85.8)
No	1,242	16.2 (14.2–18.2)

Note. All numbers are unweighted and all percentages are weighted percentages; CIs incorporate weighted percentages.

Excluded are estimates with a coefficient of variation ≥ 0.30 , estimates based on a denominator sample size < 30 , “don’t know” responses, and skipped (missing) responses. Estimates with an absolute CI width ≥ 0.30 , estimates with an absolute CI width between 5 and 30 and a relative CI width $> 130\%$, and estimates of 0% or 100% are marked with an asterisk (*) and should be interpreted with caution.

Table A-30. Receipt of, and unmet needs for, HIV ancillary services during the 12 months before interview among persons with diagnosed HIV—Medical Monitoring Project, United States, 2017–2020.

	Persons who received services		Persons who needed but did not receive services by time of interview	
	n	col% (95% CI)	n	col% (95% CI)
Overall	12,372	100	12,372	100
<i>HIV support services</i>				
HIV case management services				
Yes	7,019	54.8 (52.7–56.9)	805	7.4 (6.8–8.1)
No	5,207	45.2 (43.1–47.3)	11,421	92.6 (91.9–93.2)
Medicine through ADAP				
Yes	5,862	46.3 (44.8–47.7)	330	3.3 (2.9–3.6)
No	6,076	53.7 (52.3–55.2)	11,608	96.7 (96.4–97.1)
Professional help remembering to take HIV medicines on time or correctly (adherence support services)				
Yes	4,228	33.2 (31.3–35.2)	93	0.7 (0.6–0.9)
No	7,977	66.8 (64.8–68.7)	12,112	99.3 (99.1–99.4)
Patient navigation services				
Yes	1,812	13.9 (12.8–14.9)	568	4.9 (4.4–5.4)
No	10,419	86.1 (85.1–87.2)	11,663	95.1 (94.6–95.6)
HIV peer group support				
Yes	1,510	11.6 (10.9–12.2)	870	7.2 (6.5–8.0)
No	10,720	88.4 (87.8–89.1)	11,360	92.8 (92.0–93.5)
≥1 HIV support service				
Yes	9,264	73.6 (72.2–74.9)	1,911	16.7 (15.8–17.7)
No	2,910	26.4 (25.1–27.8)	10,263	83.3 (82.3–84.2)
<i>Non-HIV medical services</i>				
Dental care				
Yes	7,448	58.5 (57.1–60.0)	2,690	22.9 (21.9–24.0)
No	4,816	41.5 (40.0–42.9)	9,574	77.1 (76.0–78.1)
Mental health services				
Yes	4,009	31.2 (29.3–33.2)	1,025	8.6 (7.9–9.2)
No	8,239	68.8 (66.8–70.7)	11,223	91.4 (90.8–92.1)
Drug or alcohol counseling or treatment				
Yes	918	7.0 (6.4–7.6)	271	2.3 (1.9–2.6)
No	11,351	93.0 (92.4–93.6)	11,998	97.7 (97.4–98.1)
Domestic violence services				
Yes	155	1.3 (1.0–1.5)	105	0.9 (0.7–1.1)
No	12,111	98.7 (98.5–99.0)	12,161	99.1 (98.9–99.3)
≥1 non-HIV medical service				
Yes	8,968	71.1 (69.4–72.8)	3,467	29.2 (28.0–30.4)
No	3,298	28.9 (27.2–30.6)	8,799	70.8 (69.6–72.0)

	Persons who received services		Persons who needed but did not receive services by time of interview	
	n	col% (95% CI)	n	col% (95% CI)
Subsistence services				
SNAP or WIC				
Yes	4,789	37.6 (36.0–39.3)	1,378	11.5 (10.6–12.4)
No	7,474	62.4 (60.7–64.0)	10,885	88.5 (87.6–89.4)
Transportation assistance				
Yes	3,136	24.0 (23.1–25.0)	959	8.1 (7.5–8.8)
No	9,131	76.0 (75.0–76.9)	11,308	91.9 (91.2–92.5)
Meal or food services†				
Yes	2,708	21.1 (19.6–22.6)	969	8.0 (7.3–8.8)
No	9,556	78.9 (77.4–80.4)	11,295	92.0 (91.2–92.7)
Shelter or housing services				
Yes	2,159	16.8 (15.8–17.7)	1,319	10.7 (9.7–11.8)
No	10,101	83.2 (82.3–84.2)	10,941	89.3 (88.2–90.3)
≥1 subsistence service				
Yes	6,588	52.0 (50.5–53.5)	3,114	25.9 (24.3–27.4)
No	5,674	48.0 (46.5–49.5)	9,148	74.1 (72.6–75.7)

Note. All numbers are unweighted and all percentages are weighted percentages; CIs incorporate weighted percentages.

Abbreviations: CI, confidence interval; ADAP, AIDS Drug Assistance Program; SNAP, Supplemental Nutrition Assistance Program; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

Persons could report receiving or needing more than 1 service. Numbers might not add to total because of missing data. Percentages might not sum to 100 because of rounding.

Excluded are estimates with a coefficient of variation ≥ 0.30 , estimates based on a denominator sample size < 30 , “don’t know” responses, and skipped (missing) responses. Estimates with an absolute CI width ≥ 0.30 , estimates with an absolute CI width between 5 and 30 and a relative CI width $> 130\%$, and estimates of 0% or 100% are marked with an asterisk (*) and should be interpreted with caution.

† Includes services such as soup kitchens, food pantries, food banks, church dinners, or food delivery services.

Appendix B.

Use of Tables, Charts, and Maps to Illustrate Data

TABLES

A table is a set of data arranged in rows and columns. Almost any quantitative (i.e., numeric) data can be organized into a table. Tables provide a reference for all the descriptive data on a topic and are also a basis for preparing figures, which reflect relationships, trends, or patterns, not details. See Tables B-1 and B-2, which are examples of presentations with differing numbers of variables.

Table B-1. Example of table with 1 variable

Diagnoses of HIV infection, by metropolitan statistical area of residence, 2019

	No.
New York, NY-NJ-PA	4,973
Los Angeles, CA	2,101
San Francisco, CA	886
Miami, FL	2,741
Washington, DC-VA-MD-WV	1,551
Chicago, IL-IN-WI	1,516
Houston-Baytown-Sugar Land, TX	1,463

Source: CDC.

Table B-2. Example of table with 2 variables

Diagnoses of HIV infection, by geographic unit and race/ethnicity, 2019

	USA	State X	County X
	%	%	%
American Indian/Alaska Native	<1	<1	
Asian	2.0	1.4	
Black/African American	41.7	47.6	52
Hispanic/Latino	28.5	18.2	18
Native Hawaiian/other Pacific Islander	<1	0	0
White	24.5	30.0	26
Multiracial	2.5	2.7	4

Source: X

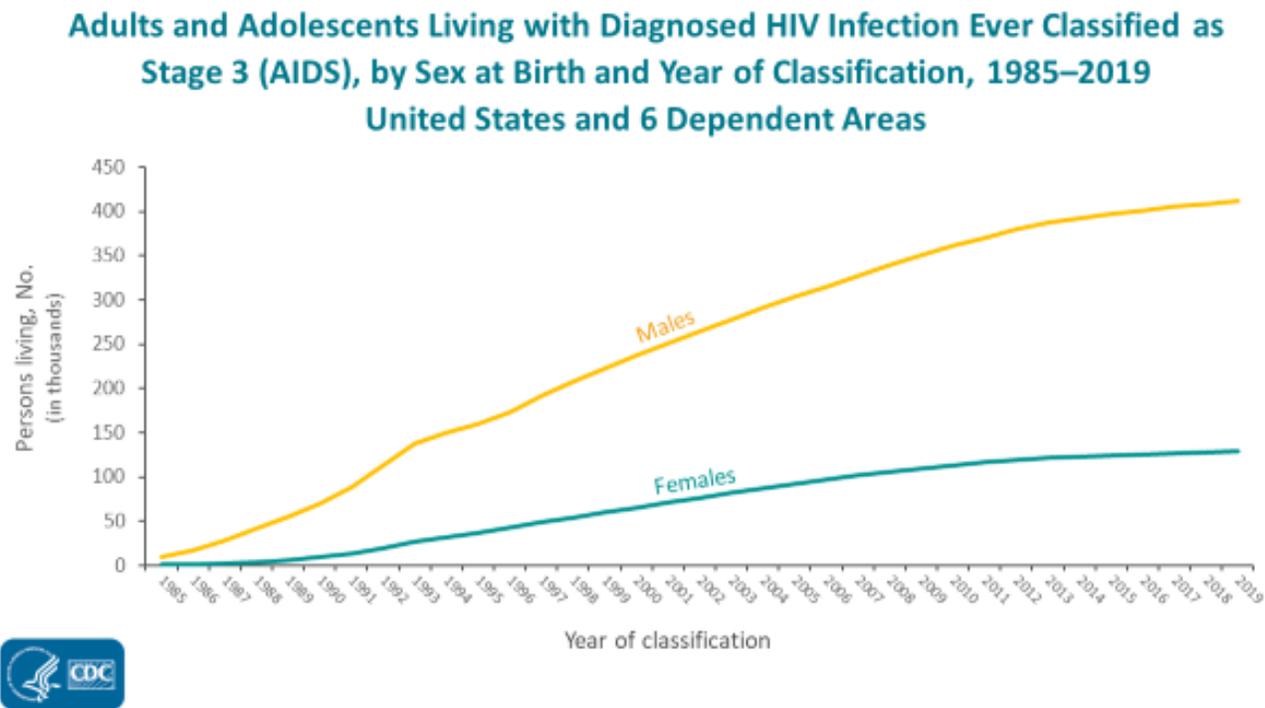
LINE GRAPHS

Line graphs display relationships between 2 variables on 2 dimensions, or axes. The dependent variable (the variable you wish to predict or explain) is usually shown on the vertical axis, and the independent variable (the variable you think will influence the dependent variable) is shown on the horizontal axis. Values are recorded as points on a graph and then connected (as a line) to show trends.

Line graphs are useful for showing patterns, trends, aberrations, similarities, and differences in the data, especially trends in data from multiple periods of equal length (e.g., years).

In Figure B-2, the dependent variable (the number of persons living with diagnosed HIV) is shown on the vertical axis, and the independent variable (the range of years) is shown on the horizontal axis. This line graph shows that the number of adult and adolescent males and females living with diagnosed HIV in the United States has been increasing.

Figure B-1. Example of line graph



Source: <http://www.cdc.gov/hiv/library/slideSets/index.html>.

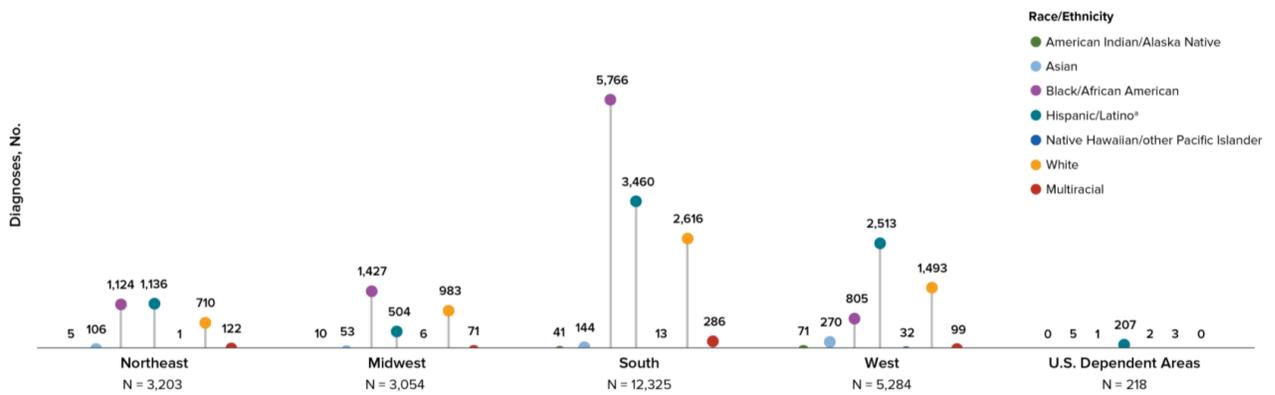
DUMBBELLS

Dumbbell graphs allow us to plot discrete data (e.g., race/ethnicity or region) or variables treated as though they were discrete (e.g., age groups). Comparison of categories is based on the length of the line leading to the dumbbell being proportional to the frequency of the event in that category. Dumbbells for different categories are separated by spaces and can be displayed as either vertical or horizontal. (This choice is usually made based on the length of text labels or the number of categories—long labels or numerous categories fit better on a horizontal graph.)

In the below figure, a grouped dumbbell graph is used to illustrate data from a three-variable (men who have sex with men, region, and race/ethnicity) table. A grouped dumbbell graph is particularly useful when you want to compare the subgroups within a group (men who have sex with men by race/ethnicity and region). Each dumbbell grouping represents a region group. Among men who have sex with men, separate bars are used to represent data by race/ethnicity.

Figure B-2. Example of dumbbell graph

Figure 14. Diagnoses of HIV Infection among Men Who Have Sex with Men, by Region of Residence and Race/Ethnicity, 2019—United States and 6 Dependent Areas



Note: Data have been statistically adjusted to account for missing transmission category. See sections C, D3, D4, and E1 in the Technical Notes for more information on interpreting numbers, race/ethnicity, transmission categories and U.S. Census Regions.

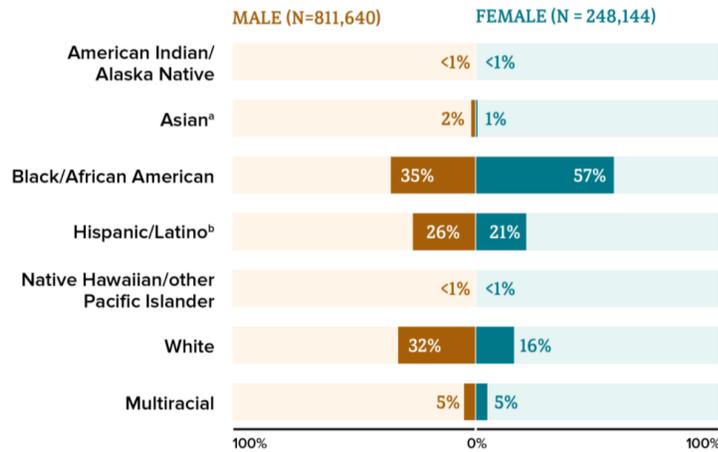
*Hispanic/Latino persons can be of any race.

BUTTERFLIES

Butterfly graphs allow us to plot two data sets using a common dimension; this allows us to visually see their differences and scales. In the below figure, the dependent variable (the number of persons with diagnosed HIV by race/ethnicity) on the vertical axis, and the independent variable (the percentage with HIV diagnosed by sex at birth) is shown on the horizontal axis. This butterfly graph compares the distribution of cases across different race/ethnicity groups and sex at birth to visualize the relationships between these dimensions. The butterfly chart allows us to juxtapose two vertical bar charts, for males and females, in a mirror-like fashion.

Figure B-3. Example of a butterfly graph

Figure 10. Percentages of Adults and Adolescents Living with Diagnosed HIV Infection, by Sex at Birth and Race/Ethnicity, Year-end 2019—United States and 6 Dependent Areas



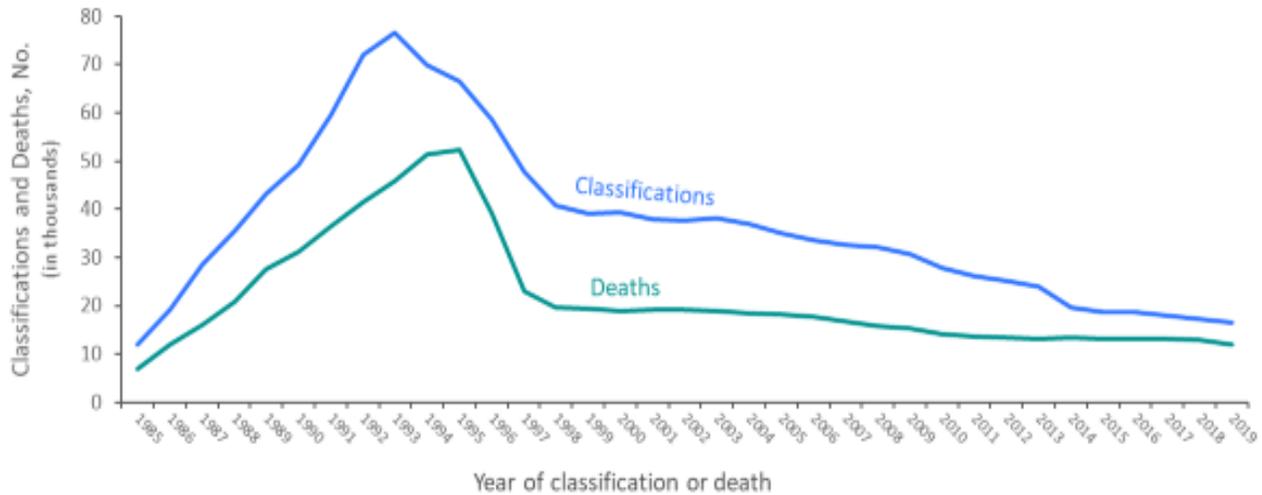
Note: Data have been statistically adjusted to account for missing transmission category. See section D4 in the Technical Notes for more information on transmission categories.
^aIncludes Asian/Pacific Islander legacy cases.
^bHispanic/Latino persons can be of any race.

EPIDEMIC CURVES

The epidemic curve (Figure B-4) is a line graph that shows the distribution of cases over time.

Figure B-4. Example of epidemic curve

Stage 3 (AIDS) Classifications and Deaths of Persons with Diagnosed HIV Infection Ever Classified as Stage 3 (AIDS) among Adults and Adolescents 1985–2019—United States and 6 Dependent Areas



Note. Deaths of persons with HIV infection, stage 3 (AIDS) may be due to any cause.

Source: <http://www.cdc.gov/hiv/library/slideSets/index.html>.

The epidemic curve is important because it tells what is happening with the disease in the population. Notice the sudden rise in stage 3 (AIDS) classifications in 1993. Figure B-3 also shows a downward trend from 1996 in stage 3 (AIDS) classifications and deaths of persons ever classified as stage 3 (AIDS). This is due in part to the effectiveness of new treatments, such as highly active antiretroviral therapy (HAART), which inhibits the progression from HIV infection to stage 3 (AIDS) and allows persons with HIV to live longer.

BAR, OR COLUMN, GRAPHS

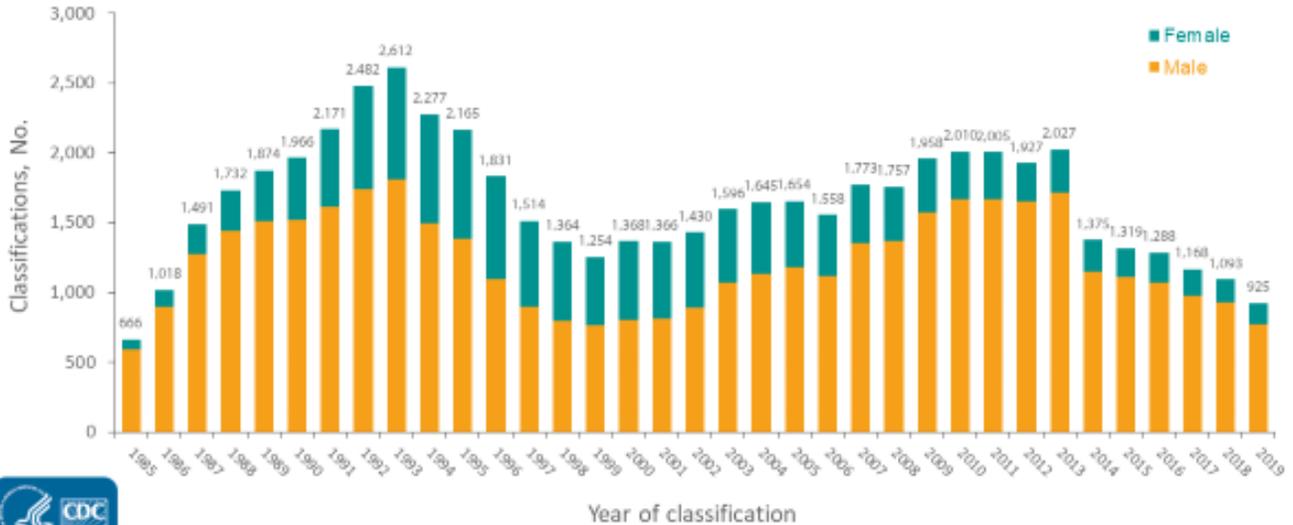
In a bar, or column, graph, data are organized so that each observation can fall into 1 category of the variable.

Bar graphs are useful for showing how data change during a period or for comparing categories. In a vertical bar graph, the measurable feature (e.g., percentage or rate) is shown on the vertical axis, sometimes called the measuring axis. Categories of a variable (e.g., locations, groups) are represented by bars on the horizontal baseline. The length of each bar corresponds to a value on the measuring axis.

For example, Figure B-5, a stacked column bar chart, shows the measurable feature—number of stage (3) AIDS classifications—along the vertical (measuring) axis and the categories of the variable—sex at birth—along the horizontal baseline. In this example, you can see that by sex at birth, the number of stage 3 AIDS classifications are higher for males compared to females.

Figure B-5. Example of bar, or column, graph

Stage 3 (AIDS) Classifications among Young Adults Aged 20–24 Years with Diagnosed HIV Infection, by Sex at Birth and Year of Classification, 1985–2019—United States and 6 Dependent Areas



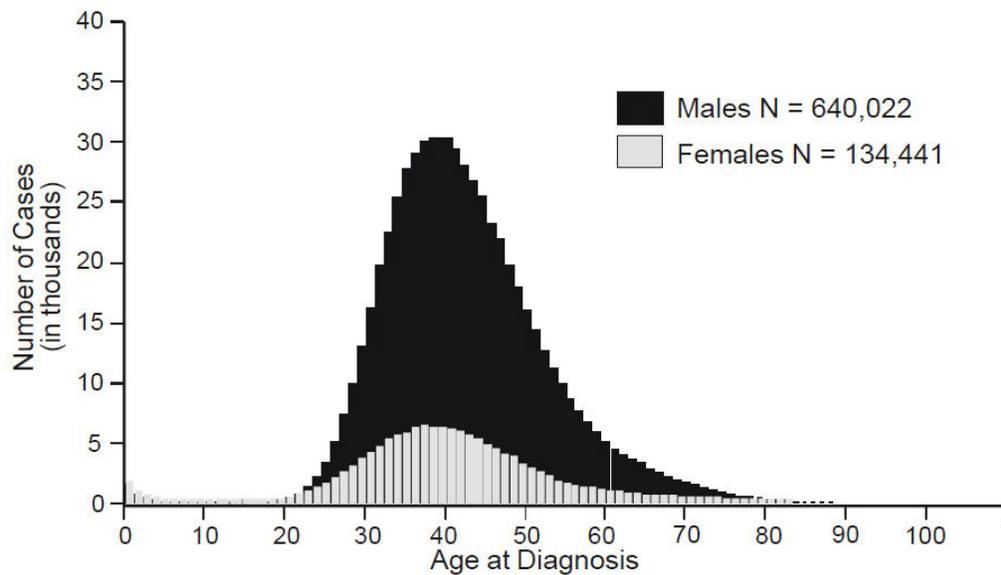
Source: X

HISTOGRAMS

The histogram a bar graphic-like representation that organizes a group of data points into user-specified ranges. The height of each rectangle is proportional to the number of observations (values) in that range.

Figure B-6. Example of Histogram

AIDS Cases by Age and Sex at Birth, reported 1985–2019, United States



Source: X

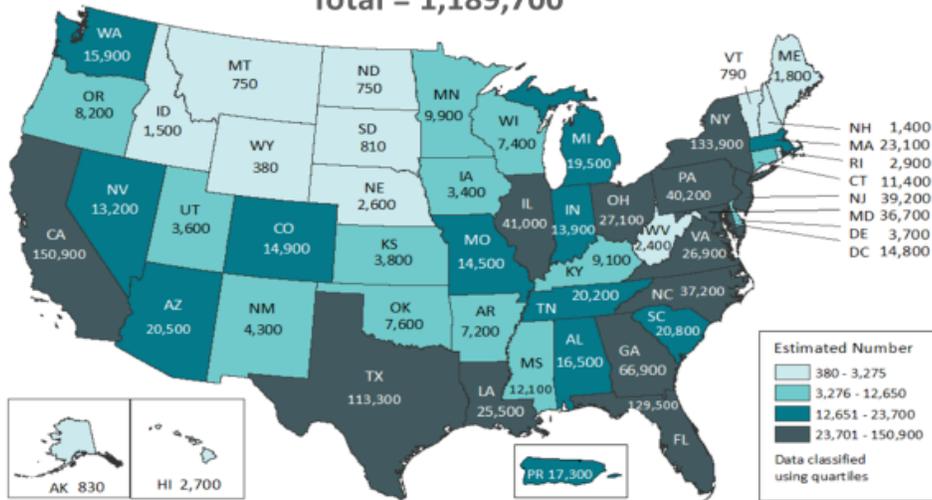
MAPS

Maps are useful for showing the geographic location of events or attributes. Spot maps show where a disease or an event occurred, area maps (see Figure B-6) show either the incidence or prevalence of an event in an area or the distribution of some condition throughout a geographic area, and maps produced by using Geographic Information Systems, or GIS, (see [Chapter 4](#)) display data based on geographic mapping coordinates.

Figure B-7. Example of area map

Estimated HIV Prevalence among Persons Aged ≥13 years, by Area of Residence 2019—United States and Puerto Rico

Total = 1,189,700 †



Note. Estimates were derived from a CD4 depletion model using HIV surveillance data. Estimates rounded to the nearest 100 for estimates >1,000 and to the nearest 10 for estimates ≤1,000 to reflect model uncertainty. Estimates for the year 2019 are preliminary and based on deaths reported to CDC through December 2020. Estimates should be interpreted with caution due to incomplete death ascertainment for Kansas, Massachusetts, Mississippi, Nevada, North Dakota, and Vermont.
 †Total estimate for the United States does not include data for Puerto Rico.

Source: <http://www.cdc.gov/hiv/library/slideSets/index.html>.

Appendix C.

Primary Data Sources

HIV SURVEILLANCE

Overview: HIV surveillance data include all persons with a confirmed diagnosis of HIV infection met by either laboratory evidence or clinical evidence (including stage 3 [AIDS]) and who have been reported to a state or local health department.

All 50 states, the District of Columbia, and 6 U.S territories require health-care providers and laboratories to report new cases of diagnosed HIV infection to their state or local health departments. Standardized case report forms are used to collect sociodemographic information, possible HIV risk factors, laboratory and clinical information, vital status, and referrals for treatment or services. HIV surveillance monitors the diagnosis of HIV infection, the demographic profile of persons with HIV, and the possible modes of transmission. HIV surveillance data are also used to allocate resources for RWHAP HIV care and services programs.

eHARS

The enhanced HIV/AIDS Reporting System (eHARS) is a browser-based application developed by the Centers for Disease Control and Prevention (CDC) to assist health departments with collecting, data management, analysis, reporting, and transferring of HIV data to CDC. It is a comprehensive document-based system that assists in the collection of HIV surveillance data such as, case report forms (adult case report form [ACRF] and pediatric case report form [PCRF]), laboratory reports, death certificates, birth certificates, and other documents.

HIV has become a manageable chronic disease, and the need exists to collect complete, timely, and high-quality data for:

- enhancing local, state, and federal efforts to prevent HIV transmission
- improving allocation of resources for treatment services
- assisting in evaluating the impact of public health interventions

Information about a persons' HIV status and care is received from several documents, eHARS stores and retrieves data by using fields mapped to these documents, and the data are linked by unique person and document identifiers, such as a STATENO or CITYNO. Each reporting jurisdiction/area submits de-identified data monthly to CDC through a secure data network (SDN).

Document-based data management allows all documents to be stored and retained electronically in their original format. As documents are entered into eHARS, they are linked to the appropriate person

through manual and automatic matching processes. The Person View document, a master record for each person entered in eHARS, is created, and updated by algorithms that select appropriate values from the documents linked to the master record. A document can be moved to another person if research indicates the document does not belong to the person to whom it was originally assigned. Summary data about each person are updated through document-based data entry. By linking multiple documents from multiple sources to a person entered in eHARS, the process of collecting, managing, analyzing, and disseminating data becomes less cumbersome to maintain and requires fewer resources and systems. In addition to data collection, eHARS provides tools to assist in the investigation of potential HIV cases, the import and export of data, data transfers to CDC, and reporting and analysis of data. Health departments can use the data available in eHARS:

- to identify patients who are not in care and link them back to HIV medical care programs
- to identify HIV clusters and outbreaks and prevent HIV transmission within the jurisdiction
- for HIV program planning
- to evaluate data quality and completeness of reporting

To obtain access to your local eHARS system check with your local HIV surveillance coordinator.

The enhanced HIV/AIDS reporting system (eHARS) is used by state and local health departments to collect data on all persons with confirmed diagnoses of HIV infection. Surveillance data include:

- patient demographics
- residence (at diagnosis and most recently known)
- facility type
- stage of disease
- risk factors for acquiring HIV
- clinical assessments (e.g., acute infection, opportunistic illnesses)
- laboratory data (e.g., CD4, viral load, genotype sequences)
- treatment history (including PrEP)
- HIV testing history
- vital status

Strengths: According to state evaluations, HIV infection reporting is estimated to be 84%–100% complete for persons who have tested positive for HIV.

HIV surveillance data can be used to:

- provide counts of persons who have received laboratory or clinical confirmation of HIV infection
- help detect trends in HIV infections among populations

- assess care outcomes among the HIV diagnosed population (linkage, receipt of care, viral suppression)
- help detect clusters of rapid transmission
- estimate HIV incidence (new infections), knowledge of status, undiagnosed infection
- estimate survival after diagnosis
- estimate lifetime risk of receiving an HIV diagnosis
- estimate life expectancy after HIV infection
- identify the social determinants of health that impact HIV diagnosis, and access to care and treatment

HIV surveillance data can also be used to anticipate unmet needs for HIV care. According to state evaluations, HIV infection reporting is estimated to be 84%–100% complete for persons who have tested positive for HIV. These data provide a basis for monitoring receipt of HIV medical care, retention in HIV medical care, and viral suppression.

Population: All persons with a confirmed diagnosis of HIV infection

Epi profile core questions addressed: Core questions 2.1, 2.2, 3.2

Limitations: All areas now have confidential name-based HIV reporting laws or regulations. However, HIV surveillance data may undercount the number of persons with HIV because some have not received a diagnosis. Persons who have tested positive at an anonymous test site and have not sought medical care, during which they would be confidentially tested, are not reported to the surveillance system. Furthermore, reporting of behavioral risk information may not be complete.

Where available: All 50 states, District of Columbia, and 6 U.S. dependent areas (American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, the Republic of Palau, and the U.S. Virgin Islands).

Contact: State or local health department, HIV surveillance coordinator

Other sources of surveillance data:

- State/local HIV Surveillance Reports (see state/local health department website)
- [National HIV Surveillance reports](https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html) (<https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>)
- [America's HIV Epidemic Analysis Dashboard](https://ahead.hiv.gov/) (AHEAD) (<https://ahead.hiv.gov/>)
- [AIDSVu](https://aidsvu.org/) (<https://aidsvu.org/>)

Reference

CDC. [Selik RM, Mokotoff ED, Branson B, Owen SM, Whitmore S, Hall HI]. Revised surveillance case definitions for HIV infection—United States, 2014. *MMWR* 2014;63(RR-03);1–0.

CDC National Center for HIV, Viral Hepatitis, STD, and TB Prevention Atlas Plus

Overview: The Atlas provides an interactive platform for accessing state- and county-level HIV surveillance data collected by CDC's National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP). This interactive tool allows users to observe trends and patterns by creating detailed reports, maps, and other graphics.

Surveillance data available through the NCHHSTP Atlas:

- HIV (including PrEP)
- Sexually transmitted disease
- Tuberculosis
- Viral Hepatitis

Where available: <https://www.cdc.gov/nchhstp/atlas/index.htm>. Accessed November 18, 2021.

CDC Medical Monitoring Project (MMP)

Overview: The Medical Monitoring Project (MMP) is an annual, cross-sectional complex sample survey that reports nationally and locally representative estimates of behavioral and clinical characteristics among adults with diagnosed HIV in the United States. MMP was designed to learn more about the experiences and needs of PWH. More information can be seen [here](#). Information from MMP that could contribute to the Epi Profile includes:

- Demographic characteristics and social determinants of health, including but not limited to: gender, sexual orientation, employment, income, housing instability (e.g., homelessness), incarceration, health care coverage, and receipt of RWHAP assistance
- HIV-related stigma and HIV healthcare discrimination
- Sexual behaviors, including prevention strategies used with sexual partners (condoms, PrEP use among partners without HIV, sex with other partners with HIV)
- Substance use, including alcohol use, injection/non-injection drug use
- Receipt of prevention services, including condoms, sterile syringes, and receipt of prevention messaging
- Clinical outcomes, including retention in HIV care, missed appointments, ART adherence, viral suppression, emergency room visits, hospitalizations
- Attendance at a RWHAP-funded facility for HIV care
- Barriers to receiving HIV care
- Unmet needs for HIV ancillary care services (e.g., case management, patient navigation services, mental health services, substance use disorder treatment)

Methodology and analysis: MMP uses a complex sample survey design with a two-stage methodology to report representative estimates both nationally and for each reporting jurisdiction. In the first stage, 16 states and Puerto Rico are sampled from all 50 U.S. states, the District of Columbia, and Puerto Rico. In the second stage, simple random samples of adults with diagnosed HIV are selected from each jurisdiction from the National HIV Surveillance System (NHSS), a census of all adults and adolescents with diagnosed HIV in the United States. To account for the complex sample methodology, data are weighted to adjust for person nonresponse and post-stratified to known population totals by age, race/ethnicity, and sex from NHSS. More details on the methodology are described elsewhere.

Guidance on analyzing MMP data is available in the MMP analysis primer. All participating MMP jurisdictions should have access to this document. The analysis primer provides guidelines for incorporating the complex sample survey methodology using SAS and SUDAAN procedures, with sample code provided. In addition, the code and accompanying tables for all recommended Epi Profile-related analyses using MMP data will be sent annually by CDC to participating jurisdictions. Funded jurisdictions should reach out to their MMP CDC project officer if they do not have access to and need any of these resources described.

Because the data are weighted based on a national probability sample, estimates should be assessed for reliability and suppressed or footnoted if reliability of estimates is questionable. Specifically, estimates should be suppressed when they have a coefficient of variation ≥ 0.30 or are based on a denominator sample size <30 . Estimates with an absolute CI width ≥ 0.30 , estimates with an absolute CI width between 5 and 30 and a relative CI width $>130\%$, and estimates of 0% or 100% should be marked with an asterisk (*) and interpreted with caution. For estimates of categorical variables with questionable reliability, staff could consider: (1) combining categories such that the CV for each category is not ≥ 0.30 , or (2) including additional years of data to improve reliability of data estimates.

Populations: Adults with diagnosed HIV infection.

Strengths: The design allows for representative estimates at the national and state or local level of certain characteristics, behaviors, and outcomes that are generalizable to adults with diagnosed HIV infection in the United States. Data will be available in the same jurisdictions over time, allowing analysis for trends.

Epi profile core questions addressed: Core questions 2.1, 2.2, 3.1, 3.2, 4.2

Limitations: Not all jurisdictions participate in MMP. Persons with diagnosed HIV under the age of 18 are not included.

Where available: As of 2013, a total of 23 project areas (16 states, 6 separately funded jurisdictions, and 1 territory) participate in MMP. Participating jurisdictions include California (including the separately funded jurisdictions of LA County and San Francisco), Delaware, Florida, Georgia, Illinois (including the separately funded jurisdiction of Chicago), Indiana, Michigan, Mississippi, New Jersey, New York (including the separately funded jurisdictions of New York City), North Carolina, Oregon, Pennsylvania (including the separately funded jurisdiction of Philadelphia), Texas (including the separately funded jurisdiction of Houston), Virginia, Washington, and Puerto Rico.

Contact: State or local health department MMP Coordinator, Principal Investigator, or Project Coordinator (available at <http://www.cdc.gov/hiv/statistics/systems/mmp/projectareas.html>); for MMP at CDC, see <http://www.cdc.gov/hiv/statistics/systems/mmp/contact.html> for detailed contact information.

CDC National HIV Behavioral Surveillance System (NHBS)

Type of data: Behavioral surveillance

Overview: The [National HIV Behavioral Surveillance \(NHBS\)](#) is a cross-sectional biobehavioral surveillance system conducted in rotating, annual cycles in three different populations in U.S. urban areas with high HIV prevalence to collect information by using a standardized, anonymous questionnaire on HIV-related risk behaviors (e.g., sexual behaviors, drug use), HIV testing, and the use of HIV prevention services (e.g., condoms, PrEP, SSP). HIV testing is offered to all participants. During each cycle, 500 eligible persons from each participating project area are interviewed and offered HIV testing. NHBS data are used to provide a behavioral context for trends seen in HIV surveillance data. NHBS data also describe populations at increased risk for HIV infection. Behavioral data include:

- demographics, including sexual orientation
- social determinants of health
- health care access and utilization
- health conditions
- sexual behavior
- substance use, including needle sharing
- drug treatment
- HIV testing and care
- PrEP/PEP
- HIV prevention services and resources
- Stigma and discrimination
- Violence
- Infectious diseases testing, including HIV, STI, and Hepatitis C

Populations: (1) Gay, bisexual and other men who have sex with men (MSM cycle), (2) Persons who inject drugs (PWID cycle), and (3) Heterosexually active persons at increased risk for HIV infection (HET cycle).

Epi profile core questions addressed: Core questions 4.1, 4.2

Strengths: Among MSM, venue-based time-space sampling is used to obtain a sample of men attending venues. Among PWID and HET, respondent-driven sampling is used. Behavioral data will be available in the same metropolitan statistical areas over time, allowing analysis for trends.

Limitations: At-risk persons who do not attend venues, or who are not recruited by their peers, are not sampled.

Where available: [Participating jurisdictions](#): In 2017–2019, 23 urban areas conducted NHBS, which represented approximately 59% of all persons with HIV infection in urban areas with a population of at least 500,000 at year-end 2016: Atlanta, Georgia; Baltimore, Maryland; Boston, Massachusetts; Chicago, Illinois; Dallas, Texas; Denver, Colorado; Detroit, Michigan; Houston, Texas; Los Angeles, California; Memphis, Tennessee; Miami, Florida; Nassau and Suffolk counties, New York; New Orleans, Louisiana; New York, New York; Newark, New Jersey; Philadelphia, Pennsylvania; Portland, Oregon; San Diego, California; San Francisco, California; San Juan, Puerto Rico; Seattle, Washington; Virginia Beach, Virginia; and Washington, DC. In 2019–2020, NHBS collected data from transgender women ([NHBS-Trans](#)) in 7 urban areas: Atlanta, GA; Los Angeles, CA; New Orleans, LA; New York, NY; Philadelphia, PA; San Francisco, CA; and Seattle, WA.

Contact: [NHBS Coordinator for your state or jurisdiction](#)

HIV Testing System

Overview: All states, territories, and selected cities receive funding to support HIV counseling, testing, and referral services as part of HIV prevention cooperative agreements with CDC. These services are provided at sexually transmitted disease (STD) clinics, family planning clinics, prenatal clinics, hospitals, community health centers, correctional facilities, drug treatment centers, tuberculosis (TB) clinics, HIV testing centers, and field (including street outreach) settings. Staff at these sites collect information about the persons tested (e.g., demographic information, behavioral risk factors), test type (i.e., anonymous or confidential), current and prior test results, and receipt of test results and posttest counseling. On a quarterly basis, health departments submit to CDC test-level data (i.e., data files with data on individual tests, not client-based). Personal identifying information is not provided to CDC. Some locations may collect client-based HIV testing data by using a code to link test results so that client-based data can be calculated.

Population: All clients who receive confidential or anonymous HIV testing services at a site funded through a CDC cooperative agreement.

Strengths: Standardized data on clients; data on both negative and positive results.

Limitations: First, data findings may be influenced by whether testing sites promoted and followed policies of routine or targeted HIV testing. For example, the number of tests may be smaller in geographic locations or sites with targeted testing; and correspondingly, the HIV positivity in these locations or sites may be higher. Second, the population of persons using CDC-funded sites for HIV CTR is not representative of all persons who are tested in the United States. Third, data are test-level and not client-level. Fourth, the HIV testing data result from a program activity and are collected in conjunction with a health service delivery, which means the information collected by service providers is not routinely validated through research or epidemiologic investigation.

Where available: State and local health departments and community-based organizations.

Contact: State, territorial, or local HIV program manager or HIV director.

Type of data: HIV testing data

Description: The National HIV Prevention Program Monitoring and Evaluation (NHM&E) system collects standardized HIV prevention program evaluation data from health departments and community-based organizations who receive funding from CDC for HIV prevention activities. HIV test event-level data are submitted to CDC by testing programs at 60 health departments (50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and 7 Metropolitan Statistical Areas or specified Metropolitan Divisions, including Baltimore City, Chicago, Houston, Los Angeles, New York City, Philadelphia, and San Francisco) and 151 community-based organizations (CBOs). In addition, data on other funded activities are collected including linkage to HIV medical care, completion of partner services interviews, HIV prevention services, and PrEP awareness, use, and support. NHM&E data are used to assess the impact of CDC-funded HIV testing efforts, inform programmatic activities, and document the progress of programs toward local, state, and national HIV prevention goals.

Epi profile core questions addressed: Core question 4.1

Where to obtain: State health department and CDC Monitoring and Evaluation Reports (<https://www.cdc.gov/hiv/library/reports/index.html>).

Ryan White HIV/AIDS Program (RWHAP)

Description: Ryan White HIV/AIDS Program recipients are required to report data to the HRSA HIV/AIDS Bureau as a condition of their award. Data are reported on a variety of topics including clients served, services provided, allocations, and expenditures. Two of the primary data collection mechanisms are the Ryan White HIV/AIDS Program Services Report (RSR) and the AIDS Drug Assistance Program Data Report (ADR).

RSR: The RSR is a client-level data reporting requirement that monitors the characteristics of Ryan White HIV/AIDS Program Parts recipients, providers, and clients served. All Ryan White HIV/AIDS Program-funded recipients Parts A, B, C, and D and their contracted service providers (i.e., subrecipients) are required to report client-level data annually to the HIV/AIDS Bureau (HAB) through the RSR.

The RSR is comprised of:

- **Recipient Report:** Each Ryan White HIV/AIDS Program recipient completes a separate Recipient Report for each program grant the recipient receives from HRSA HAB (e.g., RWHAP Part A, B, C, and D funding). The recipient completes the online report through the HRSA Electronic Handbooks (EHB) by using a web-based data entry system.
- **Provider Report:** This report is a collection of basic information about both the provider and the services the provider delivers under each of its RWHAP contracts. All agencies that provide RWHAP-funded services complete one Provider Report by using the RSR Web System. Multiple-funded providers include information from all program parts in one Provider Report.
- **Client Report:** This report is a collection of Ryan White HIV/AIDS Program client-level data uploaded as an electronic file using a standard format. Each upload file contains one record per client. Each client record includes information on demographic and socioeconomic characteristics, HIV clinical information, HIV medical and support services received, and the client's encrypted unique client identifier (eUCI).

RSR data do not include information about clients receiving services through the AIDS Drug Assistance Program (ADAP), which is reported through the ADAP Data Report (ADR).

ADR: The RWHAP legislation authorizes a portion of Part B funds to be designated for the AIDS Drug Assistance Program (ADAP), which provides U.S. Food and Drug Administration (FDA)–approved medications to and medication access through health care coverage assistance for low-income people with HIV.

The ADR is comprised of:

- **Recipient Report:** A collection of basic information about recipient characteristics and policies.
- **Client Report** (or client-level data): A collection of records (one record for each client enrolled in the ADAP), which includes the demographic and socioeconomic characteristics, enrollment and certification information, HIV clinical information, HIV treatment information, services received (e.g., insurance premium assistance), and the client’s encrypted unique client identifier (eUCI).

Although the ADR may include clients who received both ADAP and non-ADAP RWHAP services during the reporting period, ADR data do not include information on non-ADAP RWHAP services (e.g., Outpatient/Ambulatory Health Services), nor does the ADR collect information to identify which clients overlap with other RWHAP services.

Epi profile core questions addressed: Core questions 2.1, 3.1, 3.2

Where to obtain: All RWHAP grant recipients and subrecipients have a copy of the data they submitted to HRSA. Grant recipients and subrecipients are encouraged to consult their source data, HRSA HAB-published data reports (<https://hab.hrsa.gov/data/data-reports>), and the RWHAP Compass Dashboard (<https://targethiv.org/RWHAPCompass>)

Strengths: The RSR data set is well-defined (see the [HRSA website](#)). RWHAP grant recipients have source data that were submitted to HRSA’s HIV/AIDS Bureau. The Client Report can be used by RWHAP recipients for their own needs, include preparation of the Epi Profile to meet, in part, the funding requirements of the Ryan White HIV/AIDS Program.

Limitations: The quality of the source data is determined by the RWHAP grant recipient. Issues related to data collection, data completeness, and data quality must be addressed by the recipient prior to submission to HRSA HAB.

Where available: All RWHAP grant recipients and first-level providers (through recipients)—Part A cities, Part B states, Part C and D community-based organizations, hospitals, clinics, and other provider organizations.

Contact: Local Ryan White HIV/AIDS Program grant recipient.

Sexually Transmitted Disease (STD) Data

Description: These data are used in reports of notifiable STDs such as syphilis, gonorrhea, and chlamydia. Use STD surveillance data to obtain the number of cases and incidence of specific STDs.

Demographic and clinical data are available from STD surveillance. They may serve as a surrogate marker for unsafe sexual practices in a specific risk population. STDs are reportable in all 50 states, District of Columbia, and U.S. territories. Reporting of STDs from private-sector providers may be less complete.

Epi profile core questions addressed: Core questions 2.1, 4.2

Where to obtain: Available in all 50 states, the District of Columbia, and U.S. territories. Contact the STD program manager in your service area for information. STD surveillance reports that include state-, MSA-, county-, and city-level data can be found at <https://www.cdc.gov/std/statistics/>. State- and county-level data on STDs are available in CDC's NCHHSTP Atlas Plus (<https://www.cdc.gov/nchhstp/atlas/index.htm>).

SUPPLEMENTAL DATA SOURCES

Behavioral Risk Factor Surveillance System (BRFSS)

Overview: BRFSS is a state-based, random-digit-dialed telephone survey that monitors state-level prevalence of the major behavioral risks associated with premature morbidity and mortality among adults. Each month, a sample of households is contacted, and 1 person in the household who is 18 years or older is randomly selected for an interview. Multiple attempts are made to contact the sampled household. A Spanish translation of the interview is available. Respondents are asked a variety of questions about their personal health behaviors and health experiences.

Since 1994, the BRFSS questionnaire has included questions related to HIV for respondents aged 18 to 49 years. Past cycles of BRFSS have included questions about perceived risk of getting an HIV infection; use of HIV testing; reasons for testing; if tested, the type of place where tested and receipt of posttest HIV counseling; attitudes about condoms; and attitudes about when to initiate HIV education in schools. As of 2021, the BRFSS questionnaire includes questions about history of ever testing for HIV, and if ever tested, month and year of the most recent test. The questionnaire also includes a measure of self-reported past-year HIV risk on the rotating (biannual) core survey, as well as demographic information, including sexual orientation and gender identity for a subset of states.

Population: All noninstitutionalized adults, 18 years and older, who reside in a household with a telephone

Strengths: Data are population-based; thus, estimates about testing attitudes and practices can be generalized to the adult population of a state or county. BRFSS completes more than 400,000 adult interviews each year, making it the largest continuously conducted health survey system in the world. Thus, stable population-based estimates are available down to the county level. Information collected from the BRFSS survey may be useful for planning community-wide education programs.

Limitations: BRFSS data are self-reported; thus, the information may be subject to recall bias. Respondents are contacted by telephone survey, including cellphone users; thus, the data are not representative of households without a telephone. In addition, BRFSS data are representative of the general, noninstitutionalized adult population in an area, not just persons at highest risk for HIV. A

question about self-reported participation in behaviors that may increase risk for acquiring HIV is now only asked every other year. Stable estimates of HIV testing history (% ever tested and time since last test) can be generated for the subset reporting participating in these behaviors only for States and the larger county areas.

Where available: Since 1994, all 50 states and the District of Columbia have conducted BRFSS. As of 2011, American Samoa, Guam, Palau, Puerto Rico, and the U.S. Virgin Islands have participated in BRFSS.

Contact: BRFSS coordinator for your state or territory. Additional background and information on whom to contact in your area is available at <http://www.cdc.gov/brfss> (accessed November 17, 2021).

CDC Wide Ranging Online Data for Epidemiologic Reporting (WONDER)

Overview: The WONDER Web site may be useful for obtaining population estimates from the Bureau of the Census at the county level, by age and sex for a given race or by age and sex for Hispanic/Latino persons (all races combined).

Other data available through WONDER:

- Vital statistics mortality data from the National Center for Health Statistics at the county level, by age, sex, and race
- Census state population projections

Strengths: The tabulations from CDC WONDER can be printed, and some of the data sets can be downloaded in an Excel-compatible format. They provide numbers and rates, but not percentage distributions (which you would have to calculate yourself). WONDER allows users to quickly query large data sets across several years to identify trends. The Compressed Mortality application allows users the option of customizing the calculation of age-adjusted rates, selecting the demographic attributes for the standard population.

Where available: <http://wonder.cdc.gov> (accessed November 17, 2021).

Coinfection with Human Immunodeficiency Virus (HIV) among Reported Cases of Primary and Secondary Syphilis

Overview: Since 2008, HIV status has been a required data element of case report data for syphilis, including reports of primary and secondary (P&S) syphilis. These data, in addition to other required data elements like sex of sex partner, information source, and stage of diagnosis, are used to describe the current epidemiology of P&S syphilis, including affected populations.

Population: Patients with reported cases of P&S syphilis in the United States.

Strengths: Provides national-level data on populations at risk for both P&S syphilis and HIV infection (e.g., gay, bisexual, and other men who have sex with men, or MSM). Such surveillance allows

comparisons of different populations (e.g., MSM of different races/ethnicities and age groups) among different regions (e.g., the South, the West, as defined by the U.S. Census Bureau). These data assist the Centers for Disease Control and Prevention (CDC) to identify existing and emerging risk populations and focus efforts to prevent and reduce disease in these populations.

Limitations: Some public health jurisdictions do not report HIV status. Therefore, these data might not reflect the epidemiology of HIV coinfection across all areas of the United States. Some populations in the United States can only be estimated (e.g., MSM), limiting the ability to calculate rates of HIV coinfection. Because of different social factors (e.g., reluctance of patients to disclose sexual behaviors to their care providers), these data might reflect underreporting of true case counts of HIV coinfection.

Where available: Multiple states in the United States.

Contact: State and local health department STD Programs, CDC, Division of STD Prevention, Epidemiology and Surveillance Branch, Surveillance and Special Studies Team

Gonococcal Isolate Surveillance Project (GISP)

Overview: Established in 1986 to monitor trends in antimicrobial susceptibilities of strains of *N. gonorrhoea* in the United States to establish a rational basis for the selection of gonococcal therapies. GISP is a collaborative project among selected sexually transmitted disease (STD) clinics, 4 regional laboratories, and CDC.

In GISP, *N. gonorrhoeae* isolates are collected from the first 25 men with urethral gonorrhea attending STD clinics each month in approximately 27 cities in the United States. At regional laboratories, the susceptibilities of these isolates to azithromycin, ceftriaxone, cefixime, ciprofloxacin, gentamicin, penicillin, and tetracycline are determined by agar dilution.

Minimum inhibitory concentrations (MICs) are measured, and values are interpreted according to criteria recommended by the Clinical and Laboratory Standards Institute (CLSI).

Population: The first 25 men with urethral gonorrhea each month at participating STD clinics

Strengths: GISP offers ongoing data on the level of antimicrobial susceptibilities among men who seek care at public STD clinics and who have urethral discharge. Despite the convenience sampling used by GISP, the data are useful for assessing trends in gonorrhea among gay, bisexual, and other men who have sex with men and the level of repeat infections.

Limitations: GISP uses a convenience sample of men at public STD clinics to obtain patient isolates. Thus, inferences concerning the general population of men with urethral gonorrhea cannot be drawn. Depending upon the level of gonorrhea morbidity, the 25 men may represent all or a fraction of the patients seen in the public clinic. In addition, men who seek care from STD public clinics may not be representative of men who seek care elsewhere.

Where available: Albuquerque; Atlanta*; Baltimore; Birmingham*; Chicago; Cincinnati; Cleveland*; Dallas; Denver; Detroit; Greensboro; Honolulu; Kansas City (Missouri); Las Vegas; Los Angeles; Miami; Minneapolis; New Orleans; New York; Orange County; Oklahoma City; Philadelphia;

Phoenix; Portland (Oregon); Richmond; San Diego; San Francisco; Seattle*; and Tripler Army Medical Center, Honolulu. [* indicates regional laboratories]

Contact: State or local STD program manager; CDC, Division of STD Prevention, Epidemiology and Surveillance Branch

Hepatitis C Surveillance

Overview: Data on hepatitis B and C virus (HBV, HCV) infections may represent markers for needle sharing and sexual behaviors, which can be risk factors for HIV transmission. Data on hepatitis B and C are used to:

- predict the likelihood and rate of spread of viral hepatitis and HIV infections in a community
- monitor trends
- identify needs for HIV prevention and care services

Acute hepatitis B and C (i.e., clinical illness with laboratory confirmation) is reportable in all states; however, because of underreporting and asymptomatic infections, data are likely to be incomplete.

Several states have registries for HBV and HCV infection, and most have laboratory reporting laws requiring reporting of positive serologic test results for HBV and HCV infection. Although serologic markers for HBV infection can distinguish between acute and chronic infection, laboratory reports of positive HCV-antibody results cannot differentiate newly acquired infections from chronic or resolved infections, making it difficult to monitor disease trends for HCV.

Surveillance for hepatitis C includes reporting of acute hepatitis C and hepatitis C virus (HCV) infection (past or present) to CDC's National Notifiable Diseases Surveillance System. The purpose of hepatitis C surveillance is to identify new cases, determine risk factors for infection, identify infected persons who can be counseled and referred for medical follow-up, and evaluate prevention efforts.

Population: All persons whose reported cases of acute hepatitis C, or HCV, infection meet the case definitions approved by the Council of State and Territorial Epidemiologists

Epi profile core questions addressed: Core questions 2.1, 4.2

Strengths: Surveillance for acute hepatitis C provides information needed to determine incidence trends, transmission patterns, and persons at highest risk for infection. Persons can be characterized by gender, race/ethnicity, age, and risk behavior for HCV. Surveillance for HCV infection can be used to provide persons who have HCV with information on how to reduce both their risk of transmitting HCV to others and their risk for further liver injury and to provide them with referral for medical evaluation. It also can be used to evaluate prevention efforts by providing estimates of the proportion and characteristics of persons with HCV infection.

Limitations: Hepatitis C surveillance data should be interpreted cautiously because many reporting areas do not have the resources required for case investigations to determine whether a laboratory report represents acute infection, chronic infection, resolved infection, repeated testing of a person previously reported, or a false-positive result.

Where available: All 50 states and U.S. territories. The quantity and the quality of surveillance data differ between states. Refer to CDC's National Electronic Disease Surveillance System and the CDC Division of Viral Hepatitis. State- and county-level data on hepatitis are available in CDC's NCHHSTP Atlas Plus (<https://www.cdc.gov/nchhstp/atlas/index.htm>).

Contact: State or local hepatitis C (if available) or hepatitis B coordinator; CDC, Division of Viral Hepatitis. National viral hepatitis surveillance reports that include national- and state-level data can be found at <https://www.cdc.gov/hepatitis/statistics/index.htm>.

References

CDC. Hepatitis C. <https://www.cdc.gov/hepatitis/hcv/index.htm>. Accessed November 18, 2021.

CDC. Ryerson AB, Schillie S, Barker LK, Kupronis BA, Wester C. Vital Signs: Newly Reported Acute and Chronic Hepatitis C Cases—United States, 2009–2018. *MMWR* 2020;69:399–404.

CDC. Schillie S, Wester C, Osborne M, Wesolowski L, Ryerson AB. CDC Recommendations for Hepatitis C Screening Among Adults—United States, 2020. *MMWR* 2020;69(No. RR-2):1–17.

CDC. *Guidelines for Viral Hepatitis Surveillance and Case Management*. Atlanta: CDC; 2005. <http://www.cdc.gov/hepatitis/Statistics/SurveillanceGuidelines.htm>. Accessed November 9, 2021.

HIV Outpatient Study (HOPS)

Overview: HOPS is a longitudinal cohort study established in 1993 to describe and monitor trends in demographics, symptoms, diagnoses, and treatments in a population of outpatients with HIV in clinics across the United States. HOPS abstracts clinical, immunologic, and viral suppression information through periodic reviews of medical records to enhance the understanding of prolonged survival, the metabolic problems associated with highly active antiretroviral therapy (HAART), adherence to HAART, and the occurrence of comorbidities. At baseline, HOPS collects demographic information and information on risk behaviors such as smoking, alcohol consumption, and drug use.

Population: HIV-positive outpatients seeking care at HIV clinics

Strengths: Because HOPS uses a longitudinal study design and collects extensive clinical information and laboratory clinical markers, the data illustrate patterns of clinical outcomes over time, particularly among long-term survivors of HIV disease and patients who are taking HAART. In addition, HOPS data have been used to document adverse outcomes from HAART.

Limitations: HOPS is not a population-based study of persons with HIV. Thus, information from this study may not be representative of all patients with HIV in a service area. The quality of the data depends upon the completeness of documentation in the medical chart and the ability of abstractors to locate the chart.

Where available: Chicago, Denver, District of Columbia, Philadelphia, Stony Brook, and Tampa

Contact: Local study investigators; CDC, Division of HIV Prevention, HIV Research Branch

National Death Index (NDI)

Overview: This national database of state death record information cannot be accessed directly; however, NCHS performs searches for health investigators (for a fee) to determine whether their study subjects' records are potential matches to records in the NDI. If the match is accepted by the investigator as a true match, the database provides the following information: the fact that the person has died, the date of death, the U.S. state of death, and the death certificate number. For an additional fee, an enhanced service, named NDI-Plus, provides the International Classification of Diseases (ICD-9 or ICD-10) codes for the causes of death (e.g., underlying cause, multiple causes).

Population: All deaths records from 1979 for all 50 states, the District of Columbia, New York City, Puerto Rico, and the U.S. Virgin Islands. Death records for select years for Guam, American Samoa, and the Northern Marianas.

Strengths: NDI is a nationwide, population-based index in which the causes of death are properly classified by using ICD-9 or ICD-10 codes according to the rules of NCHS.

Limitations: This database cannot be searched to look for deaths with causes such as HIV infection. It can be searched only for potential matches with the investigator's records, which the investigator must identify by variables such as name, date of birth, and Social Security number. If information on such identifiers is missing, it may be impossible to know for certain whether a partial match is a true match. The identifying variables of the potential matches will not be revealed directly—only the extent to which they match or do not match. The data are available from 1979 onward.

Where available: National Center for Health Statistics, [Data Access - National Death Index - About \(cdc.gov\)](https://www.cdc.gov/nchs/data/nndss/ndi/about.html)

Contact: National Death Index
National Center for Health Statistics, Division of Vital Statistics
ndi@cdc.gov
Phone: 301-458-4444

National Household Survey of Drug Abuse (NHSDA)

Overview: The NHSDA is a source of statistical information on the use of illicit drugs by the U.S. civilian population ≥ 12 years of age. The survey collects data by administering questionnaires to a representative sample of the population through face-to-face, computer-assisted interviewing at the respondent's residence. The information includes use of cocaine, receipt of treatment for illicit drugs, and need for treatment for illicit drug use during the past year; use of alcohol, tobacco, or marijuana during the past month; and perceived risk for binge drinking, marijuana use, or smoking during the past month.

The NHSDA uses a 50-state sampling design; for the 8 states with the largest populations, the sampling design provides a sample large enough to support direct state estimates. For the 42 remaining states and the District of Columbia, small-area estimation techniques are used to calculate state estimates. Youths and young adults are oversampled so that each state's sample is approximately equally distributed among 3 age groups: 12–17 years, 18–25 years, and ≥ 26 years.

Population: Noninstitutionalized, civilian U.S. population aged ≥ 12 years

Strengths: National standardized survey of drug use behaviors of the general population. To increase the level of honest reporting, information since 1999 has been collected by using a combination of computer-assisted interviewing methods to provide respondents with highly private and confidential means of responding to questions about substance use and other sensitive behaviors.

Limitations: Direct state-level estimates are available for only 8 states; other states must rely on statistical estimates. NHSDA estimates represent behaviors in the general population; thus, the survey may underestimate the level of substance use in the population at highest risk for HIV. Further, data from the NHSDA are self-reported and thus subject to recall bias and underreporting of the level of a sensitive behavior.

Where available: Annual nationwide survey conducted by the Substance Abuse and Mental Health Services Administration (SAMHSA)

Reference

Substance Abuse and Mental Health Services Administration. <http://www.samhsa.gov/>. Accessed November 9, 2021.

National Neighborhood Indicators Partnership (NNIP)

Overview: The NNIP is a collaborative effort by the Urban Institute and local partners to further the development and use of neighborhood-level information systems in local policymaking and community building.

All local partners have built locally self-sustaining information systems with integrated and recurrently updated information on neighborhood conditions in their cities. These systems facilitate the direct use of information by local government and community leaders to build the capacities of distressed urban neighborhoods. Current NNIP activities are sponsored by the Annie E. Casey Foundation and the Robert Wood Johnson Foundation.

Strengths: NNIP partners maintain a large warehouse of local administrative data that include vital statistics, law enforcement, taxes, education, public housing, and public assistance information. Much of the information is geocoded. NNIP offers materials on how to access and analyze the warehoused data.

Limitations: NNIP data come primarily from administrative data systems. The accuracy of nonessential information that is not required for program eligibility may be less accurate than other sources of data (e.g., education attainment in public assistance records). Reporting bias may affect specific records (e.g., crime—many crimes are underreported, and reporting practices may differ by jurisdiction).

Where available: Atlanta, Austin, Baltimore, Boston, Charlotte, Chicago, Cleveland, Dallas, Denver, Detroit, Durham, Grand Rapids, Houston, Indianapolis, Kansas City, Los Angeles, Memphis, Miami, Milwaukee, Minneapolis-St. Paul, New Haven, New Orleans, New York, Oakland (California),

Philadelphia, Pinellas County, Pittsburgh, San Antonio, Seattle, St. Louis, Washington, D.C., and Urban Institute.

Reference

National Neighborhood Indicators Partnership. <http://www.neighborhoodindicators.org>. Accessed November 9, 2021.

Perinatal HIV Exposure Reporting (PHER) 2013–Current

Overview: In PHER, infants known to be exposed to HIV are monitored after birth up to 18 months of age to determine HIV status of the child and progression of HIV, stage 3 (AIDS) PHER works with providers (HIV care, prenatal, and obstetrics) early in a women’s pregnancy to identify and report pregnant women with HIV and obtain information on their children.

Population: Infants exposed to HIV born during 2013–current and their birthing mothers with HIV.

Strengths: The project is population based. The project collects information on HIV-exposed infants every 6 months until 18 months of age (or until HIV infection is determined). States can characterize trends in perinatal HIV, monitor the implementation and effect of perinatal prevention guidelines, assess resource needs, assess missed prevention opportunities, and monitor the effect of prevention programs.

Limitations: Data for the project rely upon the ability to identify infants exposed to HIV, HIV positive pregnant women, and locate the supplemental medical charts needed to complete the abstraction form. The completeness of data elements relies upon the level of documentation in each of these medical records.

Where available: 16 areas [California (excluding Los Angeles County and San Francisco), Delaware, the District of Columbia, Florida, Georgia, Houston, Louisiana, Maryland, Mississippi, New Jersey, New York City, North Carolina, Philadelphia, Puerto Rico, South Carolina, and Texas (excluding Houston)] are required under NOFO PS18-1802 to conduct PHER activities. Authority to establish notifiable disease reporting systems lies with state and local jurisdictions. Thus, jurisdictions must have appropriate legal authority in place to be eligible for PHER funding. Although all jurisdictions currently have authority to require reporting of persons with diagnosed HIV, they all do not have the authority to require the reporting of infants exposed to HIV but of undetermined HIV status.

Contact person(s): State or local health department, HIV surveillance coordinator or PHER coordinator; CDC, Division of HIV Prevention, HIV Surveillance Branch.

Pregnancy Risk Assessment Monitoring System (PRAMS)

Overview: A population-based survey that collects perinatal information, including information on prenatal HIV prevention through counseling and testing. Each month, a random sample (from state birth certificate files) of state-resident mothers are mailed a standardized questionnaire to gauge the extent of prenatal care, including counseling and testing of all pregnant women who delivered a live-

born infant. Repeated attempts are made by mail and by telephone to contact women to encourage participation. A Spanish translation of the mailed questionnaire and telephone interview are available. Since 1996, mothers who received any prenatal care were asked whether their health care provider discussed getting tested for HIV with them during a prenatal care visit. Since 2000, all mothers were asked whether they were tested for HIV during prenatal care.

Population: All state-resident women who have given birth to a live-born infant are eligible for the PRAMS sample.

Strengths: Population-based survey that collects information on prenatal HIV test counseling, along with other perinatal information. Estimates from PRAMS can be used to gauge the extent of provider HIV test counseling of all pregnant women who gave birth to a live-born infant. The level of HIV testing can also be assessed in this population.

Limitations: PRAMS data rely on self-reported information; thus, the information is subject to recall bias. PRAMS data are representative only of mothers who gave birth to a live-born infant; pregnancies that were terminated or ended in fetal loss are not represented. Because PRAMS samples all mothers in a state with no explicit oversample of mothers at high risk for HIV or HIV-positive mothers, these groups are not guaranteed to have sufficient sample size with which to make reliable inferences. Mothers who did not seek prenatal care will not have information on prenatal HIV counseling. Finally, information on HIV test result, posttest counseling, and HIV prophylaxis for women with HIV women is not gathered.

Where available: 46 states (excluding California, Idaho, North Carolina, Ohio), Washington, D.C., New York City, Northern Mariana Islands, and Puerto Rico.

Contact: PRAMS coordinator for your state. Additional background and information on whom to contact in your area available at <http://www.cdc.gov/prams>.

Reference

Gilbert B, Shulman HB, Fischer LA, Rogers MM. The pregnancy risk assessment monitoring system (PRAMS): Methods and 1996 response rates from 11 states. *Matern Child Health J* 1999;3(4):199–209.

Qualitative Data

Description: Qualitative methods are used to obtain data through observations, interviews, discussion groups, focus groups, and analysis of social networks.

Epi profile core questions addressed: Core questions 3.1, 4.1

Where to obtain: Health department staff and local community researchers often use qualitative methods to conduct research. Qualitative data could also potentially be generated in jurisdictions through cluster/outbreak response activities. Planning group members may also be aware of local studies. Additional information can be obtained from the University of Texas—Southwestern (<https://www.utsouthwestern.edu/education/school-of-health-professions/about/outreach/cpiu/>).

School Health Profiles

Overview: The School Health Profiles (Profiles) is a system of surveys assessing school health policies and practices in states, large urban school districts, and territories. Profiles are conducted biennially by education and health agencies among middle and high school principals and lead health education teachers. Profiles include questions about school health education requirements and content; physical education and physical activity requirements; school health policies related to HIV infection, tobacco-use prevention, and nutrition; asthma management activities; and family and community involvement in school health programs. Data from jurisdictions with overall response rates of $\geq 70\%$ are statistically weighted, enabling population-based inferences.

Population: High schools and middle schools in a jurisdiction are eligible for sampling. The surveys use a systematic equal-probability sampling strategy. At a sampled school, the principal and the lead health education teacher each complete a questionnaire. Profile surveys have been conducted biennially since 1996.

Strengths: The surveys provide population-based information on the provision of school health education, collecting information on whether HIV prevention is taught in a required course, whether specific topics related to HIV prevention are taught in a required course, whether teachers have received and want professional development on HIV prevention topics, the extent to which schools follow policies related to HIV infection, and other topics. Survey results serve as a springboard for enhancing activities in the school system. A minimum 70% response rate is required.

Limitations: Data are self-reported and available in selected areas. Information collected is not in-depth on any specific topic. The profiles are unable to evaluate the effect of the school health practices are applicable only to students in school. In addition, the unit of analysis is the schools, not the students.

Where available: The 2018 School Health Profiles Report provides information about 39 states, 21 large urban school districts, and 2 territories with representative Profiles data from both principal and lead health education teacher surveys, and four states with representative data from the principal survey only (Table 1). Principal and lead health education teacher data from five states (Arizona, Connecticut, Indiana, Iowa, and Louisiana) were not weighted to be representative of all schools in their jurisdictions and are not included in this report, nor are data from the two states that did not participate in Profiles in 2018 (Colorado and Wyoming).

Contact: Departments of education in states, large urban school districts, and territories; CDC, Division of Adolescent and School Health.

Reference

CDC. Adolescent and School Health: School Health Profiles.
<http://www.cdc.gov/healthyyouth/profiles/>. Accessed August 31, 2021.

Sexually Transmitted Infection Surveillance

Overview: CDC conducts surveillance to monitor the levels of syphilis, gonorrhea, chancroid, and, more recently, chlamydia, in the United States to establish prevention programs, develop and revise treatment guidelines, and identify populations at risk for sexually transmitted infections (STIs). States, local areas, and U.S. territories submit to CDC (weekly, monthly, or annually) case reports of STIs that have met the respective case definition for the infection.

Case report forms include information on patient demographics, type of infection, and source of report (private or public sector). Service areas conduct both passive and active surveillance of STIs to monitor the STI transmission in their area.

Population: All persons with a diagnosis of an infection that meets the CDC surveillance case definition for the infection and who are reported to local health department

Strengths: STI surveillance data can serve as a surrogate marker for unsafe sexual practices or demonstrate the prevalence of changes in a specific behavior (e.g., rectal gonorrhea). STI data are widely available at the state and local level and because of shorter incubation periods between exposure and infection, STIs can serve as a marker of recent unsafe sexual behavior. In addition, certain STIs (e.g., ulcerative STIs) can facilitate transmission or acquisition of HIV infection. Finally, changes in trends of STIs may indicate changes in community sexual norms (e.g., unprotected sex).

Limitations: STIs are reportable, but requirements for reporting differ by state. Reporting of STIs from private-sector providers may be less complete. Although STI risk behaviors result from unsafe sexual behavior, they do not necessarily correlate with HIV risk. Trends in chlamydia infections may reflect changes in reporting and screening practices rather than actual trends in disease.

Where available: All 50 states, District of Columbia, and U.S. territories

Contact: State or city STI program manager

Reference

CDC. Case definitions for infectious conditions under public health surveillance. *MMWR* 1997;46(RR-10):1–56.

Social Determinant of Health (SDH) Data

Type of data: Community-level SDH data

Description: As part of each service area's required HIV surveillance activities, HIV surveillance data are geocoded to the census tract level for addresses of residence at the time of diagnosis and linked at the census tract level to SDH indicator variable data for the general population in the service area from the U.S. Census Bureau's American Community Survey (ACS). Using census tract-level surveillance data increases a service area's 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. Addressing the SDH that adversely affect health outcomes may advance efforts in reducing disparities in HIV diagnosis rates between populations. SDH indicator variables may include (but are

not limited to) federal poverty status, education level, median household income, health insurance coverage, and Gini index. Service areas are not limited to the variables mentioned and should use the SDH indicator variables that best describe their populations.

Epi profile core questions addressed: Core questions 1.1, 2.2, 3.2

Where to obtain: Through your state or local service area’s HIV surveillance Geocoding and Data Linkage (GDL) activity; or CDC’s NCHHSTP AtlasPlus (<https://www.cdc.gov/nchhstp/atlas/index.htm>).

Type of data: Person-level SDH data

Description: For jurisdictions participating in MMP, estimates of person-level SDH factors among people with HIV—including health care coverage, poverty level, homelessness, and HIV-related stigma—can be reported. Other sources of data, including NIH-funded studies, could be used to describe SDH among the population in your service area in the absence of MMP data. Similar SDH factors can also be reported for MSM, PWID, heterosexually active adults, and transgender women who may be at high risk for HIV for jurisdictions participating in NHBS.

Below are the elements of person-level SDH factors that are available through CDC surveillance systems.

NHBS (People without HIV)	MMP (People with HIV)
<p><i>Variables of interest:</i></p> <ul style="list-style-type: none"> • Nativity • Language • Educational attainment • Employment status • Household income and corresponding poverty level • Health care access and utilization • Disability status • Homelessness • Discrimination due to sexual orientation • Perceived community intolerance of gay, bisexual, and other MSM • Experiences with sexual and physical violence 	<p><i>Variables of interest:</i></p> <ul style="list-style-type: none"> • Health care coverage • Receipt of RWHAP assistance • Household income and corresponding poverty level • Employment • Educational attainment • Country of birth • Housing instability, including homelessness* • HIV-related stigma* and HIV healthcare discrimination • Experiences with sexual and physical violence • History of incarceration • English proficiency

NHBS (People without HIV)	MMP (People with HIV)
<p><i>Reporting jurisdictions:</i> In 2017–2019, 23 urban areas conducted NHBS, which represented approximately 59% of all persons with HIV infection in urban areas with a population of at least 500,000 at year-end 2016: Atlanta, Georgia; Baltimore, Maryland; Boston, Massachusetts; Chicago, Illinois; Dallas, Texas; Denver, Colorado; Detroit, Michigan; Houston, Texas; Los Angeles, California; Memphis, Tennessee; Miami, Florida; Nassau and Suffolk counties, New York; New Orleans, Louisiana; New York, New York; Newark, New Jersey; Philadelphia, Pennsylvania; Portland, Oregon; San Diego, California; San Francisco, California; San Juan, Puerto Rico; Seattle, Washington; Virginia Beach, Virginia; and Washington, DC. In 2019–2020, NHBS collected data from transgender women (NHBS-Trans) in 7 urban areas: Atlanta, GA; Los Angeles, CA; New Orleans, LA; New York, NY; Philadelphia, PA; San Francisco, CA; and Seattle, WA.</p>	<p><i>Reporting jurisdictions:</i> California (including the separately funded jurisdictions of LA County and San Francisco), Delaware, Florida, Georgia, Illinois (including the separately funded jurisdiction of Chicago), Indiana, Michigan, Mississippi, New Jersey, New York (including the separately funded jurisdictions of New York City), North Carolina, Oregon, Pennsylvania (including the separately funded jurisdiction of Philadelphia), Texas (including the separately funded jurisdiction of Houston), Virginia, Washington, Puerto Rico.</p>

*National indicators used to assess progress towards meeting HIV prevention and care goals outlined in NHAS.

Epi profile core questions addressed: Core questions 2.1, 3.1, 4.1, 4.2

Where to obtain: Participating jurisdictions should have access to MMP and NHBS data through their local MMP and NHBS principal investigators/project coordinators, respectively.

Type of data: Special studies and surveys at the local level

Description: Surveys and other data collected from community-based organizations, HIV service organizations, universities, and special studies. Includes recurring surveys in at-risk populations.

Where to obtain: Local researchers and universities

STD Surveillance Network (SSuN)

Overview: SSuN was established to improve national capacity to detect, monitor and respond to emerging trends in STDs. SSuN collects data from 42 STD clinics and has implemented various projects for which STD clinic-based data are collected including (1) genital wart surveillance, (2) demographic and clinical characteristics of MSM attending STD clinics to assess the prevalence and trends in STDs, HIV and risk behaviors among MSM, and (3) STD clinic data to determine the proportion of patients screened for HIV and the prevalence of HIV. SSuN also conducts enhanced gonorrhea surveillance, where extensive data on demographics, risk and sexual behaviors, anatomic site of infection, and treatment are collected from interviews of a random sample of gonorrhea morbidity cases.

Population: All clinic patients attending participating STD clinics; persons with a laboratory-confirmed diagnosis of gonorrhea within SSuN jurisdictions.

Strengths: Provides project sites with additional resources to conduct active surveillance of STDs and HIV risk behaviors. This surveillance can help fill critical gaps in the ability to understand STD and HIV trends as well as guide local, state and national STD programs and policies and evaluate the effectiveness of public health interventions to reduce STD morbidity.

Limitations: Surveillance in STD clinics may not reflect STDs in the general population. Principal limitations of the enhanced gonorrhea surveillance component are risk and behavior data are self-reported, reporting of sensitive behavioral information may be subject to underreporting, and responses to questions may be subject to recall bias.

Where available: Alabama, Baltimore, Chicago, Colorado, Connecticut, Los Angeles/ California, Louisiana, New York City, Philadelphia, San Francisco, Virginia, Washington.

Contact person: Local or state STD program manager; CDC, Division of STD Prevention, Epidemiology and Surveillance Branch, Surveillance and Special Studies Team

Substance Misuse Data

Description: Substance misuse data are obtained from population-based surveys, medical examiner records, correctional facilities, law enforcement agencies, and drug treatment centers. These sources describe the patterns, prevalence, and consequences of drug use in the general population and specific populations.

Epi profile core questions addressed: Core questions 1.1, 4.2

Where to obtain: National Institute on Drug Abuse (<https://www.drugabuse.gov/>); Substance Abuse and Mental Health Services Administration (<https://www.samhsa.gov/data/>) for information from drug-use surveys and data on treatment and drug abuse.

National Survey on Drug Use and Health (NSDUH)

Overview: Annual survey of prevalence, patterns, and consequences of drug and alcohol use and abuse.

Population: Non-institutionalized civilian population ages 12 years and over.

Where available: Annual nationwide survey conducted by the Substance Abuse and Mental Health Services Administration (SAMHSA)

Reference

https://nsduhweb.rti.org/respweb/about_nsduh.html. Accessed November 18, 2021.

Tuberculosis Surveillance

Overview: Health departments in the 50 U.S. states and 9 cities (Baltimore, MD; Chicago, IL; District of Columbia; Houston, TX; Los Angeles, CA; New York City, NY; Philadelphia, PA; San Diego, CA; and San Francisco, CA) are funded to for tuberculosis (TB) control activities and report cases of TB to CDC through the Tuberculosis Elimination and Laboratory Cooperative Agreement. Case reports include a patient's demographic data, occupation, initial drug regimen, and information on HIV status, substance use, housing status, and residence in correctional or long-term care facilities. People with HIV are more likely than others to become sick with TB if they are exposed and become infected. Untreated latent TB infection may quickly progress to TB disease in people with HIV because the immune system is already weakened. Without treatment, TB disease can progress from sickness to death rapidly. Measuring the number of persons with HIV who also have TB is important for interrupting the spread of HIV and TB to others.

Reporting areas (the 50 states, the District of Columbia, Puerto Rico, and other U.S. jurisdictions in the Pacific and Caribbean) report tuberculosis (TB) cases to CDC by using a standard case report form, Report of Verified Case of Tuberculosis (RVCT). Reported TB cases are verified according to the TB case definition for public health surveillance. In 1993, the surveillance of TB was expanded to collect information on occupation, initial drug regimen, HIV test results, history of substance abuse and homelessness, and residence in correctional or long-term care facilities at the time of diagnosis. TB surveillance was again expanded in 2009 and the RVCT was modified to include 11 additional variables. These modifications accommodate the changing epidemiology of TB in terms of risk factors, new drug treatments, and enhanced laboratory capacity for diagnostic tests.

Population: All persons whose case of TB meets the public health surveillance definition

Epi profile core questions addressed: Core question 2.1

Strengths: As a result of the 1993 and 2009 expansions of surveillance activities, jurisdictions have been able to evaluate the success of TB control efforts including drug susceptibility results and successful completion of therapy. Additionally, TB surveillance data provide a minimum estimate of the level of HIV comorbidity.

Limitations: Data on HIV infection status of reported TB cases should be interpreted with caution. Reporting of HIV test results is incomplete due to concerns about confidentiality, laws and regulations in some jurisdictions that have been interpreted as prohibiting the HIV program from sharing HIV status of TB patients, and reluctance of health providers to report HIV results to TB program staff. Furthermore, some TB patients may decline or not be offered HIV testing and TB patients who have been tested anonymously may not share their HIV test results with their health care provider.

Where available: Available in all 50 states and 9 cities (listed above). Contact the TB program manager in your service area for information. National TB surveillance reports that include national, state, and city data can be found at <https://www.cdc.gov/tb/statistics/default.htm>.

Contact: State or territorial TB Control Offices: <http://www.cdc.gov/tb/links/tboffices.htm>. Accessed November 17, 2021.

Reference

CDC. *Reported Tuberculosis in the United States, 2009*. Atlanta, GA: U.S. Department of Health and Human Services, CDC, October 2010. <https://www.cdc.gov/tb/statistics/default.htm>. Accessed November 9, 2021.

Sources of data on syringe services programs, risk behaviors, and HIV testing among persons who inject drugs

Data Sources	Description	Data Contents	Web link
Recommended			
The Policy Surveillance Program	A cross-sectional dataset that presents state-level statutes and regulations that impact SSPs in effect as of August 1, 2019.	The map identifies the method of authorization for SSPs, requirements for the establishment of SSPs, the types of services provided directly and by referral, drug paraphernalia possession laws, and whether an SSP is operating in the jurisdiction.	Syringe Service Program Laws (lawatlas.org)
NASEN	A regularly updated directory of SSPs who have authorized NASEN to publish their information solely for NASEN directory purposes. It is not, nor is it intended to be, a comprehensive listing of all SSPs in the United States.	Directory of SSPs (including map) which can be filtered by state, by type, and by service.	https://nasen.org/map/
National HIV Behavioral Surveillance (NHBS)	Behavioral surveillance and HIV testing among persons who inject drugs. Conducted annually in 23 MSAs with high prevalence of HIV; among PWIDs every three years.	Collects data relating to behavioral risk factors for HIV (e.g., sexual behaviors, drug use), HIV testing behaviors, the receipt of prevention services, and use of prevention strategies (e.g., SSPs, PrEP). In addition to these interview data, all NHBS participants are offered an HIV test.	National HIV Behavioral Surveillance (NHBS) Surveillance Systems Statistics Center HIV/AIDS CDC
Additional Data Sources			
National Institute of Drug Abuse (NIDA)			
<p><i>From 1976–2014:</i></p> <p>Community Epidemiology Work Group (CEWG) Reports</p> <p><i>From 2015 onward:</i></p> <p>National Drug Early Warning System (NDEWS) Reports</p>	A synthesis of available data describing the epidemiology of drug misuse for both the country and participating metropolitan areas.	Drug misuse indicator data, findings from surveys, and other quantitative information compiled from local, state, and federal sources. Data are enhanced with qualitative information obtained from ethnographic research, focus groups, and other community-based sources. Local contacts with expertise on drug misuse could be obtained from the list of epidemiologists from the sentinel sites.	<p><i>From 1976–2014:</i></p> <p>http://www.drugabuse.gov/about/organization/CEWG/CEWGHome.html</p> <p><i>From 2015 onward:</i></p> <p>http://www.ndews.org</p>
Substance Abuse and Mental Health Services Administration (SAMHSA)			
Treatment Episode Data Set (TEDS)	Information collected by states from local alcohol and substance use disorder treatment facilities characterizing admissions to alcohol and drug treatment.	Demographic and drug history information about individuals admitted to treatment; changes in treatment admissions.	http://www.samhsa.gov/data/client-level-data-teds
Behavioral Health Treatment Services locator	Searchable database of treatment facilities in the U.S. for substance use disorder/addiction and/or mental health problems.	Location of the programs in a map of the city as well as general information about each program.	https://findtreatment.samhsa.gov/locator/home

Data Sources	Description	Data Contents	Web link
Centers for Disease Control and Prevention (CDC)			
Youth Risk Behavior Surveillance System (YRBSS)	National school-based survey conducted by CDC and state, territorial, and tribal governments, along with local education and health agencies. National and select state, district, territorial, and tribal results are available.	Data on health seeking and risk behaviors, including injection drug use.	http://www.cdc.gov/healthyouth/data/yrbs/
Future Data Sources			
SSP M&E/Dave Purchase Survey	SSP survey, nationally representative with state-level data, annual		TBA (estimated Fall 2022)
IDU-SP	PWUD survey, 6 states, includes rural, not representative at state level, annual		TBA (estimated Fall 2022)

U.S. Bureau of the Census (Census Bureau)

Overview: The Census Bureau collects and provides timely information about the people and the economy of the United States. The Web site for the Census Bureau includes data on demographic characteristics (e.g., age, race, Hispanic/Latino ethnicity, sex) of the population, family structure, educational attainment, income level, housing status, and the percentage of persons living at or below the poverty level. Tables and maps of census data are available for all geographic areas to the block level. Summaries of the most requested data for states and counties are provided, as well as analytical reports on population change, race, age, family structure, and apportionment. Links to other census-related sites are included.

Population: United States population

Strengths: A wide range of online statistical data on the United States population is available in different formats (e.g., tables, maps). State- and county-specific information is easily accessible, and links to other census Web sites are provided.

Limitations: Some files may not download quickly.

Where available: All states and U.S. jurisdictions.

Contact: <http://www.census.gov/aboutus/contacts.html>

Reference

U.S. Census Bureau. <http://www.census.gov>. Accessed November 9, 2021.

Vital Records—Birth Data

Overview: Vital records contain information, as stipulated by state statutes, on all births in the 50 states, the District of Columbia, and U.S. territories.

In the United States, state laws require that birth certificates be completed for all births, and federal law mandates the national collection and publication of births and other vital statistics data. The National Vital Statistics System is the federal compilation of the data, in cooperation with the National Center for Health Statistics (NCHS) and states. States use a standard form (U.S. Standard Certificate of Live Birth) to collect birth data and report this information to NCHS annually. The form collects demographic information about the newborn, the mother, and the father; insurance; prenatal care; prenatal risk factors; maternal morbidity; mode of delivery; pregnancy history; and clinical characteristics of the newborn. States have the option of collecting additional information on their birth certificates; some states have elected to include information on HIV testing.

Population: All live births in the 50 states, the District of Columbia, and U.S. territories.

Strengths: Vital records include all births in an area. Reporting is nearly 100% complete. Therefore, inferences can be made concerning the population of live births in a service area. The revised birth certificate collects additional information on the mother's insurance, smoking, and morbidity—information that may be useful for focusing prevention resources.

Limitations: Data obtained from patient medical records (e.g., smoking history, morbidity) are often not complete.

Where available: All states and local areas maintain birth registries. Tabulated state birth tables are available at the Web site. Contact the State Vital Records Registrar.

Contact: State vital records registrar; CDC, National Center for Health Statistics

Reference

CDC. National Center for Health Statistics. <http://www.cdc.gov/nchs>. Accessed November 9, 2021.

Vital Records—Death Data

Overview: In the United States, state laws require that death certificates be completed for all deaths, and federal law mandates the collection and publication of deaths. The National Vital Statistics System produces a federal compilation of death data reported to the National Center for Health Statistics by states. A standard certificate of death is used to record death information on each decedent. The death certificate includes demographic information on the decedent, underlying cause of death (using an International Classification of Diseases [ICD-10] code), and contributions of selected factors to the death (e.g., smoking, accident, or injury). For example, death records include

- the cause of death according to the rules of the National Center for Health Statistics and the International Classification of Diseases (ICD-9 or ICD-10)
- date of death
- decedent demographic data

Population: All deaths in the 50 states, the District of Columbia, and U.S. territories

Strengths: Reporting of deaths in the United States is universal and 100% complete. The data are widely available and can be used to determine the impact of HIV-related deaths related in a service area. Standardized procedures are used throughout the nation to collect death certificate data.

Limitations: Deaths resulting from, or whose underlying cause was, HIV infection may be underreported on the death certificate. Clinical information related to HIV infection or stage 3 (AIDS) may be missing. Death records are less timely than stage 3 (AIDS) case reports.

Where available: All states and local areas maintain death registries.

Contact: State vital records registrar; CDC, National Center for Health Statistics

Reference

CDC. National Center for Health Statistics. <http://www.cdc.gov/nchs>. Accessed November 9, 2021.

Youth Risk Behavior Surveillance System (YRBSS)

Overview: Established to monitor 6 priority health-risk behaviors that contribute to the leading causes of mortality, morbidity, and social problems among youth and adults in the United States. YRBSS was developed to collect data that are comparable among national, state, and local samples of youth. The YRBSS includes a national school-based survey conducted by the Centers for Disease Control and Prevention (CDC) and state, territorial, tribal, and district surveys conducted by state, territorial, and local education and health agencies and tribal governments, including Cherokee Nation and Winnebago Tribe participation in 2019.

Using a self-administered questionnaire, YRBSS collects information on 6 categories of behaviors, 1 of which comprises sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases, including HIV. Questions are also asked about exposure to HIV prevention education, sexual activity (age at initiation, number of partners, condom use, preceding drug or alcohol use), contraceptive use, and HIV testing history.

Population: YRBSS surveys representative samples of students in grades 9–12.

Strengths: YRBSS is a population-based survey that samples students in public and private high schools. The YRBSS questionnaires are self-administered, and anonymous inferences from YRBSS estimates can be drawn about behaviors of young people in high school, making the information useful for developing community-wide prevention programs focused on adolescents. YRBSS uses a standardized questionnaire so that participating states can be compared, and the questionnaire is flexible so that state, territorial, and local agencies and tribal governments can ask specific questions to meet their needs.

Limitations: YRBSS relies upon self-reported information; reporting of sensitive behavioral information may not be accurate (underreporting or overreporting may occur). Because the questionnaires are administered in schools, the data are representative only of young people who are enrolled in school and cannot be generalized to all young people. Answers to questions about behaviors

during the past year may be subject to recall bias; however, this bias may be minimal because of the young age of the respondents.

Where available: YRBSS surveys have been conducted since 1990 in selected areas and biennially since 1991. In 2011, 47 states participated.

Contact: Departments of education or health in states, large urban school districts, territories, and tribal governments; CDC, Division of Adolescent and School Health

Reference

CDC. Adolescent and School Health: Youth Risk Behavior Surveillance System.
<http://www.cdc.gov/HealthyYouth/yrbs/>. Accessed November 9, 2021.

Appendix D.

Ryan White HIV/AIDS Programs

The U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB) administers the RWHAP. In 1990, Congress passed the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act to address HIV in the United States. This legislation has been amended and reauthorized four times—in 1996, 2000, 2006, and, most recently, in 2009 as the Ryan White HIV/AIDS Treatment Extension Act of 2009.

The RWHAP was funded at \$2.39 billion in fiscal year (FY) 2020 and is the largest federal program focused exclusively on HIV care, treatment, and support services. The RWHAP leverages other funding sources and health care coverage opportunities for people with HIV.

The RWHAP has five statutorily defined Parts that provide funding for medical and support services, technical assistance, clinical training, and the development of innovative models of care to meet the needs of different communities and populations affected by HIV:

PART A

Part A provides funding for medical and support services to Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs)—population centers that are most severely affected by HIV. To qualify for EMA status, an area must have reported more than 2,000 AIDS cases in the most recent 5 years and have a population of at least 50,000. To be eligible for TGA status, an area must have reported 1,000 to 1,999 AIDS cases in the most recent 5 years and have a population of at least 50,000. EMAs and TGAs range in size from one city or county to more than 26 different geographic entities; 11 EMAs/TGAs have service areas that cross state lines.

PART B

Part B provides funding to all 50 states, the District of Columbia, Puerto Rico, the Northern Mariana Islands, American Samoa, Guam, the U.S. Virgin Islands, the Federated States of Micronesia, the Republic of the Marshall Islands, and the Republic of Palau to support HIV care and treatment services for low-income people with HIV. The RWHAP Part B grants include funding for the AIDS Drug Assistance Program (ADAP) to fund medication and health care coverage.

PART C

Part C provides funding to local community-based organizations, community health centers, health departments, academic medical centers, and hospitals in 49 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands to provide comprehensive primary medical care and support services in an outpatient setting for low-income people with HIV. The RWHAP Part C funds also may support

capacity development grants to strengthen organizational infrastructure and develop, enhance, or expand access to high-quality primary medical care for people with HIV.

PART D

Part D provides funding to local community-based organizations, community health centers, health departments, academic medical centers, and hospitals to support family-centered HIV primary medical care and support services in an outpatient setting (directly or through contracts or memoranda of understanding) for low-income women, infants, children, and youth with HIV and their affected family members.

PART F

Part F grants support several research, technical assistance, and access to care programs.

- The RWHAP **Special Projects of National Significance (SPNS)** Program supports the development, implementation, and evaluation of evidence-based, evidence-informed, and emerging interventions for HIV care and effective service delivery systems for people with HIV. The RWHAP SPNS Program also supports the dissemination of successful interventions and supports the replication and integration of these interventions by RWHAP-funded recipients
- The **AIDS Education and Training Centers (AETC)** Program works to increase the number of health care providers who are competent and willing to counsel, diagnose, treat, and medically manage individuals with HIV by providing education, training, consultation, and clinical decision support to health care professionals at the local and regional levels.
- **Minority AIDS Initiative (MAI)** provides funding to evaluate and address the disproportionate impact of HIV on Blacks/African Americans and other minority populations.

All RWHAP funds can support the provision of oral health services. Two Part F programs, however, specifically focus on funding oral health care for people with HIV:

- The **HIV/AIDS Dental Reimbursement Program** reimburses dental schools, hospitals with postdoctoral dental education programs, and community colleges with dental hygiene programs for a portion of uncompensated costs incurred in providing oral health treatment to patients with HIV disease.
- The **Community-Based Dental Partnership Program** supports increased access to oral health care services for people with HIV while providing education and clinical training for dental care providers, especially those practicing in community-based settings.

Together, the Parts of the RWHAP provide the public health infrastructure needed to ensure access to a wide range of core medical services (e.g., outpatient ambulatory health services, medical case management, mental health services) and support services (e.g., non-medical case management, housing, transportation, food bank/home delivered meals) aimed at early diagnosis of HIV, linkage to care, retention in care, medically appropriate treatment, and sustained viral suppression.

Appendix E.

Preparing Oral Presentations of Your Profile

You may be called upon to present part or all of your HIV epidemiologic profile to your HPG. Reducing the contents of the profile to a meaningful presentation is challenging, but an effective oral presentation can be a key element in communicating the information in the profile.

Developing an effective presentation involves several elements.

KNOW YOUR AUDIENCE AND DETERMINE YOUR PURPOSE AND OBJECTIVES

You have an advantage because you know that your audience is the HPG. In writing your profile, you have already thought about who they are, what information they need, and their level of familiarity with the content and terminology. You know your audience members have differing levels of experience in working with data.

The objectives of the presentation are defined by the profile.

- Explain the purpose of the profile (e.g., to help planning groups set priorities among populations who need prevention and care services and determine current and future needs for programs such as counseling and testing services).
- Describe the major trends of HIV in the service area and the implications of those trends.

ORGANIZE YOUR PRESENTATION

The Opening

The opening is intended to get the attention of your audience and prepare them for what is to come. Depending on the context of the presentation and your audience, you may want to

- provide an outline of the presentation to audience
- describe the benefit of the presentation to the audience—why they should care
- build rapport with the audience—make eye contact; if the audience is small, try to address people by name
- establish your credibility by briefly explaining your background, position, and experience
- review the agenda or topics you will cover

The Body

Structure your presentation so that you tell your audience what you are going to tell them, tell them what you want them to know, and then summarize what you've told them.

Find out how much time you will have for the presentation. Typically, you will have 30 minutes in a meeting that includes other important topics. Plan your presentation to fit the time allotted. Avoid the common mistake of trying to pack too much information into a limited time.

Keep the presentation concise and focused on the needs and interests of your audience. Present what they need to know, not what you know. If you have a lot of material, consider presenting it at several meetings.

Try not to read your presentation. Your audience will be far more engaged if you speak naturally. Use techniques for holding your audience's interest:

- Keep the pace brisk by making a point and then moving quickly to the next point.
- Consider making your presentation interactive by asking a question or soliciting opinions.
- Include visual aids, such as overheads, handouts, or slides. Allow 1 minute per slide (more if your tables and figures require detailed explanation).
- Focus on your delivery. Vary the inflection and tone of your voice (avoid speaking in a monotone).
- If appropriate, include descriptions specific to your service area. For example, describe the kind of clients a particular clinic might see, or recount a description of high-risk drug injection practices gleaned from an ethnographic study conducted in the service area.

The Closing

Many speakers lose their audience during the closing, missing an opportunity to reinforce key points. Clue the audience that you are closing: "In closing, ..." or "To summarize," Restate your key points and main ideas.

FOCUS YOUR CONTENT

Keep the presentation simple and *give the results first*. Focus on the major points in the executive summary. For example, more persons currently have HIV in the service area than at any other time, stage 3 (AIDS) incidence and mortality have decreased or increased, or the highest HIV infection rates are among MSM who also inject drugs.

Explain the confidentiality standards for your data and how the data are protected. Describe the strengths and weaknesses of the results so that users know the implications when making prevention and care program decisions.

Point out national trends. Much of the media coverage of HIV is based on national data. Help the audience differentiate the information from the media and the information they need to check locally to see whether the distribution of HIV locally is showing the same trends.

If you have surprising or puzzling results, point them out. It is possible that someone in the audience will have an interpretation. Also, be explicit about what you do not know (it is a good way to increase your credibility).

EXPLAIN EPIDEMIOLOGIC TERMS AND PRESENTATION METHODS

Depending on the expertise and experience of your audience, you may need to explain epidemiologic terms. Use simple language and provide examples. For instance, here are a definition and an example of *incidence*:

Term	Explanation	Example
Incidence	The number of new infections during a specified time, often a year.	The incidence of heterosexually acquired HIV infection remained stable among women in the United States, from 5,500 infections in 2014 to 5,700 cases infections in 2019.

You may also need to explain how to read and interpret the tables and figures. Table E-1 illustrates an aid that could accompany an explanation of how to read a table.

Table E-1. Example of aid to help explain how to read a table

Descriptive Title		Column
HIV exposure mode	Cases, No.	Total, %
Male-male sexual contact	589	34
Male-male sexual contact and injection drug use	Cell 125	7
Injection drug use	476	28
Heterosexual contact	389	23
Other or undetermined ^a	145	8
Total	1724	100

^aFootnote.

If you have time and it is appropriate to your audience, also consider explaining

- Your data sources. Show an actual HIV case report form (blank or fake data) or other data source, such as a report containing statewide hospital discharge data or a report from the Youth Risk Behavior Surveillance System (YRBS). The audience members are less likely to ask for information you do not have if they can see the data you collect.
- Your research methods and data analyses. However, do not focus too much on the methods or the data analysis. Remember that end users need to make decisions based on the profile’s results, not the analyses.

PROVIDE HANDOUTS

Consider providing the following material for your audience to take home from the meeting:

- copies of your slides or other visuals
- handouts summarizing your main points and conclusions

Depending on your resources and service area, you may wish to make your presentation available later by creating a Microsoft PowerPoint presentation.

ADDITIONAL TIPS

- Practice delivering the presentation to persons with no background in epidemiology. Ask for feedback about the clarity of your presentation, explanation of terms, and discussion of pertinent data.
- Schedule additional presentations or orientations to address more detailed issues related to 1 or more specific behavioral risk groups or to particular care issues that may be of interest to stakeholders, advocates, or planners.
- Make yourself available to attend other meetings at which users will discuss epidemiologic issues or use the profile.

Appendix F.

Epidemiologic Profile Feedback Form for Planning Groups

The purpose of this form is to provide the writers of HIV epidemiologic profiles feedback from their end users regarding the ease of use and applicability of the profile to prevention and care planning activities.

Please complete this feedback form and send it to the writer or lead writer of your HIV epidemiologic profile.

1. What is your role on the planning group?

2. Did planning group members have a role in creating the epidemiologic profile?

Yes No

If yes, explain the role.

3. Was the epidemiologic profile easy to read?

Yes No Somewhat

4. How were the findings of the epidemiologic profile communicated to you?

Print copy only

Profile writers presented epidemiologic profile to planning group

Other type of presentation

5. Were the findings of the epidemiologic profile clear to you?

Yes No Somewhat

If not, explain why.

6. Was the epidemiologic profile useful to your planning process?

Yes No Somewhat

If not, explain why.

7. Describe how you used the epidemiologic profile in your planning activities.

8. How can next year's profile be improved?

Appendix G.

Terms, Definitions, and Calculations

adjustments. Statistical calculations that allow the comparison of different groups (when the difference may affect what you are studying) as though they are alike. Differences in populations or subgroups make it difficult to make comparisons; adjustments remove the influence of a specific factor (e.g., age, gender, race, or disease status) from the analysis.

aggregated data. Information, usually summary statistics, that is summed or presented together to prevent the identification of individuals.

bar graph (vertical). A type of figure in which categories of variables (displayed on a horizontal baseline) are compared by amount, frequency, or magnitude (labeled on a vertical axis). (Bar graphs may also be horizontal.)

behavioral data. Data collected from studies of human behavior that is relevant to disease risk. Relevant behaviors for HIV risk may include sexual activity, substance use, sharing of drug paraphernalia, condom use, or responses to primary and secondary prevention messages.

capability. The extent to which a provider's services are geographically and physically accessible, culturally appropriate, and available at convenient times.

capacity. The amount of services a provider can deliver (i.e., the number of service units and the estimated number of clients who can be served).

care continuum. A coordinated delivery system, encompassing a comprehensive range of health and social services that meet the needs of people with HIV at all stages of illness.

case. A condition, such as HIV infection (e.g., an HIV case) diagnosed according to a standard case definition.

chief elected official (CEO). The official recipient of Title 1 funds within the EMA, usually the mayor or the chair of the county governing unit (e.g., board of supervisors).

cluster or outbreak. HIV clusters or outbreaks refer to groups of people that are experiencing rapid HIV transmission.

community-based organization (CBO). An organization that provides services to locally defined populations, which may include persons with, or affected by, HIV.

comorbidity. The coexistence of a disease or illness and HIV infection in one person (e.g., a person with HIV who also has TB).

comprehensive planning. The process used to determine how HIV services will be organized and delivered. Comprehensive HIV services planning requires planning councils and consortia to answer 4

questions: (1) Where are we now? (2) Where should we be going? (3) How will we get there? (4) How will we monitor our progress?

confidence interval (CI). A range of values for a measure that is believed to contain the true value at a specified level of certainty (e.g., 95%).

confidentiality. The treatment of information that an individual or institution has disclosed in a relationship of trust, with the expectation that the information will not be divulged to others in ways that are inconsistent with the individual's or institution's understanding when the individual or institution provided the information. It encompasses access to, and disclosure of, information in accordance with requirements of state law or official policy. For HIV surveillance data, confidentiality refers to the protection of private information collected by the HIV surveillance system.

convenience sampling. A sampling technique that relies upon selecting people who are more easily accessible at the time (e.g., persons at a group meeting or in a clinic when a researcher happens to be there). The advantage of convenience sampling is that it is easy to carry out. The weakness is that the findings may not be representative of the entire community.

core epidemiologic questions. The questions in an epidemiologic profile that must be answered by all prevention and care grantees, regardless of HIV morbidity in their areas.

cumulative cases: The total number of cases of a disease reported or diagnosed during a specified time regardless of current vital status. Cumulative cases therefore include cases in persons who have already died.

Example: Assume that 9,000 HIV infections had been diagnosed in a state from 1985 through the year 2019. Of the 9,000 persons with HIV, 4,000 had died. The cumulative number of HIV infection diagnoses in that state through 2019 would be 9,000.

demographic factors. Background information about the population of interest (e.g., age, gender, race/ethnicity).

eligible metropolitan area (EMA). A metropolitan statistical area that qualifies for Title I funding by reaching a certain threshold of stage 3 (AIDS) cases. EMAs may cover 1 city, several cities or counties, or more than 1 state.

epidemic curve. A type of line graph that shows the distribution of disease onset. Time is plotted on the horizontal (x) axis; the number of cases is plotted on the vertical (y) axis.

epidemiologic profile. A document that describes the distribution of HIV in various populations and identifies characteristics both of persons with and without HIV in defined geographic areas. It is composed of information gathered to describe the effect of HIV on an area in terms of sociodemographic, geographic, behavioral, and clinical characteristics. The epidemiologic profile serves as the scientific basis from which HIV prevention and care needs are identified and prioritized for a jurisdiction.

epidemiology. The study of the distribution and determinants of health-related states or events in specified populations and the application of this study to the control of health problems.

estimate. In situations in which precise data are not available, an estimate may be made based on available data and an understanding of how the data can be generalized to larger populations. In some

instances, national or state data may be statistically adjusted to estimate local conditions. Good estimates are accompanied by statistical estimates of error (a confidence interval), which describe the limitations of the estimate.

grantee. The recipient of HIV prevention or RWHAP funds. For HIV prevention funds, the state or local health department is referred to as the grantee. For RWHAP funds, the chief elected official (CEO) of each EMA is the official grantee for Title I funds. Under Title II, the governor designates a state agency (usually the state health department) as the grantee.

HIV (human immunodeficiency virus). The virus that causes HIV infection. Persons with HIV in their system are referred to as a person with HIV.

HIV Care Consortium. An association of public and private nonprofit providers of health support services and community-based organizations that plans, develops, and delivers services for people with HIV. The RWHAP authorizes states to use Title II funds to establish consortia in “areas most affected by HIV disease.”

HIV infection, stage 0. First positive HIV test result within 6 months after a negative HIV test result. The stage remains stage 0 until 6 months after the first positive test result. After 6 months, the stage may be classified as 1, 2, 3, or unknown if based on a CD4 test result or the diagnosis of an OI. The diagnosis of an AIDS-defining condition or a low CD4 test result before the 6 months have elapsed does not change the stage from stage 0 to stage 3.

HIV infection, stages 1, 2, and 3 (adopted in 2014): Documentation of an AIDS-defining OI (excluding stage 0 as described above) is stage 3. Otherwise, the stage is determined by the lowest CD4 lymphocyte test result:

- Stage 1—CD4 lymphocyte count of ≥ 500 or a CD4 percentage of total lymphocytes of ≥ 26
- Stage 2—CD4 lymphocyte count of 200–499 or a CD4 percentage of total lymphocytes of 14–25
- Stage 3—CD4 lymphocyte count of < 200 or a CD4 percentage of total lymphocytes of < 14 or documentation of an AIDS-defining condition.

HIV infection, stage unknown: No reported information on AIDS-defining OIs and no information available on CD4 lymphocyte count or percentage.

HIV planning group (HPG). A group of persons who represent, or have interests in, a given community and who work in partnership with health departments to design local prevention plans to meet the needs of persons at risk for, or with, HIV.

HIV primary medical care. Medical evaluation and clinical care that is consistent with U.S. Public Health Service guidelines for the treatment of HIV.

HIV surveillance. The systematic collection, analysis, interpretation, dissemination, and evaluation of population-based information about persons with a diagnosis of HIV.

incidence. The number of new infections in a defined population during a specific period, often 1 year, which can be used to measure disease frequency. An important difference between HIV incidence and a new diagnosis of HIV infection: HIV incidence refers to persons newly infected

with HIV, whereas persons with newly diagnosed HIV may have had HIV years before the diagnosis. Population-based incidence estimates include new infections that have been diagnosed as well as new infections that have not been diagnosed. HIV incidence data may be used to monitor emerging trends and guide prevention activities.

interpretation. The explanation of the meaning of the data. For example, interpreting a trend in the number of HIV cases diagnosed during a 5-year period enables a planning group to assess whether the number of cases has increased or decreased. However, groups should use caution in interpreting trends that are based upon small increases or decreases.

jurisdiction. A geographic area in which a government agency conducts surveillance or provides public health services.

line graph. A type of figure used to display the changes in a particular variable over time. Values are recorded periodically as points on a graph and then connected as a line to show a trend.

mean: The sum of values for a variable, a group, or other category divided by the total number of values (e.g., in a data set). The mean is what many people refer to as an average.

Example: Assume that people in a service area in 2010 are the following ages at diagnosis of HIV infection: 18, 18, 19, 20, 22, 23, 26, 31, 41. The total of the 9 ages = 218 years.

$$218 \text{ years} \div 9 \text{ people} = \text{mean age } 24.2 \text{ years}$$

median: The middle value in a data set: approximately half the values will be higher and half will be lower. The median is useful when a data set contains a few unusually high or unusually low values, which can affect the mean. It is also useful when data are skewed, meaning that most of the values are at one extreme or the other.

Example: Assume the following ages at diagnosis of HIV in the year 2010 data for a given service area: 18, 18, 19, 20, 22, 23, 26, 31, 99. Although the mean age is 30.7, the median age is 22. In this instance, the median age better reflects the central value of age for the population.

morbidity. The presence of illness in the population.

mortality. The total number of persons who have died of the disease of interest. Usually expressed as a rate, mortality (total number of deaths over the total population) measures the effect of the disease on the population as a whole.

needs assessment. The process of gathering and analyzing information from a variety of sources to determine the status and the unmet needs for HIV prevention or care among a defined population or in a geographic area.

percentage. A proportion of the whole, in which the whole is 100.

Example: Assume that 15 of the 60 cases of AIDS in a given year in a state occurred in women.

$$15 \div 60 = .25 \times 100 = 25\%$$

planning group. Refers to CDC- and HRSA-sponsored groups, such as HIV prevention planning groups (HPGs) and Ryan White HIV/AIDS planning councils and consortia.

prevalence. The proportion of cases of a disease in a population at risk, measured at a given point in time (often referred to as point prevalence). Prevalence can also be measured over a period (e.g., a year), known as period prevalence. Prevalence does not indicate how long a person has had a disease. It can provide an estimate of risk for a disease at a specific time. Prevalence data provide an indication of the extent of a condition and may have implications for services needed in a community. For HIV surveillance, prevalence refers to living persons with HIV disease, regardless of time of infection or date of diagnosis.

$$\text{prevalence} = \text{number of existing cases}^* \div \text{population at risk}^*$$

* during specified period

probability sampling. A sampling technique that relies upon random selection to select persons from a defined population; all persons have a known chance of selection. Types of probability samples include simple random sample, systematic random sample, and stratified sample.

proportion: A portion of a population or a data set, usually expressed as a fraction or a percentage of the population or the data set.

Example: Assume that 12 of 20 HIV prevention programs in a given service area are school-based programs. Calculation of the proportion as a fraction:

$$12 \div 20 = .6 = 6/10 = 3/5$$

Calculation of the proportion as a percentage:

$$12 \div 20 = .6 \times 100\% = 60\%$$

public health surveillance. The continuous, systematic collection, analysis, and interpretation of data essential to the planning, implementation, and evaluation of public health practices, all of which are closely integrated with the timely dissemination of these data to those responsible for disease prevention and control. HIV surveillance is one example of public health surveillance.

qualitative data. Information from sources such as narrative behavior studies, focus group interviews, open-ended interviews, direct observations, ethnographic studies, and documents. Findings from these sources are usually described in terms of common themes and patterns of response rather than by numeric or statistical analysis. Qualitative data often complement and help explain quantitative data.

quality of life. A subjective measure of the degree to which persons affected by a specific disease, injury, or form of treatment perceive themselves to be able to function physically, emotionally, and socially. Quality of life is useful for the planning of health services.

quantitative data. Numeric information (e.g., numbers, rates, and percentages).

range. The smallest and the largest values in a series.

Example: Assume the following ages at diagnosis of HIV in the year 2010 in a given service area: 18, 18, 19, 20, 22, 23, 26, 31, and 41. The range in values is 18–41.

rate: A measure of the frequency of an event compared with the number of persons at risk for the event. When rates are being calculated, it is usual for the denominator to be the general population rather than the population potentially exposed to HIV infection by various high-risk behaviors. The size

of the general population is known from data from the U.S Census Bureau, whereas the size of a population at high risk is usually not known.

$$(\text{number of HIV diagnoses}^* \div \text{population}) \times 100,000 = \text{population rate of HIV diagnoses}$$

*—during a given period

For ease of comparison, the multiplier (100,000) is used to convert the resulting fraction to number of cases per 100,000 population. Although arbitrary, the choice of 100,000 is standard practice.

Example: Assume that 16 cases of HIV were diagnosed during 2010 in a service area and that 400,000 persons lived in the area in 2010. Calculation of the rate:

$$(16 \div 400,000) \times 100,000 = 4 \text{ per } 100,000$$

ratio. A way of showing the relative size of 2 numbers. The first number is divided by the other number to derive the ratio. The ratio may be expressed as a fraction (e.g., 3/4), or the 2 numbers may be separated by a colon (e.g., 3:4).

reliability. Refers to the consistency and dependability of a data-collection instrument or measure. For example, if you repeat a blood test 3 times on the same specimen and the results are the same each time, the test is said to be reliable.

reporting delay. Reporting delays (time between diagnosis or death and the reporting of diagnosis or death to state/local surveillance program) may differ among demographic and geographic categories; for some, delays in reporting have been as long as several years.

representative. A sample that is similar to the population from which it is drawn and thus can be used to draw conclusions about the population.

Ryan White HIV/AIDS Program (RWHAP). The primary federal legislation created to address the needs for health and support services among persons living with HIV and their families in the United States; enacted in 1990 and reauthorized in 1996, 2000, 2006, and 2009.

sample. A group of people selected from a total population with the expectation that studying this group will provide important information about the total population.

seroprevalence. The number of persons in a defined population who test positive for HIV based on HIV testing of blood specimens. (Seroprevalence is often presented either as a percentage of the total specimens tested or as a rate per 100,000 persons tested.)

service area. The jurisdictions of CDC HPGs and the service areas or planning regions of HRSA planning groups.

social determinants of health (SDH). the overlapping social structures and economic systems (e.g., social environment, physical environment, health services, and structural and societal factors) that are responsible for most health inequities. It relates structural determinants (e.g., socioeconomic status, poverty) to intermediary determinants (e.g., psychosocial, behavioral, and biological factors) that may affect individual health status.

Stage 3 (AIDS) (acquired immunodeficiency syndrome). The condition that results from HIV infection and is marked by the presence of opportunistic infections or either a CD4count of <200 cells/ μ L or a CD4 percentage of total lymphocytes of <14.

stratification. A technique for dividing data into homogenous groups (strata).

trend. A long-term movement or change in frequency, usually upward or downward; may be presented as a line graph.

validity. The extent to which a measurement is appropriate for the question being addressed or measures what it is intended to measure (may be applied, for example, to an instrument for data collection or specific questions in a survey).

year of diagnosis. The year in which a diagnosis of HIV infection was made.

References and Suggested Readings

The suggested readings below will help you understand key issues and concepts in HIV surveillance and HIV prevention and Ryan CARE Act community planning.

HIV Prevention

CDC. HIV Prevention in the United States: Mobilizing to End the Epidemic. <https://www.cdc.gov/hiv/pdf/policies/cdc-hiv-prevention-bluebook.pdf>. Accessed January 31, 2022.

HHS. What is *Ending the HIV Epidemic in the U.S.*? <https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview>. Updated June 2, 2021. Accessed January 31, 2022.

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

The White House. *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 November 2021. Accessed February 7, 2022.

HIV Prevention and Care Planning

CDC/HRSA. Integrated HIV Prevention and Care Plan Guidance, including the Statewide Coordinated Statement of Need, CY 2022–2026. <https://hab.hrsa.gov/sites/default/files/hab/program-grants-management/integrated-hiv-guidance-6-2021.pdf>. Published June 2021. Accessed January 31, 2022.

HIV Surveillance

CDC. *HIV Surveillance Report, 2019*; vol. 32. <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Published May 2021. Accessed January 31, 2022.

CDC. Estimated HIV incidence and prevalence in the United States, 2015–2019. *HIV Surveillance Supplemental Report* 2021;26(No. 1). <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Published May 2021. Accessed January 31, 2022.

CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2019. *HIV Surveillance Supplemental Report* 2021;26(No. 2). <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Published May 2021. Accessed January 31, 2022.

CDC. Social determinants of health among adults with diagnosed HIV infection, 2018. *HIV Surveillance Supplemental Report* 2020;25(No. 3). <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Published November 2020. Accessed January 31, 2022.

CDC [Schneider E, Whitmore S, Glynn MK, Dominguez K, Mitsch A, McKenna MT]. Revised surveillance case definitions for HIV infection among adults, adolescents, and children aged <18 months and for HIV infection and AIDS among children aged 18 months to <13 years—United States, 2008. *MMWR* 2008;57(RR-10):1–12.

CDC [Selik RM, Mokotoff ED, Branson B, Owen SM, Whitmore S, Hall HI]. Revised surveillance case definition for HIV infection—United States, 2014. *MMWR* 2014;63(RR-03):1–10.

CDC [Bosh KA, Hall HI, Eastham L, Daskalakis DC, Mermin JH]. Estimated annual number of HIV infections—United States, 1981–2019. *MMWR* 2021;70:801–806.
<http://dx.doi.org/10.15585/mmwr.mm7022a1>.

CDC [Bosh KA, Johnson AS, Hernandez AL, et al.]. Vital Signs: Deaths among persons with diagnosed HIV infection, United States, 2010–2018. *MMWR* 2020;69:1717–1724.
<http://dx.doi.org/10.15585/mmwr.mm6946a1>.

CDC [Harris NS, Johnson AS, Huang YA, et al.]. Vital Signs: Status of human immunodeficiency virus testing, viral suppression, and HIV preexposure prophylaxis—United States, 2013–2018. *MMWR* 2019;68:1117–1123. <http://dx.doi.org/10.15585/mmwr.mm6848e1>.

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

Sullivan PS, Satcher Johnson A, Pembleton ES, et al. Epidemiology of HIV in the USA: Epidemic burden, inequities, contexts, and responses. *Lancet* 2021;397:1095–1106.
[https://doi.org/10.1016/S0140-6736\(21\)00395-0](https://doi.org/10.1016/S0140-6736(21)00395-0).

HIV Cluster Detection and Response

Fitzmaurice AG, Linley L, Zhang C, Watson M, France AM, Oster AM. Novel method for rapid detection of spatiotemporal HIV clusters potentially warranting intervention. *Emerg Infect Dis* 2019;25(5):988–991. doi:10.3201/eid2505.180776

Oster AM, France AM, Panneer N, et al. Identifying clusters of recent and rapid HIV transmission through analysis of molecular surveillance data. *J Acquir Immune Defic Syndr* 2018;79(5):543–550. doi:10.1097/QAI.0000000000001856

Oster AM, Lyss SB, McClung RP, et al. HIV cluster and outbreak detection and response: The science and experience. *Am J Prev Med* 2021;61(5 Suppl 1):S130–S142.
doi:10.1016/j.amepre.2021.05.029

HIV Behavioral and Clinical Surveillance

Beer L, Johnson CH, Fagan JL, et al. A national behavioral and clinical surveillance system of adults with diagnosed HIV (the Medical Monitoring Project): Protocol for an annual cross-

sectional interview and medical record abstraction survey. *JMIR Res Protoc* 2019;8(11):e15453. doi:10.2196/15453

CDC. *Behavioral and clinical characteristics of persons with diagnosed HIV infection—Medical Monitoring Project, United States, 2019 cycle (June 2019–May 2020)*. HIV Surveillance Special Report 28. <https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Published August 2021. Accessed January 31, 2022.

Conviser R, Pounds MB. The role of ancillary services in client-centered systems of care. *AIDS Care* 2002;14(Suppl 1):S119–S131. <https://doi.org/10.1080/09540120220150018>.

Dasgupta S, Tie Y, Beer L, Weiser J. Unmet needs for ancillary care services are associated with HIV clinical outcomes among adults with diagnosed HIV. *AIDS Care* 2021:1–9. doi:10.1080/09540121.2021.1946001

Gallant J, Hsue PY, Shrey S, Meyer N. Comorbidities among US patients with prevalent HIV infection: A trend analysis. *J Infect Dis* 2017;216(12), 1525–1533. <https://doi.org/10.1093/infdis/jix518>.

Hartzler B, Dombrowski JC, Crane HM, et al. Prevalence and predictors of substance use disorders among HIV care enrollees in the United States. *AIDS Behav* 2017;21(4):1138–1148. <https://doi.org/10.1007/s10461-016-1584-6>.

HIV Testing System

CDC [Branson BM, Handsfield HH, Lampe MA, et al]. Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings. *MMWR* 2006;55(RR-14):1–17.

DiNenno EA, Prejean J, Irwin K, et al. Recommendations for HIV screening of gay, bisexual, and other men who have sex with men—United States, 2017. *MMWR*. 2017;66(31):830–832.

CDC. Integrated HIV surveillance and prevention funding for health departments. PS18-1802. <https://stacks.cdc.gov/view/cdc/60903>. Published January 2018. Accessed January 31, 2022.

CDC. CDC-funded HIV testing in the United States, Puerto Rico, and the U.S. Virgin Islands, 2019. <https://www.cdc.gov/hiv/pdf/library/reports/cdc-hiv-annual-HIV-testing-report-2019.pdf>. Published March 2021. Accessed January 31, 2022.

CDC. [Dailey AF, Hoots BE, Hall HI, et al.] Vital Signs: Human immunodeficiency virus testing and diagnosis delays—United States. *MMWR* 2017;66(47):1300–1306. <http://dx.doi.org/10.15585/mmwr.mm6647e1>.

Committee on Obstetric Practice; HIV Expert Work Group. ACOG Committee Opinion No. 752: Prenatal and perinatal human immunodeficiency virus testing. *Obstet Gynecol* 2018;132(3):e138–e142.

HIV Care and Treatment

Institute of Medicine. Monitoring HIV care in the United States: indicators and data systems [consensus report]. <http://www.nap.edu/read/13225/chapter/1>. Published March 15, 2012. Accessed January 31, 2022.

Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of antiretroviral agents in adults and adolescents living with HIV. <https://clinicalinfo.hiv.gov/en/guidelines/adult-and-adolescent-arv/whats-new-guidelines>. Updated January 20, 2022. Accessed January 31, 2022.

Race and Ethnicity Classification

Office of Management and Budget. Revisions to the standards for the classification of federal data on race and ethnicity. *Federal Register* 1997;62:58781–58790. <http://go.usa.gov/xPg4F>. Accessed January 31, 2022.

Ryan White HIV/AIDS Program

Ryan White HIV/AIDS Program information (e.g., grant application guidance, service data reporting requirements, performance measure data requirements, program data reports) can be found at <https://hab.hrsa.gov/about-ryan-white-hiv-aids-program/about-ryan-white-hiv-aids-program>.