Integrated Guidance for Developing Epidemiologic Profiles

HIV Prevention and Ryan White HIV/AIDS Programs Planning

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Contents

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Abbreviations

ADAP	AIDS Drug Assistance Program
AIDS	acquired immunodeficiency syndrome
BRFSS	Behavioral Risk Factor Surveillance System
CDC	Centers for Disease Control and Prevention
DAWN	Drug Abuse Warning Network
DHAP	Division of HIV/AIDS Prevention (CDC)
DRP	Dental Reimbursement Program
eHARS	enhanced HIV/AIDS Reporting System
EMA	eligible metropolitan area
GISP	Gonococcal Isolate Surveillance Project
HAART	highly active antiretroviral therapy
HIV	human immunodeficiency virus
HOPS	Hospital Outpatient Study
HRSA	Health Resources and Services Administration
ICD	International Classification of Diseases
IDU	injection drug user
MMP	Medical Monitoring Project
MSM	gay, bisexual, and other men who have sex with men
NCHHSTP	National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (CDC)
NHBS	National HIV Behavioral Surveillance System
NHIS	National Health Interview Survey
NHSDA	National Household Survey of Drug Abuse
NIDA	National Institute on Drug Abuse
NIR	no identified risk
NNIP	National Neighborhood Indicator Project
OMB	Office of Management and Budget
PLWA	people living with AIDS
PLWH	people living with HIV
PRAMS	Pregnancy Risk Assessment Monitoring System
RSR	Ryan White HIV/AIDS Program Services Report
SAMHSA	Substance Abuse and Mental Health Services Administration
SPNS	Special Projects of National Significance
SSVRS	Sentinel Surveillance of Variant and Drug-Resistant Strains
STD	sexually transmitted disease
TB	tuberculosis
TGA	transitional grant area
YRBSS	Youth Risk Behavioral Surveillance System

Executive Summary

This guidance has been developed by the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) to assist persons who compile and interpret HIV prevention and care data for state, territorial, or local HIV epidemiologic profiles. The purpose of the document is to provide one set of guidance to help profile writers produce integrated epidemiologic profiles and advise them concerning how to interpret epidemiologic data in ways that are consistent and useful in meeting the planning and evaluation needs of both HIV prevention and care programs. Integrating prevention and care data should help to streamline the work of health department staff, HIV planning groups, and planning councils by reducing duplicated effort and by promoting consistency and comparability of data and terms in prevention as well as care planning.

The guidelines are written in 5 chapters that (1) provide an overview of integrated HIV epidemiologic profiles, (2) outline what writers need to do to start creating a comprehensive profile, (3) address how to describe the burden of HIV in a jurisdiction, (4) describe the process of completing the profile, and (5) address special issues that may arise during the writing of the profile. Each chapter is organized into sections. Specific data and elements to meet the requirements of CDC and of HRSA are also addressed. Highlights of each chapter are as follows:

- **Chapter 1**
    - Describes the purpose of the guidelines, identifies the audience for the document, and outlines what end users will learn
- **Chapter 2**
    - Describes 3 core epidemiologic questions and 2 care-related questions that help to describe the burden of HIV in a jurisdiction and suggests analyses that may be used to answer each question.
        - Core Question 1: What are the sociodemographic characteristics of the general population in your service area?
        - Core Question 2: What is the scope of HIV in your service area?
        - Core Question 3: What are the indicators of risk for HIV infection in the population covered by your service area?
        - Care-related Question 1: Using epidemiologic and related public health data, what is the impact of the care and treatment services of the Ryan White HIV/AIDS Programs on people living with HIV?
        - Care-related Question 2: What are some things to keep in mind as a Ryan White HIV/AIDS Program grantee prepares the epidemiologic profile document for HRSA's HIV/AIDS Bureau?
        - Outlines a 7-step process for developing the profile
- **Chapter 3**
    - Describes the contents of the body of the profile, including

    - supporting data to answer the core questions and the care-related questions
    - sources of, and caveats about, data
- **Chapter 4**
  - Describes how to make the profile user-friendly and disseminate the profile
- **Chapter 5**
  - Addresses confidentiality, special-needs populations, comorbidity, 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: 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

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 health department.

The data in an integrated HIV epidemiologic profile may be used for several purposes, including HIV planning, designing and implementing prevention activities and evaluation programs, and informing policy decisions and documenting care needs for underserved groups. Researchers, consumers, legislators, and the media also use the data.

The information should be used as a starting point in the development of your profile. The 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. Technical assistance with analyzing, interpreting, and presenting prevention-related data and care-related data is available from CDC and HRSA, respectively.

Chapter 1.

Introduction

Section 1: Overview

The epidemiologic profile is a document that describes the burden of HIV on the population of an area in terms of sociodemographic, geographic, behavioral, and clinical characteristics of persons with HIV. The profile is a valuable tool that is used at the state 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 2 of the agencies that use HIV epidemiologic and surveillance data. Both agencies provide guidance and funding for programs for persons with, or at risk for, HIV. The goals of these programs are to prevent HIV infection and promote 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 ways that are consistent and useful in meeting the planning needs of both HIV prevention and care programs. Integrating prevention and care data should help to streamline the work of health department staff, HIV planning groups, and planning councils by reducing duplicated effort and by promoting consistency and comparability of data and terms in prevention as well as in care planning.

HIV planning

HIV planning is a process organized by the health department in which HIV prevention decisions (e.g., programs and services provided, funding allocations) within the jurisdiction are decided via a formal voting process by the HIV Planning Group (HPG), a specially selected group of community members reflective of the jurisdiction's burden of disease. The epidemiologic profile is an essential document for this body, in that it informs the following:

- **Comprehensive HIV Prevention Plan**—The HPG is responsible for developing a comprehensive HIV prevention plan. To develop the plan, the HPG should review and discuss information presented in the epidemiologic profile, such as geographical and demographic patterns of HIV cases in the jurisdiction. Other sources of information will be reviewed, but the most crucial are epidemiologic data.
- **Composition of HIV Planning Group**—The HPG should be diverse and include representatives of persons living with HIV in the jurisdiction. The demographic breakdown of HIV prevalence and diagnoses presented in the epidemiologic profile is used to determine the composition of the HPG in order to create parity in the planning body. These statistics help to ensure that the health department meets this fundamental component of the cooperative agreement.

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 on the basis of 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
• Consistent epidemiologic profiles ○ 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	• Increased usefulness and application • Enhanced sharing of information at all levels (federal, state, regional, and local) and in all organizations • Increased quality • Increased confidence in data validity because the data are being used for two processes
• User-friendly epidemiologic profiles	• Easy interpretation and application to local needs • Enhanced possibility that data will be used in planning
• Flexibility to customize profiles to meet local needs	• Enhanced quality and sharing of information while meeting local requirements
• Shared resources for prevention and care	• Reduced strain on local capacity • Reduced duplication of effort

Section 3: Core Concepts

HIV epidemiologic profile goals

An epidemiologic profile is designed to

- provide a thorough description of HIV among the various populations (overall and subpopulations) in a service area in terms of sociodemographic, geographic, behavioral, and clinical characteristics
- describe the current status of persons with HIV infection in the service area and provide some understanding of how the HIV distribution may look in the future
- identify characteristics of the general population and of populations who are living with, or at high risk for, HIV in defined geographic areas and who need primary and secondary prevention or care services
- provide information required to conduct needs assessments and gap analyses

Users and uses of an epidemiologic profile

Epidemiologic profiles have many users. The primary users are prevention and care planning groups, grantees, 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 statistical data.

Planning groups use the HIV epidemiologic profile to

- set priorities among populations who need prevention and care services
- provide a basis for determining or projecting future needs
- 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 • HIV planning groups (HPGs) • State and local health departments • Community-based organizations	• Preventing and intervening to reduce transmission of HIV	• Prioritize target populations and identify appropriate interventions for each priority population • Develop HIV prevention plan
HRSA • Ryan White HIV/AIDS Program grantees • Ryan White HIV/AIDS planning bodies • Community-based organizations	• Providing services and care for people living with HIV	• Set priorities and allocate resources for care • 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 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 and focuses on priority setting for target 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 have the responsibility 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 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. 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 severe needs and comorbidities

Chapter 2.

Starting the Process

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

Although the data required are similar, 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 (5 years). Ryan White HIV/AIDS Program planning consortia and councils should follow their yearly program guidance from the HIV/AIDS Bureau.
- Every year, 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 yearly update can also be in the form of fact sheets, supplemental reports, slide sets, or any standardized reports utilized by the state.

Consider including, as much as possible, the sociodemographic and socioeconomic information covering the entire service area. Updated profiles will then need to include only the data from those areas in which significant changes have occurred.

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 other potential stakeholders**.

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

  - special needs of populations at risk of becoming infected with HIV
  - trends that can be identified through a comparison of HIV and stage 3 (AIDS) prevalence data
  - setting priorities for prevention and care services among prioritized populations
- ✓ 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 the HIV-positive population?
- ✓ What information is already available? More information, which is 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:

- What are the sociodemographic characteristics of the general population in your service area?
- What is the scope of HIV in your service area?
- What are the indicators of risk for HIV infection in the population covered by your service area?

It should also answer questions specific to prevention or care planning needs, such as the following:

- Using epidemiologic and related public health data, what is the impact of HIV of the care and treatment services of the Ryan White HIV/AIDS Programs on people living with HIV?
- What are some things to keep in mind as a Ryan White HIV/AIDS Program grantee prepares the epidemiologic profile document for HRSA's HIV/AIDS Bureau?

Profile sections and organization

As is true of any good document, 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
- **Abbreviations**, 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 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.

3. Analyze and interpret data.

4. Present data in user-friendly formats.

5. Draw overall conclusions 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 persons who have HIV infection and are thus eligible to be reported? For example, how well does the prevalence of HIV represent the true number of persons living with HIV in your service area?
- **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 HIV-infected persons or all HIV-infected persons 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 1990 might not provide data that are sufficiently up-to-date for current prevention activities.
- **Timeliness of the data**: How long is the reporting delay between the diagnosis of HIV and the report to the health department?
- **Surrogate, or proxy, markers**: A proxy variable 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.
- **Reliability of the data**: How accurate and complete are the data? For example, how well was information about age transcribed to the case report from the medical record (how accurate are the case report data compared with those in the medical record)?
- **Small numbers**: 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 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 National Center for Health Statistics [NCHS] 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."

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 A for an expanded list of core and supplemental data sources.

Type of data:

HIV surveillance

Description:

HIV surveillance data include all persons with confirmed diagnoses of HIV infection (including stage 3 [AIDS]) and have been reported to a state or local health department.

HIV surveillance data

- provide an estimate of the number of persons with a diagnosis of HIV infection whose test was confidential
- identify emerging patterns of transmission
- help detect trends in HIV infections among populations.

HIV surveillance data also provide a basis for establishing and evaluating linkage to care, retention in care, and viral suppression. They can be used to anticipate unmet needs for HIV care. According to state evaluations, HIV infection reporting is estimated to be 80%–90% complete for persons who have tested positive for HIV.

Where to obtain:

All areas now conduct integrated, name-based HIV surveillance. Contact your state or local service area’s HIV surveillance coordinator.

Type of data:

Behavioral surveillance

Description:

Data on behaviors that are relevant to HIV prevention, transmission, and medical care may be available from a variety of sources, including general population surveys, surveys of populations at risk for HIV, and surveys of persons with HIV. Behavioral data include

- patterns of, or deterrents to, HIV testing
- substance use and needle sharing
- sexual behavior, including unprotected sex
- sexual orientation
- health-care–seeking behavior
- adherence to prescribed antiretroviral therapies

Where to obtain:

National HIV Behavioral Surveillance (NHBS) coordinator for your state or jurisdiction

Type of data:

Clinical data

Description:

Clinical data refer to information on the condition(s) of persons with HIV. Clinical information is collected so as to understand

- disease status at the time of diagnosis and later progression (e.g., CD4+ cell count, viral load, opportunistic infections)
- type of medical care received
- prescription of antiretroviral therapy
- type of therapy received

Patient surveys collect data on adherence to therapy and health-care–seeking behavior. Depending on the source, clinical data may represent all cases of reported HIV infection or only a fraction. Because clinical data rely on the extent of documentation in a medical record and an ability to locate the record, they may be incomplete.

A lot of clinical data are reported to HIV surveillance. The data can be used to determine who was linked to care, retained in care, or virally suppressed.

Where to obtain:

Coordinators of Medical Monitoring Project (MMP) and HIV surveillance.

Type of data:

Demographic data

Description:

Demographic data are used to describe social characteristics (e.g., gender, age, and race/ethnicity) of persons in the service area.

Where to obtain:

Available for state, metropolitan areas and counties from the Bureau of the Census. Also, states maintain census centers. Obtain these data from http://www.census.gov.

Type of data:

Hepatitis B and C surveillance

Description:

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. In addition, many registries are relatively new, and their usefulness has not been evaluated.

Where to obtain:

State health department and CDC. 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.

Reference: CDC. *Guidelines for Viral Hepatitis Surveillance and Case Management*. Atlanta: CDC; 2005. Available at: http://www.cdc.gov/hepatitis/Statistics/SurveillanceGuidelines.htm.

Type of data:

Qualitative data

Description:

Qualitative methods are used to obtain data through observations, interviews, discussion groups, focus groups, and analysis of social networks.

Where to obtain:

Health department staff and local community researchers often use qualitative methods to conduct research. Planning group members may also be aware of local studies. Additional information can be obtained from the University of Texas—Southwestern (http://www.utsouthwestern.edu/education/school-of-health-professions/programs/outreach-programs/CPIU/cpiu-toolbox.html).

Type of data:

Ryan White HIV/AIDS Program

Description:

The Ryan White HIV/AIDS Services Report (RSR) is comprised of three reports used to collect information annually from grantees and service providers funded under Parts A, B, C, D or F of the Ryan White HIV/AIDS Program. The RSR Grantee Report is completed online and collects basic information about the grantee organization including a list of provider service contracts. The Provider Report is also completed online and collects general information on provider and program characteristics, including the types of organizations providing services (e.g., ownership status), sources of revenue, expenditures, and paid and volunteer staff. Finally, the Client Report is submitted online as an electronic file upload using a standard format with one record per client served. This report provides client-level on demographic status (e.g., gender, race, age, HIV exposure category), household income and health insurance status, HIV medical and support service utilization, HIV clinical information including viral load and the client's "eUCI," an encrypted, unique client identifier.

The RSR is the only source of Ryan White HIV/AIDS Program data that is available in all states and eligible metropolitan areas (EMAs). It provides demographic information and service utilization data on all Ryan White HIV/AIDS Program clients and can be deduplicated at the national, state, local or provider level. Unlike previous Ryan White data collection systems, the RSR Client Report can be used to generate demographic cross-tabulations.

Where to obtain:

All Ryan White grantees/providers have a copy of the RSR data they submitted to HRSA. Grantees/providers are encouraged to consult their source data.

Type of data:

Sexually transmitted disease (STD) data

Description:

These data are used in reports of notifiable STDs such as syphilis, gonorrhea, chancroid, 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. Although STDs are the result of unsafe sexual behavior, STDs are not necessarily good predictors of HIV infection.

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.

Type of data:

Socioeconomic data

Description:

Socioeconomic data are census data that are used to describe characteristics (e.g., income, education, poverty level) of persons in the service area.

Where to obtain:

Available for state, metropolitan areas and counties from the Bureau of the Census and the Bureau of Labor Statistics. Additionally, states maintain census and labor statistics centers. Obtain these data from http://www.census.gov, http://www.bls.gov, and state census centers.

Type of data:

Special studies and surveys at the local level

Description:

Surveys and other data collected from community-based organizations, AIDS service organizations, universities, and special studies. Includes recurring surveys in at-risk populations.

Where to obtain:

Local researchers and universities

Type of data:

Substance abuse data

Description:

Substance abuse 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.

Where to obtain:

National Institutes of Health (http://health.nih.gov/topic/DrugAbuse); Substance Abuse and Mental Health Services Administration (http://www.samhsa.gov) for information from drug-use surveys and data on treatment and drug abuse.

Type of data:

Tuberculosis surveillance

Description:

All 50 states, the District of Columbia, Puerto Rico, and other U.S. jurisdictions in the Pacific and Caribbean report tuberculosis (TB) cases to CDC on a standard case report form. In 1993, in conjunction with state and local health departments, CDC implemented an expanded surveillance system to collect additional data to

- better monitor and target groups at risk for TB
- estimate and follow the extent of drug-resistant TB
- evaluate outcomes of TB cases

Although information on HIV status among reported TB cases is available, it may not be complete because of

- confidentiality concerns that limit the exchange of data between TB and HIV programs
- local or state laws and regulations that prohibit the HIV program and the TB program from sharing information about patients
- reluctance of health care providers to report HIV test results to the TB surveillance program staff
- a lack of counseling and HIV testing for some TB patients

Where to obtain:

Available in all 50 states, the District of Columbia, and U.S. territories. Contact the TB program manager in your service area for information.

Type of data:

Vital records

Description:

Vital records contain information, as stipulated by state statutes, on all births and deaths in the 50 states, the District of Columbia, and U.S. territories. 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
- demographics of the deceased

Where to obtain:

All states maintain registries of deaths. Contact the State Vital Records Registrar.

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 in order 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 that are infected with HIV and describe their key characteristics
- understand the trends and the impact of HIV in a service area
- identify groups or populations at risk of acquiring or transmitting HIV and identify their prevention needs
- identify emerging populations and their 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 is concerned with organizing and summarizing health-related data according to time, place, and person. An example of descriptive analysis might be “The transmission category for X% of men diagnosed with HIV infection in the United States in 2010 was male-to-male sex.”

To carry out 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 been infected for a long time and may not adequately represent persons recently infected.
- 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.

Triangulation

Triangulation, or data synthesis, refers to comparing and contrasting the results of different kinds of data analyses that address the same topic. For example, you may want to see whether the same methods lead to similar findings (e.g., do biologic data and surveys indicate similar patterns in HIV prevalence). The similarity of results from very different data is referred to as *convergent validity*.

When research findings from different studies or different methods are strong, profile writers have a firm basis for making credible statements about the reliability of their findings and conclusions. If HIV prevalence data, STD prevalence data, and surveys of risk behavior show consistent evidence of higher HIV risk in a population, then you can be much more confident in saying that this population should be given a high priority for prevention services than you could be if you have only one kind of data. This is why multiple indicators of risk that address different aspects of HIV risk and use different methods are useful. Besides providing another index of validity, convergent findings may be clearer and more convincing to planning group members, service providers, policymakers, and others.

By the same token, different data may suggest contradictory findings. When this occurs, it is important for epidemiologists to account for the reasons that different studies have arrived at different conclusions. This process can be important in terms of identifying problems in data collection or previously undetected differences within populations. Surveys collected under poorly monitored conditions may yield results that are different from those in which the population is well characterized and sampling procedures are rigorously followed. Recent data such as HIV case reporting may reveal emerging populations at risk that are not evident from HIV case reporting. Survey studies of drug use may suggest that methamphetamine injection may be increasing in a particular population, but no change has yet been seen in HIV prevalence. This may mean that HIV infection has not yet entered the population, which would suggest the need to look specifically at risk practices of this population that have protected them from HIV infection and also look at “mixing patterns” (persons with whom they share drugs and persons with whom they have sex). The use of rapid assessment in such a population could lead to a better understanding of the epidemiology of a potential new burden of HIV infection. Divergent patterns like these also may suggest areas that should be investigated during the prevention needs assessment.

The simplest way to triangulate, or synthesize, data in the profile is to look at the main demographic categories and see how they differ according to data sources. Hence, you may want to look at similarities or differences across data sources by race/ethnicity, gender, geographic area, and age group. Summary statements based on triangulation of the data will be helpful to profile users in understanding how to integrate the large number of tables, figures, and findings that are typically included in an epidemiologic profile.

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.

Ryan White HIV/AIDS Program grant requirements

For technical assistance needs that relate directly to Ryan White HIV/AIDS Program grant requirements, contact HRSA. All technical assistance requests must go through the project officer:

Part A	**Part B**
HIV/AIDS Bureau	HIV/AIDS Bureau
Division of Metropolitan HIV/AIDS Programs	Division of State HIV/AIDS Programs
Health Resources & Services Administration	Health Resources & Services Administration
5600 Fishers Lane, Room 9WH04	5600 Fishers Lane, Room 9WH04
Rockville, MD 20857	Rockville, MD 20857
301-443-9086	301-443-6745

For prevention grant requirements

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

Chief, Prevention Program Branch
Division of HIV/AIDS Prevention
National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
Centers for Disease Control and Prevention
Mailstop E-58
1600 Clifton Road, NE
Atlanta, GA 30329
404-639-5230

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 Incidence and Case Surveillance Branch at CDC:

Chief, HIV Incidence and Case Surveillance Branch
Division of HIV/AIDS Prevention
National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
Centers for Disease Control and Prevention
Mailstop E-47
1600 Clifton Road, NE
Atlanta, GA 30329
404-639-2050

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.

Chapter 3.

Describing the Burden of HIV

Overview

This chapter is divided into 2 sections:

- **Section 1: Core Epidemiologic Questions** presents 3 epidemiologic questions that all HIV profiles should address. 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.
- **Section 2: Special Questions and Considerations for Ryan White HIV/AIDS Program Grantees** presents questions that are specific to epidemiologic profiles that will be used to plan HIV care programs. Profiles focusing on care as well as prevention issues should contain the answers to the core questions in Section 1 and the questions in Section 2.

Throughout your profile, it is acceptable to conduct additional analyses or analyses different from the ones recommended here as long as you answer the core epidemiologic questions and provide an interpretation of your tables in the accompanying text. If you choose to conduct additional analyses, be sure to state in the text that you have done so.

Section 1: Core Epidemiologic Questions

Whether you are preparing an HIV epidemiologic profile for prevention or care, you should answer 3 essential epidemiologic questions:

1. What are the sociodemographic characteristics of the general population in your service area?
2. What is the scope of HIV burden in your service area?
3. What are the indicators of risk for HIV infection in the population covered by your service area?

Examining groups at risk for HIV infection and answering these core questions will help you understand the characteristics of the population in your service area, the distribution of HIV disease, and how the distribution of HIV may look in the future. The answers provide the basis for setting priorities among populations and then identifying appropriate interventions and services. Answering these core questions is the first step in developing your comprehensive HIV prevention and care plan. Answer the questions as completely as possible, basing your answers on the needs, available data, and resources in your area.

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

Changes in the HIV burden and data that affect profiles

Describing the HIV burden 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.

Supplementing surveillance data with other sources of data will help provide a more comprehensive and in-depth picture of HIV in your service area. To provide a balanced and accurate description of the burden of HIV that incorporates the strengths and limitations of the data sources, you need to be aware of the changing nature of HIV and surveillance data.

Keep the following points in mind as you develop your epidemiologic profile. 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.

- The number of persons reported as living with HIV does not include persons who were not tested, or persons who were tested anonymously. CDC estimates that at the end of 2010, 1.1 million adults and adolescents were living with HIV infection; of these 15.8%

(180,900) were unaware of their infection. Thus, they are not benefiting from improved health and survival associated with antiretroviral therapy.

- Of the persons with diagnosed HIV infection reported in 2011 in the United States and 6 U.S. dependent areas, one-third 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).* Increased HIV testing early in the course of HIV disease and programs to link infected persons to ongoing care and prevention services are essential to reducing the number of new infections.
- Surveillance data on new HIV diagnoses provide estimates of persons known to be infected. HIV diagnosis data may not reflect trends in HIV incidence (new infections) because the data are affected by when in the course of disease 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.

Question 1: What are the sociodemographic characteristics of 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:

- Demographics
- Socioeconomic status

The information you develop will help you identify the risk factors associated with HIV infection—such as poverty level and lack of health insurance—and may indicate a greater need for providing prevention and care services.

Compile and analyze demographic and socioeconomic characteristics of the populations in your service area to determine changes during the past 5 to 10 years. Present substantial changes; if no substantial changes have occurred, state that.

Demographics

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

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* Centers for Disease Control and Prevention. *HIV Surveillance Report, 2011*; vol. 23. http://www.cdc.gov/hiv/library/reports/surveillance/2011/surveillance_Report_vol_23.html. Published February 2013.

categories of race: American Indian/Alaska Native, Asian, black/African American, Native Hawaiian/Other Pacific Islander, white/Caucasian, multiple racial categories or persons identifying themselves as having multiple racial background (e.g., black and white).[*] Hispanics/Latinos 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.

For tables that include cumulative counts, an additional category may be presented: Legacy Asian/Pacific Islander. This category only includes cases that were reported prior to the application of the 1997 OMB-defined race and ethnicity categories. The enhanced HIV/AIDS Reporting System (eHARS) field, RACE, is calculated based on all race and ethnicity data entered for a person. If the only information available is based on the old race categories where Asian and Other Pacific Islanders were not separated, there is not enough information to know whether the person is either, and this Legacy category is used to identify them. There should not be any cases reported after 2003 that fall into this category.

Age

The following age groups are recommended:

- <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. Consider your local needs when deciding on the age groups to use.

Recommended analyses

- Number and percentage distribution of the population by
    - age group and sex
    - race/ethnicity and sex
    - race/ethnicity and geographic subunit (e.g., planning region, county, Eligible Metropolitan Area [EMA])

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[*] 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://www.whitehouse.gov/omb/fedreg_1997standards. Accessed February 7, 2013.

Socioeconomic status (SES)

Focus your analysis and presentation of socioeconomic data on the populations and geographic areas that are most adversely affected by HIV.

Recommended analyses

Percentage of

- persons living below the poverty level in selected areas
- persons with high school diploma or higher and persons with bachelor's degree or higher
- adults (aged 19–64) without health insurance, by race/ethnicity

Data sources

- U.S. Bureau of the Census
- Kaiser Family Foundation
- State government statistics offices

Note. See Appendix A for a description of the U.S. Bureau of the Census data.

Question 2: What is the scope of HIV burden in your service area?

An examination of the extent and effect of HIV in broad population groups in your service area provides the basis for comparison with national data and allows a closer examination of the effect on specific groups, both of which will help your planning group better focus prevention and care services.

Section 1-A: Using Data from the HIV Surveillance System

CDC has developed SAS programs for creating epidemiologic profile tables using jurisdictional level HIV surveillance data in eHARS (refer to *Creating Integrated Epidemiologic Profiles: User Guide, version 4.0*). Note the same reporting delay standard applies to diagnoses, deaths, and prevalence, so that if deaths for the prior year are reported by the end of the following year and death ascertainment has been performed for the prior year, the same frozen December dataset can be used for diagnoses, deaths, and prevalence for the prior year (see Appendix G for reporting delay).

Jurisdiction HIV reporting status and corresponding data tables

Single year tables for diagnosed cases of HIV or stage 3 (AIDS)

The first group of tables presents analyses of data for the full calendar year that is designated for the profile. Persons included in these tables meet the CDC surveillance case definition for HIV or stage 3 (AIDS) (see Appendix G) and were diagnosed with HIV or stage 3 (AIDS) during the designated year.

For the most recent available calendar year:

1. Number, % distribution, rates of cases (/100,000) by: race/ethnicity and sex
2. Number, % distribution by: age group and sex
3. Number, % distribution by: transmission category and sex
4. Number, % distribution by: transmission category and race/ethnicity

For TB morbidity:

5. Number and % distribution of diagnosed HIV cases with TB by sex (by definition, any diagnosed HIV with a diagnosis of tuberculosis [*M. tuberculosis*, disseminated or extrapulmonary, or *M. tuberculosis*, pulmonary] is a stage 3 [AIDS] case).

For mortality data:

6. Number and rates of death/100,000 population among persons with diagnosed HIV infection, by race/ethnicity and sex

If HIV infection is among the 10 leading causes of death in any group in your service area, you may also wish to present these analyses:

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

Data sources

- HIV surveillance data
- Vital statistics data
- National Center for Health Statistics mortality dataset
- National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) Atlas

Note. Data in death certificates on specific causes of death may be of poor quality for several reasons. Stigmatized diseases may be underreported. In addition, the causes of death may be recorded incorrectly if, for example, they were limited to symptoms or immediate causes and did not include the underlying cause (in this instance, HIV infection). See Appendix A for a description of some of the data sources mentioned above.

Recommended analyses for geographic areas with large case numbers

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 the following tables stratified by region:

- Number and percentage distribution of cases by
  - sex
  - race/ethnicity
  - age group
  - transmission category
- 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.

Example Table Shell

Table 3-1. Diagnoses of HIV infection, by sex and race/ethnicity, Year—Jurisdiction

	Males			Females			Total		
Race/ethnicity	**No.**	**%**	**Rate[a]**	**No.**	**%**	**Rate[a]**	**No.**	**%**	**Rate[a]**
American Indian/Alaska Native									
Asian									
Black/African American									
Hispanic/Latino									
Native Hawaiian/Other Pacific Islander									
White									
Multiple race									
Unknown									
Total									

Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis.

Source:

[a] Rates are per 100,000 population.

Five-year tables for persons with diagnosed HIV infection or stage 3 (AIDS)

The second group of tables is for analyses that cover the designated profile year, as well as the four years that preceded it for diagnosed cases of HIV infection or stage 3 (AIDS) by year of diagnosis. The populations included in these tables are persons who have been diagnosed with HIV infection or stage 3 (AIDS) in the designated profile year or in one of the four years preceding it. Two cumulative columns are also provided: one for the time leading up to the five-year period, and one for all cases. Overall counts are stratified by sex, race/ethnicity, age group, and transmission category.

For the most recent five-year period:

1. Annual number of diagnosed cases, by sex
2. Annual number of diagnosed cases, by race/ethnicity
3. Annual number of diagnosed cases, by age at diagnosis
4. Annual number of diagnosed cases, by transmission category

Example Table Shell

Table 3-2. Diagnoses of HIV infection, by year of diagnosis and race/ethnicity, 2008–2012—Jurisdiction

	Number of cases						
Race/ethnicity	**Cumulative through 2007**	**2008**	**2009**	**2010**	**2011**	**2012**	**Cumulative through 2012 (Total)**
American Indian/Alaska Native							
Asian							
Black/African American							
Hispanic/Latino							
Native Hawaiian/Other Pacific Islander							
White							
Multiple race							
Unknown							
Total							

Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis.

Source:

Five-year tables for persons living with diagnosed HIV infection or stage 3 (AIDS)

The next set of tables represents five-year analyses showing the annual number of persons living with HIV infection or stage 3 (AIDS) (also known as HIV or stage 3 [AIDS] prevalence). Anyone who has ever been entered into eHARS, meets the CDC surveillance case definition for

HIV infection, and whose vital status in eHARS is “alive” for the designated year is included in this set of tables. Prevalence is defined as the number of persons ever diagnosed with HIV minus the number of persons with a diagnosis of HIV infection that died. Again, overall counts are presented, stratified by sex, race/ethnicity, age group (using age at end of specified year, rather than age at diagnosis), and transmission category.

For five-year period:

1. Persons living with a diagnosis of HIV infection, by sex
2. Persons living with a diagnosis of HIV infection, by race/ethnicity
3. Persons living with a diagnosis of HIV infection, by age at end of specified year
4. Persons living with a diagnosis of HIV infection, by transmission category

Example Table Shell

Table 3-3. Persons living with diagnosed HIV infection, by year and race/ethnicity, 2008–2012—Jurisdiction

	2008	2009	2010	2011	2012
Race/ethnicity	**No.**	**No.**	**No.**	**No.**	**No.**
American Indian/Alaska Native					
Asian					
Black/African American					
Hispanic/Latino					
Native Hawaiian/Other Pacific Islander					
White					
Multiple race					
Unknown					
Total					

Source:

Five-year tables for deaths of persons with diagnosed HIV infection or stage 3 (AIDS)

The last set of tables are for five-year analyses and present the annual number of deaths of persons with diagnosed HIV infection or stage 3 (AIDS). Persons included in these tables are anyone meeting the CDC surveillance case definition for HIV infection or stage 3 (AIDS) and who died in the designated five-year period regardless of the cause of death. Two cumulative columns are also provided. Overall counts are stratified by sex, race/ethnicity, age group (by age at death), and transmission category.

For five-year period:

1. Annual number of deaths of persons with diagnosed HIV infection, by sex
2. Annual number of deaths of persons with diagnosed HIV infection, by race/ethnicity

3. Annual number of deaths of persons with diagnosed HIV infection, by age at death
4. Annual number of deaths of persons with diagnosed HIV infection, by transmission category

Example Table Shell

Table 3-4. Deaths of persons with diagnosed HIV infection, by year of death and race/ethnicity, 2008–2012—Jurisdiction

	Number of deaths						
Race/ethnicity	**Cumulative through 2007**	**2008**	**2009**	**2010**	**2011**	**2012**	**Cumulative through 2012 (Total)**
American Indian/Alaska Native							
Asian							
Black/African American							
Hispanic/Latino							
Native Hawaiian/Other Pacific Islander							
White							
Multiple race							
Unknown							
Total							

Source:

Note. 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-developed SAS programs can be used alone (unweighted data) or together with multiple imputation (MI) and reporting delay (RD) SAS programs (weighted data). The RD and MI procedures account for reporting delays and missing risk factor information, respectively.

Section 1-B: Using Data from HIV Incidence Surveillance

In addition to case data from HIV surveillance systems, select states and local health departments, funded to conduct HIV incidence surveillance, may also conduct HIV incidence surveillance and calculate estimates of HIV incidence. Estimates of HIV incidence provide information about the estimated number of persons newly infected with HIV in a population in a defined time period. There is an important difference between HIV incidence and a new diagnosis of HIV infection: HIV incidence refers to persons newly infected with HIV, whereas persons newly diagnosed with HIV may have been infected 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.

Program areas that collect HIV testing and treatment information and STARHS (serologic testing algorithm for recent HIV seroconversion) results may estimate incidence using the stratified extrapolation approach. The references below provide additional information about the stratified extrapolation approach and examples of data output:

> Hall HI, Song R, Rhodes P, et al. Estimation of HIV incidence in the United States. *JAMA* 2008;300(5):520.
>
> Karon JM, Song R, Brookmeyer R, Kaplan EH, Hall HI. Estimating HIV incidence in the United States from HIV/AIDS surveillance data and biomarker HIV test results. *Statist Med* 2008;27(23):4617–4633.
>
> Prejean J, Song R, Hernandez A, et al. Estimated HIV incidence in the United States, 2006–2009. *PLoS One* 2011;6(8):1–13.
>
> Centers for Disease Control and Prevention. Estimated HIV incidence in the United States, 2007–2010. *HIV Surveillance Supplemental Report* 2012;17(No.4). http://www.cdc.gov/hiv/library/reports/surveillance/. Published December 2012.

Other methods for estimating incidence may be available, such as statistical methods using HIV surveillance data and back calculation approaches.

Recommended analyses for HIV incidence data

HIV incidence data are expressed either as an estimated number of persons newly infected with HIV during a defined time 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 time period.

Sample size considerations may impact the ability to present data by select demographic characteristics, limiting the strata that may be reported. Program areas with sufficient sample size may be able to stratify by age group, race/ethnicity, sex, and transmission category. Annual numbers may be reported or data may be grouped over multiple years depending on the method used and sample size.

You should work with local staff experienced with HIV incidence methodology (e.g., the incidence surveillance coordinator and a statistician) 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 (e.g., increases/decreases in HIV testing, proportion of cases with stage 3 [AIDS] diagnosed in 6 months).

CDC has guidance and SAS programs for program areas that are able to use the stratified extrapolation approach for calculating HIV incidence estimates. Check with your local HIV surveillance program for the availability of guidance for other methods for estimating incidence.

Section 1-C: HIV Program Data

HIV testing data

CDC collects, analyzes, and disseminates data on CDC-funded HIV testing events. Test-level data are reported through the National HIV Prevention Program Monitoring and Evaluation (NHM&E) system and represent a portion of all HIV testing done in the United States, Puerto Rico, and the U.S. Virgin Islands. These data can be used to provide insight into the demographics of persons tested, positive tests, and 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, and 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 considered to be "test-level" rather than "client-level" estimates. Calculating 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 minimizes this limitation. Examples of such data output are included in the following references:

> Duran D, Usman HR, Beltrami J, Alvarez M, Valleroy L, Lyles C. HIV counseling and testing among Hispanics at CDC-funded sites in the United States, 2007. *Am J Public Health* 2010;100(Suppl 1):S152–8.
>
> CDC. *HIV Testing at CDC-funded Sites, United States, Puerto Rico, and the U.S. Virgin Islands, 2008–2009*. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; July 2011. http://www.cdc.gov/hiv/pdf/testing_report_2008_2009.pdf. Accessed June 12, 2014.

You may increase the usefulness of the data by conducting analyses on test results of persons tested for the first time. Examples of such data output are included in the following reference:

> Van Handel M, Beltrami J, Margolis A, MacGowan. HIV positivity and return of HIV test results and posttest counseling at U.S. correctional facilities, 2007. Abstract presented at XVIII International AIDS Conference, Vienna, Austria. July 18–23, 2010. http://www.iasociety.org/Abstracts/A200735782.aspx. Accessed February 6, 2013.

Performance indicators for HIV prevention

Indicators are standardized measures (i.e., they are collected and reported consistently across agencies) that capture information related to priority questions about HIV prevention in a jurisdiction. They are most useful for monitoring the results of prevention efforts when viewed over time and in the context of surveillance data and other information about HIV (CDC 2010). Additionally, indicators provide useful information for documenting achievements, program planning and improvement, and demonstrating accountability.

Depending on their specific purpose or use, indicators can be defined or expressed in one of three ways: (a) percent compliance (expressed as a ratio with a numerator and denominator);

(b) actual vs. expected performance (using an agency defined performance target); and
(c) performance against a benchmark (using a national or local performance standard) (Manila 2010, p14). However defined or expressed, a good indicator should be useful, feasible, and adaptable (see Table 3-5).

Table 3-5. Criteria for a good indicator

Useful	• Provides information about key components of a program • Allows meaningful comparisons of data to show progress over time
Feasible	• Constitutes good use of time and resources • Requires reasonable efforts for data collection, and the value of the indicator outweighs any data collection burden
Adaptable for target setting	• Allows programs to develop performance targets that are locally relevant and that predict achievement in a given time period

Source: CDC. Guidance for use of HIV prevention program performance indicators. November 2010.

HIV prevention performance indicators generally focus on the processes or outcomes of services and activities being implemented in a jurisdiction (CDC 2009). *Process* indicators measure the direct outputs of program activities, populations served, and resources used. They describe what activities were implemented, and whether they were implemented as planned. For example, process indicators may focus on the extent to which an agency enrolls the planned number of clients in an intervention and delivers the services as intended to the target population. *Outcome* indicators measure changes that occur during or just after service delivery (e.g., knowledge of HIV status, linkage to medical care for HIV-positive clients) or after a period of time (e.g., behavior change). Both process and outcome indicator data should always be interpreted in the context of other relevant information about HIV in a jurisdiction.

Impact indicators are not focused specifically on the performance of programs in a jurisdiction but rather are intended to assess HIV prevention efforts more broadly. They reflect both program performance and the overall effect of other factors related to HIV in a jurisdiction. For example, following the White House’s National HIV/AIDS Prevention Strategy, impact indicators may be used to monitor reductions in new infections (HIV incidence), improvements in HIV-related health outcomes, and reductions in HIV-related disparities among MSM and racial/ethnic groups.

Setting realistic and thoughtful annual performance targets for indicators (i.e., projections about what a jurisdiction or agency expects to accomplish in a given time period) is essential for program planning and management. Performance targets establish clear expectations for staff, stakeholders, and funders (CDC 2010). In setting performance targets, agencies may consider a range of performance factors (e.g., funding, staffing, past experience, and local/state policies). Agencies can compare targets with actual data to determine whether performance expectations are being met and make adjustments as needed.

HIV prevention indicators may be calculated using one or more of the data collection systems described in this integrated guidance document. For example, HIV surveillance provides data for calculating several indicators that address impact (e.g., annual number of new infections or transmission rate) while HIV testing data are used to calculate several performance indicators that address testing-related processes and outputs/outcomes. Examples include

1) HIV-positive tests—Percent of newly identified HIV-positive testing events among all testing events
2) Return of HIV-positive test results—Percent of newly identified HIV-positive testing events where clients received their test results
3) Linkage to medical care—Percent of persons newly diagnosed with HIV who were linked to medical care; i.e., attended first HIV medical care appointment within three months of diagnosis

Grantees and providers funded by the Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau have a core set of data collection and reporting requirements that focus on outcomes, performance monitoring, and other program requirements that help to monitor service delivery and quality of care (HRSA 2010). The collection and use of HRSA program data are well-documented in the publication *Using Data to Measure Public Health Performance* (HRSA 2010).

The use of HIV prevention performance indicators is critical for demonstrating accountability and assessing and improving efforts toward meeting national, state, and local HIV prevention goals. For more information, please consult the following resources:

- Centers for Disease Control and Prevention. Framework for Program Evaluation in Public Health. *MMWR* 1999;48(No. RR-11):[1–41].
- Centers for Disease Control and Prevention/Global AIDS Program and ICF Macro. Monitoring and Evaluation for National Program Planning and Management: Facilitator Guide. Atlanta, GA: Centers for Disease Control and Prevention; 2009. Available at http://www.globalhivmeinfo.org/Monitoring/Pages/Default.aspx. Accessed June 16, 2014.
- DeGroff A, Schooley M, Chapel T, Poiser TH. Challenges and strategies in applying performance measurement to federal public health programs. *Evaluation and Program Planning* 2010;33(4):365–72.
- Health Resources and Services Administration, HIV/AIDS Bureau. HIV/AIDS Performance Measures. Available at http://hab.hrsa.gov/deliverhivaidscare/habperformmeasures.html. Accessed June 16, 2014.
- Horberg MA, Aberg JA, Cheever LW, Renner P, O'Brien Kaleba E, Asch SM. Development of national and multiagency HIV care quality measures. *Clinical Infectious Diseases* 2010;51(6):732–8.
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Question 3: What are the indicators of risk for HIV infection in the population covered by your service area?

Behaviors are monitored with regard to risk taking, HIV testing, care seeking, and adhering to treatment for HIV in different populations.

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 HIV-negative persons
- Factors that affect the risk of transmitting HIV infection among HIV-positive persons

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, including the following:

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

Note. You may also want to examine the risk for HIV infection among populations of special interest, including incarcerated persons, homeless persons, migrant laborers, commercial sex workers, persons with mental illness, deaf and hearing-impaired persons, perinatally exposed persons, transgender persons, 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 sex, race/ethnicity, and age group.

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.

The populations described in the answers to Question 2 as most affected by HIV are also the groups that must be included here as those at greatest risk for HIV infection.

For each of the transmission categories as well as for local at-risk populations of special interest, consider not only the prevention issues for persons at risk but also the prevention and care issues for infected persons.

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 STD 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 or unprotected sex
  - whether partners are anonymous
  - substance use (including injection drug use)
  - information about discordant sex partners (i.e., one partner is HIV-positive and the other is HIV-negative)
  - previous or current primary or secondary syphilis infection

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

- HIV-positive persons
    - Medical Monitoring Project (MMP)
    - National HIV Behavioral Surveillance System (NHBS)
    - In addition, seek results from locally conducted cross-sectional studies funded by NIH, CDC, and other government agencies or nongovernmental organizations.

Note. See Appendix A for a description of some of the data sources mentioned above.

Recommended analyses for MSM: 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, and syphilis among MSM
    - rectal gonorrhea among men
    - proportion of Gonococcal Isolate Surveillance Project (GISP) isolates from MSM

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 HIV-infected persons
- National HIV Behavioral Surveillance System (NHBS)
- Medical Monitoring Project (MMP)
- Local needle exchange program data

Recommended analyses for injection drug users (IDUs): 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 drug paraphernalia (cookers, cottons, water, drug solution)
    - exchanging money or drugs for sex
    - number of sex partners
    - frequency of condom use or unprotected sex

Conduct stratified analyses by sex, 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 System (NHBS)
    - Medical Monitoring Project (MMP)
    - 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.
- HIV-positive persons
    - 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 A for a description of the some of the data sources mentioned above.

Recommended analyses for injection drug users (IDUs): Indirect measures

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

Conduct stratified analyses by sex, 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 of these factors can affect HIV risk. See Appendix A 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 unprotected sex
- Substance use (including injection drug use)
- Exchanging money or drugs for sex
- Information about discordant sex partners (i.e., one partner is HIV-positive and the other is HIV-negative)

Conduct stratified analyses of by sex, 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 System (NHBS)
  - National Health Interview Survey
  - National Survey of Family Growth
- Available in some areas for persons who are HIV-positive
  - 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 A 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 and secondary syphilis*
    - recent STD history

Conduct stratified analyses by sex, 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 who are HIV-positive
    - HIV surveillance registry matches to STD registry to monitor trends in STD incidence among HIV-infected persons
    - STD programs

Note. See Appendix A for a description of some of the data sources mentioned above.

Recommended analyses for data on other populations of special interest

You may wish to include other populations in your profile because their members may belong to the groups already listed or because of unique factors that influence their risk. Evaluate the effect that these groups have on HIV in your service area. 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. Take note of cases in persons reported in one state but in care in another state (common in areas of low morbidity). 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.

Optional analyses for HIV testing

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

Data sources

- Available everywhere
    - HIV testing data

  - Behavioral Risk Factor Surveillance System (BRFSS)
  - 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 System (NHBS)
  - Pregnancy Risk Assessment Monitoring System (PRAMS)
- Available in some areas for persons who are HIV-positive
  - Medical Monitoring Project (MMP)

Note. See Appendix A for a description of some of the data sources mentioned above.

Summary of recommended analyses for question 3

- Examine direct and indirect measures of risk for HIV infection by transmission category:
  - Male-to-male sex
  - Injection drug use
  - Heterosexual contact
- If desired, examine risk for HIV among populations of special interest, including incarcerated persons, homeless persons, migrant laborers, commercial sex workers, persons with mental illness, deaf and hearing-impaired persons, perinatally exposed persons, transgender persons, and any other populations in the local area at increased risk for HIV infection
- Conduct stratified analyses of these transmission categories by sex, race/ethnicity, and age group (including adolescents).
- Analyze HIV testing data to determine HIV testing-related characteristics among specific groups.

Section 2: Special Questions and Considerations for Ryan White HIV/AIDS Program Grantees

Programmatic activities and funding allocations should be based on local public health data and information, with appropriate consideration of state and regional level public health data, when monitoring the impact of care and treatment services on people living with HIV who are served by the Ryan White HIV/AIDS Program. This section contains two questions that pertain to Health Resources and Services Administration's (HRSA) Ryan White HIV/AIDS Program planning groups (including Part A planning councils and Part B consortia) and grantees. In addition to the core epidemiologic questions in Section 1, Ryan White HIV/AIDS Program grantees should make an effort to address the following questions.

Question 1: Using epidemiologic and related public health data, what is the impact of the care and treatment services of the Ryan White HIV/AIDS Programs on people living with HIV?

Ryan White HIV/AIDS Program planning groups and grantees base program planning and funding prioritization and distribution on pertinent public health and epidemiologic data for people living with HIV and AIDS in the local area and region or state. Ryan White grantees have access to a variety of data and information that can assist them in program planning and funding allocation decisions. In the HRSA HIV/AIDS Bureau monograph entitled "Using Data to Measure Public Health Performance—A Guide for Ryan White HIV/AIDS Program Grantees" (http://hab.hrsa.gov/manageyourgrant/files/datatomeasure2010.pdf), a section is included to help grantees use various sources of data to monitor and measure the performance of their programs; the Ryan White HIV/AIDS Program grantee is encouraged to review this monograph. The above question can be considered in terms of the local measurement of public health outcomes and assessing the need for HIV services.

Measuring public health outcomes

A grantee can measure outcomes from various perspectives—perhaps assessing health outcomes through the provision of Ryan White core medical and support services or assessing provider adherence to established clinical practice standards, protocol, or HHS guidelines. Regardless of the way in which the grantee decides to measure outcomes for the program, the grantee must consider the topic in terms of race/ethnicity, sex, age, risk, insurance status, and poverty level along with other variables of interest to the local area.

Part A and Part B grantees are required to evaluate program "effectiveness." Although legislative language on evaluation is more limited for Parts C and D, program guidance requires evaluation. Specific evaluation requirements include the following:

- Each Part A planning council shall establish priorities for the allocation of funds on the basis of factors including the "demonstrated (or probable) cost effectiveness and outcome effectiveness of proposed strategies and interventions, to the extent that data are reasonably available." Each council may, at its discretion, "assess the effectiveness, either directly or through contractual arrangements, of the services offered in meeting the identified needs."

- Each Part B consortium is required to submit to the state an application that "(D) demonstrates that the consortium has created a mechanism to evaluate periodically—(i) the success of the consortium in responding to identified needs; (ii) the cost-effectiveness of the mechanisms employed by the consortium to deliver comprehensive care; and (E) demonstrates that the consortium will report to the state the results of the evaluations described in subparagraph (D) and shall make available to the state or the Secretary, on request, such data and information on the program methodology that may be required to perform an independent evaluation."
- Part C programs may spend no more than "10 percent, including planning and evaluation of the grant for administrative expenses with respect to the grant" (§ 2664(g)(3)).
- Each Part D program is required by the Secretary to "directly or through contracts with public and private entities, provide for evaluations of programs carried out pursuant to subsection (a)" (§ 2671(e)(2)).

Many factors contribute to the need for outcomes evaluation among Ryan White HIV/AIDS Program grantees and their providers. Client-level outcomes data are available through the Ryan White HIV/AIDS Program Services Report (RSR). Grantees and planning bodies need outcomes evaluation data to support their work at the state and local levels. Both grantees and lead agencies need outcome measures to include in their Requests for Proposals (RFPs) and in provider contracts so they can document results. Planning bodies need outcomes data as input to their planning and priority setting. States and municipalities often require documentation that programs are making a difference, whether they are supported solely through the resources of the Ryan White HIV/AIDS Treatment Extension Act of 2009 or by a combination of public and other funding sources. Providers must document program outcomes as they seek public and private funds and as they work to improve and coordinate services.

HIV care is now based largely on a medical service delivery model designed to reduce morbidity and mortality. Determining the effectiveness of Ryan White HIV/AIDS Program services therefore requires understanding whether such services help clients to access care and achieve improved health status. As a result, outcomes evaluation for almost any Ryan White HIV/AIDS Program–supported service category, from case management to transportation, needs to include an indication of whether program participation can demonstrate linkages to primary care—which, in turn, contributes to improved clinical outcomes. Most providers lack access to data on client health status, but they can document their ability to link clients to outpatient or ambulatory medical care (e.g., helping them engage in care, keep appointments, and adhere to medications).

Ryan White HIV/AIDS Program grantees, especially Part A and Part B grantees typically help support a system of HIV services. Grantees and planning bodies want evaluation data that can guide decision making about program priorities and resource allocation. Ideally, that means understanding the outcomes associated with not just one category of services (e.g., primary medical care or medical case management) but rather a combination of core medical and support services—or an entire system of care.

Assessing the need for HIV services

A grantee can assess need from various perspectives—perhaps HIV seroprevalence and surrogate markers, target populations and their unique needs, or barriers to care. Regardless of the way in which the grantee decides to assess need, the Ryan White grantee must consider the topic in terms of race/ethnicity, gender, age, risk, insurance status, and poverty level along with other variables of interest to the local area.

Parts A, B, C, and D grantees are responsible for assessing the need for services for their service population, so that they can address those needs through Ryan White HIV/AIDS Program and other funds. Needs assessment responsibilities are summarized in the Ryan White HIV/AIDS Treatment Extension Act of 2009 and grant guidance, which identify several components of needs assessment, including use of HIV seroprevalence and surrogate markers to estimate current and future demand for HIV services; the social context of HIV, such as HIV risk behaviors, that help describe populations needing services and their unique requirements; the current HIV service delivery and financing system; barriers to care; demand for care on the basis of the number of people living with HIV who do not have health insurance or other resources to pay for care; and estimated unmet need on the basis of the size of the population aware that they are living with HIV but are not in care.

Ryan White HIV/AIDS Program grantees use many data sources to conduct needs assessment. Table 5.3 of the HRSA HIV/AIDS Bureau monograph "Using Data to Measure Public Health Performance—A Guide for Ryan White HIV/AIDS Program Grantees" (http://hab.hrsa.gov/manageyourgrant/files/datatomeasure2010.pdf) summarizes the types of data and their sources. Factors to consider when using the data include:

- HIV epidemiologic profiles address the scope of HIV in the service area, document unmet need, and demonstrate the disproportionate impact of HIV on vulnerable populations. Availability of timely, detailed epidemiologic data is vital.
- In some jurisdictions, HIV name-based reporting is relatively recent, therefore, data to calculate long-term trends in HIV diagnosis and prevalence may not be available. Information regarding the various components of the HIV service delivery and financing systems may vary. Data regarding HIV-related hospitalization rates, emergency department admissions, and public or commercial insurance expenditures may be unavailable or untimely because of the time required to gather and report data.
- Detailed survey or other data that can be used to describe the demographic, economic, health insurance coverage, and geographic characteristics of persons living HIV. In some jurisdictions, government or other sponsors have supported the cost of those surveys. In other jurisdictions, Ryan White HIV/AIDS Program grantees have sponsored surveys.

The type of the service area to be addressed by the needs assessment contributes to the approach taken. For example, urban areas in a state may have detailed data available for needs assessment, but rural areas may have minimal data.

Table 3-6. Types and sources of HRSA/HAB* data sources used in HIV needs assessments

Responsibilities	Examples of data	HAB/Grantee data sources
HIV seroprevalence and surrogate markers	HIV incidence and prevalence, CD4 and viral load, resistance, geographic distribution of HIV, demographic characteristics of persons with HIV, year of HIV and AIDS diagnosis, and HIV risk behaviors	RSR Client Report, MAI Report
Social context of HIV	Demographic characteristics of persons with HIV , social and economic characteristics, health insurance coverage	RSR Client Report, MAI Report
Target populations and their unique needs	Rates of homelessness, unstable housing, addiction, mental illness, and other social characteristics; income and other economic characteristics; type of health insurance coverage and scope of benefits; family characteristics	RSR Client Report, MAI Report
HIV service delivery and financing system	Inventory of providers delivering HIV services, types and amounts of Ryan White HIV/AIDS Program and other funds, eligibility criteria for health insurance, eligibility criteria for disability income programs, mix of services available, HIV-related inpatient admissions and emergency room visits	RSR Provider Report, ADAP Quarterly and Annual Reports
Barriers or facilitators to care	Eligibility determination process, capacity to serve more clients, travel time to HIV providers, parking, transportation, hours of operation, wait time for appointments, wait time at provider site, culturally or linguistically competent clinicians and other workers, availability of services, use of personnel to facilitate navigation of the care continuum	RSR Client Report
Documenting demand for care	Service utilization rates, frequency of visits or other units of service, mix of services used□RDR, RSR Client Report, MAI Report, ADAP Quarterly and Annual Report, CBDPP and DRP	Dental Services Report
Unmet need for care	HIV seroprevalence rates, AIDS rates, enrollment in health insurance or other insurance coverage, incarceration rates of persons with HIV	RSR Client Report

*HRSA/HAB: Health Resources and Services Administration/HIV/AIDS Bureau

The Ryan White HIV/AIDS Program encourages grantees to use epidemiological and related public health data to understand the impact of HIV in a service area. For the Ryan White HIV/AIDS Program, the use of epidemiology and related public health data must be used to improve decisions about the management of health services for people living with HIV and clients of the Ryan White HIV/AIDS Program. Ryan White HIV/AIDS Program grantees must clearly illustrate how epidemiology and related public health data have been incorporated in public health planning and evaluation activities along with the implementation and management of Ryan White public health care and treatment services for people living with HIV in a service area. The Ryan White HIV/AIDS Program expects that many of the suggestions contained in this document would be included in reports and documents submitted to HRSA’s HIV/AIDS Bureau.

Question 2: What are some things to keep in mind as a Ryan White HIV/AIDS Program grantee prepares the epidemiologic profile document for HRSA's HIV/AIDS Bureau?

For the Ryan White HIV/AIDS Program, the epidemiologic profile provides important information about the HIV experience in a state or local area. As such, it is essential for HIV services planning, priority-setting and service delivery, as well as coordination with HIV prevention and related public health activities. HRSA's HIV/AIDS Bureau expects that Ryan White HIV/AIDS program grantees will demonstrate and apply knowledge of the local epidemiologic experience when proposing public health activities in grant applications.

Parts A and B

The HIV/AIDS Bureau requires new and existing Ryan White grantees to demonstrate the following in the epidemiologic profile submitted to HRSA:

1. Determine the size and demographics of the population with HIV infection.
2. 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.
3. Identify populations with severe needs and comorbidities.
4. If applying for funds from multiple Ryan White funding streams, use the epidemiologic profile information consistently to inform each grant application/service plan.

Parts C and D

The epidemiologic profile or needs assessment section of your grant application or grant reports should outline (or update) the needs of your community and provide information on the impact of HIV in your community. (If this section contains an "update," please make note of this fact in the narrative.) The epidemiologic profile should define your service area, provide information on the rate of HIV in your service area, describe the target populations to be served, the medical and social support needs of the people you serve or propose to serve, and any unmet health needs. Describe gaps in HIV primary care services for the targeted populations within the proposed service area and the impact these gaps have on clients.

Please pay particular attention to these four (4) components in your epidemiologic profile discussion:

1. HIV seroprevalence and surrogate markers
2. Social context of HIV
3. Target populations
4. Local HIV service delivery system

The Funding Opportunity Announcement (aka, grant announcement) describes what should be included within each component.

HRSA/HAB grantees use data to address responsibilities including achieving health outcomes; clinical quality management QM and performance assessment; resource allocation; financing, organizing, and delivering services; training; and needs assessment.

The types of data needed by grantees vary by Part, size of the service area, size and scope of the burden of HIV addressed by the grantee, amount of funds allocated to the grantee, number of clients served, number of providers, service mix, and interventions undertaken.

Reports required by HRSA/HAB can be used to address many grantee responsibilities. The availability of Ryan White HIV/AIDS Program Services Report (RSR) client-level data submitted to HAB, if also used by grantee, may greatly improve the ability to meet various administrative, programmatic, QM, planning, resource allocation, and other responsibilities. The grantee is encouraged to examine the RSR data submitted to HRSA/HAB for possible utilization in this section.

The HRSA/HAB HIV/AIDS Core Clinical Performance Measures for Adults and Adolescents can be used in monitoring the quality of care provided by their programs or their contracted providers. Several of the measures are incorporated into the RSR Client Report. Grantees should select measures that are most important to their agencies and the populations they serve. Some HRSA/HAB Group 1 performance measures are included in the RSR.

Chapter 4.

Completing the Epidemiologic Profile

Section 1 Making Your Profile User-Friendly

Section 2 Writing Your Narrative

Section 3 Disseminating Your Profile

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.

Presenting your data

Summarizing your data and presenting them in tables or figures are critical to an effective profile because raw data are difficult to

- understand
- visualize
- aggregate
- use in detecting trends

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 planning groups.

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

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.
- 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.
- For figures, write clear and consistent labels, and label all elements to avoid misunderstanding. For tables, write clear and consistent column headings and row entries (use consistent terms).
- 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).
- Write a clear, concise title.
- Name the source of your data.
- Discuss the key points of the table or figure in your text.
- 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 of 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 planning group. 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.

Mapping using geographic information system (GIS)

Geocoding of addresses of persons with a diagnosis of HIV infection allows for geographic analyses of the burden of disease. In addition, linkage of HIV surveillance data to U.S. Census or other data, based on geographic area (e.g., census tract), allows assessments of social determinants of health (e.g., socioeconomic status, poverty, and education) to identify populations that are disproportionately affected by HIV and related diseases and conditions in order to help eliminate health disparities.

GIS technology can be used to display epidemiologic data by a geographic reference (e.g., a city or a neighborhood census block). From the geocoded data, users can create thematic maps (e.g., choropleth map, dot density map, or graduated symbol map), which illustrate the distribution of HIV infection without disclosing the locations of individuals. This information can be used to inform planning for prevention and care and treatment services, and to identify areas to target for counseling and testing and/or care and treatment services or facilities. This method of representation of data illustrates an enhancement of the epidemiologic, analytic, and technological capacity at the local and state level. For more details on geocoding, GIS, and guidance for creating maps, please refer to *Technical Guidance for HIV Surveillance Programs—Policies and Procedures for Geocoding and Linking Activities with HIV Data* (available at https://partner.cdc.gov/sites/NCHHSTP/HICSB/default.aspx).

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.

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?
- How would I describe their professions, their viewpoints on HIV disease, 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 planning group members, their experience and expertise with epidemiology, and the uses to which they will put 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 will have had formal training in epidemiology or statistics. 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. Still others will know their communities well but have little or no experience working with data.

Members will also have diverse experience and expertise with HIV, and that diversity will influence what you include in your profile and how you frame the information. For example, consider questions such as 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 will 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 with vision defects 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
    - 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 also may affect service delivery (e.g., changes in case reporting resulting from named reporting)
- Recognize and respect different world views among end users. For example, service providers and advocates tend to think in terms of individuals and trends among the individuals they see 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 be focused on the uses of the data 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 HIV risk (geographic and by population)
    - describing differences in the burden of HIV (geographic and by population)
    - presenting trends in risk and effect
    - detailing changes in policy, diagnostics, and treatment strategies that may affect risk, effect, or care and prevention needs
- prepare for needs assessments and for analysis of gaps in prevention and care by
    - describing differences in HIV risk (geographic and by population)
    - describing differences in the effect of HIV (geographic and by population)
    - presenting trends in risk and burden of HIV
    - detailing changes in policy, diagnostics, and treatment strategies that may affect risk, burden of HIV or care and prevention needs
    - identifying questions that cannot be answered from the epidemiologic data

- set priorities among interventions by
    - defining populations who need prevention or care services
    - identifying and describing areas that need prevention or care services
    - describing whether 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 the conclusions they should draw from the information presented.

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

Here 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.

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.

Many people view jargon and overly technical terms as pretentious. The use of jargon and technical terms is also seen as a way of talking above a group or avoiding direct discussion of controversial issues.

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 terms are necessary to describe HIV in the service area (e.g., prevalence, incidence, rates). 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.

> *Example*
>
> Jargon: The data show an increase in the prevalence of persons living with HIV in 2011. Data show an increase in adolescent drinking and unprotected sex; thus, there is an increased risk of exposure for adolescents.
>
> Useful information: In 2011, compared with earlier years, adolescents in County X were at increased risk for exposure to HIV. Data show an increased prevalence (the total number of persons with HIV who were alive) of HIV in 2011. 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 those 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

Examples

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.

Example

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.

> *Examples*
>
> 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 intuit 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 not very familiar 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 and 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 completed profile is disseminated by the state health department to members of HIV prevention planning groups. The epidemiologic profiles should also be disseminated to Ryan White HIV/AIDS Program grantees 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 services 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 types of groups use these elements to identify gaps in the coverage of prevention services, set priorities among infected populations, and conduct interventions for high-risk populations. In addition, care planning groups use these elements to identify gaps in the coverage of Ryan White HIV/AIDS Program services and to set priorities that address the care needs of HIV-infected 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 Web site. This is recommended as the primary method of distribution.
- Draw the attention of relevant individuals and agencies to the availability of the profile online: executive directors of local CBOs; the major providers of HIV care, including physicians, nurses, and physician assistants; sister government agencies or departments (e.g., STD and TB program directors); community activists; local academic HIV researchers; and local government officials.
- Mail hard copies when it is necessary to do so.
- Make presentations to HPGs, Ryan White planning councils, 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 risk group, refer the caller to the profile.

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

Chapter 5.

Special Considerations

Section 1: Confidentiality

Confidentiality is defined as the protection of information that an individual or institution has disclosed in a relationship of trust, with the expectation that it will not be divulged to others in ways that are inconsistent with the individual's or the institution's understanding of the original disclosure.

Why is it 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 living with, 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.

What is confidential information?

Confidential information is any information about an identifiable person or establishment, when the person or establishment providing the data or described in it has not given consent to make that information public and was assured of confidentiality when the information was provided.

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 1 or more persons. A breach in confidentiality may cause a person to be subject to harassment and discrimination because his or her 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 to protect the confidentiality of HIV surveillance data and other information and to protect the privacy of HIV-infected persons. 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 "HIPPAA 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 follow CDC's Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, STD, and TB Programs: Standards to Facilitate Sharing and Use of Surveillance Data for Public Health Action.[*] These standards cover health department responsibilities for the ways in which HIV data are collected, analyzed, maintained, transmitted to CDC or other state agencies, released, and disposed of.

Confidentiality and epidemiologic profiles

When developing your epidemiologic profile, keep confidentiality concerns regarding the data in mind. Use aggregate—rather than individual—data throughout, including tables and figures. Aggregate data include summary statistics compiled from personal information that have been grouped to preclude 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., <3 or <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 that caution regarding stability of rates based on small numbers 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 or <20 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*. 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." Contractors should become familiar with the local data release policies. When preparing the profile, writers should indicate when data were suppressed because of small cell size.

Analyze cases by geographic area within strict guidelines for the confidentiality and release of HIV surveillance data as specified by the health department.

Do not include in the profile or in summary data or provide to the planning group any information (e.g., name, address, month and day of birth, or Social Security number) that could identify an individual.

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[*] 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.

Section 2: Special-Needs Populations

The Ryan White HIV/AIDS Treatment Extension Act of 2009 (Public Law 111-87, October 30, 2009; aka the Ryan White HIV/AIDS Program law) requires that applicants for program funds demonstrate the need for Ryan White program funds. Furthermore, the law requires that needs assessments and comprehensive plans used by Ryan White planning councils or consortia in setting priorities and allocating funds identify and address the unmet service needs of special populations. (Section 2 of the HRSA HIV/AIDS Bureau data monograph entitled “Using Data to Measure Public Health Performance: A Guide for Ryan White HIV/AIDS Program Grantees” [http://hab.hrsa.gov/manageyourgrant/files/datatomeasure2010.pdf] describes the conditions that unpin the collection and submission of Ryan White program data. The Ryan White grantee should be familiar with this data monograph.)

In planning for special 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 special or targeted populations, which should be carried out during needs assessment, is important in determining how to direct resources to people living with HIV (PLWH) who may be disenfranchised from HIV care services.

HRSA’s HIV/AIDS Bureau identified the following populations as requiring special attention during the planning and resource allocations processes conducted in a particular Ryan White service area:

- Youth 13–24 years of age
- Injection drug users
- Substance users other than injection drug users
- Men of color who have sex with men
- White, or Anglo, men who have sex with men
- Women of childbearing age (13 years of age and older)

In addition, Ryan White HIV/AIDS Program applicants 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.

Section 3: Comorbidity

The Ryan White HIV/AIDS Program law provides additional guidance on how HRSA's HIV/AIDS Bureau is to consider the severe-need factor in distributing Part A supplemental grant funds among Part A EMAs/TGAs (transitional grant areas). The Manager's Statement, which accompanies the Ryan White HIV/AIDS Program law, defines areas most in need of Part A funding as having "the greatest or expanding public health challenges in confronting the burden of HIV."

In setting service priorities and allocating Ryan White program funding, Part A planning councils/planning groups are required to consider epidemiologic data on comorbid conditions. They must especially consider how these conditions may increase the cost and complexity of delivering HIV primary medical care and support services to PLWH in the EMA.

A useful epidemiologic profile provides information on HIV prevalence among populations identified by a comorbid condition, such as STDs, hepatitis B or C, TB, substance use, or severe mental illness. It will also be important to provide information on increases or decreases in comorbid conditions among PLWH in the HIV care system. When possible, match the cost of comorbidities with the HIV population data to document the additional treatment costs.

Section 4: Areas with Low Morbidity and Minimal Data

For areas with a small number of cases, data may need to be aggregated to protect confidentiality. The epidemiologists providing data for the profile should determine when aggregating data is appropriate and which aggregates are most useful. For data re-release, CDC suppresses cells <5 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 *Technical Guidance for HIV Surveillance Programs: Policies and Procedures* (available at https://partner.cdc.gov/Sites/NCHHSTP/HICSB/Technical%20Guidance/).

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. EMAs/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, 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.

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

Table A-1. HIV diagnoses and rates among persons in State X, by race/ethnicity and sex, 2010

	Males			Females			Total		
Race/ethnicity	**No.**	**%**	**Rate[a]**	**No.**	**%**	**Rate[a]**	**No.**	**%**	**Rate[a]**
American Indian/Alaska Native	16	<1	18.9	10	<1	11.9	26	<1	15.4
Asian	42	1	9.4	16	1	3.3	58	1	6.2
Black/African American	2,107	52	106.1	1,179	69	53.9	3,286	56	78.9
Hispanic/Latino	597	14	54.9	195	11	17.9	792	14	36.4
Native Hawaiian/Other Pacific Islander	3	<1	48.9	1	<1	22.3	4	<1	32.1
White	1,300	32	10.2	305	18	2.3	1,605	28	6.1
Total	**4,065**	**100**	**25.1**	**1,706**	**100**	**10.1**	**5,771**	**100**	**17.0**

Source: X

[a] Rates are per 100,000 population.

Interpretation: In 2010, HIV was diagnosed for 5,771 persons of whom 4,065 (70%) were male and 1,706 (30%) were female. By race/ethnicity, 3,286 (56%) were black, 1,605 (28%) were white, 792 (14%) were Hispanic/Latino, 58 (1%) were Asian. American Indians/Alaska Natives (26) and Native Hawaiians/Other Pacific Islanders constituted less than 1% each.

The rate of diagnosed cases of HIV was 17 per 100,000 in State X. The rate for males was 2 times that for females (25/100,000 compared with 10/100,000). By race/ethnicity, the rate was highest for blacks (79/100 000) compared with Hispanics (36/100,000), American Indians/Alaska Natives (15/100 000), Native Hawaiian/Other Pacific Islander (32/100,000), and Asians and whites (6/100,000). The rates for black and Hispanic males were higher than those for all other groups (106/100,000 and 55/100,000, respectively). The third highest rate was that for black females (54/100,000). Note that 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 (refer to Chapter 6, Section 1, Confidentiality).

Table A-2. HIV diagnoses among persons in State X, by age group and sex, 2010

	Males		Females		Total	
Age (yrs)	**No.**	**%**	**No.**	**%**	**No.**	**%**
0–1	7	<1	7	<1	14	<1
2–12	7	<1	12	<1	19	<1
13–24	320	8	216	12	536	10
25–44	2,725	64	1,111	64	3,836	63
45–64	984	24	363	21	1,347	23
≥65	64	1	22	1	86	1
Total	**4,107**	**100**	**1,731**	**100**	**5,838**	**100**

Source: X

Interpretation: In 2010, a diagnosis of HIV was made for 5,838 persons in State X. Most of the diagnoses (66%) were for males aged 25–44 years.

Table A-3. HIV diagnoses among persons in State X, by transmission category and sex, 2010

	Males		Females		Total	
Transmission category	**No.**	**%**	**No.**	**%**	**No.**	**%**
Male-to-male sexual contact	2,095	51	N/A		2,095	36
Injection drug use	1,016	25	476	28	1,492	26
Male-to-male sexual contact and injection drug use	188	5	NA		188	3
Heterosexual contact	751	18	1,204	70	1,955	34
Other/unknown	44	1	33	2	77	1
Total	**4,094**	**100**	**1,713**	**100**	**5,807**	**100**

Source: X

N/A, not applicable

Interpretation: By transmission category, 2,095 (36%) persons were classified as infected through male-to-male sexual contact, 1,955 (34%) through heterosexual contact, and 1,492 (26%) through injection drug use. Among the 4,094 males diagnosed with HIV infection, the predominant transmission category was male-to-male sexual contact (51%), followed by injection drug use (25%) and heterosexual contact (18%). Among the 1,713 females diagnosed with HIV infection, the primary transmission category was heterosexual contact (70%), followed by injection drug use (28%).

Table A-4. HIV diagnoses among persons in State X, by transmission category and race/ethnicity, 2010

	American Indian/ Alaska Native		Asian		Black/African American		Hispanic/Latino		Native Hawaiian/ Other Pacific Islander		White		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Male-to-male sexual contact	7	27	21	34	874	27	261	33	—		921	57	2,084	36
Injection drug use	5	19	13	21	924	28	243	31	—		284	18	1,469	26
Male-to-male sexual contact and injection drug use	—		—		86	3	28	4	—		69	4	183	3
Heterosexual contact	14	54	27	45	1,349	41	241	31	—		299	19	1,930	34
Other/unknown	—		—		33	1	9	1	—		28	2	70	1
Total	26	100	61	100	3,253	100	782	100	—		1,601	100	5,736	100

Source: X

Dash indicates cell size of ≤3.

Interpretation: The percentage of persons with HIV infection attributed to male-to-male sexual contact was higher among whites than other racial/ethnic groups; injection drug use was higher for blacks/African Americans and Hispanics/Latinos. The percentage of blacks/African Americans, Asians, and American Indians/Alaska Natives with infection attributed to heterosexual contact was more than twice the percentage for whites and 1.5 times the percentage for Hispanics/Latinos.

Table A-5. Number of deaths of persons diagnosed with HIV infection and death rates per 100,000 population in State X, by race/ethnicity, 2010

	Males			Female			Total		
Race/ethnicity	**No.**	**%**	**Rate[a]**	**No.**	**%**	**Rate[a]**	**No.**	**%**	**Rate[a]**
American Indian/Alaska Native	7	1	8.3	0	—	—	7	1	5.9
Asian	6	1	1.2	0	—	—	6	<1	0.9
Black/African American	738	61	37.3	338	71	15.4	1,076	64	25.8
Hispanic/Latino	135			43	9	4.0	178	11	8.2
Native Hawaiian/Other Pacific Islander	1	<1	—	—				1	<1
White	323	26	2.5	88	19	0.7	411	24	1.6
Total	**1,210**	**100**	**7.4**	**469**	**100**	**2.8**	**1,679**	**100**	**5.0**

Source: X

Note. Deaths may be due to any cause.

Dash indicates cell size of ≤3.

[a] Rates are per 100,000 population.

Interpretation: The rate of death of persons diagnosed with HIV infection was much greater among males than among females and greater among blacks than among whites. The rate for Hispanics was intermediate between the rate for whites and the rate for blacks.

Note. The denominator used in calculating death rates is the population of interest in a service area. For example, in Table A-5, since the numbers and 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 HIV-infected persons aged 25–44, the denominator would be limited to the population in this age group.

Table A-6. Ranking of 10 leading underlying causes of death among persons 25–44 years of age in State X, 2010

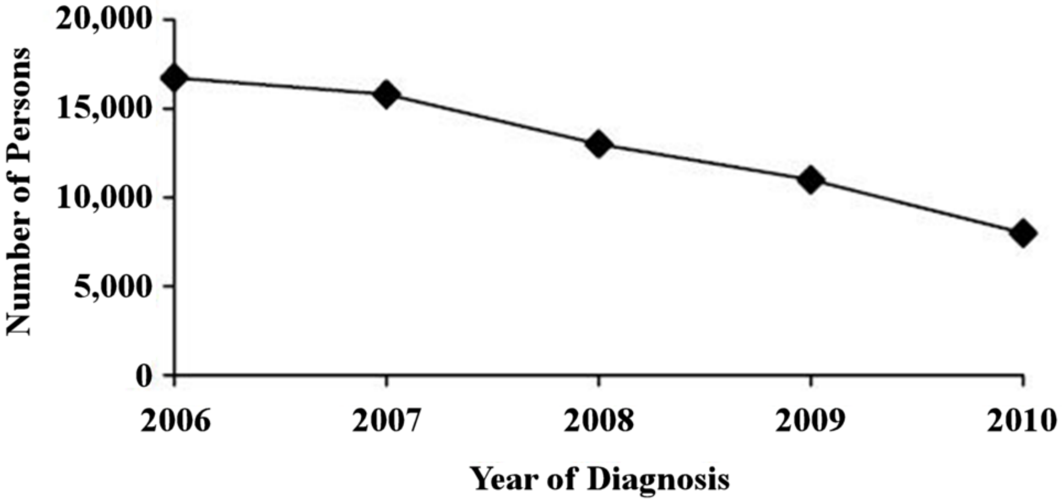
Cause	Ranking	Deaths, No.	Total deaths, % (N=934)
Unintentional injury	1	238	25.5
Malignant neoplasms	2	139	14.9
HIV disease	3	115	12.3
Homicide	4	86	9.2
Heart disease	5	80	8.6
Suicide	6	65	7.0
Cerebrovascular disease	7	16	1.7
Chronic liver disease	8	15	1.6
Diabetes mellitus	9	7	0.7
Pneumonia and influenza	10	6	0.6

Source: X

Note. Restricted to groups with at least 50 deaths from all causes and excluding causes of death that resulted in 3 or fewer deaths per group. 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 third leading cause of death in 2010 among persons 25–44 years old in State X, accounting for 12% of all deaths in this age group.

Figure A-1. Annual number of HIV diagnoses among persons in State X, 2006–2010



Source: X

Interpretation: From 2006 through 2010, the number of HIV diagnoses steadily declined. In 2006, the number of cases diagnosed was 17,500; in 2010, the number was 9,500.

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, 2009

	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, January–December, 2009

	USA	State X	County X
	%	%	%
Black/African American	51	34	52
Hispanic/Latino	17	20	18
White	28	40	26
Other races	4	6	4

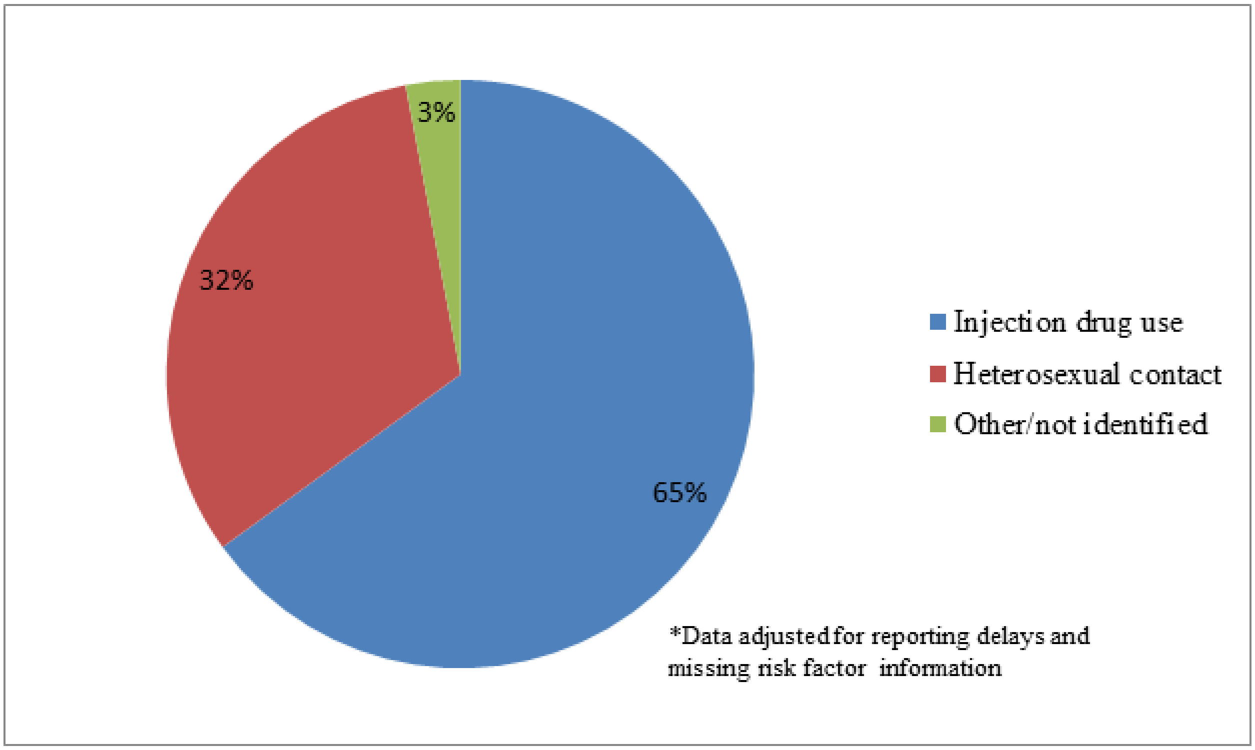
Source: X

PIE CHARTS

In the pie chart, the size of a "slice" is proportional to its percentage contribution to the whole. That is, each slice shows how much of the pie each group represents. Pie charts are useful for showing differences in proportions. For example, a pie chart can be used to show diagnosis of HIV among female adults and adolescents, by transmission category (see Figure B-1).

Figure B-1. Example of pie chart

Estimated HIV diagnoses* among female adults and adolescents, by transmission category, County X, 2010



*Data adjusted for reporting delays and missing risk factor information

Source: X

Tip: More than 8 slices can be ineffective because slices become too small for clear labels or visibility.

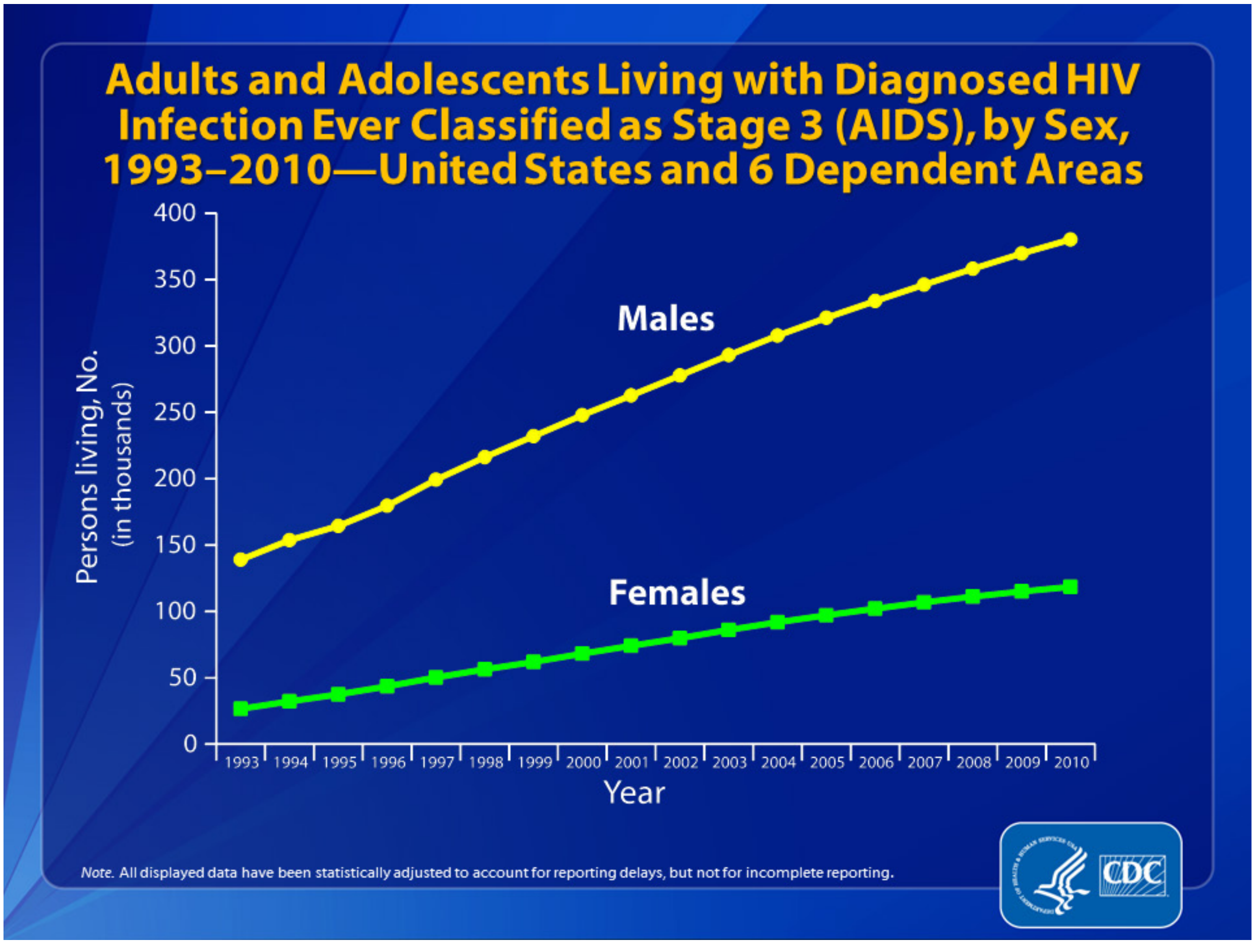
LINE GRAPHS

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-2. Example of line graph



Adults and Adolescents Living with Diagnosed HIV Infection Ever Classified as Stage 3 (AIDS), by Sex, 1993–2010—United States and 6 Dependent Areas

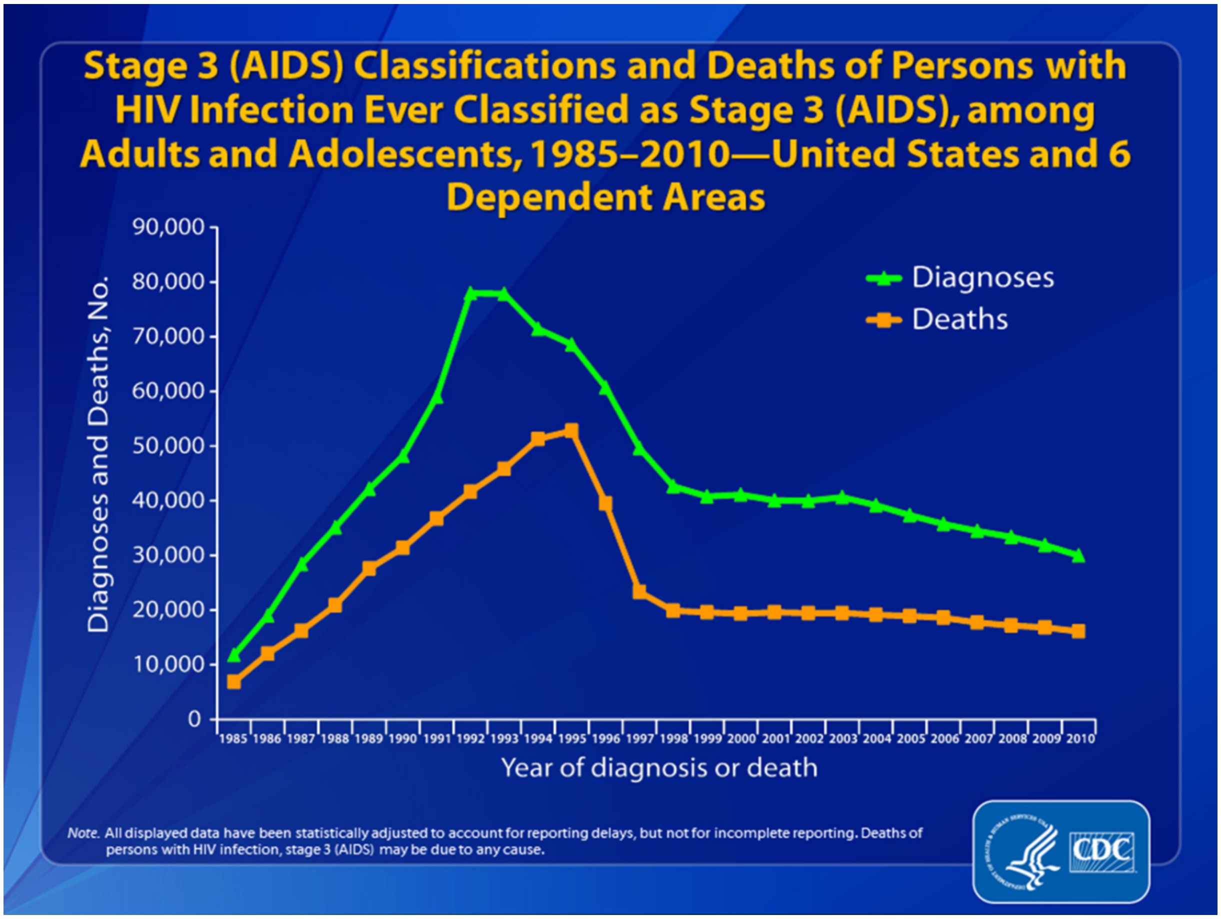
Note. All displayed data have been statistically adjusted to account for reporting delays, but not for incomplete reporting.

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

EPIDEMIC CURVES

The epidemic curve (Figure B-3) is a line graph that shows stage 3 (AIDS classifications) and deaths of persons ever classified as stage 3 (AIDS) by year of diagnosis or death.

Figure B-3. Example of epidemic curve



Stage 3 (AIDS) Classifications and Deaths of Persons with HIV Infection Ever Classified as Stage 3 (AIDS), among Adults and Adolescents, 1985–2010—United States and 6 Dependent Areas

Note. All displayed data have been statistically adjusted to account for reporting delays, but not for incomplete reporting. 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. This is due to an expansion of the HIV surveillance case definition implemented in 1993. Figure B-3 also shows a downward trend from 1966 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

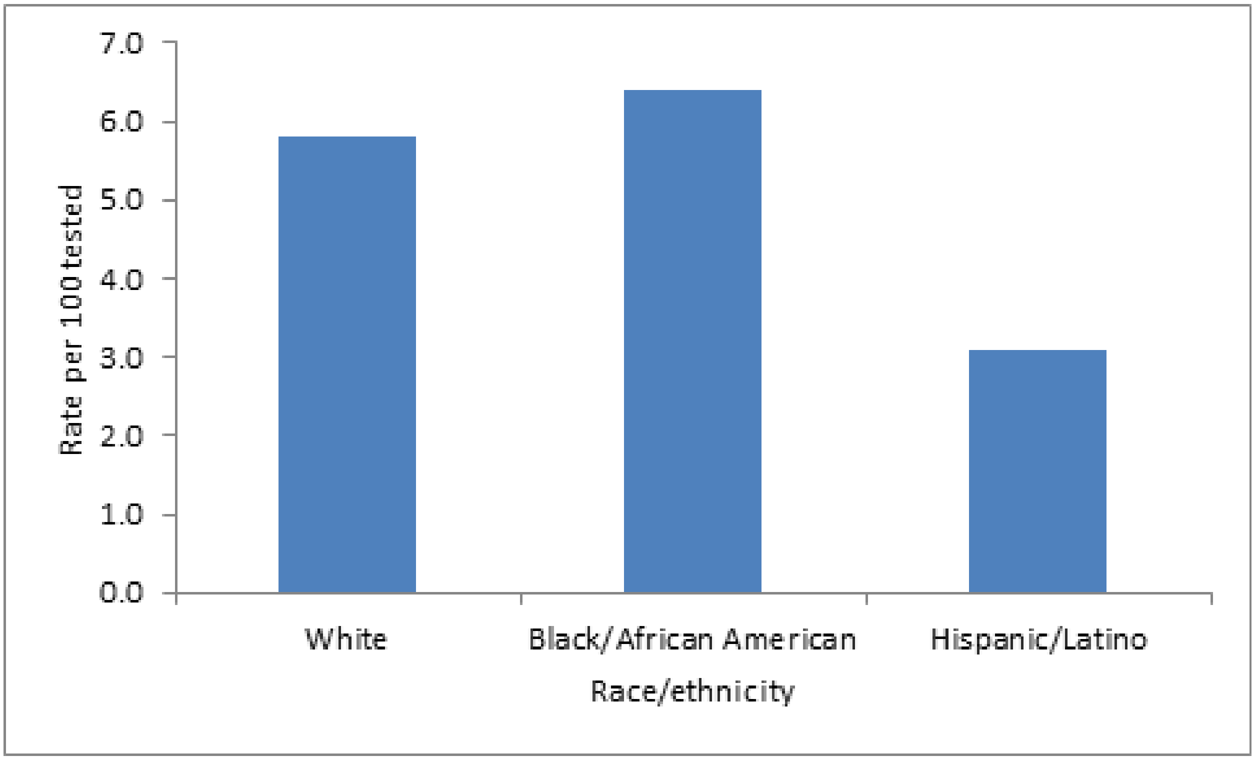
In a bar, or column, graph, data are organized so that each observation can fall into 1category of the variable.

Bar graphs are useful for showing how data change during a time 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-4 shows the measurable feature—rates per 100 tested—along the vertical (measuring) axis and the categories of the variable—race/ethnicity—along the horizontal baseline. In this example, you can see that among IDUs, the rate of testing positive for HIV infection is higher for blacks than for whites or Hispanics/Latinos.

Figure B-4. Example of bar, or column, graph

HIV-positive injection drug users, by race/ethnicity, County X, STD Clinics, 2000–2010



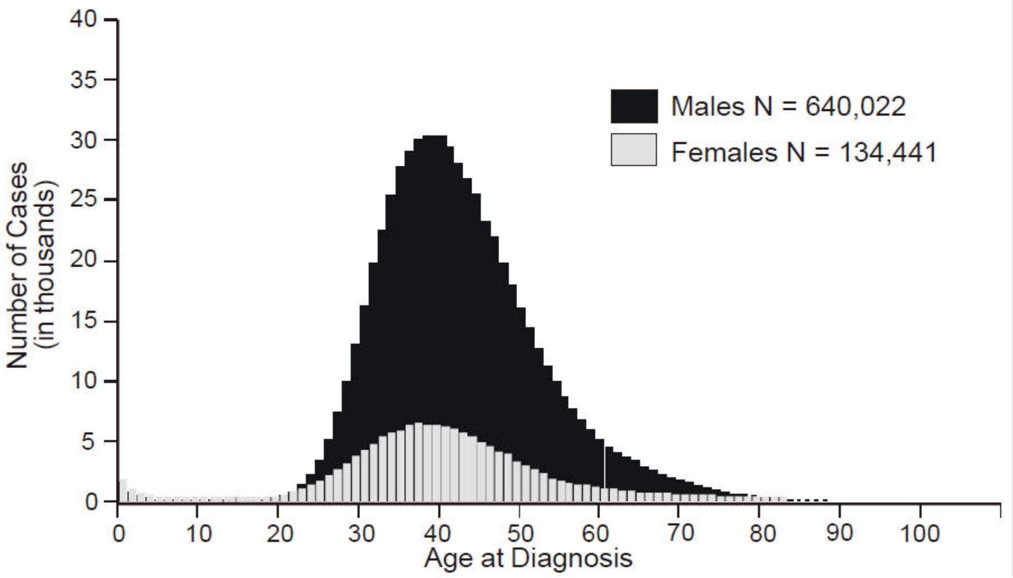
Source: X

HISTOGRAMS

The histogram, which resembles a bar graph because of the use of series of contiguous rectangles, represents the frequency distribution of an ordinal variable with interval properties (i.e., a variable, such as age, which has an infinite number of values). The contiguous, or adjoining, rectangles represent the number of observations for each class of interval in the distribution. The height of each rectangle is proportional to the number of observations (values) in that range.

Figure B-5. Example of Histogram

AIDS Cases by Age and Sex, reported 1981–2000, United States

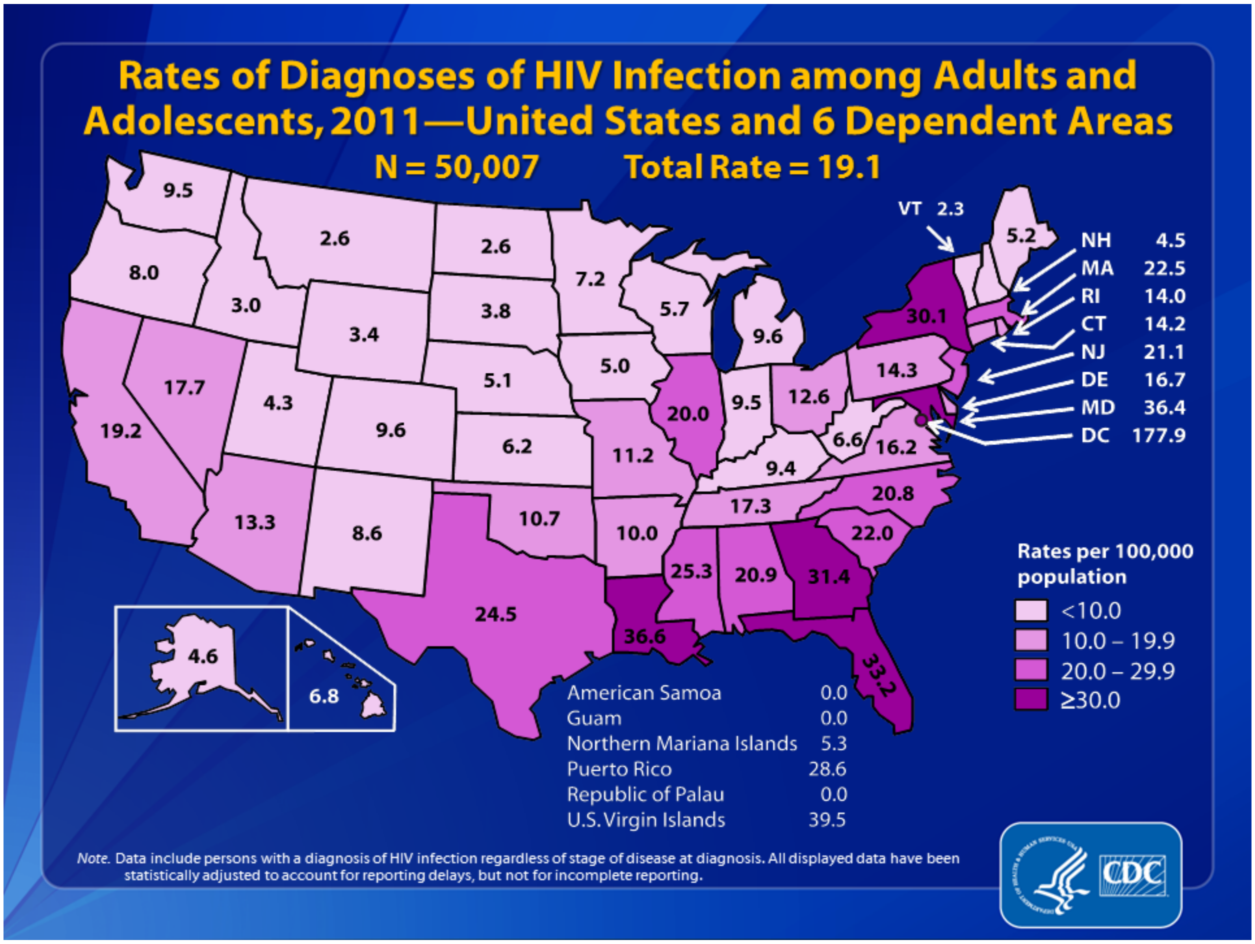


Source: X

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 of an event in an area or the distribution of some condition throughout a geographic area, and maps produced by the use of Geographic Information Systems, or GIS, (see Chapter 4) display data based on geographic mapping coordinates.

Figure B-6. Example of area map



Rates of Diagnoses of HIV Infection among Adults and Adolescents, 2011—United States and 6 Dependent Areas

N = 50,007 Total Rate = 19.1

American Samoa	0.0
Guam	0.0
Northern Mariana Islands	5.3
Puerto Rico	28.6
Republic of Palau	0.0
U.S. Virgin Islands	39.5

Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. All displayed data have been statistically adjusted to account for reporting delays, but not for incomplete reporting.

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

Appendix C.

Data Sources

CORE DATA SOURCES

HIV Surveillance

Overview: HIV surveillance data include all persons with confirmed diagnosis of HIV infection (including stage 3 [AIDS]) and who have been reported to a state or local health department. State and local health departments solicit disease reports from health care providers and laboratories. Standardized case report forms are used to collect sociodemographic information, mode of exposure, laboratory and clinical information, vital status, and referrals for treatment or services. HIV surveillance monitors the diagnosis of HIV infection, the demographic profile of HIV infected persons, and the mode of transmission. HIV surveillance data are also used to allocate resources for Ryan White HIV/AIDS Programs.

Population: All persons who test positive for HIV

Strengths: According to state evaluations, HIV infection reporting is estimated to be 80%–90% complete for persons who have tested positive for HIV. HIV surveillance provides information on persons known to be HIV infected and reported to the health department, emerging patterns of transmission, and trends in HIV infections among populations of particular interest (e.g., children, adolescents, women). HIV data also provide a basis for establishing and evaluating linkage to care, retention in care, and viral suppression. They can be used to anticipate unmet needs for HIV care.

Limitations: All areas now have confidential name-based HIV reporting laws or regulations. However, HIV surveillance data may underestimate the number of infected persons because some infected persons have not been diagnosed. 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; U.S. territories; District of Columbia.

Contact: State or local health department, HIV surveillance coordinator

Reference

CDC. Revised surveillance case definitions for HIV infection among adults, adolescents, and children <18 months and for HIV infection and AIDS among children aged 18 months to <13 years—United States, 2008. *MMWR* 2008;57(RR-10);1–8.

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. These questions include 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 2001, respondents have been asked about their perception of the importance of HIV testing.

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. 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; 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.

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 June 12, 2014).

CDC Medical Monitoring Project (MMP)

Overview: MMP is a supplemental surveillance project designed to produce nationally representative data on people living with HIV who are receiving care in the United States. MMP has a 3-stage sampling design. During the first stage of sampling, geographic areas were sampled with probability proportional to size based on stage 3 (AIDS) prevalence at the end of 2002.

During the second stage of sampling, a representative sample of HIV care providers is chosen from each area. During the third stage of sampling HIV-infected patients are selected from sampled providers. MMP's data collection has two primary components: an interview and medical record abstraction. Collection of data from interviews with HIV-infected patients will provide information on the current behaviors that may facilitate HIV transmission; patients' seeking access to and use of HIV-related prevention services; utilization of HIV-related medical services; and adherence to medication regimens. Through abstraction of medical records, MMP provides information on clinical conditions that result from HIV-infected persons' disease or the medications they take, as well as the HIV care and support services they receive and the quality of these services.

Populations: Patients receiving outpatient medical care for HIV infection.

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

Limitations: HIV-infected individuals not receiving HIV medical care are not sampled. Additionally, HIV-infected individuals receiving HIV care in federal, state and local correctional and work-release facilities; tribal facilities; health facilities located on military installations; and facilities that have provided HIV care only to patients under the age of 18 are not included.

Where available: As of 2013, a total of 23 project areas (17 states and 6 separately funded metropolitan statistical areas within funded states) are conducting MMP activities: California; Chicago, IL; Delaware; Florida; Georgia; Houston, Texas; Illinois; Indiana; Los Angeles, CA; Michigan; Mississippi; New Jersey; New York; New York City, NY; North Carolina; Oregon; Pennsylvania; Philadelphia, PA; Puerto Rico; San Francisco, CA; Texas; Virginia; and Washington.

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)

Overview: NHBS is CDC's comprehensive system for conducting behavioral surveillance among persons at highest risk for HIV infection in the US. The overall strategy for NHBS involves conducting rotating 12-month cycles of surveillance in 3 different populations at high risk for HIV: men who have sex with men (MSM), injection drug users (IDU) and heterosexuals at increased risk of HIV infection (HET). The behavioral survey assesses risk behaviors (including sex and drugs) and use of and access to prevention services among persons older than 18 years of age who are at increased risk for HIV infection. Anonymous HIV testing is offered to all participants, which can then be used to estimate HIV prevalence in these populations.

Populations: Men who have sex with men, injection drug users, and heterosexuals at increased risk.

Strengths: Among MSM, venue-based time-space sampling is used to obtain a sample of men attending venues. Among IDU 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: 20 state and local health departments and their grantees in metropolitan statistical areas (from 2011–2015) where HIV prevalence is highest: Atlanta, GA; Baltimore, MD; Boston, MA; Chicago, IL; Dallas, TX; Denver, CO; Detroit, MI; Houston, TX; Los Angeles, CA; Miami, FL; Nassau-Suffolk, NY; New Orleans, LA; New York City, NY; Newark, NJ; Philadelphia, PA, San Diego, CA; San Francisco, CA; San Juan, PR; Seattle, WA; and Washington, DC.

Contact: State or local health department NHBS Coordinator (available at http://www.cdc.gov/hiv/statistics/systems/nhbs/contacts.html); for NHBS at CDC, see http://www.cdc.gov/hiv/statistics/systems/nhbs/contacts.html for detailed contact information.

CDC National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention ATLAS

Overview: The Atlas provides an interactive platform for accessing state and county-level HIV surveillance data collected by CDC's National Center for HIV/AIDS, 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
- Sexually transmitted disease
- Tuberculosis
- Viral Hepatitis

Where available: http://gis.cdc.gov/GRASP/NCHHSTPAtlas/main.html. Accessed June 12, 2014.

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 Hispanics (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 in order 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 February 7, 2013.

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., 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

Drug Abuse Warning Network (DAWN)

Overview: DAWN is a national data system that collects information on drug-related deaths from participating medical examiner offices and information on drug-related visits to hospital emergency departments from a nationally representative sample of short-stay general hospitals throughout the contiguous United States. Emergency department estimates are produced for 21 large metropolitan areas and for the nation. Drug-related death data are produced for more than 40 metropolitan areas.

DAWN was established to provide national, state, and local areas with data for program planning and policy; to identify substances associated with drug abuse deaths; to monitor drug abuse patterns and trends and detect new drugs of abuse; and assess adverse health outcomes associated with drug abuse.

Population: Persons who died at 6–97 years of age, whose death was drug induced or drug related, and who had used the substance because of dependence, to commit suicide, for recreational purposes, or to achieve other psychic effects.

Strengths: DAWN provides ongoing data on the patterns of drug-induced and drug-related deaths from many areas of the United States. Standardized data collection and data management procedures are used to ensure the accuracy of DAWN data. Because of concerns about the accuracy of DAWN data, the methods were revised, and the protocol modifications were delivered in 2001.

Limitations: Participation in DAWN is voluntary; thus, counts of deaths do not represent the entire service area if participation is not universal. DAWN collects information only about drug abuse episodes that have resulted in a death and deaths that have been identified as drug induced or drug related. Finally, because DAWN relies on death investigation case files for reporting, the drugs may be underreported (if not reported), or the drug information may not be specific (if drug name is recorded differently).

Where available: Atlanta, Baltimore, Boston, Buffalo, Chicago, Dallas, Denver, Detroit, District of Columbia, Los Angeles, Miami, Minneapolis, Newark, New Orleans, New York City, Philadelphia, Phoenix, San Diego, San Francisco, Seattle, St. Louis.

Source: http://www.samhsa.gov. Accessed June 12, 2014.

Enhanced Perinatal Surveillance (EPS) 1999–2011

Overview: The project was established to monitor the implementation and effect of the Public Health Service recommendations for preventing perinatal HIV transmission on pediatric HIV trends, provide a data collection system that enables states to respond to selected requirements of the Ryan White HIV/AIDS Program, and assist with timely evaluation of perinatal prevention efforts. The project collects data by the use of the HIV case report form and collects additional information from supplemental records by the use of a medical record abstraction form. The enhanced surveillance methods used to identify HIV-infected mothers and their perinatally exposed children include matching the birth registry to the HIV surveillance registry and the linking of mother-infant pairs. Information on HIV-infected mothers and their perinatally exposed children is abstracted from multiple sources: the maternal HIV record, prenatal care records, labor and delivery records, birth records, pediatric HIV records, birth and death certificates, and laboratory reports. The data that are collected include maternal and prenatal care, mother's HIV test history, prenatal and neonatal antiretroviral therapy, other interventions to prevent transmission, receipt of prophylaxis and treatment of the infant, appropriate follow-up care of the mother and child, and other interventions relevant to the evaluation of recommended public health actions to prevent perinatal HIV transmission. Infants identified through enhanced surveillance are followed up every 6 months until their HIV infection status is determined; if they meet the case definition, they are followed up to determine their vital status.

Population: All HIV-exposed infants born during 2005–2010 and their HIV-positive mothers

Strengths: The project is population-based in most areas. In the facility-based project areas, the selected facilities were those where most of the births to HIV-positive women take place. The project collects information on HIV-exposed infants every 6 months until HIV infection is diagnosed. Study sites are able to 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 an HIV-exposed infant 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. Because the Survey of Childbearing Women was discontinued in 1994, no population-based seroprevalence data are available to estimate the completeness of ascertainment of infants born to HIV-infected mothers for birth cohort years 2005 and later.

Where available: Chicago, Connecticut, Delaware, Georgia, Houston, Los Angeles, Louisiana, Maryland, New Jersey, New York City, New York State, Philadelphia, Puerto Rico, South Carolina, and Texas.

Contact: State or local health department, HIV surveillance coordinator; CDC, Division of HIV/AIDS Prevention, HIV Incidence and Case Surveillance Branch

Perinatal HIV Exposure Reporting (PHER) 2013–Current

Overview: PHER differs from EPS in that information collected focuses on fewer key data elements to be collected on the standard pediatric case report form. In PHER, infants known to be HIV-exposed are monitored after birth up to 18 months of age to determine HIV infection status of the child and progression to HIV, stage 3 (AIDS). PHER attempts to get women reported as early as possible in their pregnancy by working with providers (HIV care providers, prenatal and obstetric care providers) to identify and report HIV-infected women who are pregnant and obtain information on their children.

Population: All HIV-exposed infants born during 2013–current and their HIV-positive mothers.

Strengths: The project is population based. The project collects information on HIV-exposed infants every 6 months until HIV infection is diagnosed. Study sites are able to 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 an HIV-exposed infant 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: 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 diagnosed with HIV infection, 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/AIDS Prevention, HIV Incidence and Case Surveillance Branch.

Gonococcal Isolate Surveillance Project (GISP)

Overview: Established in 1986 to monitor trends in antimicrobial susceptibilities of strains of *N. gonorrhea* in the United States in order to establish a rational basis for the selection of gonococcal therapies. GISP is a collaborative project among selected sexually transmitted disease (STD) clinics, 5 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 28 cities in the United States. At regional laboratories, the susceptibilities of these isolates to penicillin, tetracycline, spectinomycin, ciprofloxacin, ceftriaxone, cefixime, and azithromycin are determined by agar dilution. Minimum inhibitory concentrations (MICs) are measured, and values are interpreted according to criteria recommended by the National Committee for Clinical Laboratory Standards (NCCLS).

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 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: 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

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 infected persons 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

Contact: State or local hepatitis C (if available) or hepatitis B coordinator; CDC, Division of Viral Hepatitis

References

CDC. Recommendations for prevention and control of hepatitis C virus (HCV) infection and HCV-related chronic disease. *MMWR* 1998;47(RR-19):1–39.

CDC. *Guidelines for Viral Hepatitis Surveillance and Case Management*. Atlanta: CDC; 2005. http://www.cdc.gov/hepatitis/Statistics/SurveillanceGuidelines.htm. Accessed February 7, 2013.

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/AIDS director.

HIV Incidence Surveillance

Overview: As an extension of HIV case surveillance, state and local health departments that conduct HIV incidence surveillance collect additional information about HIV testing and treatment history as part of routine surveillance activities. Health department incidence surveillance personnel work with commercial, private, public, and hospital-based laboratories to obtain remnants of the diagnostic blood specimens to test for recent infection. Remnant specimens are tested as part of a serologic testing algorithm for recent HIV seroconversion (STARHS) to determine, at the population level, how many of the HIV-positive test results indicate new HIV infections. HIV testing and treatment history information and results from STARHS are used in a complex statistical model to calculate population-based estimates of HIV incidence.

Population: All persons with newly reported HIV infections who do not have advanced disease, such as stage 3 (AIDS), and who are not taking antiretroviral medications for HIV prevention or to treat or try to prevent hepatitis B.

Strengths: Estimates of HIV incidence can be used to monitor emerging trends in HIV, to assess progress in decreasing the number of new HIV infections that occur each year, to evaluate the effectiveness of prevention programs, and to allocate program resources.

Limitations: Any significant recent changes in HIV testing behavior may impact the underlying assumption inherent in the statistical model that HIV testing behavior be constant over the recent 2-year period, which may lead to bias in incidence estimates. The estimation model does not currently address individual motivation to be tested for HIV infection, which may lead to slight overestimates of HIV incidence if a significant number of individuals are motivated to be tested due to a recent exposure. STARHS may misclassify some persons with long-standing HIV infection as recent. Although this potential for misclassification is minimized in the statistical model by classifying all cases diagnosed with stage 3 (AIDS) at or within 6 months of HIV diagnosis as long-standing HIV infection, there may be some cases that are diagnosed late in infection but not as close to a stage 3 (AIDS) diagnosis that could still be misclassified, potentially adding to uncertainty in the estimates.

Where available: Since 2008, 25 jurisdictions have conducted HIV incidence surveillance: Alabama, Arizona, California, Chicago, Colorado, Connecticut, District of Columbia, Florida, Houston, Indiana, Los Angeles, Louisiana, Massachusetts, Michigan, Mississippi, New Jersey, New York, New York City, North Carolina, Philadelphia, San Francisco, South Carolina, Texas, Virginia, and Washington. Additional areas were previously funded for HIV incidence surveillance, including: Maryland, Missouri, Ohio, Oklahoma, Tennessee, Puerto Rico, and Seattle.

Contact: Local HIV incidence surveillance site coordinator; CDC, Division of HIV/AIDS Prevention, HIV Incidence and Case Surveillance Branch

Hospital 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 HIV-infected outpatients in clinics across the United States. HOPS abstracts clinical, immunologic, and virologic 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 HIV-infected persons. Thus, information from this study may not be representative of all HIV-infected patients 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, New York City, Oakland (California), Philadelphia, and Tampa

Contact: Local study investigators; CDC, Division of HIV/AIDS Prevention, Epidemiology Branch

Molecular HIV Surveillance (MHS)

Overview: As a part of the routine HIV case reporting, data are collected on HIV-1 nucleotide sequences to assess prevalence and trends in acquired and transmitted HIV drug resistance; evaluate HIV genetic diversity; and describe HIV transmission patterns to help evaluate the impact of HIV prevention strategies, guide public health action, and estimate the burden of HIV in the United States.

Population: HIV-1–infected persons residing in jurisdictions conducting MHS.

Strengths: MHS is built on the strength of the HIV surveillance system in the United States and merges demographic and transmission risk data of persons diagnosed with HIV-1 infection and HIV-1 nucleotide sequence data to assemble epidemiologic profiles of HIV-1 at the molecular level, including mutations associated with drug resistance, subtypes, and transmission cluster networks.

Limitations: Not all surveillance jurisdictions collect HIV-1 nucleotide sequence data.

Contact: State or local health department MHS Coordinator; CDC, Division of HIV/AIDS Prevention, HIV Incidence and Case Surveillance Branch, MHS Coordinator.

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: Deaths since 1979 in the entire United States, Puerto Rico, and the U.S. Virgin Islands

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

Limitations: This database cannot be searched to look for deaths of, or with, particular causes of death, 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
Contact:
National Death Index
National Center for Health Statistics
Division of Vital Statistics
6525 Belcrest Road, Room 820
Hyattsville, MD 20782
Phone: 301-458-4101
Fax: 301-458-4034

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 February 7, 2013.

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, the John D. and Catherine T. MacArthur Foundation, the Open Society Foundations, and the Rockefeller 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, Baltimore, Boston, Camden, Chattanooga, Chicago, Cleveland, Columbus, Des Moines, Detroit, Dallas, Denver, Grand Rapids, Hartford, Indianapolis, Kansas City, Louisville, Memphis, Miami, Milwaukee, Minneapolis-St. Paul, Nashville, New Haven, New Orleans, New York, Oakland (California), Philadelphia, Pittsburg, Portland, Providence (Rhode Island), Sacramento, St. Louis, San Antonio, Seattle, Washington, and Urban Institute

Reference

National Neighborhood Indicators Partnership. http://www.neighborhoodindicators.org. Accessed June 12, 2014.

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 14-page questionnaire to gauge the extent of prenatal care, including counseling and testing of all pregnant women who delivered a live-born infant. Repeated questionnaire mailings are sent to the mother to encourage participation. Attempts to interview the mother by telephone are made soon thereafter. 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 or at the time of delivery.

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 infection 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 HIV-infected women is not gathered.

Where available: 37 states (Alabama, Alaska, Arkansas, Colorado, Delaware, Florida, Georgia, Hawaii, Illinois, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, North Carolina, Nebraska, New Jersey, New Mexico, New York, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin, Wyoming) and New York City.

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. *Maternal and Child Health Journal* 1999;3(4):199–209.

Ryan White HIV/AIDS Program Services Report (RSR)

Overview: Beginning in 2009, Ryan White Program grantees and service providers started using a new data collection and reporting system to report information on their programs and the clients they serve to the HIV/AIDS Bureau.

The Ryan White HIV/AIDS Program Services Report, or the RSR for short, is comprised of:

- **The Grantee Report**. Grantees completes this report online through the HRSA Electronic Handbooks (EHBs) using a Web-based data entry system. Besides providing basic information about their organization, they will view, update, and verify a pre-filled list of their service provider contracts that were active in the most recent reporting period. For each of the contracts, grantees will view a list of Ryan White Program services and then check the boxes next to all services that their organization funded under the contract.
- **The Service Provider Report**. Service providers will complete this report online. In addition to providing some basic information about their organization, providers will view a pre-filled list of their active service provider contracts for the most recent reporting period. For each of the service contracts, providers will view a list of Ryan White Program services and check the boxes next to all services that their organization delivered to RW Program clients during the reporting period.
- **The Client Report**. Each service provider will submit this report online as an electronic file upload using a standard format. Each upload file will contain one record per client. Each client record will include information on demographic status, HIV clinical information, HIV-care medical and support services received, and the client's 'UCI', an encrypted, unique client identifier.

Strengths: The RSR data set is well-defined (see the HRSA Web site). The Ryan White grantee has the source data that was submitted to HRSA's HIV/AIDS Bureau. The "Client Report" can be used by the Ryan White grantee 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 Ryan White grantee. So issues related to data collection, data completeness, and data quality must be addressed by the Ryan White grantee prior to submission to HRSA.

Where available: All Ryan White grantees and first-level provider (through grantees).

Contact: Local Ryan White HIV/AIDS Program grantees.

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, territories, and tribal governments. 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 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 ≥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: In 2010, 49 states, 20 large urban school districts, 5 territories, and 2 tribal governments obtained the minimum response rate for their data to be weighted for the principal questionnaire, the lead health education teacher questionnaire, or both.

Contact: Departments of education in states, large urban school districts, territories, and tribal governments; CDC, Division of Adolescent and School Health

Reference

CDC. Adolescent and School Health: School Health Profiles. http://www.cdc.gov/healthyyouth/profiles/. Accessed February 7, 2013.

Sexually Transmitted Disease Surveillance

Overview: CDC conducts surveillance to monitor the levels of syphilis, gonorrhea, chancroid, and, more recently, chlamydia, in the United States in order to establish prevention programs, develop and revise treatment guidelines, and identify populations at risk for sexually transmitted diseases (STDs). States, local areas, and U.S. territories submit to CDC (weekly, monthly, or annually) case reports of STDs 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 STDs to monitor the STD 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: STD 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). STD data are widely available at the state and local level and because of shorter incubation periods between exposure and infection, STDs can serve as a marker of recent unsafe sexual behavior. In addition, certain STDs (e.g., ulcerative STDs) can facilitate transmission or acquisition of HIV infection. Finally, changes in trends of STDs may indicate changes in community sexual norms (e.g., unprotected sex).

Limitations: STDs are reportable, but requirements for reporting differ by state. Reporting of STDs from private-sector providers may be less complete. Although STD 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 STD program manager

Reference

CDC. Case definitions for infectious conditions under public health surveillance. *MMWR* 1997;46(RR-10):1–56.

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

Tuberculosis Surveillance

Overview: 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 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

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/AIDS 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: All 50 states, the District of Columbia, Puerto Rico, and other U.S. jurisdictions in the Pacific and Caribbean.

Contact: State or territorial TB Control Offices: http://www.cdc.gov/tb/links/tboffices.htm. Accessed February 7, 2013.

Reference

CDC. *Reported Tuberculosis in the United States, 2009*. Atlanta, GA: U.S. Department of Health and Human Services, CDC, October 2010. http://www.cdc.gov/tb/statistics/reports/2009/default.htm. Accessed February 7, 2013.

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 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 June 12, 2014.

Vital Records—Birth Data

Overview: 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 (i.e., 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: State vital records registrar; CDC, National Center for Health Statistics

Reference

CDC. National Center for Health Statistics. http://www.cdc.gov/nchs. Accessed February 7, 2013.

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 (i.e., smoking, accident, or injury).

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 February 7, 2013.

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.

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 February 7, 2013.

Youth Risk Behavior Surveillance System (YRBSS) among American Indian or Alaska Native Students

Overview: The Youth Risk Behavior Surveillance System (YRBSS) was 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. Included in the YRBSS is the national Youth Risk Behavior Survey (YRBS) from which the prevalence of health risk behaviors among different racial/ethnic groups can be determined, including American Indian or Alaska Native students (see http://www.cdc.gov/yrbss, then click **Enter Youth Online**). The YRBS also is conducted among some Native American populations: (a) Navajo Nation; (b) Cherokee Nation; (c) Bureau of Indian Education; and (d) Montana.

Using a self-administered questionnaire, the YRBS 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: For the Navajo YRBS, targeted schools are all schools with at least 10 students enrolled in the middle or high school grades, at least 50% Navajo student enrollment, and located within the Navajo Nation or the Navajo Area Indian Health Service Area. All students in those targeted schools are asked to participate.

For the Cherokee YRBS, a probability sample of regular public middle and high schools within the Cherokee Nation jurisdiction are used.

For the Bureau of Indian Education YRBS, targeted schools are all schools funded by the Bureau of Indian Education with at least 10 students enrolled in the middle or high school grades. All students in those targeted schools are asked to participate.

Montana samples Native American students attending public high schools outside Montana Indian reservations and high school students enrolled in schools within a reservation or bordering one. State level YRBS data are also stratified by four racial/ethnic groups, including American Indian.

Strengths: The YRBS is conducted among some Native American middle and high school students. The questionnaire is administered anonymously to students during school. Inferences from YRBS data can be drawn about the behaviors of Native American adolescents attending schools within the jurisdiction that the YRBS was conducted, making the information useful for developing community-wide prevention programs aimed at adolescents in those communities. The data from the Bureau of Indian Education YRBS can be generalized to Native American students attending Bureau-funded schools in the continental United States.

Limitations: Limitations of the YRBS conducted among Native American populations include those identified with the YRBS project among the general population. Principal limitations are that the data are self-reported; reporting of sensitive behavioral information may not be accurate (underreporting or overreporting may occur); the data are representative only of children and adolescents who are enrolled in school; and answers to questions about behaviors during the past year may be subject to recall bias. The Bureau of Indian Education survey is conducted among students attending Bureau-funded schools; thus, survey estimates cannot be generalized to students who attended schools not funded by the Bureau of Indian Education.

Where available:

- 1997–2008—Navajo Nation and selected bordering high schools
- 2000–2008—Navajo Nation and selected bordering middle schools
- 2009–2011—Cherokee Nation middle and high schools
- 1994–2008—Bureau of Indian Education high schools
- 1997–2008—Bureau of Indian Education middle schools
- 1999–2011—Montana high schools;

Contact:

- Navajo Nation Department of Health, 928-349-1385 for Navajo YRBS.
- Bureau of Indian Education, Division of Performance and Accountability, 505-563-5266 for the Bureau of Indian Education YRBS.
- Cherokee Nation Community Health Promotion 918-453-5616 for Cherokee YRBS.
- Montana Office of Public Instruction 406-444-3178 and available online at www.opi.mt.gov/yrbs. Accessed February 7, 2013.

Appendix D.

Ryan White HIV/AIDS Programs

The Ryan White HIV/AIDS Program is divided into several “Parts,” following from the authorizing legislation.

PART A

Part A provides grant 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. EMA eligibility requires an area to report more than 2,000 stage 3 (AIDS) cases in the most recent 5 years and to have a population of at least 50,000. To be eligible as a TGA, an area must have at least 1,000 reported but fewer than 2,000 new stage 3 (AIDS) cases in the most recent 5 years. The FY 2010 Part A appropriation was approximately $679.1 million.

PART B

Part B provides grants to States and Territories to improve the quality, availability, and organization of HIV health care and support services. Part B grants include a base grant; the AIDS Drug Assistance Program (ADAP) award; ADAP Supplemental Drug Treatment Program funds; and supplemental grants to States with “emerging communities,” defined as jurisdictions reporting between 500 and 999 cumulative stage 3 (AIDS) cases over the most recent 5 years. Congress designates, or “earmarks,” a portion of the Part B appropriation for ADAP. With the dramatic increase in the cost of pharmaceutical treatment, the ADAP earmark is now the largest portion of Part B spending.

The FY 2010 Part B appropriation was approximately $1.25 billion of that, $835 million was for ADAP. Five percent of the ADAP earmark is set aside for the ADAP Supplemental Drug Treatment Program, which assists States needing additional ADAP funds.

- Part B provides $5 million in supplemental grants to States for Emerging Communities.
- In 2009, $50,000 awards were made to 2 newly eligible U.S. Pacific Territories (American Samoa and the Commonwealth of the Northern Mariana Islands) and 3 Associated Jurisdictions (the Republic of the Marshall Islands, the Federated States of Micronesia, and the Republic of Palau).

PART C

Part C supports outpatient HIV early intervention services and ambulatory care. Unlike Part A and Part B grants, which are awarded to local and State governments that contract with organizations to deliver services, Part C grants are awarded directly to service providers, such as ambulatory medical clinics. Part C also funds planning grants, which help organizations more effectively deliver HIV care and services. The FY 2010 Part C appropriation was approximately $206.8 million.

PART D

Part D grants provide family-centered comprehensive care to children, youth, and women and their families and help improve access to clinical trials and research. In FY 2010, Part D programs received approximately $77.8 million in appropriations.

PART F

Part F grants support several research, technical assistance, and access to care programs.

- The **Special Projects of National Significance** (**SPNS**) Program supports the demonstration and evaluation of innovative models of HIV care delivery for hard-to-reach populations. SPNS also funds special programs to support the development of standard electronic client information data systems by Ryan White HIV/AIDS Program grantees. A total of $25 million was set aside for the SPNS Program in FY 2010.
- The **AIDS Education and Training Centers** (**AETC**) Program supports education and training of health care providers through a network of 11 regional and 4 national centers. In FY 2010, the AETC appropriation was approximately $34.8 million.
- **Minority AIDS Initiative** (**MAI**) was established initially in FY 1999 via the Congressional appropriations process to provide funding to improve access to HIV care and health outcomes for disproportionately impacted minority populations, under Parts A, B, C and D. The types of MAI-funded services provided under Parts A, C and D were consistent with their 'base' programs, while the Part B MAI focused on education and outreach to improve minority access to State ADAP's. The MAI was then codified with respect to each Part by the Ryan White HIV/AIDS Treatment Modernization Act of 2006, which also made the Part A and B MAI separate, competitive grant programs for EMA/TGA's and States respectively. However, under the Ryan White HIV/AIDS Treatment Extension Act of 2009, the Congress directed that both be returned to a formula grant basis and 'synchronized' with the Part A and B grant awards, similar to the Parts C and D MAI.

All grant programs of the Ryan White HIV/AIDS Treatment Extension Act of 2009 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 who are HIV positive while providing education and

clinical training for dental care providers, especially those practicing in community-based settings.

In total, the Dental Program receives a combined $13.6 million in appropriations in FY2010.

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

- 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 are currently living with 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).

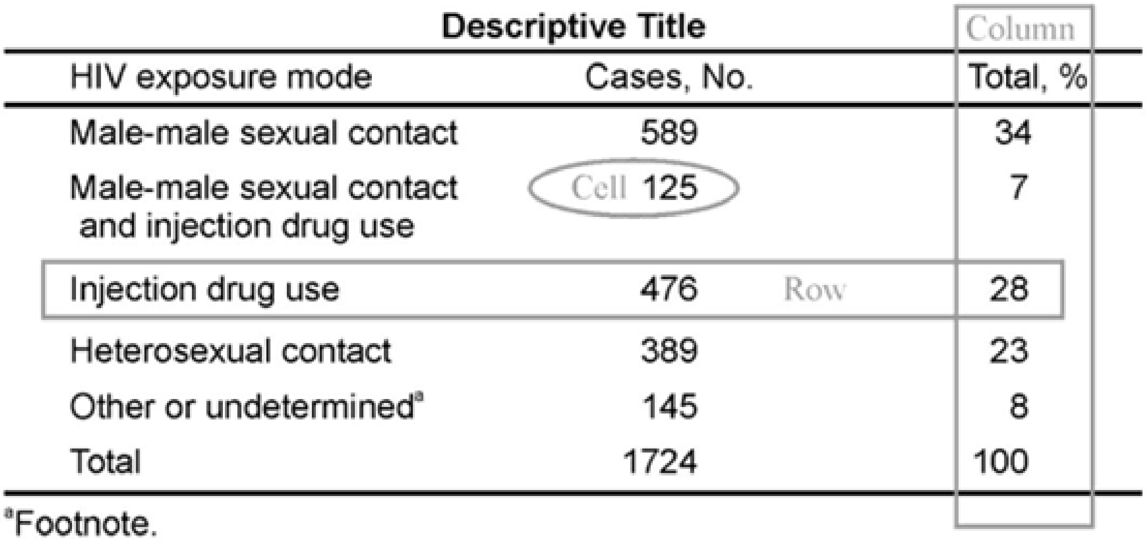
EXPLAIN EPIDEMIOLOGIC TERMS AND PRESENTATION METHODS

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 2007 to 5,700 cases infections in 2010.

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

HIV exposure mode	Cases, No.	Total, %
Male-male sexual contact	589	34
Male-male sexual contact and injection drug use	125	7
Injection drug use	476	28
Heterosexual contact	389	23
Other or undetermined[a]	145	8
Total	1724	100

[a] Footnote.

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. 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.

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/µL or a CD4 percentage of total lymphocytes of <14.

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).

case. A condition, such as HIV infection (e.g., an HIV case) diagnosed according to a standard case definition.

case fatality. The number of deaths among persons with a diagnosis of the disease of interest. Usually expressed as a rate (number of deaths after disease onset or diagnosis divided by the number of persons with the disease); measures the effect of the disease on persons with a diagnosis.

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).

community-based organization (**CBO**). An organization that provides services to locally defined populations, which may include persons infected with, or affected by, HIV.

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 infected with, HIV.

comorbidity. The coexistence of a disease or illness and HIV infection in one person (e.g., an HIV-infected person 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.

continuum of care. A coordinated delivery system, encompassing a comprehensive range of health and social services that meet the needs of people living with HIV at all stages of illness.

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 2010. Of the 9,000 persons with HIV, 4,000 had died. The cumulative number of HIV infection diagnoses in that state through 2010 would be 9,000.

cumulative incidence: The proportion of a group of people who experience the onset of a health-related event during a specified period of time. Cumulative incidence is calculated by dividing the number of new infections during a specified period by the population at risk for the health-related event during that period.

$$\text{cumulative incidence} = \frac{\text{number of new infections during a given period of time}}{\text{population at risk}}$$

It is important to pay attention to the time period to which the cumulative incidence relates. Cumulative incidence is commonly calculated for annual time periods, but it can also be calculated for shorter or longer periods. Use caution when comparing incidence calculations for differing periods.

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 HIV-infected and HIV-negative persons 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 on the basis of 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 Ryan White HIV/AIDS Program funds. For HIV prevention funds, the state or local health department is referred to as the grantee. For Ryan White HIV/AIDS Program 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 HIV infected.

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 living with HIV. The Ryan White HIV/AIDS Program authorizes states to use Title II funds to establish consortia in “areas most affected by HIV disease.”

HIV infection, stage 1. No AIDS-defining condition and either CD4 count of ≥500 cells/µL or CD4 percentage of total lymphocytes of ≥29.

HIV infection, stage 2. No AIDS-defining condition and either CD4 count of 200–499 cells/µL or CD4 percentage of total lymphocytes of 14–28.

HIV infection, stage 3. Documentation of an AIDS-defining condition or either CD4 count of <200 cells/µL or CD4 percentage of total lymphocytes of <14. Documentation of an AIDS-defining condition supersedes a CD4 count or percentage that would not, by itself, be the basis for stage 3 (AIDS) classification.

HIV infection, stage unknown. No reported information on AIDS-defining conditions and no information available on CD4 count or percentage.

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. There is an important difference between HIV incidence and a new diagnosis of HIV infection: HIV incidence refers to persons newly infected with HIV, whereas persons newly diagnosed with HIV may have been infected 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.

Program areas that collect HIV testing and treatment information and STARHS (serologic testing algorithm for recent HIV seroconversion) results may estimate incidence using the stratified extrapolation approach.

CDC is currently funding selected surveillance programs to conduct HIV incidence surveillance. Data from these areas will be used to provide national estimates of new HIV infections (not just the number of cases newly diagnosed and reported to surveillance).

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 given 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 years ÷ 9 people = mean age 24.2 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 current status and the unmet needs for HIV prevention or care among a defined population or in a geographic area.

no identified risk (**NIR**). Cases in which epidemiologic follow-up has been conducted, sources of data have been reviewed—which may include an interview with the patient or provider—and no mode of exposure has been identified. Any case that continues to have no reported risk 12 or more months after the report date is considered NIR.

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 ÷ 60 = .25 x 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 of time (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.

$$\text{prevalence} = \frac{\text{number of existing cases*}}{\text{population at risk*}}$$

* 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.

probability (*P*) value. The probability that a statistical result (an observed difference or relationship) could have occurred by chance alone. Statistical results usually are regarded as significant if there is less than 5% probability that the observed difference or relationship was due to chance alone. In such situations, the P value is said to be less than .05 ($P <.05$).

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.

$$\frac{\text{number of HIV diagnoses*}}{\text{population*}} \times 100{,}000 = \text{population rate of HIV diagnoses}$$

* 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 disease 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).

raw data. Data that are in their original form (i.e., not coded or analyzed).

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. 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.

sociodemographic factors. Background information about the population of interest (e.g., age, sex, race, educational status, income, geographic location). These factors are often thought of as explanatory because they help us to make sense of the results of our analyses.

socioeconomic status (**SES**). A measure of social and economic factors that helps to describe a person's standing in society (e.g., income level, relationship to the national poverty line, educational achievement, neighborhood of residence, home ownership).

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.

triangulation. Synthesis of data to compare and contrast the results of different kinds of research that address the same topic.

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.

years of potential life lost (**YPLL**). The number of years that persons would have lived if they had not died of the disease of interest. Calculated by summing the years that persons would have lived had they attained normal life expectancy, YPLL measures the effect of mortality on the community.

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The suggested readings will help you understand key issues and concepts in HIV surveillance and HIV prevention and Ryan CARE Act community planning.

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RYAN WHITE HIV/AIDS PROGRAM

Ryan White Program information (e.g., grant application guidance, service data reporting requirements, performance measure data requirements, program data reports) can be found at http://hab.hrsa.gov/abouthab/aboutprogram.html.

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