Integrated Guidelines for Developing Epidemiologic Profiles

HIV Prevention and Ryan White CARE Act Community Planning

DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention

Integrated Guidelines for Developing Epidemiologic Profiles

HIV Prevention and Ryan White CARE Act
Community Planning

Centers for Disease Control and Prevention
and
Health Resources Services Administration

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention
Atlanta, Georgia

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Suggested citation
Centers for Disease Control and Prevention and Health Resources and Services Administration. *Integrated Guidelines for Developing Epidemiologic Profiles: HIV Prevention and Ryan White CARE Act Community Planning*. Atlanta, Georgia: Centers for Disease Control and Prevention; 2004.

The guidelines are available at http://www.cdc.gov/hiv/pubs/guidelines.htm and at http://www.hrsa.gov/hab.

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Abbreviations

ADAM	Arrestee Drug Abuse Monitoring
ADAP	AIDS Drug Assistance Program
AETC	HIV/AIDS Education and Training Center
AIDS	acquired immunodeficiency syndrome
ASD	Adult/Adolescent Spectrum of Disease Study
BRFSS	Behavioral Risk Factor Surveillance System
CADR	CARE Act Data Report
CARE	Comprehensive AIDS Resources Emergency (Act)
CBR	code-based reporting
CDC	Centers for Disease Control and Prevention
CHIP	Context of HIV Infection Project
CIDUS	Collaborative Injection Drug Users Study
DAWN	Drug Abuse Warning Network
DHAP	Division of HIV/AIDS Prevention (CDC)
DRP	Dental Reimbursement Program
EHRAP	Expanded HIV Risk Assessment Project
EMA	eligible metropolitan area
GISP	Gonococcal Isolate Surveillance Project
HARS	HIV/AIDS Reporting System
HERS	HIV Epidemiologic Research Study
HITS	HIV Testing Survey
HIV	human immunodeficiency virus
HOPS	Hospital Outpatient Study
HRSA	Health Resources and Services Administration
ICD	International Classification of Diseases
IDU	injection drug user
MSM	men who have sex with men
NCHSTP	National Center for HIV, STD, and TB Prevention (CDC)
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
NRR	no reported risk
NTC	name-to-code
OASIS	Outcome Assessment through Systems of Integrated Surveillance
OMB	Office of Management and Budget
ORS	other reporting system
PDF	portable document format
PLWA	people living with AIDS

PLWH	people living with HIV
PRAMS	Pregnancy Risk Assessment Monitoring System
PSD	Pediatric Spectrum of Disease
RARE	Rapid Assessment and Response and Evaluation
RNR	reporting [HIV] not required
RWCA	Ryan White Comprehensive AIDS Resources Emergency (Act)
SAMHSA	Substance Abuse and Mental Health Services Administration
SHAS	Supplement to HIV/AIDS Surveillance
SHDC	Survey of HIV Disease and Care
SPNS	Special Projects of National Significance
SSVRS	Sentinel Surveillance of Variant and Drug-Resistant Strains
STD	sexually transmitted disease
TB	tuberculosis
YMS	Young Men's Survey
YRBSS	Youth Risk Behavioral Surveillance System

Executive Summary

These guidelines have been developed by the Centers for Disease Control and Prevention (CDC) and the Health Resources Services Administration (HRSA) to assist the persons who compile and interpret HIV prevention and care data for state, territorial, or local HIV/AIDS epidemiologic profiles. The purpose of the document is to provide 1 set of guidelines 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 needs of both HIV/AIDS prevention and care programs. Integrating prevention and care data should help to streamline the work of health department staff, community 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 epidemic 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. Some sections include examples of analyses and formats for presenting data to help illustrate key points. Other sections include questions that should be considered during development. 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 epidemic 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 the HIV/AIDS epidemic in your service area?
    - Core Question 3: What are the indicators of risk for HIV infection and AIDS in the population covered by your service area?
    - Care-Related Question 1: What are the patterns of service utilization of HIV-infected persons in your area?
    - Care-Related Question 2: What are the number and characteristics of persons who know they are HIV-positive but who are not receiving HIV primary medical care?
  - Outlines a 7-step process for developing the profile
  - Outlines skills and desired proficiencies for preparing 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
    - recommended analyses for areas with and areas without HIV reporting
- **Chapter 4**
  Describes how to make the profile user-friendly; write the front matter, introduction, conclusion, appendixes, and other back matter (in addition to appendixes); prepare effective oral presentations of the profile; and disseminate the profile
- **Chapter 5**
  Addresses confidentiality, special-needs populations, comorbidity, and areas with low morbidity and minimal data

The guidelines also include appendixes, a glossary of terms and concepts common to HIV epidemiologic profiles, and a list of references and suggested readings. The appendixes consist of the following:

- Appendix A: Data Sources
- Appendix B: Data Sources by Jurisdiction
- Appendix C: Web Data for Core Epidemiologic Question 1
- Appendix D: Table Formats for Mortality Data
- Appendix E: Table with Descriptions of Ryan White CARE Act Programs
- Appendix F: Planning Group Epidemiologic Profile Feedback Form

- **Sample Integrated Epidemiologic Profile for HIV/AIDS Prevention and Care Planning—Louisiana**

  Staff in Louisiana's HIV/AIDS Surveillance Program collaborated with other health department entities and CDC to create the sample profile. The format is similar to the structure recommended in the guidelines: multiple sources of prevention and care-related data are used to describe the epidemic, the presentation is user-friendly, and the profile includes a detailed list of the sources of data. Louisiana has had HIV reporting since 1993; therefore, both HIV and AIDS data are presented.

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.

The data in an integrated HIV epidemiologic profile may be used for several purposes, including community 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.

We hope you will find these guidelines helpful. 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. Once you start writing your document, you may have questions about the development process. 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
Section 2 The Need for Integrated Guidelines
Section 3 Core Concepts

Chapter 1 presents background information about HIV/AIDS epidemiologic profiles and this document—*Integrated Guidelines for Developing Epidemiologic Profiles: HIV Prevention and Ryan White CARE Act Community Planning*. It describes the use and importance of profiles and provides an overview of how to develop epidemiologic profiles by using the guidelines.

Section 1: Overview

The epidemiologic profile is a document that describes the effect of the HIV/AIDS epidemic on an area in terms of sociodemographic, geographic, behavioral, and clinical characteristics. 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.

Two of the agencies that use HIV/AIDS epidemiologic and surveillance data are the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA). Both agencies provide guidance and funding for programs for persons with, or at risk for, HIV/AIDS. The goals of these programs are to prevent HIV infections and, for those who are infected, to promote testing, care, and treatment.

Purpose of the Guidelines

The *Integrated Guidelines for Developing Epidemiologic Profiles* is a joint project of CDC and HRSA. The purpose of the document is to provide 1 set of guidelines to help writers appropriately create integrated epidemiologic profiles and advise them on how to interpret epidemiologic data in ways that are consistent and useful in meeting the planning needs of both HIV/AIDS prevention and care programs.

The guidelines describe how to develop an epidemiologic profile. They include all the steps in the process, from determining the scope of the profile through obtaining, analyzing, and presenting data. They also include techniques for creating user-friendly profiles that can be used effectively by end users who have varied experience with interpreting epidemiologic data. The guidelines are intended to serve as a technical assistance tool to help state, territorial, and local health departments develop profiles for HIV prevention and care community planning.

This document should streamline the work of health department staff, community planning groups, and planning councils by reducing redundancy and duplication of effort and by promoting consistency and comparability of data and terms used in prevention as well as care planning. The data analysis and presentation techniques were developed from input provided by a wide range of collaborators. Health department staff who have produced profiles by using methods that they find effective but that 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.

Audience

The audience for the guidelines is writers of HIV/AIDS epidemiologic profiles. However, skills and experience can vary widely—from a person with limited public health experience to a senior epidemiologist with years of experience in preparing profiles.

Because it is beyond the scope of the guidelines to address the skills and needs of **all** profile writers, the document is focused on writers with an intermediate level of experience and expertise with epidemiologic data and profile preparation, such as

- an epidemiologist with knowledge of HIV/AIDS
- a health care professional with clinical experience in HIV/AIDS
- an experienced member of an HIV/AIDS prevention or care planning group with a data or statistics background

What You Will Learn

The guidelines provide the technical assistance guidance and information you need to prepare a profile. This document

- includes questions and elements common to epidemiologic profiles used by prevention and care planning groups
- includes specific data and elements needed to meet individual HRSA or CDC requirements
- can be customized to meet local needs

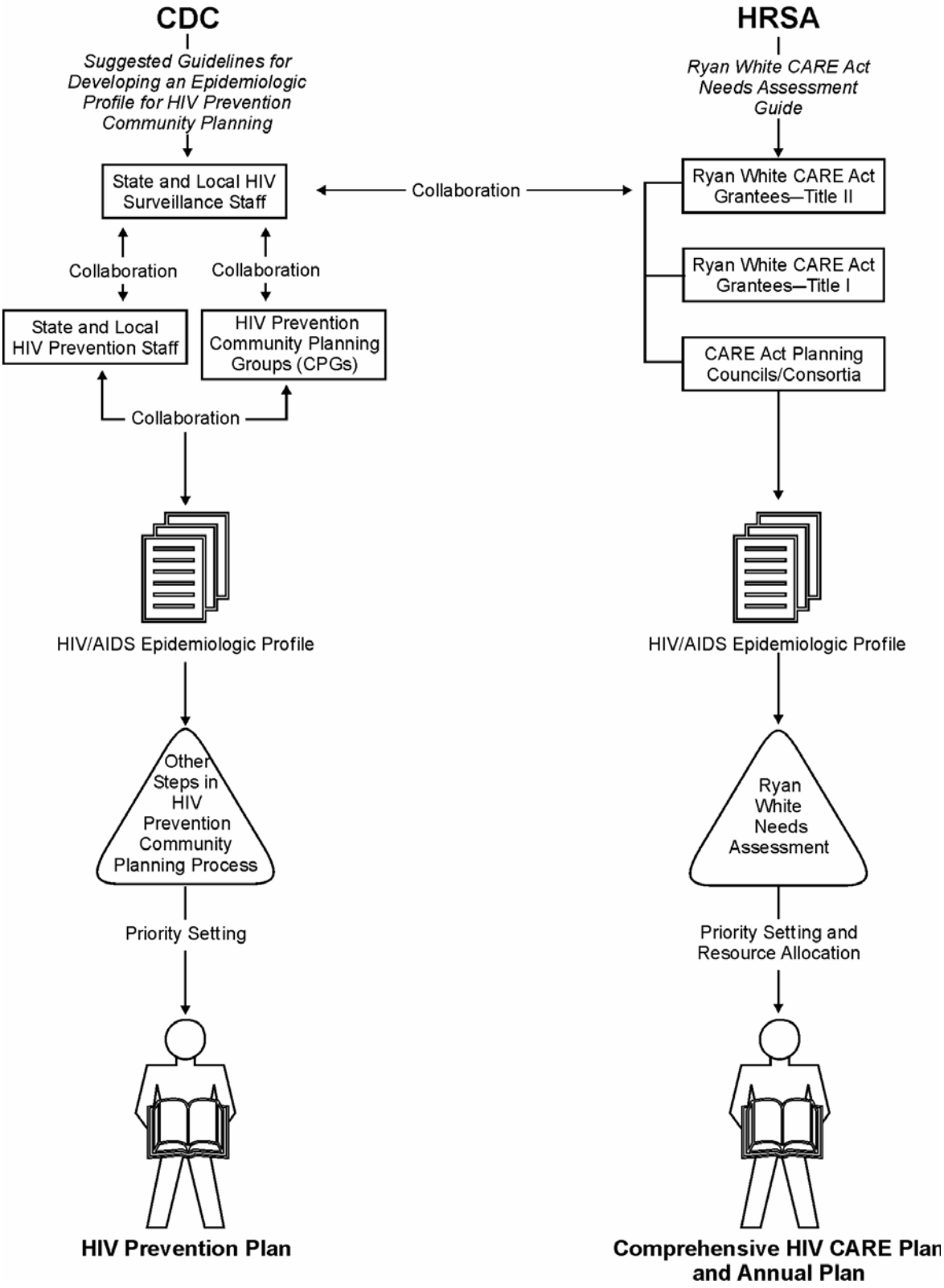
You will learn a number of specific skills, including

- how to determine the scope of a profile
- the process for developing a profile
- what content to include in an epidemiologic profile and how to organize it
- how and where to obtain the core and supplemental epidemiologic data
- how to analyze, interpret, and present epidemiologic data
- the level of staffing and time required to develop a profile
- techniques for creating user-friendly profiles for a variety of end users
- how to prepare data for a presentation
- how to prepare a plan for disseminating the profile

Section 2: The Need for Integrated Guidelines

Prevention and care planning groups sponsored by CDC and HRSA use HIV/AIDS epidemiologic profiles for multiple purposes. Despite the overlap in many of the data needs of prevention and care planning groups, profile writers now use separate guidelines to prepare their epidemiologic profiles (Figure 1).

Figure 1-1. Current development of HIV/AIDS epidemiologic profiles



Current Process

The current process for preparing separate epidemiologic profiles has several disadvantages:

- The demands of preparing 2 profiles may put a burden on state and local resources.
- Data sharing and collaboration between prevention and care are complicated by different time frames and methods of presentation.
- Variations in profile quality and content may result.
- Lack of consistency and comparability of profiles may lead to disparities in setting priorities or allocating resources.

Goals and Benefits of Integrated Guidelines

Recognizing that epidemiologic profiles for HIV prevention and care share common purposes, data needs, and staff demands, CDC and HRSA agreed to create a set of common guidelines 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

To increase the usefulness of the HIV/AIDS epidemiologic profiles for end users, preparers should have a common understanding of

- common terms associated with profiles and epidemiology
- profile goals
- how profiles are used and by whom

Common Terms

At the end of the guidelines is a glossary—a comprehensive list of terms associated with epidemiology and the HIV/AIDS epidemiologic profiles. In addition, Chapter 2 includes common terms and methods that apply to analytical concepts, such as incidence, incidence rate, and prevalence. This section provides some fundamental terms and concepts that all profile writers should understand.

- **Epidemiology:** The study of the distribution and determinants of health, disease, or injury in human populations and the application of this study to the prevention and control of health problems.
- **HIV/AIDS epidemiologic profile:** A document that describes the HIV/AIDS epidemic in various populations in defined geographic areas. It identifies characteristics of the general population, HIV-infected populations, and noninfected (and untested) persons whose behavior places them at risk for HIV. It consists of information gathered to describe the effect of HIV/AIDS on an area in terms of sociodemographic, geographic, behavioral, and clinical characteristics. The epidemiologic profile serves as a source of quantitative data from which HIV prevention and care needs are identified and priorities set for a given jurisdiction.
- **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/AIDS surveillance is one example of public health surveillance.

The following terms are used throughout the document:

- **Planning group** refers to CDC- and HRSA-sponsored groups, such as HIV prevention community planning groups (CPGs) and CARE (Comprehensive AIDS Resources Emergency) Act planning councils and consortia.
- **Service area** refers to the jurisdictions of CDC CPGs and the planning regions of HRSA planning groups.

HIV/AIDS Epidemiologic Profile Goals

An epidemiologic profile is designed to

- provide a thorough description of the HIV/AIDS epidemic among the various populations (overall and subpopulations) in a service area
- describe the current status of HIV/AIDS cases in the service area and provide some understanding of how the epidemic may look in the future
- identify characteristics of the general population and of populations who are living with, or at high risk for, HIV/AIDS 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/AIDS epidemiologic profile to

- help develop a comprehensive HIV prevention or care plan
- set priorities among populations who need prevention and care services
- provide a basis for determining or projecting future needs
- develop requests for proposals for providers and subcontractors
- increase general community awareness of HIV/AIDS
- 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)
- modify the composition of planning or advisory group membership to reflect the demographics of HIV/AIDS in the service area

Profile End User	Focus	Specific Uses
CDC • Community planning groups • State and local health departments • Community-based organizations	• Preventing and intervening to reduce transmission of HIV/AIDS	• Prioritize target populations and identify appropriate interventions for each priority population • Develop HIV prevention plan
HRSA • Ryan White CARE Act grantees • Ryan White planning bodies • Community-based organizations	• Providing services and care for people living with HIV/AIDS	• 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 community planning process should be used to develop a comprehensive HIV prevention plan. The plan is jointly developed by the health department and the HIV prevention CPGs and focuses on priority setting for target populations for which HIV prevention will have the greatest impact. The first step in HIV prevention community planning is the development of an epidemiologic profile. State, local, and territorial health departments have the responsibility for providing an epidemiologic profile that describes the HIV/AIDS epidemic in the CPG's service area.

Using the profile to meet HRSA CARE Act legislative requirements

As part of a needs assessment, an epidemiologic profile is an essential component of Ryan White CARE Act planning. Legislative requirements and the expectations of HRSA's HIV/AIDS Bureau differ by Title. In general, each Title calls for profile preparers to

- determine the size and demographics of the population with HIV disease
- determine the service needs of these populations, with particular attention to those who know they have HIV disease 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

Section 1 Determining the Scope
Section 2 Determining the Content and Organization of the Profile
Section 3 Determining the Development Process
Section 4 Obtaining Profile Data
Section 5 Identifying Skills for Preparing Profiles
Section 6 Understanding Basic Analytic Concepts

Chapter 2 gets down to the nuts and bolts: How do you begin to develop an HIV/AIDS epidemiologic profile? How do you determine the scope, content, and organization of the profile? What skills are required to prepare it? What data do you include? Where can you find those data? Once you get the data, how should you analyze and interpret them? Where can you get help? How do you address differences between prevention and care guidelines and differences such as service area boundaries, time frames, and due dates?

This chapter provides guidance for answering these questions. Of particular importance are the basic concepts and recommended methods for analyzing the profile data.

Establishing the foundation, presented in this chapter, is critical for developing consistent profiles that meet the specific needs of prevention and care planning groups.

Note. In this document, the term *HIV/AIDS* is used to refer to three categories of cases: (1) new diagnoses of HIV infection only, (2) new diagnoses of HIV infection with later diagnoses of AIDS, and (3) concurrent diagnoses of HIV infection and AIDS.

Section 1: Determining the Scope

The first step in preparing an HIV/AIDS epidemiologic profile is to determine its scope. 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/AIDS prevention and care services. At the same time, the scope needs to be narrow enough to meet specific requirements of prevention and care programs.

The appropriate scope of the epidemiologic profile depends on several factors outlined in this section.

CDC and HRSA Considerations

Although the data required are similar, CDC and HRSA have different requirements for developing and updating the HIV/AIDS epidemiologic profile. Below are several suggestions:

- 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.

- Less often, the health department should comprehensively revise its epidemiologic profile. CDC prevention planning groups should complete such a revision at a minimum of once every 5 years. CARE Act planning consortia and councils should follow their yearly program guidance from the HIV/AIDS Bureau.

Consider including as much as possible of 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.

Factors Affecting the Scope

Scope refers to the boundaries, such as the time frame and geographic area, which define the extent of information in your profile. Determining the scope of your epidemiologic profile is a **collaborative** effort that requires consultation **with your planning groups and other potential stakeholders.**

Because each jurisdiction's needs differ, it is not possible to say how much time or how many resources should be allotted to complete an epidemiologic profile. The scope of your profile will affect the time and resources needed to complete it. It will be important to factor the time and resources needed into the planning process.

The following is a checklist of questions to guide your data gathering and analysis. Your answers will enable you to determine

- the geographic boundaries of the area described in your profile
- the extent to which the profile can address the core epidemiologic questions
- any special considerations pertinent to your service area and planning group requirements
- the time and resources needed to complete the profile

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 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 in the epidemic that can be identified through a comparison of HIV and 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?

Example

- If your service area does not have HIV reporting, you will need to use estimates of HIV prevalence derived from AIDS case reporting.

✔ What data are available to supplement the HIV/AIDS Reporting System 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 the HIV/AIDS epidemic in your service area?

- What are the indicators of risk for HIV infection and AIDS in the population covered by your service area?

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

- What are the patterns of service utilization of HIV infected persons in your area?

- What are the number and characteristics of persons who know they are HIV-positive but who are not receiving primary HIV medical care?

The material should be contained in sections organized in a logical sequence that allows end users to locate information quickly. Chapter 3 explains how to answer the core questions and the questions specific to care programs. The remainder of this section describes the organizational framework of an effective and user-friendly profile.

Profile Sections and Organization

As is true of any good document, a well-organized profile is divided into logical sections:

- front matter
- introduction
- body
- conclusion
- appendixes
- 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
- **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
- **Preparation information** that describes the development guidelines, process, key players, and how the development of the profile followed the guidelines and process

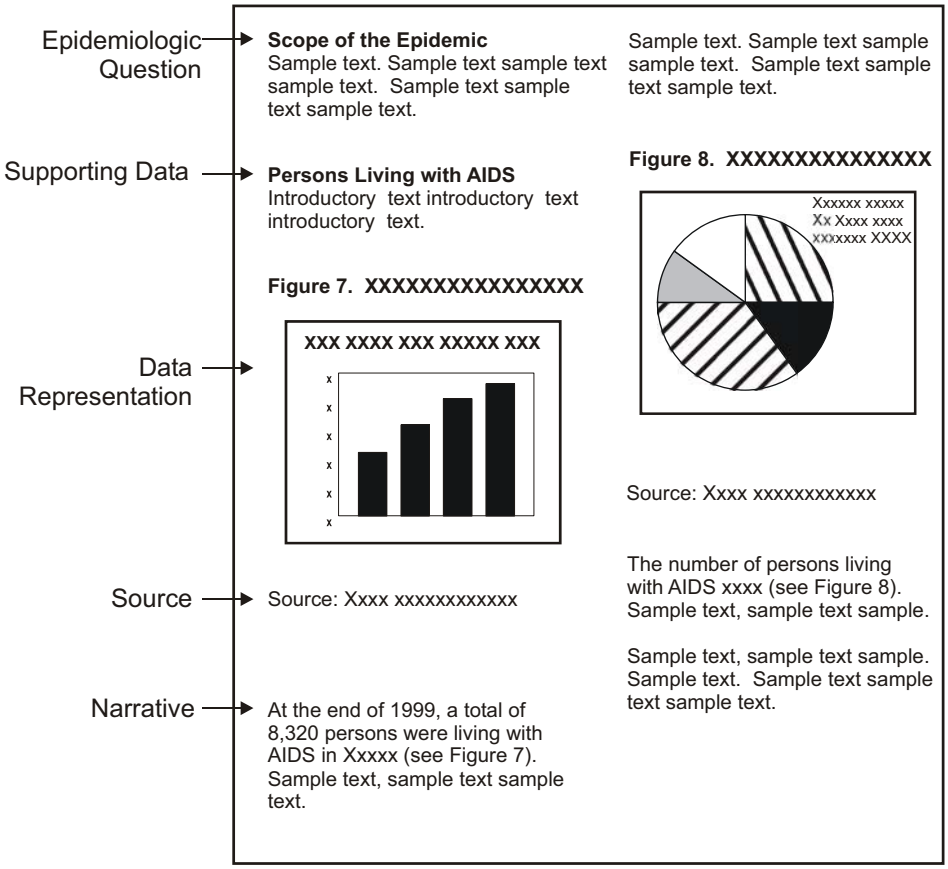
Body

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.

Figure 2-1 illustrates the content requirements of a page in the profile. No particular page layout for the profile is preferred. The one below is just an illustration.

Figure 2-1
Example of layout of profile body



Conclusion, appendixes, and other back matter

The back matter should consist of the following:

- The **Conclusion** summarizes the data and trends and highlights key findings.
- **Appendixes** 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 appendixes)** includes items such as a glossary and a list of references or suggested readings.

Section 3: Determining the Development Process

This section outlines a recommended process for developing the epidemiologic profile. It presents a logical and ideal flow. You may find that the process you use to develop your profile is different and that you need to revisit some steps as you go along. The key is to incorporate the principles of the process to ensure that your profile is comprehensive and the presentation is of high quality.

Development Process

There is a 7-step process recommended for developing the epidemiologic profile (see box below). One of the keys to a comprehensive and user-friendly profile is to ensure that the development process is a collaboration between you, as the writer(s), and the planning group. This process may be different for planning groups that have merged.

At the beginning of the development process, it would be useful for the writer(s) to meet with the planning group to

- get to know the dynamics of the group and the challenges they face
- introduce the new guidelines and why HRSA and CDC developed them
- determine the planning group's experience with past profiles and where improvement is needed
- determine whether the group has special requests for data or interpretation

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

The next step in preparing the profile is to obtain the data you will use to address the scope of the profile and answer the epidemiologic questions.

As the profile writer, you need to be aware of several considerations concerning the acquisition and use of data to describe the epidemic in a service area. You also need to know what types of data are available and where to obtain them.

This section presents a *general* discussion of those considerations—the types of available data and where to find them—as preparation for Chapter 3, where these issues are applied to the specific core epidemiologic questions.

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 or AIDS cases reflect the true number of persons who have HIV infection or AIDS and are thus eligible to be reported? For example, how well does the prevalence of AIDS represent the true number of persons living with AIDS 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 or AIDS and the report to the health department?
- **Limitations of the data source or variable of interest**: Consider the limitations of the data source or variable. For example, AIDS case data are the only HIV-related data that are consistently available on a population-wide basis in all states by sex, race/ethnicity, age, and mode of HIV exposure. However, AIDS case data may not reflect the characteristics of people who were recently infected with HIV.

- **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.
- **Validity of the data:** How well does a variable measure what it is intended to measure? 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:** You may need technical assistance to interpret the data when analyzing small numbers of cases 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. These analyses may also require the use of advanced statistical tests. Rates calculated from numerators smaller than 20 should be denoted in a footnote as 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 and AIDS cases and clinical conditions of persons with a diagnosis of HIV infection or AIDS. Other sources are used to round out the picture of the HIV/AIDS epidemic in your service area. Other sources also are used if no HIV incidence data are available. See Appendix A for an expanded list of core and supplemental data sources and references.

Type of Data	Description	Where to Obtain
AIDS surveillance	AIDS reporting began in 1981, and AIDS is a reportable condition in all states and territories. The AIDS surveillance system was established to • monitor incidence and the demographic profile of AIDS • describe the modes of HIV transmission among persons with AIDS • guide the development and implementation of public health intervention and prevention programs • assist in the evaluation of the efficacy of public health interventions State and local health departments actively solicit disease reports from health care providers, laboratories, and other sources. Standardized case report forms are used to collect sociodemographic information, mode of exposure, testing history, and clinical information. AIDS surveillance has been determined to be more than 85% complete.	All 50 states, the District of Columbia, and US territories collect AIDS surveillance data. Contact your state or local service area's HIV/AIDS surveillance coordinator.
HIV surveillance	HIV surveillance data include all persons who meet the 1999 case definition for HIV infection and have been reported to a state or local health department. HIV	As of January 2004, 34 states (Alabama, Alaska, Arizona, Arkansas, Colorado, Florida, Georgia, Idaho, Indiana, Iowa,

Type of Data	Description	Where to Obtain
	surveillance data • provide a minimum 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 of particular interest (e.g., children, adolescents, women) that may not be evident from AIDS surveillance data HIV surveillance data also provide a basis for establishing and evaluating linkages to the provision of prevention and early intervention services. 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.	Kansas, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Texas, Utah, Virginia, West Virginia, Wisconsin, Wyoming), American Samoa, Northern Mariana Islands, Puerto Rico, the Virgin Islands, and Guam have implemented HIV case surveillance, using the same confidential system for name-based case reporting for HIV infection and AIDS. Pennsylvania implemented name-based reporting in areas outside the city of Philadelphia. Connecticut implemented mandatory HIV reporting in January 2002. For adults and adolescents 13 years of age and older, reporting is by name or code (if patients or physicians prefer this method). For children < 13 years of age and for persons who are co-infected with tuberculosis, reporting is by name. New Hampshire allows HIV cases to be reported with or without a name. Five states use names to initiate case reports and then convert to a code (Delaware, Maine, Montana, Oregon, Washington), and 10 areas are using a coded identifier rather than patient name to report HIV cases (California, Hawaii, Illinois, Kentucky, Maryland, Massachusetts, Rhode Island, Vermont, and the District of Columbia).
Behavioral surveillance	Data on behaviors that are relevant to HIV prevention, transmission, and medical care are available from a variety of sources, including general population surveys, surveys of populations at risk for HIV, and surveys of persons with HIV or AIDS. Behavioral data include • patterns of, or deterrents to, HIV testing	Refer to Appendix A to locate sources of behavioral data in your service area.

Type of Data	Description	Where to Obtain
	• substance use and needle sharing • sexual behavior, including unprotected sex • sexual orientation • health-care-seeking behavior • adherence to prescribed antiretroviral therapies **Examples:** Supplement to HIV/AIDS Surveillance; HIV Testing Survey; Behavioral Risk Factor Surveillance System; Young Men's Survey; Survey of HIV Disease and Care Project; Monitoring Trends in Prevalence of STDs, TB, and HIV Risk Behaviors Among Men Who Have Sex with Men Project; Gonococcal Isolate Surveillance Project; CDC HIV Behavioral Surveys; Project One; and the Context of HIV Infection Project	
Clinical data	Clinical data refer to information on the condition(s) of persons with HIV or AIDS. 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 and AIDS 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. **Examples:** Adult /Adolescent Spectrum of Disease Project, Survey of HIV Disease and Care Project, AIDS Progression Study, HIV Outpatient Study, and other locally available cohort data	Refer to Appendix A to locate sources of clinical data in your service area.
Demographic data	Demographic data are used to describe social characteristics (e.g., gender, stage of life, and race/ethnicity) of persons in the service area.	Available for state and metropolitan areas from the Bureau of the Census. Also, states maintain census centers. Obtain these data from http://www.census.gov.
Hepatitis B and C surveillance	Data on hepatitis B and C virus (HBV, HCV) infections may represent markers for needle sharing and sexual behaviors, which can be	State health department and CDC staff. The quantity and the quality of surveillance data differ

Type of Data	Description	Where to Obtain
	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. More than 40 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.	between states. Refer to CDC's National Notifiable Disease Surveillance System (soon to become the National Electronic Disease Surveillance System) and the CDC Division of Viral Hepatitis. **Reference:** CDC. *Guidelines for Viral Hepatitis Surveillance and Case Management.* Atlanta: CDC; 2002. Available at: http://www.cdc.gov/ncidod/diseases/hepatitis/resource/pubs.htm.
Qualitative methods	Qualitative methods are used to obtain data through observations, interviews, discussion groups, focus groups, and analysis of social networks. **Example:** Rapid Assessment Response and Evaluation project	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://www3.utsouthwestern.edu/preventiontoolbox).
Ryan White CARE Act data reports	The CARE Act data report (CADR) is a form used to collect information annually from grantees and service providers funded under Titles I, II, III, or IV of the Ryan White CARE Act. The CADR collects general information on provider and program characteristics, including the types of organizations providing services (such as ownership status), sources of revenue, expenditures, and paid and volunteer staff. Additionally, the CADR is used to collect aggregate demographic information from which duplicates have been removed (e.g., gender, race, age, HIV exposure category) on total counts of clients served by each provider as well as health insurance coverage and utilization data	Available in all 50 states and all 51 EMAs. Obtain these data from local Ryan White Title I or Title II grantees.

Type of Data	Description	Where to Obtain
	about medical and support services. The CADR is the only source of Ryan White CARE Act data that is available in all states and eligible metropolitan areas (EMAs). It provides demographic information and service utilization data on all Ryan White CARE Act clients. In some areas, Title I or Title II grantees have access to unduplicated data across an entire EMA or state. Because it is a summary report by provider, the CADR cannot be used to generate demographic cross-tabulations.	
Sexually transmitted disease (STD) surveillance	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 data. They may serve as a surrogate marker for unsafe sexual practices in a specific risk population. STDs are reportable in all 50 states and US territories. Despite widespread availability, 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.	Available in all 50 states and US territories. Contact the STD program manager in your service area for information.
Socioeconomic data	Socioeconomic data are used to describe characteristics (e.g., income, education, poverty level) of persons in the service area.	Available for state and metropolitan areas 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.
Special studies and surveys at the local level	Surveys and other data collected from community-based organizations, AIDS service organizations, universities, and special studies. Includes recurring surveys in at-risk populations.	Local researchers and universities

Type of Data	Description	Where to Obtain
Substance abuse data	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.	National Institutes of Health (http://www.drugabuse.gov/NIDAHome.html); Substance Abuse and Mental Health Services Administration (http://www.samhsa.gov) for information from drug-use surveys and data on treatment and drug abuse; National Institute of Justice (http://www.adam-nij.net) for drug abuse among persons who have been arrested
Tuberculosis surveillance	All 50 states, the District of Columbia, New York City, Puerto Rico, and other US 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/AIDS programs • local or state laws and regulations that prohibit the HIV/AIDS 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	Available in all 50 states and US territories. Contact the TB program manager in your service area for information.
Vital records	Vital records contain information, as stipulated by state statutes, on all births and deaths in the 50 US states, the District of Columbia, and US 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	All states maintain registries of deaths. Contact the State Vital Records Registrar.

Section 5: Identifying Skills for Preparing Profiles

The goal of the guidelines is to help you produce epidemiologic profiles that are consistent in content, format, usefulness, and quality for prevention and care so as to promote comparability across jurisdictions and the equitable allocation of scarce resources to populations most in need. The guidelines dictate a common set of standards and principles for epidemiologic profiles. The achievement of these goals relies in part on the skills and knowledge of the profile writers and the resources available to them. However, the personnel, expertise, and resources for preparing HIV/AIDS epidemiologic profiles differ by service area.

A Multidisciplinary Approach

A multidisciplinary team approach is recommended, even if one person takes the lead in writing the profile. A team can reduce strain on local resources (i.e., one person who prepares the profile in addition to other responsibilities) and bring multiple skills and experience to the work.

Skills for a multidisciplinary team

A multidisciplinary team should include persons with knowledge and skills in the following areas:

- familiarity with clinical aspects of HIV/AIDS and its treatment
- familiarity with the local HIV/AIDS epidemic
- familiarity with strengths and limitations of available data sources
- skills in data analysis and interpretation
- knowledge of, and experience with, programs and research
- knowledge of the needs and duties of the prevention and care planning groups (setting priorities among populations, interventions, and services)
- understanding of how the epidemiologic profile relates to HRSA and CDC requirements for needs assessment and gap analysis
- knowledge of the data needs of the people carrying out prevention and care programs
- knowledge of policy issues
- knowledge and acceptance of the tenets of applicable confidentiality protocols
- ability to communicate to a diverse audience in user-friendly language

Desired Proficiencies

Whether the profile is being prepared by in-house staff or a consultant(s), certain minimum skills and knowledge are needed to ensure a valid, useful profile. Additional capabilities can enhance the development of the profile.

Minimum knowledge base

- knowledge of HIV/AIDS surveillance systems
- knowledge of basic principles of epidemiology and statistics
- basic knowledge of CDC and HRSA programs in HIV/AIDS prevention and care
- understanding of the confidential nature of HIV/AIDS and other data (e.g., restrictions in reporting small numbers)

- familiarity with the local HIV/AIDS epidemic
- understanding of how data are collected and the strengths and weaknesses of the data
- ability to interpret data from HIV/AIDS and other surveillance systems to make inferences for HIV prevention and care planning

Minimum skills

- statistical skills
  - using descriptive statistics (e.g., mean, median, frequency, percentage, statistical relationships)
  - calculating rates
  - assessing trends over time
- computer skills
  - word processing
  - use of basic statistical and graphics software (e.g., Microsoft Excel, Microsoft PowerPoint, Epi Info, Statistical Package for the Social Sciences, Statistical Analysis Software)
- writing and speaking skills, including the ability to communicate difficult concepts clearly to a variety of end users
- interpersonal skills and ability to work with persons from diverse backgrounds and disciplines

Special Considerations: Working with a Consultant

Some planning groups may wish to employ a consultant to prepare or assist in preparing the profile. For example, a small EMA with limited resources might hire an epidemiologist from a local university to work with the planning groups.

When using a consultant, be sure to observe the following:

- Develop a contract that clearly delineates the scope of work, the timeline, and ownership of the final product (the final document should be in the public domain [i.e., not copyrighted]; the consultant should acknowledge the source when publishing work that includes information from the profile).
- Choose a person with the skills and experience necessary to execute the work defined in the scope of work (some consultants may need help understanding CDC and HRSA requirements, and the added "costs" of ensuring that the consultant is knowledgeable enough to complete the work should be factored into your planning for the time and resources you will need to develop the profile).
- Provide ongoing supervision and oversight of the consultant's work; build in supervision through such activities as periodic reviews of drafts.
- Ensure that people who have experience with, and expertise in, collecting and working with surveillance data review drafts of the profile.
- Ensure that consultants who need access to, or use, confidential public health surveillance data (e.g., HIV, STD, TB data) be required to adhere to confidentiality and data release restrictions and be subject to penalties for violating these restrictions.

For more guidance on choosing and working with a consultant, see the HRSA HIV/AIDS Bureau, Evaluation Monograph Series Report 1, *Choosing and Using an External Evaluator* (http://www.hab.hrsa.gov/tools/topics/monographs.htm).

Section 6: Understanding Basic Analytic Concepts

A common understanding of key terms in data analysis and the methods to be used in developing the HIV/AIDS epidemiologic profile is critical for a planning group. This section presents basic terms and definitions and, when applicable, the methods you are encouraged to adopt when preparing your profile. See the glossary for other relevant terms.

Terms, Definitions, Calculations

case: A condition, such as HIV (e.g., an HIV case) or AIDS (e.g., an AIDS case), according to a standard case definition.

confidence interval (CI): A range of values for a measure that is believed to contain the true value at a specified level of statistical certainty (e.g., 95%).

convenience sampling: A technique that relies upon selecting people who are easily accessible at the time of a survey (e.g., a survey of clients who attend a group meeting or are 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 represent the group you are trying to study.

cumulative cases: The total number of cases of a disease reported or diagnosed during a specified time. Cumulative cases can include cases in people who have already died.

> *Example:* Assume that 9,000 AIDS cases had been diagnosed in a state from the beginning of the epidemic through the year 2001. Among the 9,000 persons with AIDS, 4,000 had died. The cumulative number of AIDS cases diagnosed in that state through 2001 would be 9,000.

cumulative incidence rate: The total number of cases during a specified time period, among all people at risk for the disease.

A cumulative incidence rate is calculated by dividing cumulative incidence for a specified time period by the population in which cases occurred during the time period. A multiplier is used to convert the resulting fraction to a number (numerator) over a common denominator, often 100,000.

$$\frac{\text{Number of new cases in specified period}}{\text{Population at risk in specified period}} \times 100{,}000$$

Example: Assume that from 1990 through 2001, 19,000 AIDS cases occurred in a state. During the same time 1,900,000 people lived in the state.

$$\text{Cumulative incidence rate} = \frac{19{,}000}{1{,}900{,}000} \times 100{,}000 = 1{,}000 \text{ AIDS cases per } 100{,}000 \text{ persons}$$

estimate: When accurate data are not available, an estimate may be based on the data that are available and an understanding of how they can be generalized to larger populations. In some instances, national or state data may be statistically adjusted to estimate local conditions. Estimates should be accompanied by statistical estimates of error (a confidence interval), which describe the uncertainty associated with the estimate.

Example: The estimated HIV incidence in State X was 2.1% per year (95% CI, 1.4–2.6).

incidence: The number of new cases in a defined population in a certain time period, often 1 year, which can be used to measure disease frequency. It is important to understand the difference between HIV incidence and reported HIV diagnoses. HIV incidence refers to all persons infected with HIV during a specified period of time (usually 1 year). However, new diagnoses include cases in persons who have been infected for longer periods; they do not include cases in persons who were tested anonymously. Because anonymous test results are not included, HIV surveillance data may not represent incident cases.

Example: During the year 2001, a total of 1,100 AIDS cases were diagnosed in a given state. This is the incidence of AIDS for 2001 in that state.

incidence rate: The number of new cases in a specific area during a specific time period among those at risk in the same area and time period.

Incidence rate provides a measure of the effect of illness relative to the size of the population. Incidence rate is calculated by dividing incidence in the specified period by the population in which cases occurred. A multiplier is used to convert the resulting fraction to a number over a common denominator, often 100,000.

$$\frac{\text{Number of new cases in specified period}}{\text{Population at risk in specified period}} \times 100{,}000$$

Example: Assume that during the year 2001, a total of 1,100 AIDS cases were diagnosed in a given state. This is the incidence of AIDS for 2001 in that state. The population in the state was 2,200,000 in 2001.

$$\text{The incidence rate} = \frac{1{,}100}{2{,}200{,}000} \times 100{,}000 = 50 \text{ per } 100{,}000 \text{ persons in the state}$$

interpretation: The explanation of the meaning of available data. An example is examining a trend, such as the number of HIV cases diagnosed during a 5-year period. Interpreting a trend enables a planning group to assess whether the number of events is increasing or decreasing. However, groups should use caution in interpreting trends that are based on small increases or decreases.

mean: The sum of individual scores in a data set divided by the total number of scores. The mean is what many people refer to as an average.

> *Example:* Assume that people in a given service area in 2001 are the following ages at diagnosis of HIV: 18, 18, 19, 20, 22, 23, 26, 31, 41. The total of the 9 ages = 218 years.
>
> $$\frac{218 \text{ years}}{9} = 24.2 \text{ years}$$

median: The middle value in a data set. Usually, 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 2001 data for a given service area: 18, 18, 19, 20, <u>22</u>, 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 for age in the population.

no identified risk (NIR): Cases for 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.

no reported risk (NRR): Cases in which risk information is absent from the initial case report because the information had not been reported by the reporting source, had not been sought, or had not been found by the time the case was reported. Cases may remain NRR until epidemiologic follow-up has been completed and potential risks (exposures) have been identified. If risk has not been identified within 12 months of being reported as NRR, the case may be 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.

$$\frac{15}{60} = .25 \times 100 = 25\%$$

prevalence: The total number of cases of a disease in persons not known to have died in a given population at a particular time.

Example: By the end of 2001, if the cumulative number of persons with AIDS in State X is 1,900 and 1,000 have died, then the prevalence of AIDS in State X is 900 (1,900 persons who have ever had a diagnosis of AIDS minus 1,000 who have died).

Prevalence does not indicate how long a person has had a disease and cannot be used to calculate rates of disease. It can provide an estimate of probability that an individual in a population will have a disease at a point in time. For HIV/AIDS surveillance, prevalence refers to persons living with HIV or AIDS regardless of time of infection or diagnosis date. Note the difference between the prevalence of a condition in the population and the prevalence of cases, namely, that a case must be diagnosed according to a definition.

probability sampling: A technique that relies upon random selection to choose individuals from a defined population; all individuals have a known chance of selection. Types of probability samples include simple random sample, systematic random sample, stratified sample, and cluster sample.

proportion: A portion of a complete population or data set, usually expressed as a fraction or percentage of the population or data set.

Example: Assume that 12 of 20 HIV prevention programs in a given service area are school-based programs.

To calculate the proportion as a fraction,

$$\frac{12}{20} = .6 = 6/10 = 3/5$$

To calculate the proportion as a percentage,

$$\frac{12}{20} = .6 \times 100\% = 60\%$$

qualitative data: Information from sources such as narrative behavior studies, focus groups, 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 numerically or statistically. For the purposes of epidemiologic profiles, qualitative data are useful as supplements to surveillance data to obtain information on risk behaviors and associated factors in specific locales or populations that may not be well represented in routine surveillance data.

quantitative data: Numeric information (e.g., numbers, rates, and percentages).

range: The values of the largest and smallest values in a data set.

> *Example:* Assume the following ages at diagnosis of HIV in the year 2001 in a given service area: 18, 18, 19, 20, 22, 23, 26, 31, and 41. The range is 18–41.

rate: A measure of the frequency of an event or a disease compared to the number of persons at risk for the event or disease. Usually, when rates are being calculated for an epidemiologic profile, the general population, rather than the population potentially exposed to HIV infection by various high-risk behaviors, is used as the denominator. The size of the general population is known from census data, whereas the size of the high-risk population is usually not known.

$$\frac{\text{Number of reported HIV cases occurring during a given period}}{\text{Population at risk during the same period}} \times 100{,}000$$

For ease of comparison, the multiplier (100,000) is used to convert the resulting fraction to number of cases per 100,000 population. The choice of 100,000, although arbitrary, is standard practice.

> *Example:* Assume that 16 cases of HIV were reported in a service area and that 400,000 persons live in the area.

To calculate the rate,

$$\frac{16}{400{,}000} \times 100{,}000 = 4 \text{ per } 100{,}000$$

This means that 4 of every 100,000 persons at risk have been reported.

sample: A group selected from a total population with the expectation that studying this group will provide relevant information about the total population.

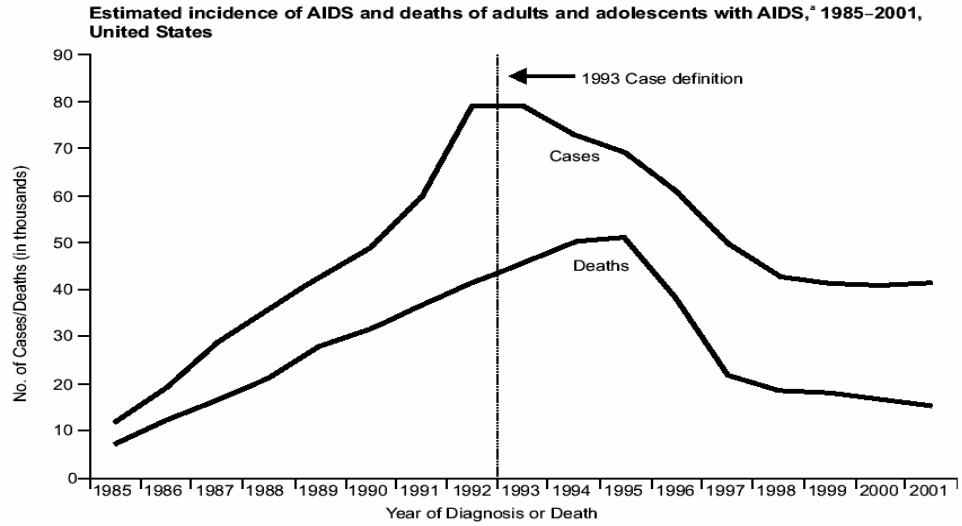
seroprevalence: The number of persons in a defined population who test positive for HIV infection (based on HIV testing of blood specimens). (Seroprevalence is often presented either as a percentage of the total specimens tested or as a rate per 100,000 persons tested.)

stratification: The separation of a sample into subsamples according to predetermined criteria, such as age group, gender, socioeconomic status. Stratification is used to control confounding effects and to detect modifying effects.

trend: A long-term change in frequency, usually an increase or a decrease. A simple linear trend could be described by calculating how much the quantity being measured increased (or decreased) from the beginning value (at the beginning of the period) to the ending value (at the end of the period). The trend could be further described by calculating a time-rate of change in the quantity measured. This is the difference between the beginning and ending values, divided by the number of time units (e.g., years) for which the trend is measured. This calculation yields the amount of increase (or decrease) per time unit. Another key factor is the statistical significance of the trend, which could be a problem if the annual values fluctuate widely from year to year, which would be likely for small numbers.

Trends can be illustrated graphically, by plotting the number of events by time, as shown in Figure 2-2.

Figure 2-2
Example of trend graph



Source. CDC.

[a]Adjusted for reporting delays.

Introduction to Analysis and Interpretation

Collecting and presenting HIV/AIDS 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/AIDS epidemiologic profile are to:

- identify populations that are infected with HIV and describe their key characteristics
- understand the trends and the impact of HIV/AIDS 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/AIDS epidemiologic profile.

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 exposure category for 44% of men reported with AIDS in the United States in 1999 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 the HIV/AIDS epidemic 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,
  - AIDS data do not include those who have been infected most recently.
  - Not all areas report HIV data.
  - EMA service areas may have dissimilar HIV reporting systems (e.g., EMA geographic boundaries cross state lines of 2 states that have different HIV reporting requirements).

- Surveillance data reflect where a person lived when the diagnosis of HIV or AIDS 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 overinterpreting large percent 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 1999 to 6 cases in 2000; 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 2000 should have been reported in 1999. If so, then 4 cases would have been diagnosed in each of the 2 years, and there would have been no increase.

Triangulation

Triangulation, or data synthesis, refers to comparing and contrasting the results of different kinds of research 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 robust (i.e., not very sensitive to departures from assumptions, for example, that the data are normally distributed), profile writers have an empirical basis for making stronger statements about the validity of their findings and conclusions. If HIV prevalence data, AIDS 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 AIDS 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 epidemic. 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

If a state or local HIV/AIDS surveillance coordinator is not preparing the profile or is not part of the team preparing the profile, you may want to seek that person's assistance. The HIV/AIDS surveillance coordinator will be able to provide technical assistance in acquiring, analyzing, and interpreting core HIV/AIDS 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.

For CARE Act grant requirements

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

HIV/AIDS Bureau
Division of Service Systems
Health Resources and Services Administration
5600 Fishers Lane, Room 7A-07
Rockville, MD 20857
301-443-9086

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, STD, and TB Prevention
Centers for Disease Control and Prevention
Mailstop E-58
1600 Clifton Road, NE
Atlanta, GA 30333
404-639-5230

For developing epidemiologic profiles for HIV prevention community planning

For technical assistance needs that relate to developing epidemiologic profiles for HIV prevention community 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, STD, and TB Prevention
Centers for Disease Control and Prevention
Mailstop E-47
1600 Clifton Road, NE
Atlanta, GA 30333
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 EPIDEMIC

Section 1 Core Epidemiologic Questions
Section 2 Special Questions and Considerations for Ryan White CARE Act Grantees

Once you have determined the scope of your profile and the process you will use to develop it, decided on the content and organization, identified the data sources you will use, and established a multidisciplinary team, you will be ready to begin preparing your HIV/AIDS epidemiologic profile. To be effective and useful, the profile should describe the epidemic from various perspectives, including

- characteristics of the general population in the geographic area covered by the profile
- characteristics of HIV-infected persons and persons engaged in high-risk behaviors
- indicators of risk
- distribution of the disease (geographically and by population)
- trends, if any

This chapter is divided into 2 sections:

- **Section 1: Core Epidemiologic Questions** presents 3 epidemiologic questions that *all* HIV/AIDS 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 CARE Act Grantees** presents questions that are specific to epidemiologic profiles that will be used to plan HIV/AIDS 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/AIDS 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 the HIV/AIDS epidemic in your service area?

3 What are the indicators of risk for HIV infection and AIDS 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 epidemic 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 the epidemic and HIV/AIDS surveillance data and their potential effect on epidemiologic profiles.

Changes in the Epidemic and Data That Affect Profiles

Describing the HIV/AIDS epidemic 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. The epidemiologic profile you prepare is part of the local dissemination of data to provide an understanding of the HIV/AIDS epidemic and assist in setting priorities for prevention and care in your service area.

Supplementing surveillance data with other sources of data will help provide a more comprehensive and in-depth picture of the epidemic in your service area.

To provide a balanced and accurate description of the epidemic that incorporates the strengths and limitations of the data sources, you need to be aware of the changing nature of HIV/AIDS 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 to HIV infection, you may see changes in the trends of the epidemic in your service area.

- The number of persons reported as living with AIDS does not include persons who were not tested, persons who were tested anonymously, or infected persons in whom HIV infection has not progressed to AIDS. CDC estimates that at the end of 2000, 850,000 to 950,000 adults and adolescents were living with HIV (not AIDS) and AIDS.[1]
- In 2000, about one fourth of infected persons had no diagnosis and may continue to be unaware of their infection.[1] Thus, they are not benefiting from improved health and survival associated with antiretroviral therapy. Of HIV-infected persons with a diagnosis, one third may not be receiving care.[1]
- Of the persons whose diagnosis of HIV was made during 1994–2000 and who were reported from the 25 states with HIV reporting since 1994, approximately one fourth of those with a new HIV diagnosis received a diagnosis of AIDS at the same time (these persons represent those who are tested late in the disease process).[2] Increased HIV testing early in the course

[1]Fleming PL, Byers RH, Sweeney PA, Daniels D, Karon JM, Janssen RS. HIV prevalence in the United States, 2000. In: Program and abstracts of the 9th Conference on Retroviruses and Opportunistic Infections; February 24–28, 2002; Seattle, Washington. Abstract 11.

[2]CDC. Diagnosis and reporting of HIV and AIDS in states with HIV/AIDS surveillance—United States, 1994–2000. *MMWR* 2002;51:595–598.

of HIV disease and programs to link infected persons to ongoing care and prevention services are essential to reducing the number of new infections.

- To enable us to better monitor and characterize the epidemic, CDC and the Council of State and Territorial Epidemiologists have recommended that national surveillance be expanded to include both HIV infection and AIDS cases.[3,4] Such an integrated national HIV/AIDS case surveillance system will provide information about persons whose HIV infection has been newly diagnosed, including those with evidence of recent infection, those with severe HIV disease (AIDS), and those dying of HIV disease or AIDS.
- Integrated HIV/AIDS surveillance data on new HIV and AIDS diagnoses provide a minimum estimate 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. Data on new infections can reflect incidence when incidence, testing patterns, and mortality from competitive causes are constant over an extended time. In addition, these data do not represent total HIV prevalence because not all HIV-infected persons have been tested. Furthermore, because diagnoses based on anonymous tests are not reported to confidential name-based registries, these data may not represent all persons who test positive for HIV infection.
- Currently, HIV surveillance data must be interpreted with data from additional sources (e.g., behavioral surveillance) to provide a more complete picture of the epidemic. Whether a trend in the number of new HIV diagnoses is stable, increasing, or decreasing may reflect current or historical patterns in HIV incidence, changes in testing behaviors, or the maturity of the epidemic in the geographic area.[5]

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[3]CDC. Guidelines for national human immunodeficiency virus case surveillance, including monitoring for human immunodeficiency virus infection and acquired immunodeficiency syndrome. *MMWR* 1999;48(No. RR-13):1–31.

[4]Council of State and Territorial Epidemiologists. CSTE position statement ID-4: national HIV surveillance—addition to the national public health surveillance system. Atlanta: Council of State and Territorial Epidemiologists; 1997.

[5] CDC. *HIV/AIDS Surveillance Update* 2000;1(No. 1):1–48.

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 (see pages 42-45)
- Socioeconomic status (see pages 45-47)

The information you develop will help you identify the risk factors associated with HIV infection—such as poverty level and lack of health insurance—that may indicate a greater cost 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 significant changes; if no significant changes have occurred, state that.

Demographics

Look at demographic data by age, race/ethnicity, sex, and geographic distribution. HIV/AIDS data are stratified in the same way, allowing you to compare the persons with HIV/AIDS and the general population in your service area.

Note that data sources may refer to population groups in different ways. For example, through December 2002, CDC's HIV/AIDS Reporting System (HARS) used

- white, not Hispanic
- black, not Hispanic
- Hispanic
- Asian/Pacific Islander
- American Indian/Alaska Native

In 2003, HARS began collecting data according to the latest OMB (Office of Management and Budget) standards for race and ethnicity (available at http://www.whitehouse.gov/omb/inforeg/statpolicy.html#dr). According to the OMB recommendation, HARS collects data on ethnicity separately (Hispanic or Latino, Not Hispanic or Latino) and will collect data on the following five racial categories: American Indian/Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White. If a person's ethnicity or racial category is not known, it is listed as "Unknown." The number of Hispanics within each racial category can also be reported. For the first time, HARS allows data collection on multiple races. The OMB recommends at a minimum that the number of cases be presented separately for each of the five racial categories for those who selected one racial category. For persons who selected more than one racial category, the data should be presented at a minimum as "more than one race." When more detailed information on racial

subgroups is collected, the category "more than one race" should include respondents who selected more than one of the five racial categories in the new standard. The term *nonwhite* is no longer acceptable.

No ideal solution exists for how to present trend data for periods before and after the implementation of the OMB categories. For example, cases coded as Hispanic before 2001 would not belong to any particular race and would be considered "unknown." Cases coded as Asian/Pacific Islander under the old standard may be Native Hawaiian/Other Pacific Islander under the new standard. We suggest that HIV/AIDS data collected before the new OMB standard (before January 2003) be presented the way they were collected and that data reflecting the new OMB standard be presented the new way. CDC will provide further guidance on the use of race and ethnicity when presenting HIV/AIDS surveillance data.

For collecting and reporting data on racial categories and ethnicity, the Bureau of the Census uses

- Hispanic
- non-Hispanic of one race (e.g., white, black, American Indian, Asian, Native Hawaiian or other Pacific Islander, other)
- non-Hispanic of two or more races (summation of 57 categories)

Through December 2002, HARS collected race data in the pre-2000 census format. The 2000 census allowed respondents to indicate "other race" and "two or more races." To obtain race/ethnicity-specific population data similar to the categories used in HARS before 2003, the proportional allocation method is used at the county level. The proportional allocation method calculates the proportional contribution of each group of interest to the total non-Hispanic 2000 census population count in the county. The proportional contribution is then applied to the HARS race/ethnicity categories.

In the 2000 census, "other" and "two or more races" constituted only 2% of the non-Hispanic total. In the future, the racial/ethnic groups used in the 2000 census will be included in the HARS software. For additional assistance in using the proportional allocation method, contact CDC.

> *Example:* In the 2000 census, assume that a given age/sex group encompasses a non-Hispanic population of 5,000. Among these, 50 are "other race" or "two or more races" and 4,950 are in one of the groups with only one race. For each "one race" category in the given age/sex group, its proportion of the total "one race" count for that group is computed. Each proportion is then multiplied by the count of 50 and added to the corresponding "one race" count for that age/sex group. This technique is applied separately to each of the 3,141 counties to produce an adjusted count. This adjusted count thus is computed for each sex/age group for each race in each county. For the "Hispanic regardless of race" category, the Hispanic ethnicity counts in each age/sex group are summed across all the racial groups.

Recommended analyses

- Number and percentage distribution of the general population by age group and sex (see Table 3-1). The following age groups are recommended:
  - >2 years
  - 2–12
  - 13–24
  - 25–44
  - 45–64
  - ≥65

  Other age groupings can also be used in the epidemiologic profile. Consider your local needs when deciding on the age groups to use. To make comparisons easier, use the same age groupings in answering each of the questions. An example of an alternative age grouping might be
  - <2 years
  - 2–12
  - 13–19
  - 20–24
  - 25–29
  - 30–49
  - 50–64
  - ≥65

Table 3-1
Distribution of the general population in State X, by age group and sex, 2000

Age (yrs)	Males, % (*n* = 2,289,037)	Females, % (*n* = 2,461,122)	Total, % (*N* = 4,750,159)
<2	2.8	2.5	2.7
2–12	17.1	15.2	16.1
13–24	16.2	14.7	15.4
25–44	31.8	31.7	31.8
45–64	22.9	23.3	23.1
≥65	9.2	12.6	11.0

Source. Census 2000 Summary File 2, available at http://factfinder.gov.

Interpretation: For males and females, one third were under 25 years of age, one third were 25 to 44 years old, and one tenth were at least 65 years old.

- Number and percentage distribution by race/ethnicity and sex (see Table 3-2)
- Number and percentage distribution by geographic subunit (a planning region, county, or EMA) and race/ethnicity (see Table 3-3)

In all your analyses, ensure that the categories and time periods are the same for demographic and surveillance data.

Data sources

- Bureau of the Census
- State census centers

Note: The appendixes provide Web sites and instructions for downloading data used to describe the general population in the epidemiologic profile.

Table 3-2
Percentage distribution of the population, by race/ethnicity for each sex, 2000

Race/ethnicity	Males, % (*n* = 2,289,037)	Females, % (*n* = 2,461,122)	Total, % (*N* = 4,750,159)
Hispanic	6.9	5.9	6.4
Not Hispanic, of 1 race			
White	60.7	59.6	60.1
Black	24.9	26.9	25.9
American Indian or Alaska Native	0.3	0.2	0.2
Asian	5.0	5.1	5.0
Native Hawaiian or other Pacific Islander	0.2	0.2	0.2
Some other race	0.2	0.2	0.2
Not Hispanic, of ≥2 races	1.9	1.8	1.9

Source. http://factfinder.census.gov.

Interpretation: A greater proportion (about 61%) of the population consisted of whites; about 25% consisted of blacks. Hispanics accounted for another 6% and Asians for 5%. The racial/ethnic distribution of males was similar to that of females.

Table 3-3
Percentage distribution of the population, by race/ethnicity and county of residence, 2000

	Percentage of population		
Race/ethnicity	County A (*n* = 1,200)	County B (*n* = 5,000)	County C (*n* = 9,000)
Hispanic	20	10	15
Not Hispanic, of 1 race			
White	50	40	30
Black	20	35	45
American Indian or Alaska Native	3	5	1
Asian	4	5	2
Native Hawaiian or other Pacific Islander	1	3	3
Some other race	1	1	2
Not Hispanic, of ≥2 races	1	1	2

Source. Census 2000 Summary File 1. Available at http://factfinder.census.gov.

Interpretation: Compared with the populations of County B and County C, a larger proportion of persons residing in County A were white, and a smaller proportion were black. County A also had a higher proportion of Hispanics than did the other counties.

Socioeconomic status (SES)

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

Recommended analyses

Percentage of

- persons living below the poverty level in selected areas (see Table 3-4)
- persons with high school diploma or higher and persons with bachelor's degree or higher (see Table 3-5)
- adults (aged 19–64) without health insurance, by race/ethnicity (see Table 3-6)

Table 3-4
Percentage of population under the poverty level in selected counties, Georgia

County	Under poverty level, %
Bibb	20.0
Clayton	13.5
Cobb	6.6
DeKalb	13.2
Forsyth	5.1
Fulton	18.3
Gwinnett	5.6
Henry	6.4
Macon	29.0
Entire state	14.7

Source. 1997 model-based estimates. Available at http://www.fedstats.gov or http://www.quickfacts.census.gov.

Interpretation: Much higher proportions of the population were under the poverty level in Bibb, Clayton, DeKalb, Fulton, and Macon counties than in Cobb, Forsyth, Gwinnett, and Henry counties.

Table 3-5
Percentage of population 25 years and older, with high school diploma or higher or with bachelor's degree or higher, 2000

Area	High school diploma or higher, %	Bachelor's degree or higher, %
MSA		
Atlanta	84.1	31.8
Augusta	80.4	18.6
Macon	81.6	19.8
Savannah	84.6	22.4
Entire state	77.5	23.2

Source. Census 2000 Supplementary Survey. Profile data available for selected areas from Table 2. Available at http://www.census.gov/c2ss/www/Products/Profiles/2000/index.htm.

MSA, metropolitan statistical area.

Interpretation: The proportion of the population at least 25 years old with a high school diploma or higher was similar among MSAs but was slightly lower in the state as a whole and therefore lower in rural areas. The proportion of the population with at least a bachelor's degree was substantially higher in the Atlanta MSA than in the other MSAs and the rest of the state.

Data sources

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

Table 3-6
Percentage of adults (aged 19–64) without health insurance in State X, by race/ethnicity

Race/ethnicity	%
White, not Hispanic	13
Black, not Hispanic	20
Hispanic	34

Source. Health Coverage and Uninsured, Kaiser Family Foundation. Available at http://www.statehealthfacts.kff.org.

Interpretation: The proportion of the population without health insurance was much greater among Hispanics than among whites or blacks.

Summary of Recommended Analyses for Question 1

- 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, EMA)

- Percentage of
  - persons living below the poverty level
  - persons with a high school diploma or higher and those with a bachelor's degree or higher
  - adults (aged 19–64) without health insurance coverage

Question 2

What is the scope of the HIV/AIDS epidemic in your service area?

An examination of the extent and effect of the HIV epidemic 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. Examine this issue from the following perspectives:

- HIV and AIDS case surveillance
- HIV surveys

If your service area…	Then go to…
Has AIDS case surveillance and has had HIV reporting for at least 2 years	Section A: HIV and AIDS case surveillance (pages 48–61) and Section C: HIV surveys (pages 71–72 for HIV serosurveys and HIV incidence surveillance; pages 72–73 for HIV counseling and testing data)
Has had HIV reporting for less than 2 years **OR** Does not have HIV reporting and has access only to AIDS reporting data	Section B: AIDS case surveillance (pages 62–71) and Section C: HIV surveys (pages 71–72 for HIV serosurveys and HIV incidence surveillance; pages 72–73 for HIV counseling and testing data)

Section A: HIV and AIDS case surveillance

If your service area has HIV and AIDS case surveillance and you plan to present data from both in your profile, keep the following points in mind:

- Areas should have the HIV reporting system in place for 2 or more years before you use HIV data for the epidemiologic profiles. HIV reporting should be in place for longer periods before you analyze trends.
- Before presenting HIV and AIDS data together, consider the length of time areas have been reporting HIV; consider also variations in reporting policies. Specifically, consider whether prevalent cases are reportable, whether there are differences in reporting from various reporting sources, or whether the completeness of reporting is known to be low. If these problems exist, do not include HIV data in the profile until they are resolved.
- HIV and AIDS data may be combined for analyses of new diagnoses and presented separately for prevalence analysis. Data presented for HIV and AIDS should be consistent

with state and local policies concerning data release to prevent the inadvertent identification of individuals.

HIV and AIDS case surveillance data will provide the information you need to analyze HIV and AIDS cases for the most recently available calendar year and for the most recent 5-year period. To provide a more complete picture of the extent and effect of the epidemic, look at TB comorbidity among AIDS cases (see page 52) and at HIV/AIDS mortality (see pages 53-54). Vital statistics and health statistics data will give you information for these analyses.

Recommended analyses for data from the most recently available calendar year

- Number of cases diagnosed in that year, adjusted for reporting delay. Cases with NRR should be redistributed.

Notes

NRR (no risk reported). Frequently, HIV and AIDS cases are reported to the state and local health department with no risk specified. The case is considered NRR if risk information is absent from the initial case report because the information had not been reported by the reporting source, had not been sought, or had not been found by the time the case was reported. Cases may remain NRR until epidemiologic follow-up has been completed and potential risks (exposures) have been identified. If epidemiologic follow-up has been completed and risk has not been identified within 12 months of being reported as NRR, the case may be considered NIR.

NIR (no identified risk). The case is considered NIR if after 12 months from report date, 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 remains NRR 12 or more months after the report date will be considered NIR.

Given that the number of cases considered NRR or NIR is increasing, CDC is piloting studies to explore the usefulness of sampling strategies in providing unbiased estimates of risk distribution. CDC is also developing guidelines for scientifically and statistically valid methods for risk redistribution. The most important determinants of whether it is reasonable for any state or locality to redistribute risk are the overall number of cases reported, the proportion reported without risk, and the initial risk distribution. Until formal guidelines are developed for these procedures, CDC will provide technical assistance specific to the project area on the feasibility of using regional weights to conduct risk redistribution.

Adjustments for reporting delays. Because of the delay from the time that a case is diagnosed to the time it is reported to the health department, it is recommended that states make adjustments to account for reporting delays when they present data by date of diagnosis. Cases diagnosed, for example, at

the end of 1 year may not be reported until the following year. If data are presented by year of diagnosis, some cases from the most recent year(s) will not yet have been reported. Without adjustment for the additional cases expected to be reported, it will appear that fewer cases were diagnosed during the recent year, giving a false impression that diagnoses are declining or declining more quickly than they are. CDC plans to write and distribute computer software programs for use with HARS that use local data to adjust for reporting delays.

If adjustment for reporting delay is not available, you may use the following alternatives for your analyses:

- cases reported in the most recent year
- cases diagnosed in the most recent year without adjustment for reporting delay
- cases diagnosed in the year before the most recent year to allow time for reporting (this alternative may be helpful to allow for the lag in reporting and to allow time for NRR follow-up investigations if adjustment for NRR redistribution is not possible)

- Number, percentage distribution, and rates (per 100,000 population) of cases for the most recent calendar year, analyzed by race/ethnicity and sex (see Table 3-7)
- Number and percentage distribution of cases for the most recent calendar year, analyzed by
  - age group and sex (see Table 3-8)
  - exposure category and sex (see Table 3-9)
  - exposure category and race/ethnicity (see Table 3-10)

Data sources

- HIV surveillance data
- AIDS surveillance data

Table 3-7
HIV diagnoses and rates among persons in State X, by race/ethnicity and sex, 2000

	Males			Females			Total		
Race/ethnicity	No.	%	Rate[a]	No.	%	Rate[a]	No.	%	Rate[a]
White, not Hispanic	1,300	32	10.2	305	18	2.3	1,605	28	6.1
Black, not Hispanic	2,107	52	106.6	1,179	69	53.9	3,286	56	78.9
Hispanic	597	14	54.9	195	11	17.9	792	14	36.4
Asian/Pacific Islander	46	1	9.4	18	1	3.3	64	1	6.2
American Indian/ Alaska Native	16	< 1	18.9	10	< 1	11.9	26	< 1	15.4
Total	4,066	100	25.1	1,707	100	10.1	5,773	100	17.0

[a]Per 100,000.

Interpretation: In 2000, HIV was diagnosed for 5,773 persons of whom 4,066 (70%) were male and 1,707 (30%) were female. By race/ethnicity, 3,286 (56%) were black, 1,605 (28%) were white, 792 (14%) were Hispanic, 64 (1%) were Asian/Pacific Islander, and 26 (<1%) were American Indian/Alaska Native.

The rate of diagnosed cases of HIV in 2000 was 17 per 100,000 in State X. The rates for males were 2 times that for females (25/100,000 compared with 10/100,000). By race/ethnicity, rates were highest for blacks (79/100 000) compared with Hispanics (36/100,000), American Indians/Alaska Natives (15/100 000), and Asians/Pacific Islanders and whites (6/100,000). The rates for black and Hispanic males were higher than those for all other groups (107/100,000 and 55/100,000, respectively). The third highest rate was that for black females (54/100,000).

Table 3-8
HIV diagnoses among persons in State X, by age group and sex, 2000

	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	66	1,111	64	3,836	66
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

Interpretation: In 2000, 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 3-9
HIV diagnoses among persons in State X, by exposure category and sex, 2000

	Males		Females		Total	
Exposure category	No.	%	No.	%	No.	%
Male-to-male sex	2,095	51	NA		2,095	36
Injection drug use	1,016	25	476	27	1,492	26
Male-to-male sex and injection drug use	188	5	NA		188	3
Heterosexual contact	751	18	1,204	70	1,955	33
Mother with/at risk for HIV infection	13	<1	19	1	32	<1
Other/unknown	44	1	33	2	77	1
Total	4,107	100	1,732	100	5,839	100

NA, not applicable.

Interpretation: By risk exposure category, 2,095 (36%) persons were classified as infected through male-to-male sex, 1,955 (33%) through heterosexual contact, 1,492 (26%) through injection drug use, and 297 (9%) through other exposures. Among the 4,107 males with HIV infection, the predominant mode of exposure was male-to-male sex (51%), followed by injection drug use (25%) and heterosexual contact (18%). Among the 1,732 females with HIV infection, the predominant mode of exposure was heterosexual contact (70%), followed by injection drug use (27%).

Table 3-10
HIV diagnoses among persons in State X, by exposure category and race/ethnicity, 2000

	White, not Hispanic		Black, not Hispanic		Hispanic		Asian/Pacific Islander		American Indian/ Alaska Native		Total	
Exposure category	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Male-to-male sex	921	57	874	27	261	33	21	34	7	27	2,084	36
Injection drug use	284	18	924	28	243	31	13	21	5	19	1,469	26
Male-to-male sex and injection drug use	69	4	86	3	28	4	—		—		183	3
Heterosexual contact	299	19	1,349	41	241	30	27	45	14	54	1,930	33
Mother with/at risk for HIV infection	—		20	<1	9	1	—		—		29	< 1
Other/Unknown	28	2	33	1	9	1	—		—		70	1
Total	1,601	100	3,286	100	791	100	61	100	26	100	5,765	100

Dash indicates cell size of ≤ 3.

Interpretation: The distribution of risk differs by race/ethnicity. Male-to-male sex was much higher for whites than for other racial/ethnic groups; injection drug use was higher for blacks and Hispanics. Exposure through heterosexual contact for blacks, Asians, and American Indians/Alaska Natives was more than double the proportion for whites and 1.5 times the proportion for Hispanics.

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
  - race/ethnicity
  - age group
  - exposure 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 dictated by the planning jurisdiction. For example, a regional CPG 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.

Recommended analyses for TB comorbidity

Number and percentage distribution of persons with AIDS who also have TB

> *Note:* If the number of these cases is large, it may be useful to do additional cross-tabulations by sex, exposure category, geographic location, or race/ethnicity.

Recommended analyses for HIV/AIDS mortality

Number and rates of death (per 100,000 population) of persons with HIV infection and/or AIDS, by race/ethnicity and sex, based on HIV/AIDS surveillance data (see Table 3-11).

Table 3-11
Number of deaths of persons with HIV infection or AIDS and the death rates per 100,000 population in State X, by race/ethnicity and sex, 2000

	Males			Females			Total		
Race/ethnicity	No.	%	Rate	No.	%	Rate	No.	%	Rate
White, not Hispanic	323	26	2.5	88	19	0.7	411	24	1.6
Black, not Hispanic	738	61	37.3	338	71	15.4	1,076	64	25.8
Hispanic	135	11	12.4	43	9	4.0	178	11	8.2
Asian/Pacific Islander	6	1	1.2	—	<1	0.6	6	<1	0.9
American Indian/ Alaska Native	7	1	8.3	—	<1	3.5	7	1	5.9
Total	1,209	100	7.4	469	100	2.8	1,678	100	5.0

Dash indicates cell size of ≤ 3.

Note. A small proportion of deaths of persons with HIV/AIDS included here are due to causes unrelated to HIV infection, such as motor vehicle accidents or lung cancer.

Interpretation: Rates of death of persons with HIV infection or AIDS were 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 3-11, since the numbers and rates of deaths are being calculated for persons with a diagnosis of HIV infection or AIDS, 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.

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:

- Number of deaths by underlying cause among persons 25 to 44 years of age, based on vital statistics mortality data (see Table 3-12)
- 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 and AIDS surveillance data
- Local offices of vital statistics
- National Center for Health Statistics

- CDC WONDER (Wide Ranging Online Data for Epidemiologic Reporting)

  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).

Table 3-12
Ranking of 10 leading underlying causes of death among persons 25–44 years of age in State X, 1999

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

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. The appendixes contain additional examples of vital statistical mortality data.

Interpretation: HIV disease (including AIDS) was the third leading cause of death in 1999 among persons 25–44 years old in State X, accounting for 12% of all deaths in this age group.

Recommended analyses for the most recent 5-year period

- It is a good idea to present the results of the stratified analyses whether or not you detect important changes in percentages or differences in trends among groups. It is not necessary to include a table for each stratified trend analysis. Important or relevant changes can be reported in narrative form or as a figure. If you find no differences, you may state that.
- For substantial shifts in the demographic composition or geographic distribution of the general population in your service area, it is helpful to control for these changes by analyzing trends in the demographic group–specific **rates** in addition to, or instead of, the trends in the number of cases.
- For the years of diagnosis to more accurately reflect the years closest to when HIV transmission occurred, you may wish to restrict trend analyses to younger ages (persons under 25 years of age at diagnosis) for HIV exposure categories such as male-to-male sex, injection drug use, and heterosexual contact. However, once you have completed the

analyses, if the trend with the age restriction does not differ from the trend without it, then do not restrict the age in presenting the data.

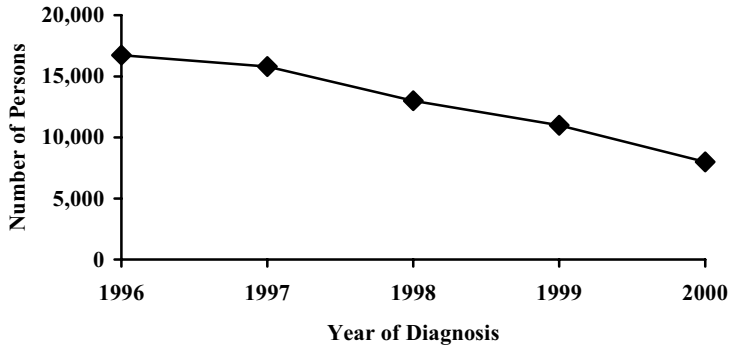
- If the numbers of cases per year are too small (<20) for meaningful analysis, combine cases in the most recent few years and compare them with cases in a preceding period of an equal number of years (e.g., compare 1995–1997 cases with 1998–2000 cases).

Analyze trends in the following manner. Stratify your analyses by sex, race/ethnicity, age group, geographic area, and exposure category, and include a table for each:

- Annual number of HIV (combined with AIDS) cases, adjusting for reporting delay (see Figure 3-1)

  Note: If it is not possible to adjust the number of diagnoses for reporting delay, you may analyze the trend in cases by year of report, but it could be misleading if the completeness of reporting or case-finding activities have not been uniform over time.

Figure 3-1
Annual number of HIV (combined with AIDS) diagnoses among persons in State X, 1996–2000



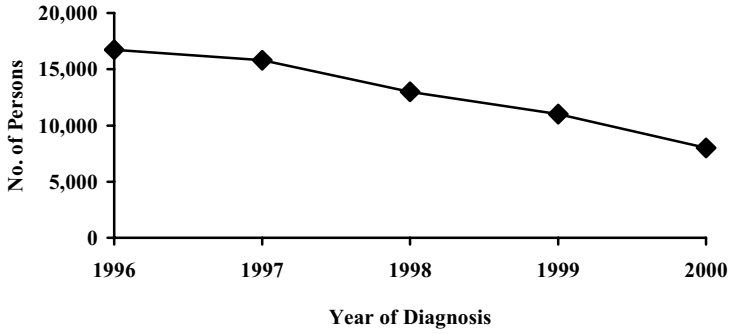
Note. Adjusted for delays in reporting.

Interpretation: From 1996 through 2000, the number of AIDS diagnoses steadily declined. In 1996, the number of cases diagnosed was 17,500; in 2000 the number was 9,500. The greatest annual decline occurred between 1997 and 1998, from 16,000 to 14,000 persons, respectively.

- AIDS cases alone (excluding cases of HIV infection that have not progressed to AIDS) (see Figure 3-2)
- Prevalence of diagnosed HIV and AIDS cases (i.e., refers to persons living with HIV infection and AIDS) (see Figure 3-3)

  Note: If you present data by age group, it is preferable to define age according to current age, rather than age at diagnosis. For purposes of care planning, consider defining persons with diagnosis by their current (or last known) residence rather than their residence at diagnosis.

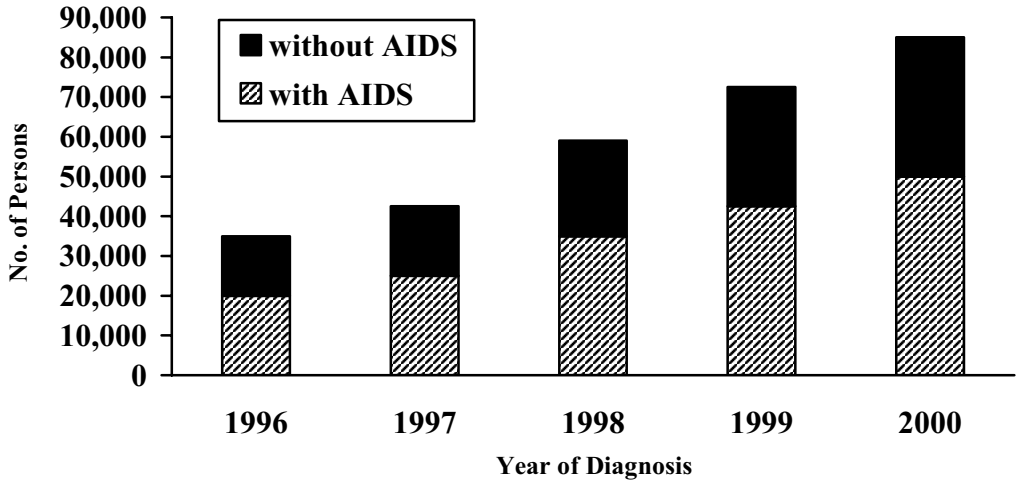
Figure 3-2
Annual number of AIDS diagnoses among persons in State X, 1996–2000



Note. Adjusted for delays in reporting.

Interpretation: From 1996 through 2000, the number of AIDS diagnoses steadily declined. In 1996, the number of cases diagnosed was 17,500; in 2000 the number was 9,500. The greatest annual decline occurred between 1997 and 1998, from 16,000 to 14,000 persons, respectively.

Figure 3-3
Annual number of persons living with HIV infection and AIDS in State X, 1996–2000



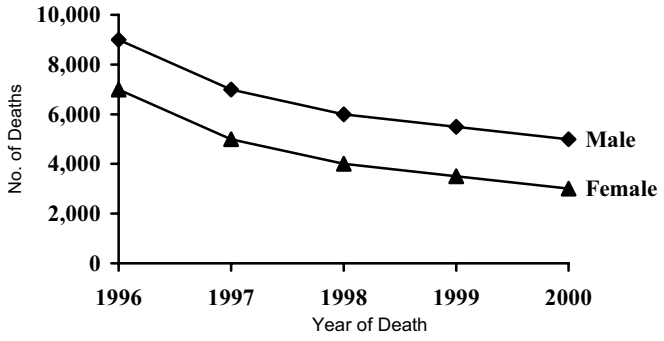
Interpretation: The number of persons living with HIV infection and AIDS has increased steadily over time. As of December 2000, an estimated 80,000 persons were living with HIV infection and AIDS in State X, representing a 129% increase since 1996. The proportion of persons living with AIDS increased from 57% in 1996 to 63% in 2000.

- Annual number of deaths of persons with HIV/AIDS (based on case surveillance data) (see Figure 3-4)
- Number of HIV cases in perinatally infected children, by year of birth

Note: Analyze the number of perinatally exposed children (including those not necessarily infected) by year of birth so that you can calculate rates of infection. Rates of infection among exposed infants can inform your prevention program about the use and effectiveness of treatments to prevent perinatal transmission.

- Estimated total HIV/AIDS prevalence (including persons with and persons without a diagnosis) for the most recent year for which required data are available

Figure 3-4
Annual number of deaths of persons with HIV/AIDS in State X, 1996–2000



Interpretation: During 1996–2000, the number of deaths of persons with HIV infection or AIDS declined steadily among males and females. Among males, deaths declined 37%, from 9,500 in 1996 to 6,000 in 2000. Among females, deaths declined 43%, from 7,000 in 1996 to 4,000 in 2000.

Extrapolation Methods
Here are two acceptable extrapolation methods for obtaining an estimated range of the number of persons living with HIV and AIDS in your area. CDC can provide a national range for these extrapolation methods, or you may choose an estimate based on other available local data.

Method 1

a. To get the proportion of cases in your service area, divide the number of persons living with AIDS in your service area by the US total of persons with AIDS.

b. Multiply this number by the national estimate of all persons living with HIV (i.e., 850,000 to 950,000 persons).

Example: At the end of 2000, an estimated 323,000 persons were living with AIDS in the United States, including US dependencies, possessions, and associated nations. (Source: CDC. *HIV/AIDS Surveillance Report* 2000;12[No. 2]:1-48. Available at www.cdc.gov/hiv/stats/hasr1202.pdf .2.)

At the end of the year, 35,000 persons were living with AIDS in State X. (Source: HIV/AIDS surveillance program in State X.)

a. To obtain the proportion of persons living with AIDS in State X, divide the number of persons living with AIDS in the state by the number of persons living with AIDS in the United States

35,000/323,000 = 11.0% of the US total of persons living with AIDS

b. To estimate HIV prevalence for State X, multiply 11% by the lower and upper values of the national HIV prevalence estimate of 850,000 to 950,000. (Source of national prevalence estimate: Fleming PL, Byers RH, Sweeney PA, Daniels D, Karon JM, Janssen RS. HIV prevalence in the United States, 2000. In: Program and abstracts of the 9th Conference on Retroviruses and Opportunistic Infections; February 24–28, 2002; Seattle, Washington. Abstract 11.)

HIV prevalence estimate for State X
= (.11 x 850,000) to (.11 x 950,000)
= 93,500 to 104,500

Data source
HIV/AIDS surveillance data

Method 2
Divide the number of persons with a diagnosis of HIV (including AIDS) by the estimated range of persons with HIV infection (71%–79%, or approximately 75%).

Example: At the end of 2000, there were an estimated 35,000 persons living with AIDS and 20,000 persons living with HIV (not AIDS) in State X. (Source: HIV/AIDS surveillance program in State X.) The HIV/AIDS surveillance program in State X has determined that completeness of AIDS case reporting is 85% and that completeness of HIV case reporting is 80%.

Using the preceding information, you need to estimate the number of persons in State X who are living with AIDS and HIV (not AIDS) but who have not been reported.

Estimate of number of living persons in State X with a diagnosis of AIDS but who have not been reported:
= 35,000 x ([1/0.85] – 1)
= 35,000 x (1.18 – 1)
= 35,000 x (0.18)
= 6,300 persons with AIDS but unreported to the HIV/AIDS surveillance program

Estimate of number of persons in State X living with HIV (not AIDS) who have not been reported:
= 20,000 x ([1/0.80] -1)
= 20,000 x (1.25 -1)
= 20,000 x (0.25)
= 5,000 persons with HIV (not AIDS) but unreported to the HIV/AIDS surveillance program

The total number of persons living with AIDS and HIV (not AIDS) in State X who know their status:
= 35,000 + 6,300 + 20,000 + 5,000
= 66,300

Determine the prevalence estimate by using Method 2.

If 75% of persons are alive and know their status, the HIV prevalence estimate in State X
= 66,300/0.75
= 88,400

Or express as a range:
66,300/0.79 to 66,300/0.71
= 83,900 to 93,400

Data source
HIV/AIDS surveillance data

Note: Because the numbers are estimates, you should round to the nearest 100 or 1,000. Of these two methods, Method 2 is preferred.

Also, some states may have to use locally developed methods to estimate the number of persons living with HIV and AIDS in order to account for variations in surveillance practices (e.g., the reporting of prevalent HIV cases only).

Example
In Table 3-13, HIV and AIDS surveillance data are used to show differences among persons for whom HIV infection was diagnosed before AIDS compared with persons for whom HIV infection was not diagnosed before AIDS. Surveillance data on persons for whom HIV infection was diagnosed before AIDS may be used to specify populations requiring prevention and treatment services.

The data are from 25 states that have conducted name-based surveillance for HIV as well as AIDS since at least 1994. Patients are grouped by whether or not clinical and laboratory criteria of the 1993 case definition for AIDS were identified within 1 calendar month of the HIV diagnosis. HIV and AIDS data were adjusted for delays in case reporting and for anticipated reclassification of cases originally reported without a mode of exposure.

Table 3-13
Persons with HIV infection, by selected characteristics—25 states[a] with HIV reporting, 1994–2000

Characteristic	HIV without AIDS No.	HIV without AIDS %	HIV with AIDS[b] No.	HIV with AIDS[b] %	Total No.	Total %	Met AIDS case definition at time of diagnosis[b] %
Sex							
Male	68,120	71	26,687	81	94,807	74	28
Female	27,549	29	6,457	19	34,006	26	19
Age group (yrs)							
<13	1,073	1	224	1	1,297	1.0	17
13–24	13,462	14	1,175	4	14,637	11	8
25–34	35,853	38	10,023	30	45,876	36	22
35–44	30,752	32	13,325	40	44,077	34	30
45–54	11,043	12	5,971	18	17,014	13	35
55–64	2,693	3	1,798	5	4,491	4	40
≥ 65	792	1	629	2	1,421	1	44
Race/ethnicity							
White, not Hispanic	32,378	34	13,469	41	45,847	36	29
Black, not Hispanic	54,590	57	16,400	50	70,990	55	23
Hispanic [c]	6,837	7	2,849	9	9,686	8	29
Asian/Pacific Islander	411	1	212	1	623	1	34
American Indian/ Alaska Native	654	1	188	1	842	1	22
Unknown	799	1	27	<1	826	1	3
Exposure category							
Male-to-male sex	39,020	41	15,694	47	54,714	43	29
Injection drug use	21,514	23	7,913	24	29,427	23	27
Male-to-male sex and injection drug use	4,666	5	1,540	5	6,206	5	25
Heterosexual contact	28,223	30	7,085	21	35,308	27	20
Other	2,246	2	912	3	3,158	3	29
Year of diagnosis							
1994	15,945	17	5760	17	21,705	17	27
1995	15,016	16	5724	17	20,740	16	28
1996	14,102	15	5131	16	19,233	15	27
1997	13,564	14	4650	14	18,214	14	26
1998	12,539	13	4060	12	16,599	13	25
1999	11,892	12	3832	12	15,724	12	24
2000	12,612	13	3987	12	16,599	13	24
Total[d, e]	95,669	74	33,144	26	128,813	100	26

Source. CDC. Diagnosis and reporting of HIV and AIDS in states with HIV/AIDS surveillance—United States, 1994–2000. *MMWR* 2002;51:595–598.

[a]Alabama, Arizona, Arkansas, Colorado, Idaho, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, Wyoming. All estimates adjusted for reporting delays and no reported mode of exposure.

[b]AIDS diagnosed within 1 calendar month of HIV diagnosis.

[c]Persons of Hispanic origin may be of any race.

[d]Includes persons for whom sex, age, race/ethnicity, region, or vital status is missing.

[e]Subpopulation totals may not equal overall total because of rounding.

Interpretation: From January 1994 through December 2000, HIV infection with or without AIDS was diagnosed for 128,813 persons in the 25 states. AIDS was the initial diagnosis for 33,144 (26%); HIV infection without AIDS was the initial diagnosis for 95,699 (74%). The number of new diagnoses for HIV-infected persons (without AIDS) declined 21% over the period of the analysis, from 15,945 in 1994 to 12,612 in 2000. A larger relative decline of 31% occurred in the number of infected persons for whom the first diagnosis was AIDS, from 5,760 in 1994 to 3,987 in 2000. However, during the last 3 years of this period, the number of reported cases remained essentially constant.

Over time, the proportion of persons for whom the first diagnosis was AIDS changed little. In 1994, the proportion was 27%; by 2000, it was 24%. However, the proportion of infected persons who also had a diagnosis of AIDS differed by demographic subgroup and mode of exposure. More of the persons with AIDS at the time of the first diagnosis were older males. A first diagnosis of AIDS was made for fewer blacks (23%) and Native Americans (22%) than for whites (29%), Hispanics (29%), or Asians/Pacific Islanders (34%). Of newly diagnosed HIV infections with and without AIDS, 55% were in blacks. Male-to-male sex was the exposure category for the highest proportion of new diagnoses of AIDS (28%). Heterosexual contact was the exposure category for the lowest proportion of new diagnoses (20%).

The surveillance data on HIV diagnoses with and without AIDS from these 25 states suggest that the number of diagnosed infections declined during the mid-1990s but that these counts stabilized during the latter part of the decade. Most of the decline occurred among infected persons aged 25–44 years, and heterosexual contact took on greater prominence as a mode of exposure.

Section B: AIDS case surveillance

Areas without 2 or more years of HIV reporting will need to rely on AIDS case surveillance data for their profile.

Include data for the most recently available calendar year and for the most recent 5-year period. To prevent the inadvertent disclosure of identity, follow state and local data-release policies when presenting data on AIDS cases.

To provide a more complete picture of the extent and effect of the epidemic, also look at TB comorbidity among AIDS cases (see page 52) and at HIV/AIDS mortality (see pages 53–54). Vital statistics data and health statistics data will give you the information you need for these analyses.

Recommended analysis for the most recently available calendar year

- Number of cases diagnosed in that year, adjusted for reporting delay. Cases with NRR should be redistributed.

Notes

NRR (no risk reported). Frequently, HIV and AIDS cases are reported to the state and local health department with no risk specified. The case is considered NRR if risk information is absent from the initial case report because the information had not been reported by the reporting source, had not been sought, or had not been found by the time the case was reported. Cases may remain NRR until epidemiologic follow-up has been completed and potential risks (exposures) have been identified. If epidemiologic follow-up has been completed and risk has not been identified within 12 months of being reported as NRR, the case may be considered NIR.

NIR (no identified risk). The case is considered NIR if after 12 months from report date, 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 remains NRR 12 or more months after the report will be considered NIR.

Given that the number of cases considered NRR or NIR is increasing, CDC is piloting studies to explore the usefulness of sampling strategies in providing unbiased estimates of risk distribution. CDC is also developing guidelines for scientifically and statistically valid methods for risk redistribution. The most important determinants of whether it is reasonable for any state or locality to redistribute risk are the overall number of cases reported, the proportion reported without risk, and the initial risk distribution. Until formal guidelines are developed for these procedures, CDC will provide technical assistance specific to the project area on the feasibility of using regional weights to conduct risk redistribution.

Adjustments for reporting delays. Because of the delay from the time that a case is diagnosed to the time it is reported to the health department, it is recommended that states make adjustments to account for reporting delays when they present data by date of diagnosis. Cases diagnosed, for example, at the end of 1 year may not be reported until the following year. If data are presented by year of diagnosis, some cases from the most recent year(s) will have not yet been reported. Without adjustment for the additional cases expected to be reported, it will appear that fewer cases were diagnosed during the recent year, giving a false impression that diagnoses are declining or declining more quickly than they are. CDC plans to distribute software programs for use with HARS that use local data to adjust for reporting delays.

If adjustment for reporting delay is not available, you may use the following alternatives:

- cases reported in the most recent year
- cases diagnosed in the most recent year without adjustment for reporting delay
- cases diagnosed in the year before the most recent year to allow time for reporting (this alternative may be helpful to allow for the lag in reporting and to allow time for NRR follow-up investigations if adjustment for NRR redistribution is not possible)

- Number, percentage distribution, and rates (per 100,000) of cases by race/ethnicity and sex (see Table 3-14)

Table 3-14
AIDS diagnoses and rates per 100,000 population in State X, by race/ethnicity and sex, 2000

	Males			Females			Total		
Race/ethnicity	No.	%	Rate	No.	%	Rate	No.	%	Rate
White, not Hispanic	900	32	7.1	193	18	1.5	1,093	28	4.2
Black, not Hispanic	1,467	52	74.2	723	69	33.0	2,190	57	52.6
Hispanic	403	14	37.1	118	11	10.8	521	14	24.0
Asian/Pacific Islander	25	<1	5.1	5	1	1.0	30	<1	3.0
American Indian/Alaska Native	8	<1	9.0	7	<1	8.7	15	<1	8.9
Total	2,803	100	17.1	1,046	100	6.1	3,849	100	11.5

Interpretation: In 2000, AIDS was diagnosed for 3,849 persons. Of these, 2,803 (73%) were male, and 1,046 (27%) were female. By race/ethnicity, 2,190 (62%) were black, 1,093 (26%) were white, 521 (11%) were Hispanic, 30 (<1%) were Asian/Pacific Islander, and 15 (<1%) were American Indian/Alaska Native.

The 2000 rate of diagnosed AIDS cases was 12 per 100,000 in State X. The rate for males was almost 3 times the rate for females (17/100,000 compared with 6/100,000). By race/ethnicity, rates were highest for blacks (53/100,000) compared with Hispanics (24/100,000), American Indians/Alaska Natives (9/100,000), whites (4/100,000), and Asians/Pacific Islanders (3/100,000). Compared with the rates by sex and race/ethnicity for all other groups, those rates were higher for black and Hispanic males (74/100,000 and 37/100,000, respectively). The third highest rate (33/100,000) was that for black females.

- Number and percentage distribution of cases by
  - age group and sex (see Table 3-15)
  - exposure category and sex (see Table 3-16)
  - exposure category for each race/ethnicity (see Table 3-17)

Table 3-15
AIDS diagnoses for persons in State X, by age group and sex, 2000

	Males		Females		Total	
Age (yrs)	No.	%	No.	%	No.	%
0–1	—	<1	—	<1	—	<1
2–12	4	<1	6	1	10	<1
13–24	78	3	49	5	127	3
25–44	1,858	66	741	71	2,599	67
45–64	817	29	241	23	1,058	27
≥ 65	46	2	10	1	56	1
All ages	2,803	100	1,047	100	3,850	100

Dash indicates cell size of ≤ 3.

Interpretation: In 2000, AIDS diagnosis was made for 3,853 persons in State X. More of the persons with AIDS were males in the 25–44 age group. Overall, most of the persons with AIDS (67%) were in the age group 25–44 years.

Table 3-16
AIDS diagnoses for persons in State X, by exposure category and sex, 2000

	Males		Females		Total	
Exposure category	No.	%	No.	%	No.	%
Male-to-male sex	1,371	49	NA	NA	1,371	36
Injection drug use	761	27	355	34	1,116	29
Male-to-male sex and injection drug use	176	6	NA	NA	176	5
Heterosexual contact	451	16	653	62	1,104	29
Mother with, or at risk for, HIV infection	8	1	8	1	16	<1
Other/unknown	38	1	29	3	67	1
Total	2,805	100	1,045	100	3,850	100

NA, not applicable.
Note. Adjusted for delays in reporting and redistribution of cases reported as no identified risk (NIR).

Interpretation: By risk exposure category, 1,371 (36%) were persons classified as infected through male-to-male sex, 1,104 (29%) through heterosexual contact, 1,116 (29%) through injection drug use, 176 (5%) through male-to-male sex and injection drug use, and 67 (1%) through other exposures. AIDS diagnoses were made for 2,805 males, among whom the predominant mode of exposure was male-to-male sex (49%) followed by injection drug use (27%) and heterosexual contact (16%). AIDS diagnoses were made for 1,045 females, among whom the predominant mode of exposure was heterosexual contact (62%) followed by injection drug use (34%).

Table 3-17
AIDS diagnoses for persons in State X, by exposure category, 2000

Exposure category	White, not Hispanic		Black, not Hispanic		Hispanic		Asian/ Pacific Islander		American Indian/Alaska Native		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Male-to-male sex	601	55	591	27	163	31	11	35	—	21	1,366	36
Injection drug use	205	19	715	33	184	35	6	19	4	29	1,114	29
Male-to-male sex and injection drug	78	7	70	—	26	5	—	—	—	—	174	5
Heterosexual contact	184	17	765	35	137	26	13	42	6	43	1,105	29
Mother with, or at risk for, HIV infection	—	<1	12	<1	—	—	—	—	—	—	12	<1
Other/unknown	23	<2	37	<1	8	<1	—	—	—	—	68	<1
Total	1,091	100	2,190	100	518	100	30	100	10	100	3,839	100

Dash indicates cell size of ≤ 3.

Interpretation: The distribution of risk differs by race/ethnicity. For male-to-male sex, injection drug use, and heterosexual contact, proportions of AIDS cases were 55%, 19%, and 17% among white persons; 27%, 33%, and 35% among blacks; 31%, 35%, and 26% among Hispanics; 35%, 19%, and 42% among Asians/Pacific Islanders; and 21%, 29%, and 43% among American Indians/Alaska Natives, respectively.

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), develop the following tables stratified by region:

- Number and percentage distribution of cases by
  - race/ethnicity
  - age group
  - exposure category
- Case rates (cases per 100,000 population) by race/ethnicity
- Case rates by race/ethnicity for each sex

These analyses will be somewhat dictated by the planning jurisdiction. For example, a regional CPG will need a regional profile. However, areas with 1 state planning group should stratify by geographic or public health area, whichever makes sense at the local level.

Recommended analyses for TB comorbidity

Number and percentage distribution of persons with AIDS who also have TB

> *Note:* If the number of these cases is large, it may be useful to do additional cross-tabulations by sex, exposure category, geographic location, or race/ethnicity.

Recommended analyses for AIDS mortality

Number and rates of death (per 100,000 population) of **persons with AIDS**, by race/ethnicity and sex, based on AIDS surveillance data (see Table 3-18)

Table 3-18
Number of deaths among persons with AIDS and death rates per 100,000 population in State X, by race/ethnicity and sex, 2000

	Males			Females			Total		
Race/ethnicity	No.	%	Rate	No.	%	Rate	No.	%	Rate
White, not Hispanic	386	29	3.0	96	19	0.7	482	26	1.9
Black, not Hispanic	809	59	40.9	356	70	16.3	1,165	62	28.0
Hispanic	155	11	14.3	53	10	4.8	208	11	9.6
Asian/Pacific Islander	5	<1	1.1	3	<1	0.6	8	<1	0.8
American Indian/ Alaska Native	8	<1	9.8	3	<1	3.6	11	<1	6.7
Total	1,363	100	8.3	511	100	3.0	1,874	100	5.6

Note. A small proportion of deaths of persons with HIV/AIDS included here are due to causes unrelated to HIV infection, such as motor vehicle accidents or lung cancer.

Interpretation: Rates of death of persons with AIDS were much greater among males than among females and greater among blacks (28/100,000) than among whites (2/100,000). The rate among Hispanics (10/100,000) was intermediate between the rates for whites and blacks.

> *Note:* The denominator used in calculating death rates is the population of interest in a service area. For example, in Table 3-18, since the numbers and rates of deaths are being calculated for persons with a diagnosis of AIDS, 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.

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

- Number and rates of death (per 100,000 population) **due to HIV infection and AIDS**, by race/ethnicity and sex, based on vital statistics mortality data
- Number of deaths by underlying cause among persons 25–44 years of age, based on vital statistics mortality data (see Table 3-19)

These analyses will allow you to determine the ranking of AIDS among underlying causes of death for the most recent year for which data are available.

Table 3-19
Ranking of 10 leading underlying causes of death among persons 25–44 years of age in State X, 1999

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

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. The appendixes contain additional examples of vital statistics mortality data.

Interpretation: HIV disease (including AIDS) was the third leading cause of death in 1999 among persons 25–44 years old in State X, accounting for 12% of all deaths in this age group.

Data sources

- AIDS surveillance data
- Local offices of vital statistics
- National Center for Health Statistics
- CDC WONDER

> *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, AIDS).

- **Recommended analyses for the most recent 5-year period**
  It is a good idea to present the results of the stratified analyses whether or not you detect important changes in percentages or differences in trends among groups. If you find no differences, you may state that.

- For substantial shifts in the demographic composition or geographic distribution of the general population in your service area, it is helpful to control for these changes by analyzing trends in the demographic group–specific **rates** in addition to, or instead of, the trends in the numbers of cases.

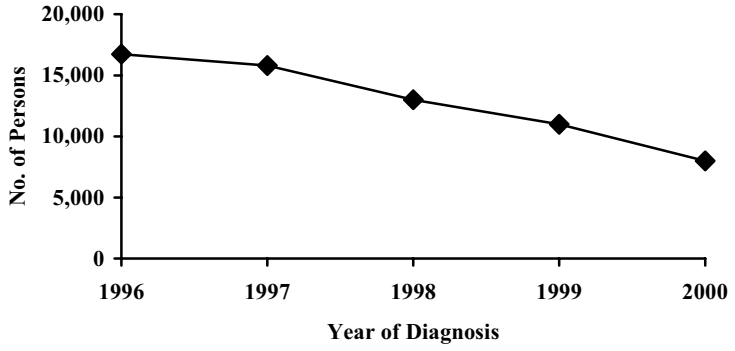
- For the years of diagnosis to more accurately reflect the years when HIV transmission occurred, you may wish to restrict trend analyses to younger ages (persons under 25 years of age at diagnosis) for HIV exposure categories such as male-to-male sex, heterosexual contact, and injection drug use, and mother-to-child transmission in children less than 2 years old at diagnosis. However, once you have completed the analyses, if the trend with the age restriction does not differ from the trend without it, then do not restrict the age in presenting the data.
- If the numbers of cases per year are too small (<20) for meaningful analysis, combine cases in the most recent few years and compare with cases in a preceding period of an equal number of years (e.g., compare 1995–1997 cases with 1998–2000 cases).

Analyze trends in the following. Stratify by sex, race/ethnicity, age group, geographic area, and exposure category and include a table for each:

- Annual number of AIDS diagnoses, adjusted for reporting delay (see Figure 3-5)

> *Note:* If it is not possible to adjust the number of diagnoses for reporting delay, you may analyze the trend in cases by year of report, but it could be misleading if the completeness of reporting or case-finding activities have not been uniform over time.

Figure 3-5
Annual AIDS diagnoses among persons in State X, 1996–2000



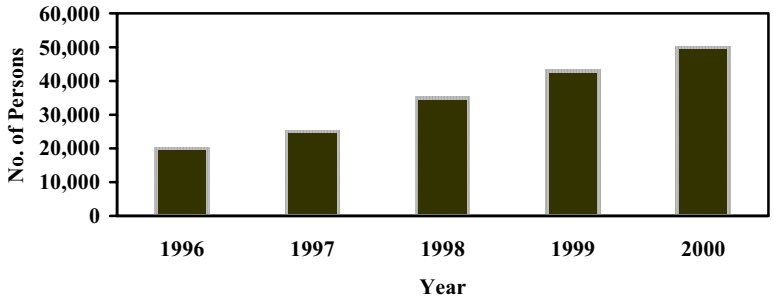
Note. Adjusted for delays in reporting.

Interpretation: From 1996 through 2000, the number of AIDS diagnoses steadily declined. In 1996, the number of cases diagnosed was 17,500; in 2000 the number was 9,500. The greatest annual decline occurred between 1997 and 1998, from 16,000 to 14,000 persons, respectively.

- Prevalence of diagnosed AIDS cases (i.e., refers to persons living with AIDS) (see Figure 3-6)

Note: If you present data by age group, it is preferable to define age according to current age, rather than age at diagnosis. For purposes of care planning, consider defining persons with diagnosis by their current (or last known) residence rather than their residence at first diagnosis.

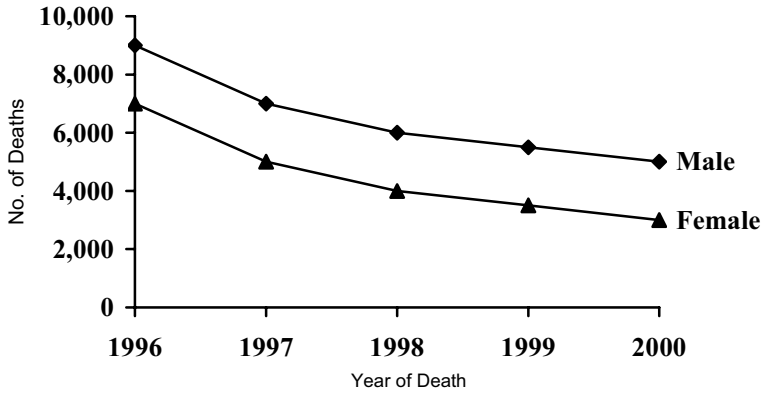
Figure 3-6
Annual number of persons living with AIDS in State X, 1996–2000



Interpretation: The number of persons living with AIDS has increased steadily over time. As of December 2000, an estimated 52,000 persons were living with AIDS in State X, representing a 160% increase since 1996.

- Annual number of deaths of persons with AIDS (based on case surveillance data) (see Figure 3-7)
- Estimated total HIV/AIDS prevalence (including persons with and persons without a diagnosis)

Figure 3-7
Annual number of deaths of persons with AIDS in State X, 1996–2000



Interpretation: During 1996–2000, the number of deaths of persons with AIDS declined steadily among males and females. Among males, deaths declined 37%, from 9,500 in 1996 to 6,000 in 2000. Among females, deaths declined 43%, from 7,000 in 1996 to 4,000 in 2000.

Extrapolation Method
You may use this method to get an estimated range of the number of persons living with HIV in your area. This method is the only acceptable method for states without HIV reporting.

a. To get the proportion of cases in your area, divide the number of persons living with AIDS in your service area by the US total of persons with AIDS.

b. Multiply this by the national estimate of all persons living with HIV (i.e., 850,000 to 950,000 persons).

Example: At the end of 2000, an estimated 322,865 persons were living with AIDS in the United States, including US dependencies, possessions, and associated nations. (Source: CDC. *HIV/AIDS Surveillance Report* 2000;12[No. 2]:1-48. Available at http:www.cdc.gov/hiv/stats/hasr1202.pdf.)

At the end of the year, 35,670 persons were living with AIDS in State X. (Source: HIV/AIDS surveillance program in State X)

a. To obtain the proportion of persons living with AIDS, divide the number of persons living with AIDS in state X by the number of persons living with AIDS in the United States

   35,670/322,865 = 11.0% of the US total of persons living with AIDS.

b. To estimate HIV prevalence for State X, multiply 11% by the lower and upper values of the national HIV prevalence estimate of 850,000 to 950,000. (Source of national prevalence estimate: Fleming PL, Byers RH, Sweeney PA, Daniels D, Karon JM, Janssen RS. HIV prevalence in the United States, 2000. In: Program and abstracts of the 9th Conference on Retroviruses and Opportunistic Infections; February 24–28, 2002; Seattle, Washington. Abstract 11.)

   HIV prevalence estimate for State X
   (.11 x 850,000) to (.11 x 950,000) = 93,500 to 104,500

Data Source
AIDS surveillance data

Section C: HIV surveys

HIV serosurveys

HIV serosurvey data will provide the supporting evidence you need to analyze seroprevalence rates.

Recommended analyses for seroprevalence rates

- Seroprevalence rates across groups, using the most recently available data, stratified by age group, sex, race/ethnicity, exposure category, and geographic area (if available)
- Trends, using data for the most recent 5-year period (if available)

Data sources
For select populations, HIV seroprevalence survey data may be available only in some geographic areas. Check the following resources for data covering your service area:

- Survey of Childbearing Women (testing of newborns)
- Job Corps
- Military applicants
- STD clinics
- Correctional facilities
- Substance abuse treatment centers
- Other (e.g., special studies done locally by the health department, universities, private researchers, or community-based organizations)

> *Note:* Results from surveys (whether or not the surveys were blinded, or masked) may be biased by self-selection. As a result, these data may not represent the general population.

HIV incidence surveillance

The comparison of incident and prevalent infections will allow you to monitor emerging trends in the epidemic, choose appropriate interventions, evaluate prevention programs, and provide a population-based estimate of HIV incidence. The goals of HIV incidence surveillance are to (a) collect and test diagnostic blood specimens from all persons reported to HIV surveillance as having newly diagnosed HIV infections, (b) collect the HIV testing history needed for the statistical estimates of incidence, and (c) link incidence test data and testing history data in order to make population-based estimates of HIV incidence.

Recommended analyses for HIV incidence surveillance

Number and percentage of HIV incident infections stratified by age group, sex, race/ethnicity, and exposure category

Data source

CDC HIV incidence surveillance

HIV counseling and testing system data

Counseling and testing system (CTS) data can serve as an additional source of information on new HIV diagnoses in your service area. However, these data represent only persons who seek, or are offered, testing at selected venues. HIV cases or tests reported from private physicians, health maintenance organizations, and hospitals are not included in CTS unless these sites are also directly or indirectly funded by CDC to do HIV counseling, testing, and referral and to report data to local and state health departments. Most CTS data represent test results, not necessarily individual patients. As a result, it may not be possible to distinguish a single client who has been tested multiple times from multiple clients, each of whom has been tested a single time. CTS data represent about 20% to 50% of persons reported with HIV infection. Estimates from local or state health departments may be slightly higher.

You can present demographically stratified tables whether or not you detect important differences among groups. If you find no differences, be sure to state that.

Because these data may represent only persons tested in CDC-funded settings, you may increase the usefulness of the data by limiting analysis to the following:

- test results of persons tested for the first time
- HIV-positive test results without record of a previous HIV-positive test result
- unduplicated data if the area has a system for eliminating duplicate test results

Recommended analyses
Trends for the most recent 5-year period, stratified by age group, sex, race/ethnicity, exposure category, and geographic area (if available)

Data source
State or local HIV counseling and testing program

Summary of Recommended Analyses for Question 2

The analyses summarized here will guide you in analyzing, interpreting, and presenting HIV and AIDS surveillance data. Depending on your local needs, you may choose to perform additional analyses. For example, you may need additional analyses by sex and race/ethnicity. You may decide to perform additional analyses by using the expanded race data in HARS. We recommend that patient self-report or detailed race/ethnicity, when available, be presented in epidemiologic profiles.

HIV and AIDS case surveillance

For the most recently available calendar year

- Cases diagnosed in that year, adjusted for reporting delay (cases with NRR should be redistributed)
- Number, percentage distribution, and rates of cases by race/ethnicity and sex
- Number and percentage distribution of cases by
  - age group and sex
  - exposure category and sex
  - exposure category for each race/ethnicity

For geographic areas with large numbers of cases

- Number and percentage distribution of cases by
  - race/ethnicity
  - age group
  - exposure category
- Case rates (cases per 100,000 population) by race/ethnicity for
  - each geographic subunit
  - each sex

For TB comorbidity
Number and percentage distribution of persons with AIDS who also have TB

For HIV and AIDS mortality

- Number and rates of death (per 100,000 population) of persons with HIV infection and persons with AIDS, by race/ethnicity and sex, based on HIV/AIDS surveillance data
- Number of deaths, by underlying cause, among persons aged 25–44 years, based on vital statistics mortality data
- Number and rates of death (per 100,000 population) due to HIV infection and AIDS, by race/ethnicity and sex, based on vital statistics mortality data

Recommended analyses for the most recent 5-year period

- Annual number of HIV diagnoses (combined with AIDS), adjusted for reporting delay
- AIDS cases alone (excluding cases of HIV infection that have not progressed to AIDS)
- Prevalence of HIV and AIDS cases (refers to persons living with HIV infection and persons living with AIDS)
- Annual number of deaths of persons with HIV and persons with AIDS (based on case surveillance data)
- Number of HIV cases among perinatally infected children, by year of birth

AIDS case surveillance

For the most recently available calendar year

- Cases diagnosed in that year, adjusted for reporting delay (cases with NRR should be redistributed)
- Number, percentage distribution, and rates of cases by race/ethnicity and sex
- Number and percentage distribution of cases by
  - age group and sex
  - exposure category and sex
  - exposure category for each race/ethnicity and sex

For geographic areas with large numbers of cases

- Number and percentage distribution of cases by
  - race/ethnicity
  - age group
  - exposure category
- Case rates (cases per 100,000 population) by race/ethnicity
- Case rates by race/ethnicity for each sex

For TB comorbidity

Number and percentage distribution of persons with AIDS who also have TB

For HIV and AIDS mortality

- Number and rates of death (per 100,000 population) among persons with AIDS, by race/ethnicity and sex, based on AIDS surveillance data
- Number and rates of death (per 100,000 population) due to HIV infection and AIDS, by race/ethnicity and sex, based on vital statistics mortality data

- Number of deaths, by underlying cause, among persons 25 to 44 years old, based on vital statistics mortality data

For the most recent 5-year period

- Annual number of AIDS diagnoses, adjusted for reporting delay
- Prevalence of AIDS cases (refers to persons living with AIDS)
- Annual number of deaths of persons with HIV infection and persons with AIDS (based on case surveillance data)
- Estimated total prevalence of HIV infection and AIDS (including persons with and persons without a diagnosis)

HIV surveys

For HIV seroprevalence

- Seroprevalence rates across groups, based on the most recently available data, stratified by age group, sex, race/ethnicity, exposure category, and geographic area (if available)
- Trends based on data from the most recent 5-year period (if available)

For HIV incidence surveillance

Number and percentage of HIV incident infections, stratified by age group, sex, race/ethnicity, and exposure category

For counseling and testing data

Trends for the most recent 5-year period, stratified by age group, sex, race/ethnicity, exposure category, and geographic area (if available)

Question 3

What are the indicators of risk for HIV infection and AIDS in the population covered by your service area?

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 on page 78 to examine the risk for HIV infection and AIDS by exposure 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 and AIDS 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 your local area at increased risk for HIV infection.

Conduct stratified analyses of these exposure categories by sex, race/ethnicity, and age group.

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

For each of the exposure 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

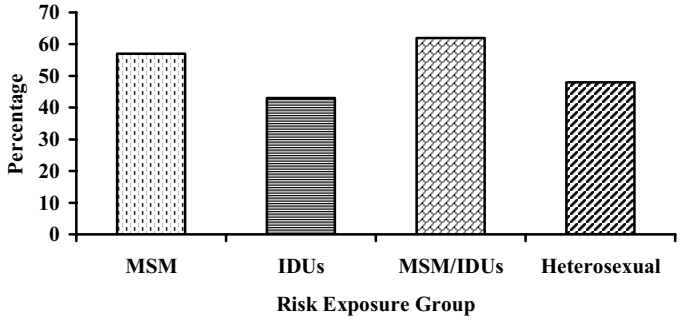
Direct measures of risk provide information about risk behavior that is directly associated with HIV transmission. Indirect measures do not directly describe HIV risk behaviors. Rather, they are indicators of *possible* HIV risk that may need further investigation. For example, an increase in STD or 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 (see Figure 3-8)
  - 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)

Conduct stratified analyses of these exposure categories by sex, race/ethnicity, and age group (include adolescents).

Figure 3-8
Proportion of men who had more than 1 sex partner in the past 12 months, by risk exposure group, Supplement to HIV/AIDS Surveillance, State X, 2000



Interpretation: Having sex with more than 1 person for a defined period can indicate increased risk for the sexual transmission of HIV. Stratified analysis of this behavior by sex, race/ethnicity, or HIV exposure can indicate populations that need prevention activities. In this example, a higher proportion of men who have sex with men (MSM) and MSM who are also injection drug users, compared with other groups, reported having had multiple sex partners during the past 12 months. Local prevention planners may consider implementing prevention messages about reducing the number of sex partners, focusing on MSM and MSM who inject drugs.

Data sources
No national data exist on the prevalence of behavioral risk factors for HIV or of sexual orientation (at the county or state level). In some areas, the following survey data are available:

- At-risk populations
  - HIV Testing Survey
  - Young Men's Survey
  - Monitoring Trends in Prevalence of STDs, TB, and HIV Risk Behaviors among MSM Project
  - Youth Risk Behavioral Survey (Some project areas collect same-sex data; others do not.)
  - Behavioral Surveillance Project (CDC, Division of HIV/AIDS Prevention)
  - In addition, seek results from locally conducted cross-sectional studies funded by the National Institutes of Health (NIH) and CDC, such as the Gay Urban Men's Study (GUMS). Baseline data from intervention studies such as the Community Intervention Trials for Youth (CITY; racial/ethnic groups in Atlanta, Birmingham [Alabama], Chicago, Milwaukee, Minneapolis, San Diego, and Seattle and Los Angeles County and Orange County [California]) also may be useful. Note how the sampling frames for such studies relate to population estimates and whether some studies may have more historical than contemporary value. Because of the varying applicability of such studies, they are not included in Appendix A.
- HIV-positive persons
  - Young Men's Survey
  - Survey of HIV Disease and Care
  - Supplement to HIV/AIDS Surveillance
  - In addition, seek results from locally conducted cross-sectional studies funded by NIH and CDC, such as the Seropositive Urban Men's Study (SUMS; conducted in New York City and San Francisco). Baseline data from intervention studies such as the Intervention for Seropositive Injection Drug Users, Research & Evaluation (INSPIRE; conducted in Baltimore, Miami, New York City, and San Francisco) also may be useful. Note how the sampling frames for such studies relate to population estimates and consider the timeliness of the data and whether some studies may have more historical than contemporary value. Because of the varying applicability of such studies, they are not included in Appendix A.

Recommended analyses for MSM: indirect measures

- For data available for every state and county, 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

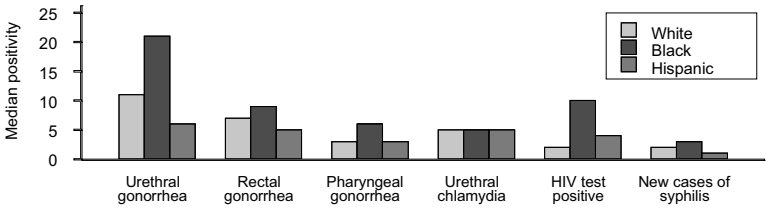
- gonorrhea, chlamydia, and syphilis among men with same-sex partners (see Figure 3-9)
- trends in rectal gonorrhea among men
- proportion of Gonococcal Isolate Surveillance Project (GISP) isolates from MSM

Conduct stratified analyses of these exposure categories by sex, race/ethnicity, and age group (include adolescents).

Data sources

- STD notifiable disease surveillance data
- Gonococcal Isolate Surveillance Project
- Sentinel County Surveillance System for Hepatitis
- Supplement to HIV/AIDS Surveillance
- HIV/AIDS surveillance registry matches to STD registry to monitor trends in STD incidence among HIV-infected persons
- Adult/Adolescent Spectrum of Disease
- Behavioral Surveillance Project (CDC, Division of HIV/AIDS Prevention)

Figure 3-9
Median positivity of STD test results among men who have sex with men (MSM), by race/ethnicity, STD clinics in State X, 2000



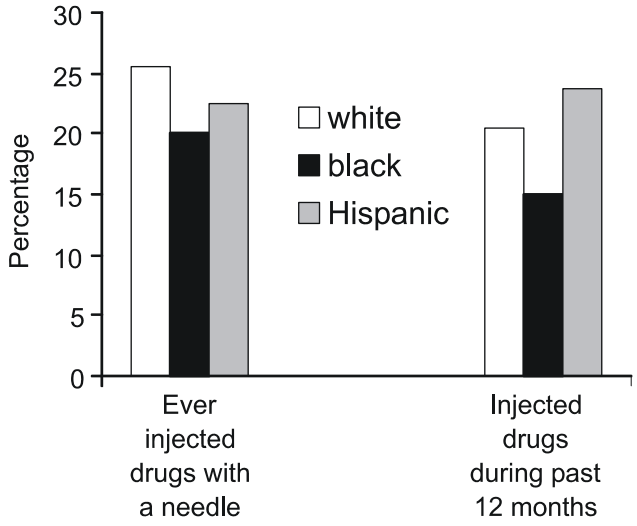
Interpretation: Among MSM at STD clinics in 2000, median positivity was higher for blacks than for other races/ethnicities for urethral gonorrhea, rectal gonorrhea, pharyngeal gonorrhea, HIV, and new cases of syphilis. The median positivity was similar for all races/ethnicities for urethral chlamydia.

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

- Factors that may affect risk of acquiring or transmitting HIV, such as
  - Injection drug use (see Figure 3-10) 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 of these exposure categories by sex, race/ethnicity, and age group (include adolescents).

Figure 3-10
Injection drug use among participants in Supplement to HIV/AIDS Surveillance, by race/ethnicity, State X, 2000



Interpretation: A history of injection drug use can provide general information on risk behavior. However, having injected drugs within the past 12 months provides a stronger indication of recent risk of acquiring or transmitting HIV. Stratified analysis of recent injection drug use by sex or race/ethnicity can indicate populations that need specific prevention activities. In the example here, the highest proportion of persons who had ever injected drugs were white; the highest proportion who had injected within the past 12 months were Hispanic. Local prevention planners may consider implementing prevention messages for current injection drug users, focusing on Hispanics who inject drugs.

Data sources

- Available everywhere for persons at risk
  - Behavioral Risk Factor Surveillance System
  - Youth Risk Behavior Surveillance System
  - National Household Survey of Drug Abuse
- Available in some areas for persons at risk
  - Arrestee Drug Abuse Monitoring
  - HIV Testing Survey
  - Collaborative Injection Drug Users Studies
  - Monitoring the Future (National Institute on Drug Abuse survey of drug abuse among youth in high school)
- Available in some areas for persons infected with HIV
  - Supplement to HIV/AIDS Surveillance
  - Adult/Adolescent Spectrum of Disease Project
  - Survey of HIV Disease and Care
  - In addition, seek results from locally conducted cross-sectional studies funded by NIH and CDC, such as the Seropositive Urban Drug Injectors Study (SUDIS; conducted in New York City and San Francisco). Baseline data from intervention studies such as the Intervention for Seropositive Injection Drug Users, Research & Evaluation (INSPIRE; conducted in Baltimore, Miami, New York City, and San Francisco) also may be useful. Note how the sampling frames for such studies relate to population estimates and consider the timeliness of the data and whether some studies have more historical than contemporary value. Because of the varying applicability of such studies, they are not included in Appendix A.

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 (the period examined should coincide with that of risk-behavior questions)

Conduct stratified analyses of these exposure categories by sex, race/ethnicity, and age group (include adolescents).

Data sources

- Available for every state and county
  - National Notifiable Diseases Surveillance System
  - Sentinel County Surveillance System for Hepatitis
  - Rates of mortality due to substance abuse
- Available in some areas

- Drug Abuse Warning Network
- National Household Survey on Drug Abuse
- 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.

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 these exposure categories by sex, race/ethnicity, and age group (include adolescents).

Data sources

- Available in all areas for persons at risk
  - Behavioral Risk Factor Surveillance System
  - Kaiser Family Foundation
- Available in some areas for persons at risk
  - Youth Risk Behavior Surveillance System
  - National Health Interview Survey
  - National Survey of Family Growth
  - HIV Testing Survey
  - CDC behavioral surveillance
- Available in some areas for persons who are HIV-positive
  - Supplement to HIV/AIDS Surveillance
  - In addition to routine surveillance data, seek results from locally conducted cross-sectional studies funded by NIH, CDC, other government agencies, or nongovernmental organizations.

Recommended analyses for heterosexual populations: indirect measures

- Trends in
  - teen pregnancy rates
  - gonorrhea rates
  - primary and secondary syphilis
  - recent STD history (The period examined should coincide with that of the risk-behavior questions.)

Conduct stratified analyses of these exposure categories 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 cases (<20), use this analysis with caution: sporadic outbreaks do not necessarily indicate changes in risk behavior in the community.

Data sources

- Available for every state and county
  - pregnancy rates—vital statistics

  Note: Use pregnancy rates cautiously: some pregnancies are planned.

- Available in some areas for persons who are HIV-positive
  - HIV/AIDS surveillance registry matches to STD registry to monitor trends in STD incidence among HIV-infected persons
  - Adult/Adolescent Spectrum of Disease project
  - Survey of HIV Disease and Care
  - gonorrhea rates—STD programs
  - primary and secondary syphilis—STD programs

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 the epidemic 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.

Populations of interest and recommended sources of data may include

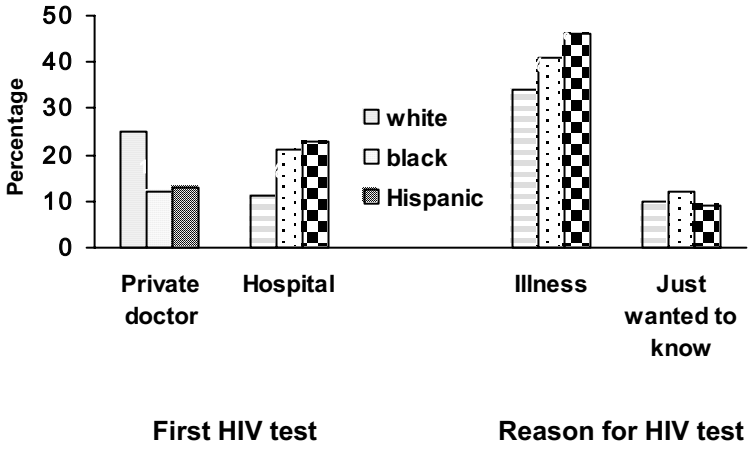
- Commercial sex workers
- Incarcerated persons (see HIV/AIDS surveillance, Arrestee Drug Abuse and Monitoring, Supplement to HIV/AIDS Surveillance, STD surveillance)
- Homeless persons
- Migrant laborers (see Special Programs of National Significance and CDC Border Infectious Disease Surveillance)
- Persons with mental illness

- Deaf and hearing-impaired persons
- Perinatally exposed children (see Enhanced Perinatal Surveillance data)
- Transgender persons

Optional analyses for HIV counseling and testing

Planning groups may find it useful to analyze testing data in their communities to help focus testing campaigns (see Figure 3-11). Some population-based surveys may provide data on testing practices in the greater community; others provide data on specific populations at increased risk for HIV infection. Additionally, counseling and testing data may provide information on the extent of testing at publicly funded sites. Specific analyses of reasons for being tested, barriers to testing, and availability of testing services may be useful. Despite their limitations, counseling and testing data may provide useful information for planning purposes.

Figure 3-11
First positive HIV test result: patients' choice of location for test and main reason for being tested, by race/ethnicity, Supplement to HIV/AIDS Surveillance, State X, 2000



Interpretation: The location of the first test for which the result was positive, along with the main reason for seeking the test, can indicate the perception of risk for infection. Stratified analysis of location and reason for being tested can indicate populations who do not perceive themselves as at risk for HIV. In this example, a higher proportion of blacks and Hispanics, compared with whites, were tested as hospital inpatients. Also, a higher proportion of blacks and Hispanics reported having sought the test because of illness. Local prevention planners may consider focusing HIV testing campaigns on persons who do not perceive themselves to be at risk, in this instance, blacks and Hispanics.

Data sources

- Available everywhere
  - counseling and testing data (trends in number of tests at publicly funded counseling and testing sites)
  - Behavioral Risk Factor Surveillance System
  - Youth Risk Behavior Surveillance System (may not include testing questions)
  - school health profiles
- Available in some areas
  - National Health Interview Survey
  - HIV Testing Survey
- Available in some areas for persons who are HIV-positive
  - Supplement to HIV/AIDS Surveillance
  - Pregnancy Risk Assessment Monitoring System

Example:
In the following example, multiple data sources are used to examine differences in testing behaviors among Hispanics (Source: Klevens et al., 40th Annual Meeting of the Infectious Disease Society of America; October 24-27, 2002; Chicago. Abstract 100760.)

Differences in HIV testing behaviors among US Hispanics, by place of birth
Background: Hispanics in the United States have been disproportionately affected by the HIV/AIDS epidemic. One of the challenges for prevention and treatment is the diversity of the Hispanic population. We describe the differences among Hispanics and present implications for the prevention and treatment of HIV among Hispanics, by place of birth.

Methods: We used selected epidemiologic indicators from 3 sources of data: (a) US AIDS surveillance, which since 1981 has included reports of persons with AIDS from all states, the District of Columbia, and US territories by use of a standard case definition and form; (b) the Supplement to HIV/AIDS Surveillance project, which from May 2000 through April 2002 interviewed persons with HIV infection or AIDS in 16 states; and (c) the HIV Counseling and Testing Data System, which in 2000 received data on HIV tests conducted in CDC-funded testing facilities in 50 states, 7 cities, and 8 US territories. We restricted analyses to Hispanics and defined foreign-born persons as those born in Puerto Rico or a country other than the United States.

Results: Of the 151,455 Hispanics with a diagnosis of AIDS through June 2001 in the United States, 53% were foreign-born, 36% were US-born, and the place of birth was missing or unknown for 11%. Of the 758 Hispanics interviewed, 494 (65%) were foreign-born. Foreign-born Hispanics were more likely to report that the main reason they sought an HIV test was illness (odds ratio [OR], 2.3; 95% confidence interval [CI], 1.6–3.2). Foreign-born Hispanics (87%) were more likely than US-born Hispanics (80%) to report a

confidential rather than an anonymous HIV test (OR, 2.9; 95% CI, 1.8–4.7). Of 3,214 Hispanics with positive test results, 681 (21%) did not report a posttest counseling session. Among the 42,767 Hispanics whose diagnosis of AIDS was made since highly active antiretroviral therapy became available, foreign-born Hispanics were more likely to have been tested in an inpatient facility or emergency room (OR, 1.2; 95% CI, 1.2–1.3).

Conclusions: Among Hispanics with AIDS, about half were foreign-born. Hispanics tested in hospitals may not have been aware of their HIV status. Barriers to early diagnosis and services should be identified and eliminated to prevent HIV/AIDS and improve the quality of life of Hispanics with HIV/AIDS.

Summary of Recommended Analyses for Question 3

- Examine direct and indirect measures of risk for HIV infection and AIDS by exposure category:
  - male-to-male sex
  - injection drug use
  - heterosexual contact
- If desired, examine risk for HIV/AIDS 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 exposure categories by sex, race/ethnicity, and age group (including adolescents).
- Analyze HIV counseling and testing data to determine testing decisions and behaviors among specific groups at risk.

Section 2: Special Questions and Considerations for Ryan White CARE Act Grantees

This section contains two questions that pertain to HRSA HIV/AIDS care planning groups. You should answer these questions in addition to the core epidemiologic questions in Section 1.

Question 1

What are the patterns of service utilization of HIV-infected persons in your area?

In this section of your profile, describe the patterns of service utilization of the HIV-infected persons in your area (see Tables 3-20, 3-21, and 3-22 and Figures 3-12 and 3-13).

Many types of data are available to help you answer this question. Some, such as the CARE Act Data report (CADR), are available everywhere; others are available only in some areas. Recommended analyses using CADR data are described here. Other potential data sources, along with suggested analyses, are described after the illustrative tables and figures for CADR data analyses.

Recommended analyses

- HIV primary medical care, by sex, race/ethnicity, age group, exposure categories, TB status, and viral hepatitis (B and C) status
- Support services, by sex, race/ethnicity, and age group

Notes:

- HIV primary medical care includes the following:
  - medical evaluation and clinical care consistent with US Public Health Service guidelines, including the monitoring of CD4 cell counts; viral load testing; antiretroviral therapy; prophylaxis and treatment of opportunistic infections, malignancies, and other related conditions
  - oral health care
  - outpatient mental health care
  - outpatient substance abuse treatment
  - nutritional services
  - specialty medical care referrals
- Duplicates in CADR data are removed at the provider level. Furthermore, because all the data elements are required elements of the CADR, an agency with a client-level system will be able to compute these analyses for its clients. If a grantee does

not have a way to remove the duplicates from the provider records, these data will be duplicated at the EMA or state level. Use caution when working with these data.

Table 3-20
Comparison of characteristics of CARE Act clients and those of persons with AIDS reported to the CDC HIV/AIDS surveillance system, State X, 2000

Characteristic	CARE Act clients,[a] % (*N* = 950)	Persons with AIDS reported to CDC HIV/AIDS surveillance system, % (*N* = 3,500)
Race/ethnicity		
White (not Hispanic)	43	58
Black (not Hispanic)	25	17
Hispanic	29	22
Asian/Pacific Islander	2	2
American Indian/Alaska Native	1	1
Sex		
Male	79	87
Female	21	13
Age (yrs)		
<13	4	2
13–19	1	1
20–44	71	77
≥ 45	24	20

[a] Includes all persons who had at least 1 visit for an eligible service during the reporting period. Client counts are duplicated at the grantee level (state or eligible metropolitan area).

Interpretation: This table shows that the Ryan White CARE Act is serving a greater proportion of persons from communities of color compared with the proportion of persons with AIDS in State X. In addition, although most of the clients being served by the Ryan White CARE Act are male, the proportion of females being served is greater than the proportion of females with AIDS. The CARE Act is serving a greater proportion of persons less than 13 years of age and more than 45 years of age compared with the proportion of persons with AIDS in these age groups.

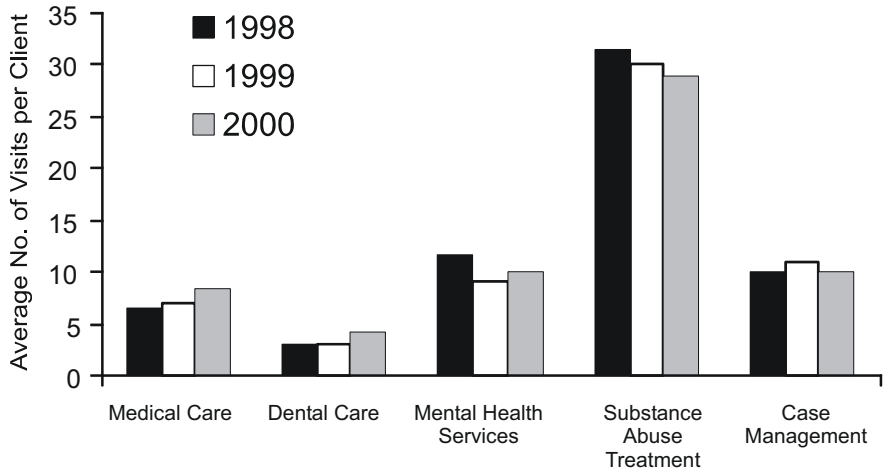
Table 3-21
Visits for services per CARE Act client, by type of Title I service, 2000

	Medical care	Dental care	Mental health services	Substance abuse treatment	Case management
No. of providers supplying valid data[a]	387	167	393	259	568
Average no. of visits per client	8.7	3.8	9.9	29.4	9.8
Median no. of visits per client	5.4	2.7	6.9	9.6	5.6
Range of visits per client	1.0–365.0	1.0–1.9	1.0–128.4	1.0–384.1	1.0–317.0

[a] Data based on valid reports only. Valid data defined as providers' reports of complete data both for the number of clients served and the number of visits. Because providers may offer multiple services, a provider may be included in more than 1 service category.

Interpretation: For the 387 medical care providers who supplied data on valid numbers of clients and visits, the average number of visits per client in 2000 was 8.7 (median, 5.4; range, 1.0 to 365.0). The average number of visits for dental care was 3.8 (median, 2.7). For the 167 providers of dental care who supplied valid data, the number of visits per client ranged from 1.0 to 71.9. In 2000, the average number of visits for mental health counseling and treatment was 9.9 (median, 6.9; range, 1.0 to 128.4). Among clients receiving substance abuse counseling and treatment, the average number of visits was 29.4. This figure must be interpreted with caution: visits for substance abuse services include outpatient and residential care. In a residential treatment setting, visits are often counted in terms of inpatient days. The median number of visits for substance abuse treatment was 9.6 (average, 9.8; range, 1.0 to 384.1). Visits with case-management providers averaged 9.8 (median, 5.6; range, 1.0 to 317.0).

Figure 3-12
Average number of visits per client, by type of Title I service, 1998–2000



Note. Data based on valid reports only. Valid data defined as providers' reports of complete data both for the number of clients and the number of visits.

Interpretation: This figure shows a comparison of the average number of visits per client by type of service from 1998 through 2000. The average number of visits per client remained relatively constant for all service categories for the 3-year period, although the average number of visits per client for substance

abuse treatment declined slightly and the average visits per client for medical care and dental care increased slightly.

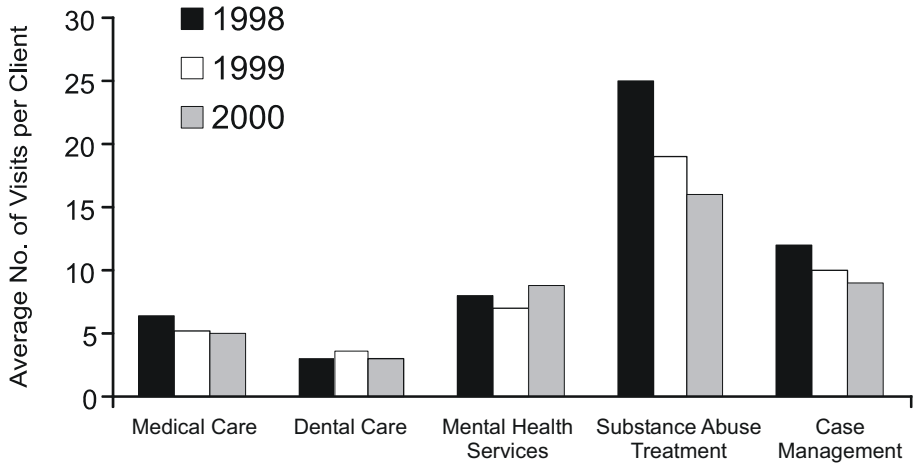
Table 3-22
Average number of visits per client, by type of Title II service, 2000

	Medical care	Dental care	Mental health services	Substance abuse treatment	Case management
No. of providers supplying valid data	414	312	411	183	734
Average no. of visits per client	5.3	2.5	8.6	16.2	8.6
Median no. of visits per client	4.1	2.0	4.8	4.4	5.9
Range of visits per client	1.0–101.6	1.0–16.7	1.0–455.2	1.0–240.0	1.0–194.0

Note. Data based on valid reports only. Valid data defined as providers' reports of complete data both for the number of clients and the number of visits. The actual number of providers is higher than shown for each type of service. Because providers may offer multiple services, a provider may be included in more than one service category.

Interpretation: In 2000, the average number of visits per client to the 414 medical care providers who supplied valid numbers of clients and visits was 5.3 (median, 4.1). The average number of visits for dental care was 2.5 (median, 2.0); among the 312 providers of dental care who supplied valid data, the number of visits per client ranged from 1.0 to 16.7. The average number of visits for mental health counseling and treatment services was 8.6 (median, 4.8; range, 1.0 to 455.2). The average number of visits per client for substance abuse counseling and treatment was 16.2. This number must be interpreted with caution: visits for substance abuse services include outpatient and residential care. In a residential treatment setting, visits are often counted in terms of inpatient days. The median number of visits for substance abuse treatment was 4.4, and the number of visits per client ranged from 1.0 to 240.0. Visits with case-management providers averaged 8.6 (median, 5.9; range, 1.0 to 194.0).

Figure 3-13
Average number of visits per client, by type of Title II service, 1998–2000



Note. Data based on valid reports only. Valid data defined as providers' reports of complete data both for the number of clients and the number of visits.

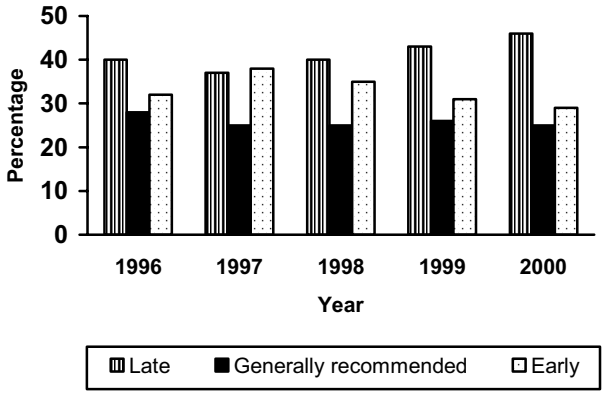
Interpretation: This figure shows that the average number of visits per client consistently decreased from 1998 through 2000 for all services except dental care and mental health. Medical care and case-management services experienced a modest decline in average number of visits per client from 1998 through 2000. The largest decline was in substance abuse counseling and treatment services: the average number of visits per client was 25.2 in 1998 and 16.2 in 2000.

Other recommended analyses and possible data sources

- Demographics of HIV-infected clients receiving services from agencies not funded by the Ryan White CARE Act, including substance abuse, mental health, outreach, and homeless programs as well as community health centers, county clinics, and jails. Examine sex, race/ethnicity, age group, TB status, and exposure categories of these populations. These data may be available at the local level.
- Data from Medicaid and State Children's Health Insurance Program. Examine primary care services and antiretroviral treatment among HIV-infected persons enrolled by sex, age group, and race/ethnicity.
- AIDS Drug Assistance Program. These data may be influenced by Medicaid and other insurance coverage but may provide information on the extent of coverage by this program. Suggested analyses include enrolled persons by sex, age, and race/ethnicity.
- Statewide hospital discharge data. Analyze HIV-related hospital discharges (with any diagnosis of HIV) by year, age group, sex, and, if reliable, by race/ethnicity. Multiply by length of stay to similarly analyze days of hospitalization. Hospital days are a better measure of burden on the health care system than are discharges.
- Survey of HIV Disease and Care and Adult/Adolescent Spectrum of Disease (see Figure 3-14). These studies focus on HIV-positive persons enrolled in primary health care. Analyses include description of the following variables: antiretroviral treatments,

AIDS opportunistic infections—morbidity, mortality, prophylaxis, monitoring of CD4 counts and viral load, immunization coverage, TB screening, and hospitalization. Suggested analyses include examining these variables by sex, age, and race/ethnicity.

Figure 3-14
Proportion of patients who received antiretroviral treatment late, at the recommended time, or early, Adult Spectrum of Disease Study—State X, 1996–2000



Note. Late (CD4 count of <200 cells/μL or AIDS-defining opportunistic infection), generally recommended time (CD4 count of ≥ 200, but <350 cells/μL), or early (CD4 count of ≥ 350 cells/μL).

Interpretation: This figure illustrates the timing of the initiation of antiretroviral treatment and the proportions of patients whose treatments began at each of 3 times (each time corresponds to a category of CD4 cell count). Of patients receiving care, the proportion whose antiretroviral treatment was begun late increased from 37% in 1997 to 46% in 2000.

Note: The Survey of HIV Disease and Care provides data on inpatient, outpatient, and emergency room visits specific to HIV as well as other variables for standard of care. Using these data, you can compare standards of care among Ryan White CARE Act–supported providers vs. providers not supported by the CARE Act, urban providers vs. non-urban providers, and other variables.

- Supplement to HIV/AIDS Surveillance. For areas collecting population-based data, this study can describe all HIV-infected persons, including those who may not be in care. You should conduct analyses to identify the proportion of persons receiving care in your service area. For persons who are in care, your analysis may include a description of antiretroviral treatments, prophylaxis for opportunistic infections, CD4 and viral load testing, and data on hospitalizations. Analyses of home health care,

mental health services, case management, and service needs may be useful. The analyses of data on persons enrolled in care can also be performed by areas with facility-based data collection. Suggested analyses include examination of these variables by sex, age, and race/ethnicity.

- Client-level data reporting systems. In areas with client-level data systems, such as HRSA's CAREWare, unique client identifiers permit the removal of duplicated counts of service utilization. Track and analyze data carefully to protect client confidentiality and avoid duplicate counts. Select data from providers of outpatient medical care, substance abuse treatment, mental health treatment, and case management. For data from these providers, examine the patterns of HIV service utilization by sex, race/ethnicity, and age group.

Client data allow specialized analyses, including the following:

- Comparison of number and percentage of persons whose first HIV diagnosis was also an AIDS diagnosis and persons whose diagnosis was made in earlier stages of HIV infection (before progression to AIDS). This comparison shows which population groups do not have access to, or are not using, counseling and testing services early in the course of infection.
- Comparisons of persons with AIDS (and HIV where data are available) in a service area and persons receiving services through CARE Act providers may reveal which population groups are underserved. Shortfalls in services for particular populations are likely to differ by type of service.

Question 2

What are the number and characteristics of persons who know they are HIV-positive but who are not receiving HIV primary medical care?

HRSA's HIV/AIDS Bureau (www.hab.hrsa.gov) is working to develop methods to help grantees assess the number of persons who know they are HIV-positive but who are not receiving HIV primary medical care. A recommended framework is described here.

Establishing and using a framework for measuring unmet need for HIV primary medical care

Operational definitions
The following definitions can be strengthened or expanded by a jurisdiction to include, for example, additional HIV-related services. However, the basic definitions meet minimum HRSA requirements for operational definitions.

Unmet need for HIV primary medical care[6]: No evidence of any of the following 3 components of HIV primary medical care: viral load testing, CD4 count, or provision of antiretroviral therapy during a 12-month period.

Met need for HIV primary medical care: Demonstration of one or more of the 3 components during the specified 12-month period.

Inputs
The framework uses 2 types of inputs—population size and care patterns. To measure unmet need for HIV primary medical care according to the basic operational definition, you must first determine the population size inputs and the care pattern inputs for a particular geographic area. The geographic area could be a state, an EMA, or another geographic area, such as a county, region, or public health service area.

- **Population size:** The measure of how many people with HIV disease are living in the area during a particular period. These data come mainly from AIDS and HIV case surveillance.

[6]HIV primary medical care is defined as medical evaluation and clinical care that is consistent with US Public Health Service guidelines for the treatment of HIV/AIDS. For a more detailed definition, see page 87.

Data needed are:

a. number of people living with AIDS (PLWA) (i.e., aware of status)
b. number of people living with HIV, without AIDS (PLWH) (i.e., aware of status)

Note: Combining a and b results in the total number of persons who know they are HIV infected.

- **Care patterns:** Measures of how many HIV-infected persons who are aware of their status are receiving primary HIV medical care from any provider (not just Ryan White CARE Act care providers). These data may come from several possible sources: CD4 and viral load reporting in surveillance, studies (e.g., Adult Spectrum of Disease), claims databases (e.g., Medicaid and AIDS Drug Assistance Program), or other sources. Total-count methods provide data in numbers; methods based on sampling typically provide data as percentages.

Data needed are:

c. percentage or number of PLWA that meet primary care definition
d. percentage or number of PLWH that meet primary care definition

Unmet need = (a − c) + (b − d).
(a – c) = unmet need among PLWA
(b – d) = unmet need among PLWH

Method 1
A simple framework using data on counts of population and care patterns:
a = number of persons living with AIDS (PLWA)
b = number of persons living with HIV (PLWH)
c = number of PLWA who received specified services in 12-month period
d = number of PLWH who received specified services in 12-month period

Example: Unmet need in State X
In State X, there were 4,291 persons living with AIDS and 3,942 persons living with HIV. The proportion of persons living with AIDS who received primary medical care within the past 12 months was 62%. The proportion of persons living with HIV who received primary medical care within the past 12 months was 27%.
a = 4,200
b = 3,900
c = 3,600
d = 2,000

Unmet need = (a − c) + (b − d)
= (4,200 – 3,600) + (3,900 – 2,000)
= 600 + 1,900
= 2,500 persons

Method 2
A simple framework using counts of population and care patterns based on sampling:

a = number of PLWA
b = number of PLWH
c = % of PLWA who received specified services in 12-month period
d = % of PLWH who received specified services in 12-month period
Unmet need = [a X (1 − c)] + [b X (1 − d)]

Example: Unmet need in State X
In state X, there were 4,291 persons living with AIDS and 3,942 persons living with HIV. The proportion of persons living with AIDS who received primary medical care within the past 12 months was 62%. The proportion of persons living with HIV who received primary medical care within the past 12 months was 27%.
a = 4,291
b = 3,942
c = 62%, or 0.62
d = 27%, or 0.27

Unmet need = [a X (1 − c)] + [b X (1 − d)]
= [4,291 X (1 − 0.62)] + [3,942 X (1 − 0.27)]
= [1,631 + 2,878]
= 4,509 persons

Summary of Recommended Analyses for Question 2

The analyses summarized here will guide you in analyzing, interpreting, and presenting data describing the patterns of service utilization of HIV-infected persons in your state or EMA. Depending on your local needs, you may choose to perform analyses in addition to those recommended below:

- HIV primary medical care, stratified by sex, race/ethnicity, age group, exposure categories, TB status, and viral hepatitis (B and C)
- Support services, stratified by sex, race/ethnicity, and age group
- Number and characteristics of persons who know they are HIV-positive but who are not receiving HIV primary medical care

Chapter

4

COMPLETING THE EPIDEMIOLOGIC PROFILE

Section 1 Making Your Profile User-Friendly
Section 2 Writing the Remaining Sections
Section 3 Preparing Presentations of Your Profile
Section 4 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 *can and will* apply the information to their planning activities.

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 these sections:
  - front matter
  - introduction
  - body
  - conclusion
  - appendixes
  - other back matter (in addition to appendixes)

- Present your data in clear, easy-to-understand tables and figures (graphs, charts, maps).
- Analyze and 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?

Important considerations for presenting data

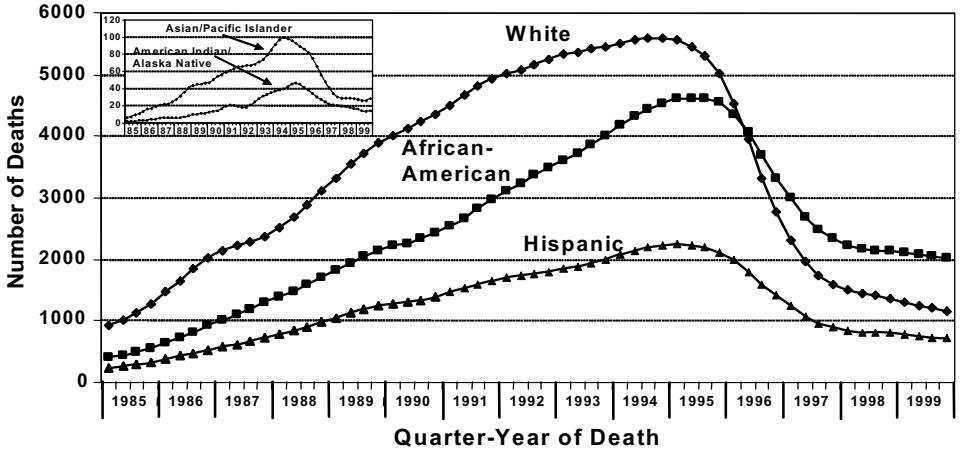
The following guidelines apply to all graphic aids:

- 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 CPG 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 (see Figure 4-1). In the explanation below the figure, point out the differences between the larger and smaller groups.
  - When the numbers for a group are small, observe restrictions on cell size to protect confidentiality.

Figure 4-1
Estimated number of deaths among adults with AIDS,[a] 1985–1999, United States



[a]Adjusted for reporting delays; data reported through June 2000.

Note: Edward Tufte's book *The Visual Display of Quantitative Information* (Cheshire, Conn.: Graphics Press; 2001) contains numerous excellent examples of how to (and how not to) present 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 4-1 and 4-2, which are examples of presentations with differing numbers of variables.

Table 4-1
Example of table with 1 variable

Number of AIDS cases, by city, reported through June 30, 2000

	AIDS cases, No.
New York	117,792
Los Angeles	41,394
San Francisco	27,567
Miami	23,521
Washington, DC	22,321
Chicago	21,173
Houston	18,735

Table 4-2
Example of table with 2 variables

AIDS cases, by geographic unit and race/ethnicity, reported January – December, 1999

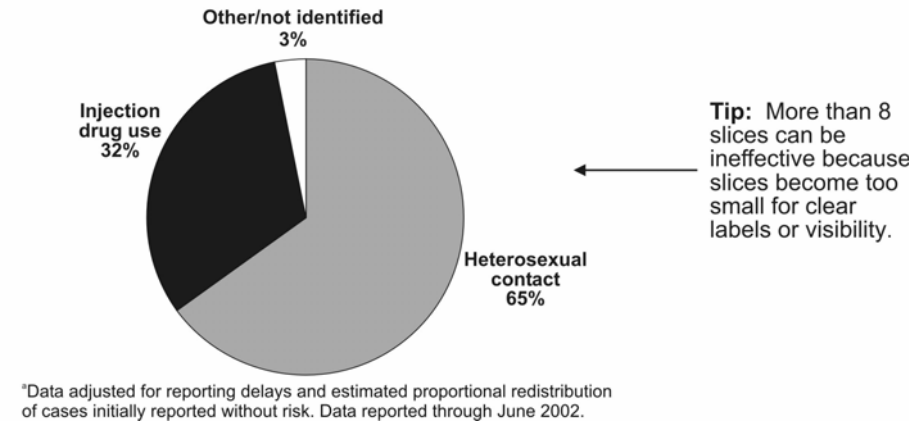
	USA, %	State X, %	County X, %
White, not Hispanic	36	40	26
Black, not Hispanic	42	34	52
Hispanic	20	26	21

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 AIDS incidence among female adults and adolescents, by exposure category (see Figure 4-2).

Figure 4-2
Example of pie chart

Estimated AIDS incidence[a] among female adults and adolescents, by exposure category, County X, diagnosis in 2001



Line graphs

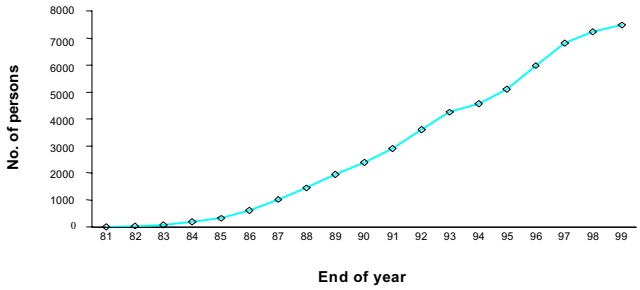
Line graphs display relationships between 2 variables on 2 dimensions, or axes. The dependent variable (the variable you wish to predict or explain) is usually shown on the vertical axis, and the independent variable (the variable you think will influence the dependent variable) is shown on the horizontal 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 4-3, the dependent variable (the number of persons living with AIDS) 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 persons living with AIDS in County X has been increasing.

Figure 4-3
Example of line graph

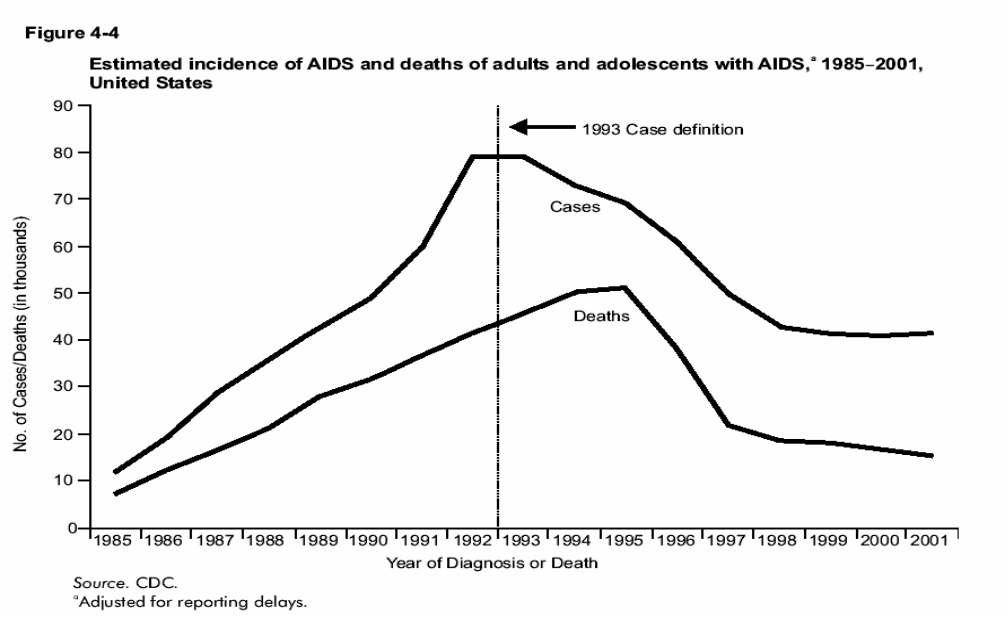
Number of persons living with AIDS, County X, 1981–1999



Epidemic curves

The epidemic curve (Figure 4-4) is a line graph of the number of new cases by date of diagnosis.

Figure 4-4
Example of epidemic curve



The epidemic curve is important because it tells what is happening with the disease in the population. Figure 4-4 shows the incidence of AIDS cases and deaths from 1985 through 1999. Notice the sudden rise in AIDS cases in 1993. This is due to a change in the definition of AIDS cases; after implementation of the case definition, the AIDS surveillance system began to reflect cases that had not been reported. Figure 4-4 also shows a downward trend in recent years in AIDS deaths and AIDS cases. This is due in part to the effectiveness of new treatments, such as highly active antiretroviral therapy, which inhibits the progression from HIV infection to AIDS and allows persons with AIDS to live longer. Figure 4-4 shows what happened after the change in case definition and the introduction of effective treatment.

Bar, or column, graphs

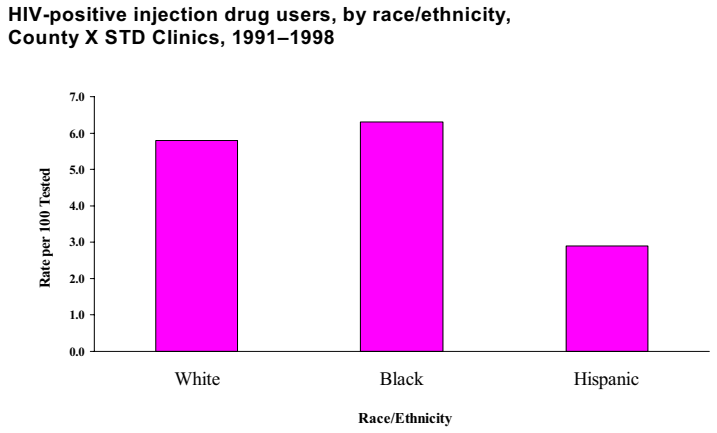
In a bar, or column, graph, data are organized so that each observation can fall into 1, but only 1, category of the variable.

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 4-5 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 for the IDUs tested, the rate of HIV positivity is higher for blacks than for whites or Hispanics.

Figure 4-5
Example of bar, or column, graph

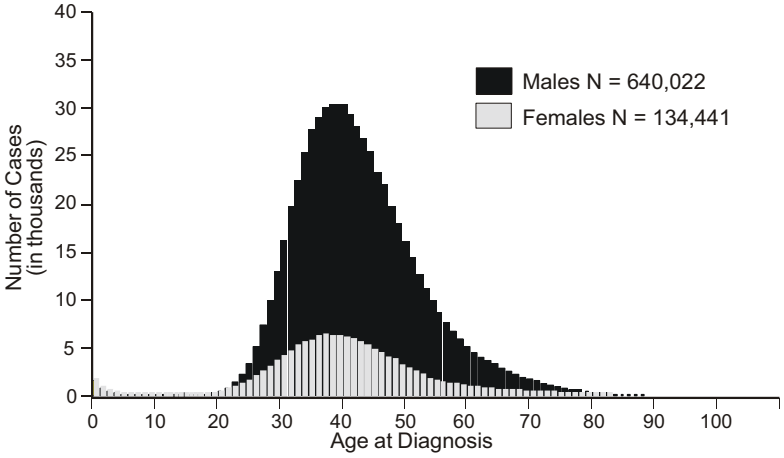


Histograms

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 4-6
Example of histogram

AIDS cases, by age and sex, reported 1981–2000, United States

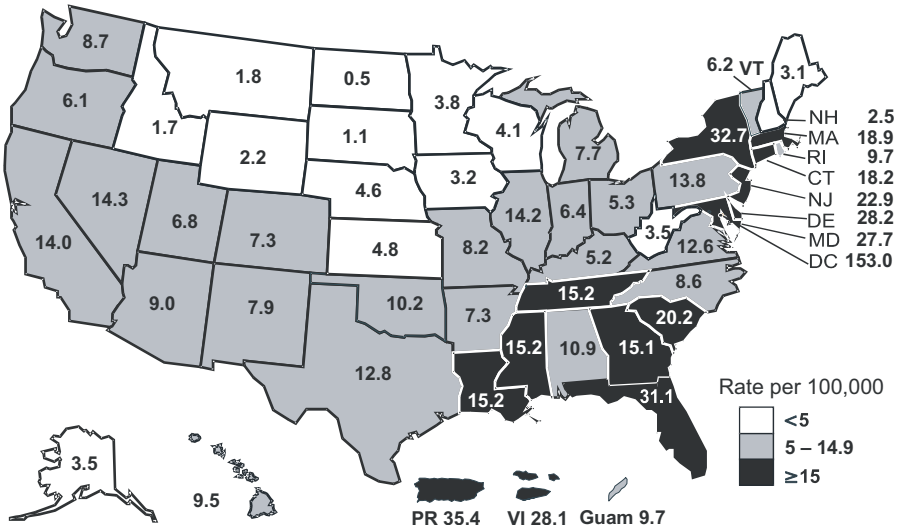


Maps

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 4-7) 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 (see Figure 4-8) display data based on geographic mapping coordinates.

Figure 4-7
Example of area map

AIDS rates per 100,000 population, reported July XXXX–June XXXX



Geographic Information Systems maps

Geographic Information Systems (GIS) technology is used to map geographic data such as map coordinates and land features. By overlaying demographic data within known geographic boundaries (e.g., state, county, or census boundaries) for health services, socioeconomic indicators, risk behavior, or prevalence of a disease, users of this technology can determine where to focus efforts for prevention or care services. GIS technology can be used to display epidemiologic data by a geographic reference (e.g., city to a neighborhood census block level).

In GIS, geographic information is described in terms of geographic coordinates (e.g., latitude and longitude or national grid coordinates) or by a street address, census boundaries, postal code, or forest stand identifier. This system is capable of translating implicit geographic data into an explicit map location. Maps can be obtained from public sources or companies that specialize in collecting and organizing geographic information. The process of converting implicit geographic data into explicit or map-form images is called geocoding.

Geographic data can be stored in a database, and many GIS programs can map data to produce images in various formats, including vector and raster formats. In a vector format, 2-dimensional data are stored as *x* and *y* coordinates. A road or a river can be described by using a series of *x,y* coordinate points. Nonlinear features such as town boundaries can be stored as a closed loop of coordinates. The vector model is good for describing well-delineated features, including sites where counseling and testing are offered or facilities where HIV care or other health services are provided. A raster format expresses data as a continuously changing set of grid cells. Raster models can be used when comparing the prevalence of HIV/AIDS cases in an area (Figure 4-8). Both types of formats are used by most GIS.

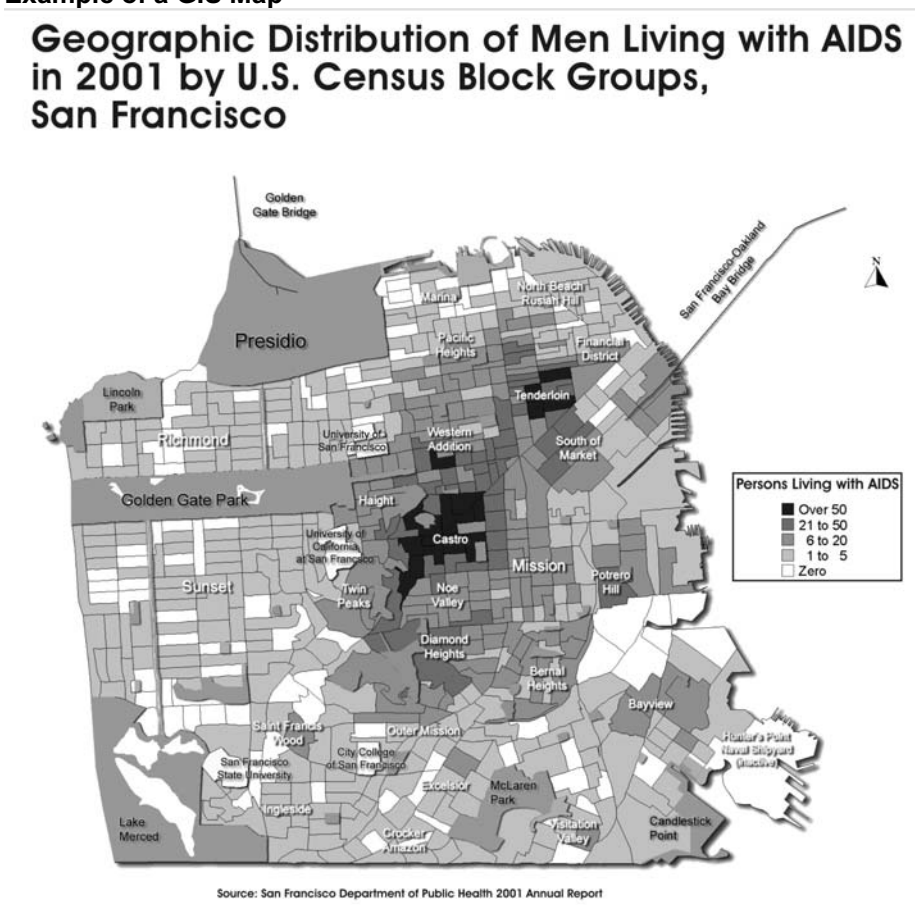
Users of GIS should be aware of the limitations before drawing conclusions based on mapping results. This is particularly important when explaining potential associations between data. For example, when one examines the distribution of persons with HIV infection by risk behavior and residence at diagnosis, the next logical step may seem to be to describe the relationship between infection and residence. However, residence at the time of HIV diagnosis may not be the location of the risk-taking behavior that resulted in infection. Therefore, a city map showing areas with large numbers of persons with HIV may not be equivalent to a map of the same city showing the locations of high-risk activity.

Confidentiality is also a concern when mapping data by use of GIS technology. As is true of other methods of data presentation, disclosure of information is a potential risk. However, GIS technology includes mapping techniques (e.g., spatial smoothing) that may be used to decrease the risk of disclosure when presenting small numbers of cases. Spatial smoothing is similar to moving averages, collapsing space rather than time. Users of GIS should become familiar with this and other techniques to ensure the confidentiality of data.

Local restrictions on small cell size should be observed when creating maps by using GIS technology.

Overall, remember the purpose of using GIS to display HIV surveillance data and other public health information. For some health services programs, the purpose may be to show the location of persons with HIV or AIDS in order to develop care-related services. Other HIV prevention programs may use GIS to focus interventions by locating populations at risk for infection.

Figure 4.8
Example of a GIS Map



Source: San Francisco Department of Public Health 2001 Annual Report

Tips for Presenting Data in Tables or Figures

- Tables and figures explain the who, what, when, and where of the data. Each should stand alone (i.e., all relevant information needed to interpret the table or figure should be part of the table or figure) so that the reader can understand without reference to the text.
- Figures are used to illustrate trends, relationships, or patterns, often eliminating the need for a complex passage in the text. Tables provide specific numeric values.
- Do not try to communicate too many ideas at once (the ideal is one main idea per table or figure).
- Write clear, explanatory titles.
- Keep the table or figure uncluttered and free of unnecessary words.
- Word clearly and format consistently the labels on the axes of figures and the column headings and row entries in tables. A consistent format cues readers so they know at a glance that they are looking at HIV data, AIDS data, or HIV and AIDS data combined.
- Label all elements (e.g., lines on a line graph) of a figure. If the space doesn't allow you to label each element, include a legend.
- Do not create 3-dimensional graphs. They are harder to read and more likely to mislead than are 2-dimensional graphs.
- Make the scale appropriate for the findings you want to convey.
- Use the same scale for the *y* axis when figures are meant to be compared.
- Use no more than 8 slices in a pie chart, and label all slices.
- When you present only percentages, include the total number (N). Do not chart percentages and numbers in the same graph.
- Name the sources of the data.
- In the accompanying text, refer to the key points of the table or figure; do not simply duplicate in words the content of the table or figure.

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 the HIV/AIDS epidemic 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.

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 the epidemic, and their familiarity with epidemiology?
- How much do they already know about the epidemic?
- 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 the epidemic, 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 CPGs 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 CPG in developing the profile. In doing so, keep the following in mind:

- Understand the perspectives of the CPG; 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 rather than in terms of grouped data (such as means) and trends among the individuals they see.

Focus your narrative on the needs of users

Although the profile is not the only resource that CPGs 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 guidelines. 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 effect 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 effect
  - detailing changes in policy, diagnostics, and treatment strategies that may affect risk, effect, 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 the epidemic 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 CPG 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 the epidemic (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 2001. Data show an increase in adolescent drinking and unprotected sex; thus, there is an increased risk of exposure for adolescents.

Useful information: In 2001, 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 in 2001) of HIV in 2001. 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 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 Community Action 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 Community Action 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've written or stumbles into the pitfalls already described, you should revise. Having another person read your draft is particularly helpful for catching implicit writing.
- Use consistent formats for headings in the overall profile and within sections and for tables and figures.
- Use bullets to break up text and highlight key information.

Section 2: Writing the Remaining Sections

All HIV/AIDS epidemiologic profiles should have 6 sections. Chapter 2 describes these sections:

- front matter
- introduction
- body
- conclusion
- appendixes
- other back matter (in addition to appendixes)

Chapters 2 and 3 describe how to develop the body of the profile. The body of the profile consists of core and supplemental data that describe the epidemic. This section focuses on the front matter, introduction, conclusion, and the appendixes.

Front Matter

Include these elements at the front of the profile in the order shown:

- Contributors: The names of profile writers and other contributors
- List of abbreviations: The short forms (including acronyms and initialisms) used to refer to certain terms and organizations
- Executive summary: A synopsis of the profile's content
- Table of contents: A list (usually just called Contents) of the topics covered (along with appropriate page numbers)
- List of Tables and Figures

The list of contributors, list of abbreviations, and the table of contents are self-explanatory; however, writing an executive summary takes time, skill, and an understanding of its purpose.

Executive summary

Although the executive summary goes at the beginning of the profile, it is one of the last elements you should write. It is also one of the most vital because it meets the need of the reader who does not have the time or has no reason to read the entire report.

The executive summary presents the highlights. Use it to summarize the purpose (e.g., to help CPGs set priorities among populations who need prevention and care services and determine present and future needs for programs such as counseling and testing services) and to convey key points about the epidemic in your service area. Keep it to 1 or 2 pages.

Introduction

The introduction should describe the overall intent of the profile—what it will accomplish—the major issues it will address, the time period and service area covered, and any technical or other specific factors that affect the profile. It also provides a roadmap to orient the reader to the format and content of the document. For example, explain how you organized the profile (perhaps around the core epidemiologic questions).

Include these elements in your introduction:

- background
- data sources
- strengths and limitations (For example, a strength might be that the report draws upon many data sources so that it presents a rich portrait of particular populations; a limitation might be that because the HIV surveillance data included represent only

people who have been confidentially tested, they do not represent those who have been recently infected and thus are not a true measure of HIV incidence.)
- process followed in preparing the profile

Background
State the purpose of the profile. Exclude extraneous historical data. Indicate whether the profile is an update or a full profile, and highlight differences between the previous and the current profile.

Data sources
In general terms, describe the sources of data for the profile and the overall strengths and limitations of those sources. You may include discussion of how complete the data are, whether they are representative and timely, and whether they can be generalized.

Strengths and weaknesses
Your goal in describing the strengths and weaknesses is to provide the user with a realistic basis for evaluating the profile's data and conclusions.

Explain the overall strengths and weaknesses of the profile to ensure that users understand what the profile can and cannot explain. Describe how the limitations affect the conclusions and how this may affect the decisions of the CPG.

Process followed in preparing the profile
Describe how the profile was developed to meet the needs of end users. Typically, address
- methods used to obtain data
- persons involved in preparing and reviewing the profile
- statistical methods used to analyze data

Conclusion
Summarize the results of the analysis described in the body of the profile and your evaluation of the epidemic. In the body of your profile, it is a good idea to synthesize the results of your findings on each question before you move to the next question. You can use these syntheses as the foundation for your Conclusion section. Discuss the implications of your findings for planning prevention or care services for the service area.

Appendixes
The appendixes are not a catchall for information that did not fit into the other sections. Appendixes should include information that supports the content of the profile but is not vital to an understanding of the main points and the analysis. Appendixes are also a good place for information that is too technical for the body of the report, such as the methods used for calculations. At a minimum, include the following in your appendixes:
- list of data sources

- feedback form for planning groups

Other Back Matter (in addition to appendixes)

This section consists of any other items that do not belong in the front matter, the body, or the appendixes, such as

- glossary of terms
- references

Section 3: Preparing Oral Presentations of Your Profile

You may be called upon to present part or all of your HIV/AIDS epidemiologic profile to your CPG.

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

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 CPG. 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 the HIV/AIDS epidemic in the service area and the implications of those trends.

Organize your presentation

The opening

The opening is intended to get the 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, 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, 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 the epidemic 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 local epidemic 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 cases during a specified time, often a year	The incidence of heterosexually acquired AIDS increased steadily among women in the United States, from 1,100 cases diagnosed in 1985 to 5,700 cases diagnosed in 1995.

You may also need to explain how to read and interpret the tables and figures. Table 4-3 illustrates an aid that could accompany an explanation of how to read a table.

Table 4-3
Example of aid to help explain how to read a table

Descriptive Title			Column
HIV exposure mode	Cases, No.		Total, %
Male-male sexual contact	589		34
Male-male sexual contact and injection drug use	Cell 125		7
Injection drug use	476	Row	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/AIDS case report 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 recording it on a cassette tape or 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.

Section 4: Disseminating Your Profile

Writers of epidemiologic profiles that are intended for use in planning care programs should ensure that the completed profile is disseminated to Ryan White CARE Act grantees and planning councils and consortia as part of the comprehensive needs assessment. Writers of epidemiologic profiles that are intended for use in planning prevention programs should ensure that the completed profile is disseminated by the state health department to members of HIV prevention CPGs.

The epidemiologic profile is the first step in the planning process both for 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 and resources for 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 CARE Act 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.
- Plan a mass mailing of the profile to executive directors of local community-based organizations; the major providers of HIV care, including physicians, nurses, physician's assistants; sister government agencies or departments (e.g., STD and TB program directors); community activists; local academic HIV researchers; and local government officials.
- After the initial mass mailing, continue to distribute the profile at presentations made by program staff to, for example, community-based organizations, university audiences, and provider groups.
- Post the profile on your Web site.
- 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.
- The person writing the profile should attend the planning meetings and should certainly get on the agenda before and after writing the profile

Chapter

5

SPECIAL CONSIDERATIONS

Section 1 Confidentiality
Section 2 Special-Needs Populations
Section 3 Comorbidity
Section 4 Areas with Low Morbidity and Minimal Data

This chapter is a brief consideration of several issues that may apply to only some service areas or profiles. These issues include confidentiality, special needs populations, comorbidity, and areas with low morbidity and minimal data.

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/AIDS 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/AIDS surveillance data and other information and to protect the privacy of HIV-infected persons. These laws are supported by several federal statutes. HIV/AIDS surveillance data reported to CDC are

protected by federal assurance of confidentiality. In addition, CDC requires, as a condition of funding, that states follow strict security standards and guidelines.[1] These standards cover health department responsibilities for the ways in which HIV/AIDS data are collected, analyzed, maintained, transmitted to CDC or other state agencies, released, and disposed of.

Confidentiality and HIV/AIDS Epidemiologic Profiles

When developing your epidemiologic profile, keep confidentiality concerns in mind with all data used, not just HIV/AIDS surveillance data. 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 restrictions on small cell size to prevent the inadvertent disclosure of confidential information. Because it can be easy to inadvertently identify people when small numbers of cases are broken down by age, race/ethnicity, gender, or other factors, HRSA and most state HIV/AIDS surveillance programs have a restriction policy on small cell size. Follow it when presenting data in tables. Specifically, cells whose value is 3 **or fewer** are suppressed (not shown in data presentations). Contractors should become familiar with the cell-size restriction policy. 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/AIDS surveillance data as specified by the health department.

Confidentiality derives from an individual's right to privacy. Persons participating in HIV/AIDS and other public health surveillance activities, such as clinic clients or persons reported to surveillance, have the right to privacy regarding disclosure of information related to their HIV status. Confidentiality is protected by law and by the ethical guidelines for various professionals, including physicians, psychologists, and social workers. For purposes of the epidemiologic profile, confidential information includes anything that would identify a person as having HIV or AIDS, being a user of counseling and testing services, having TB or an STD, or participating in a public health survey (e.g., Youth Risk Behavior Surveillance System). That means that their risk behavior, HIV status, and status with respect to other diseases cannot be disclosed publicly. These data are collected with an explicit promise to the participant that the data will remain private. Breaching this promise has legal and ethical consequences for the people or organization that collected the data, anyone who discloses the data, and the person from whom the data were collected.

Source: Adapted from the American Bar Association's "Model HIV/AIDS Confidentiality Policy."

[1]CDC. Guidelines for national human immunodeficiency virus case surveillance, including monitoring for human immunodeficiency virus infection and acquired immunodeficiency syndrome. *MMWR* 1999;48 (No. RR-13):1–31.

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, Social Security number) that could identify an individual.

Section 2: Special-Needs Populations

The CARE Act requires that needs assessments and comprehensive plans used by planning councils in setting priorities and allocating funds identify and address the unmet service needs of special populations.

In planning for special populations, unmet needs may refer to the service needs of persons not currently in the system of HIV/AIDS care. It may also refer to persons in the system of HIV/AIDS 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 PLWH who may be disenfranchised from HIV/AIDS care services.

As of the FY 2002 application cycle, HRSA's HIV/AIDS Bureau identified the following populations as requiring special attention during the planning and resource allocations processes conducted in Title I EMAs and Title II states:

- 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, CARE Act applicants are encouraged to identify other populations that have been significantly or disproportionately affected by the epidemic. 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 Reauthorized CARE Act of 2000 provides additional guidance on how HRSA's HIV/AIDS Bureau is to consider the severe-need factor in distributing Title I supplemental grant funds among Title I EMAs. The Manager's Statement, which accompanies the CARE Act Amendments of 2000, defines areas most in need of Title I funding as having "the greatest or expanding public health challenges in confronting the epidemic."

In setting service priorities and allocating CARE Act funding, Title I 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/AIDS primary medical care and support services to PLWH in the EMA.

A useful epidemiologic profile provides information on HIV/AIDS 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/AIDS care system. When possible, match the cost of comorbidities with the HIV/AIDS 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 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 often consist of a single county or multiple counties of which one (the "dominant" county) typically has most of the cases. The numbers of cases in the other counties are generally 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 areas (e.g., EMAs) within states, not to counties or other smaller areas within EMAs. Apply the same rationale when examining rural and urban data.

If the epidemic 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 epidemic 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.

APPENDIXES

Appendix A	Data Sources
Appendix B	Data Sources by Jurisdiction
Appendix C	Web Data for Core Epidemiologic Question 1
Appendix D	Table Formats for Mortality Data
Appendix E	Table with Descriptions of Ryan White CARE Act Programs
Appendix F	Planning Group Epidemiologic Profile Feedback Form

Appendix A: Data Sources

Core Data Sources

AIDS Surveillance

Overview: AIDS is a reportable condition in all states and territories. AIDS cases, reportable since the early 1980s, have been defined according to the prevailing CDC surveillance case definition (last revised in 1993). The AIDS surveillance system was established to monitor incidence and the demographic profile of AIDS, describe the modes of HIV transmission among persons with a diagnosis of AIDS, guide the development and implementation of public health intervention and prevention programs, and assist in the assessment of the efficacy of public health interventions. AIDS surveillance data are also used to allocate resources for Titles I and II of the Ryan White CARE Act.

State and local health departments actively 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.

Population: All persons whose conditions meet the 1993 CDC AIDS surveillance case definition

Strengths: Only source of AIDS information that is available in all areas (states), these data reflect the effect of AIDS on a community and the trends of the epidemic in a community. AIDS surveillance has been determined to be >85% complete. The data include all demographic groups (age, race/ethnicity, gender).

Limitations: Because of the prolonged and variable period from infection to the development of AIDS, trends in AIDS surveillance do not represent recent HIV infections. Asymptomatic HIV-infected persons are also not represented by AIDS case data. In addition, incomplete HIV or CD4+ T-cell testing may interfere with the representativeness of reporting. Further, the widespread use of highly active antiretroviral therapy complicates the interpretation of AIDS case surveillance data and estimation of the HIV/AIDS epidemic in an area. Newly reported AIDS cases may reflect treatment failures or the failure of the health care system to halt the progression of HIV infection to AIDS. AIDS cases represent late-stage HIV infections.

Where available: All 50 states; US territories; Chicago, District of Columbia, Houston, Los Angeles, New York City, Philadelphia, San Francisco

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator

Reference: CDC. Guidelines for national human immunodeficiency virus case surveillance, including monitoring for human immunodeficiency virus infection and acquired immunodeficiency syndrome. *MMWR* 1999;48(RR No. 13):1–31.

HIV Surveillance

Overview: Reporting of HIV infections to local health authorities as an integral part of AIDS surveillance activities has been recommended by CDC and other professional organizations since HIV was identified and a test for HIV was licensed. As part of ongoing active HIV surveillance, state and local health departments educate providers on their reporting responsibilities, establish active surveillance sites, establish liaisons with laboratories conducting CD4+ T-lymphocyte cell analysis and enzyme immunoassay and Western blot testing and follow-up of HIV cases of epidemiologic importance.

Population: All persons who test positive for HIV

Strengths: HIV surveillance data, compared with AIDS surveillance data, represent more recent infection. According to state evaluations, HIV infection reporting is estimated to be >85% complete for persons who have tested positive for HIV. HIV surveillance provides a minimum estimate of the number of persons known to be HIV infected and reported to the health department, may identify emerging patterns of transmission, and can be used to detect trends in HIV infections among populations of particular interest (e.g., children, adolescents, women). These trends may not be evident from AIDS surveillance. HIV surveillance provides a basis for establishing and evaluating linkages to the provision of prevention and early intervention services and can be used to anticipate unmet needs for HIV care.

Limitations: HIV surveillance data may underestimate the number of recently infected persons because some infected persons either do not know they are infected or have not sought testing. 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 eligible to be reported to the surveillance system. HIV surveillance data represent infections in jurisdictions that have reporting laws for HIV. HIV reporting laws differ by jurisdiction; therefore, consultation with local surveillance staff on how to interpret local HIV surveillance data is advised. Furthermore, reporting of behavioral risk information may not be complete.

Where available: As of April 2003, 34 states (Alabama, Alaska, Arizona, Arkansas, Colorado, Florida, Idaho, Indiana, Iowa, Kansas, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Pennsylvania, South Carolina, South Dakota, Tennessee, Texas, Utah, Virginia, West Virginia, Wisconsin, Wyoming); American Samoa, Guam, Northern Mariana Islands, Puerto Rico, and the US Virgin Islands have implemented HIV case surveillance, using the same confidential system for name-based case reporting for both HIV infection and AIDS.

Connecticut implemented mandatory HIV reporting in January 2002. For adults and adolescents ≥ 13 years of age, reporting is by name or code (if patients or physicians prefer this method). For children <13 years of age and for persons who are coinfected with tuberculosis (TB), reporting is by name. In New Hampshire, a case may be reported by name or code.

Four states use names to initiate case reports and then convert to codes (Delaware, Maine, Montana, Oregon), and 9 areas are using a coded identifier rather than patient name to report HIV cases (California, Hawaii, Illinois, Kentucky, Maryland, Massachusetts, Rhode Island, Vermont, and District of Columbia). In Washington, reporting of persons with symptomatic HIV infection and of persons with AIDS is by name; a name-to-code system is used to report asymptomatic HIV cases. Georgia plans to initiate HIV case surveillance.

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator

Reference: CDC. Guidelines for national human immunodeficiency virus case surveillance, including monitoring for human immunodeficiency virus infection and acquired immunodeficiency syndrome. *MMWR* 1999;48(RR No. 13):1–31.

Supplemental Data Sources

Adult/Adolescent Spectrum of Disease (ASD)

Overview: An ongoing longitudinal surveillance cohort study that describes the spectrum and progression of HIV disease, including severe illness and death. Information on AIDS-defining conditions, other illnesses and symptoms, treatments, and lab parameters are abstracted from medical records by using a standardized form. In addition, gynecologic information (e.g., Pap smear, cervical cytology) is collected for women. Data are collected for the 12 months preceding enrollment, and re-abstractions are done every 6 months, until the patient either dies or is lost to follow-up.

Population: Persons 13 years and older with diagnosed HIV infection or AIDS who receive health care at a participating facility in the project area are eligible to participate in ASD. In each project area, facilities serving HIV-infected persons (clinics, hospitals, neighborhood health centers, private medical practices, and emergency rooms) are selected to participate as project sites. ASD project areas have designed sampling schemes to be as representative of the HIV/AIDS population in that area as possible.

Strengths: ASD data describe the spectrum of HIV disease that is documented in the medical chart. Data since January 1990 are available. ASD data are useful for assessing the use of prophylactic and antiretroviral treatment over time and for describing the occurrence of opportunistic illnesses and other conditions in persons infected with HIV. As of December 2002, more than 50,000 persons had been included in the ASD project.

Limitations: ASD data describe morbidity among persons who received medical care for HIV infection at a participating site (i.e., not population-based). The morbidity information in the medical chart may not be complete. Gynecologic information may be underreported because this information may appear elsewhere (woman may have gone to her Ob/Gyn rather than her HIV care provider). ASD data rely on the thoroughness of diagnostic testing and recording and the accuracy and completeness of medical records. Treatment and prophylaxis regimens in ASD refer to prescribed therapies: information on adherence is not collected.

Where available: Atlanta, Dallas, Los Angeles County, Denver, Detroit, Houston, New Orleans, New York City, Seattle; and Bayamon (Puerto Rico)

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator or ASD site coordinator; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

AIDS Progression Study

Overview: The AIDS Progression Study was designed to help in understanding the characteristics of HIV-infected persons in whom HIV infection progresses to AIDS and to explain why the progression to AIDS occurs. This study examines data on persons who died with AIDS to learn the reasons for the progression from AIDS to death. Data are abstracted from medical records during the 12 months preceding AIDS diagnosis. Data collected for this study include patient characteristics, HIV/AIDS–related history, testing history, AIDS-defining conditions, HIV exposure, and laboratory data.

Population: All persons with a diagnosis of AIDS or who died of AIDS, who were reported to the HIV/AIDS Reporting System after January 2000, and whose diagnosis of AIDS was made no earlier than January 1, 1999

Strengths: Data from the AIDS Progression Study are population-based and can be used to explain reasons for the progression from HIV infection to an AIDS diagnosis and to death from AIDS. The time frame for participation excludes persons whose diagnosis was made when appropriate treatment regimens were not available. Therefore, this study can examine whether progression is due to lack of adherence to treatment, failure to seek or receive appropriate care, infection with a resistant strain, or resistance to treatment. The 12-month period of review before diagnosis allows investigators to examine a patient's medical history.

Limitations: The quality of information on a patient depends on the completeness of documentation in the patient's medical chart. Locating all medical charts may not be possible; thus, the data may not represent all cases of AIDS diagnosed within the study time frame.

Where available: Boston, Chicago, Denver, Hartford (Connecticut), Los Angeles, San Francisco

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator or AIDS Progression Study site coordinator; CDC, Division of HIV/AIDS Prevention, HIV Incidence and Case Surveillance Branch

Antiretroviral Drug Resistance Testing (ARVDRT) Study

Overview: The ARVDRT study will evaluate the prevalence of antiretroviral drug resistance (ARVDR) and non-B HIV-1 subtypes among persons with a recent diagnosis of HIV infection. The study will be conducted in public health settings for 5 years in participating areas. The project will also evaluate the feasibility and usefulness of incorporating ARVDR surveillance into routine public health surveillance systems.

Population: Study population will be enrolled from HIV testing and care sites supported by the participating health departments and from additional sites where diagnostic testing is performed in the public health laboratories or other health department-supported laboratories. These sites may include confidential or anonymous HIV counseling and testing sites, HIV early intervention clinics, sexually transmitted disease clinics, hospital clinics, or health maintenance organizations.

Strengths: Data from the ARVDRT study are representative in publicly supported settings. The methods differentiate recently infected and chronically infected persons, making it possible to evaluate both the ARVDR transmission rate (approximated by rate for persons recently infected) and overall prevalence. The research study will also evaluate the feasibility of implementing ARVDRT. Additional primers will be developed if necessary to evaluate mutations in non-B HIV-1 subtypes.

Limitations: The participating areas are too few to produce a national picture. This study may also underestimate the prevalence of mutations among the chronically infected group of persons with a recent diagnosis because some mutations do not persist in the absence of drug pressure.

Where available: Colorado, Illinois, Maryland; and Seattle

Contact person(s): State or local health department, ARVDRT coordinator; CDC, Division of HIV/AIDS Prevention, HIV Incidence and Case Surveillance Branch

Arrestee Drug Abuse Monitoring (ADAM*)*

Overview: ADAM was established in the late 1990s by the National Institute of Justice to provide participating communities with information for developing drug-control strategies and related public policy responses. ADAM measures the extent of drug use among persons who have recently been arrested. Four times a year, local research teams in participating study counties interview arrestees at booking facilities; the arrestees are asked to provide a urine specimen. The ADAM questionnaire concerns drug use, frequency of drug use, housing during the past year, financial support, health insurance, how and where drugs are purchased, and demographic information. ADAM adopted a probability-based sampling scheme to enable inferences to the general population of arrestees in participating counties and to increase the reliability of the data collected.

During 1999 and 2000, 3 ADAM sites added an addendum of HIV-related questions to their ADAM questionnaire. These questions concern HIV testing; sexual behavior; needle sharing; history of sexually transmitted diseases, tuberculosis, or hepatitis; receipt of care (for HIV-infected participants); and exposure to HIV prevention messages.

Population: Arrestees booked at facilities in 38 participating counties. However, the sampling scheme is not yet sufficient to enable estimates of the information from female adults or juveniles.

Strengths: ADAM provides population-based information on drug use, patterns of use, socioeconomic factors, and health insurance among arrestees in a participating county. The project collects self-reported information through a confidential interview and collects a urine specimen that is tested for the presence of 10 commonly used illicit drugs.
At sites where the HIV addendum is used, ADAM collects information on testing patterns; history of sexually transmitted disease, tuberculosis, and hepatitis; risk behaviors and awareness of HIV prevention messages, all of which are valuable for designing prevention programs and policies focused on incarcerated populations.

Limitations: The ADAM survey instrument relies upon self-reported data; thus, the data may be subject to recall bias or may not be reliable because of participants' sensitivity about the topics. Although not all ADAM participants agree to submit a urine specimen, the refusal rate is low (10%). For sites without the HIV addendum, HIV status among ADAM participants is not known.

Where available: Albuquerque, Anchorage, Atlanta, Birmingham, Cleveland, Denver, Des Moines, Indianapolis, Laredo (Texas), Las Vegas, Miami, Minneapolis, New Orleans, New York City, Oklahoma City, Omaha, Philadelphia, Phoenix, Portland (Oregon), Sacramento, Salt Lake City, San Antonio, San Diego, San Jose (California), Seattle, Spokane (Washington), Tucson.

1999–2000 HIV addendum sites: Denver, Miami, Portland (Oregon).

Additional information available at http://www.ojp.usdoj.gov

Contact person(s): CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

Reference: Methodology Guide for ADAM (May 2001) available at http://www.adam-nij.net/report.asp

Behavioral Risk Factor Surveillance System (BRFSS)

Overview: 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/AIDS 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, receipt of posttest HIV counseling; attitudes about condoms; and attitudes about when to initiate HIV/AIDS 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. The sample is large (212,501 respondents in 2001). 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/AIDS. The extent of HIV behavioral risk information collected by the BRFSS questionnaire is limited, and inferences can be made only at the state level.

Where available: Since 1994, all 50 states and the District of Columbia have conducted BRFSS. As of 2001, Guam, Puerto Rico, and the US Virgin Islands have participated in BRFSS**.**

Contact person(s): 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.

CARE Act Data Report (CADR)

Overview: The CADR is an annual data report form used to collect information from grantees and service providers funded under Titles I, II, III, or IV of the Ryan White CARE Act. The CADR is used to collect general information on provider and program characteristics, including the types of organizations providing services (such as ownership status), sources of revenue, expenditures, paid and volunteer staff. The form is also used to collect aggregate unduplicated demographic information (e.g., gender, race, age, HIV exposure category) on total numbers of clients served by each provider as well as health insurance coverage and utilization data about medical and support services.

Strengths: Only source of Ryan White CARE Act data that is available in all states and eligible metropolitan areas (EMAs). These data provide demographic information and service utilization data on all Ryan White CARE Act clients.

Limitations: Unless a Title I or Title II grantee has access to unduplicated data from an entire EMA or state, the data are duplicated across the EMA or the state. Because the CADR is a summary report by provider, it cannot generate demographic cross-tabulations.

Where available: All 50 states and all 51 EMAs

Contact person(s): Local Ryan White Title I or Title II grantee

CDC National HIV Behavioral Surveillance

Overview: This system will assess risk behaviors and trends in behaviors among persons older than 18 years of age who are at increased risk for HIV infection through injection drug use and sexual activity between men. In later cycles, these studies will be expanded to include high-risk heterosexual adults. In addition, access to, and the use of, HIV prevention programs, including HIV testing, will be assessed. A subset of these areas will conduct studies to estimate HIV prevalence and incidence in high-risk populations.

Population: Men who have sex with men and injection drug users

Strengths: Among men who have sex with men, venue-based systematic sampling will be used to obtain a representative sample. Among injection drug users, respondent-driven sampling will be piloted. 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 are not sampled.

Where available: 15 metropolitan statistical areas where AIDS prevalence is highest: Atlanta, Baltimore, Boston, Chicago, Dallas, District of Columbia, Fort Lauderdale, Houston, Los Angeles, Miami, New York City, Newark, Philadelphia, San Francisco; and San Juan (Puerto Rico)

Contact person(s): Local study site coordinator; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

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 (through 1999) 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 (through 1999) at the county level, by age, sex, and race
- AIDS public use data
- Census state population projections
- Sexually transmitted disease morbidity

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

CDC/HRSA Demonstration Project (CDP)

Overview: The CDP, jointly funded by CDC and HRSA, consists of a network of 7 community demonstration projects. The purpose of CDP is to develop model programs that increase collaboration among public health departments, correctional facilities, and community-based organizations in order to enhance prevention and care services to incarcerated persons at high risk for HIV or living with HIV/AIDS. The primary objective is to expand and enhance HIV-related services to inmates in correctional facilities, especially these preparing for release or recently released from prisons, jails, or juvenile facilities.

Population: Individuals, specifically members of racial minority groups, in correctional settings

Strengths: CDP collects prevention and care services information from HIV-positive incarcerated and recently released persons as well as HIV-negative incarcerated and recently released persons who are engaging in high-risk behaviors. Data from CDP may be useful both to prevention and care planning groups interested in developing programs specifically designed to meet the needs of incarcerated or recently released populations.

Where available: California, Florida, Georgia, Illinois, Massachusetts, New Jersey, and New York

Contact person(s): Local study coordinators, HRSA, Special Projects of National Significance (SPNS) program; CDC, Division of HIV/AIDS Prevention

Collaborative Injection Drug Users Study (CIDUS)

Overview: A prospective cohort study that was established to describe the epidemiology of HIV and other blood-borne and sexually transmitted infections among young injection drug users (IDUs) who recently began injecting drugs and to describe factors in the initiation into injection drug use. Persons recruited to participate in CIDUS completed a baseline questionnaire on the following: frequency of injection drug use, needle sharing, number of sex partners, unprotected sex, history of sexually transmitted diseases, and exchange of money or drugs for sex. At baseline, blood was drawn from study participants and tested for HIV and hepatitis B and C viruses. Participants were followed up every 6 months for 1 year. At each follow-up, participants completed a questionnaire, and blood was drawn. The 3 phases of the study are CIDUS I (1994–1996), CIDUS II (1997–1998), and CIDUS III (Drug Users Intervention Trial).

Population: Persons aged 15–30 years who had injected any drug during the preceding 12 months

Strengths: CIDUS collected information on sexual behaviors and drug injection behaviors that put young persons who had recently begun to inject drugs at high risk of acquiring HIV infection or, if they were HIV infected, increased the risk of transmitting the virus. The longitudinal study design permitted estimation of the incidence of HIV, hepatitis B, and hepatitis C infections in a high-risk population and assessment of the behavioral risks associated with infection.

Limitations: CIDUS relied on self-reported data for behavioral information. Study results may not be representative of all young, recently initiated IDUs in the project area.

Where available: Baltimore, Chicago, Los Angeles, New Orleans, New York City (Harlem and Lower East Side)

Contact person(s): CDC, Division of HIV/AIDS Prevention, Epidemiology Branch

Context of HIV Infection Project (CHIP)

Overview: CHIP is a case-control study designed to investigate risk behaviors associated with recent HIV infection, to identify both HIV prevention opportunities and missed opportunities for HIV prevention and to ascertain the usefulness of the serological testing algorithm for recent HIV seroconversion (STARHS) as a method for identifying recent HIV infections. Persons classified as cases are those recently infected with HIV who are identified through health provider networks, public health clinics, hospitals, and HIV health providers; controls are noninfected persons recruited from similar locations. To achieve sufficient statistical power, 200 cases and 600 controls (1-to-3 ratio for cases and controls) will be recruited. STARHS will be used to analyze the test results of study participants, and quantitative and qualitative questionnaires will be used in interviewing participants. The quantitative questionnaire will collect information on sociodemographic characteristics, HIV testing history, risk behaviors (substance use and sexual behavior), perceived needs for HIV prevention, incarceration history, and history of other diagnoses. The qualitative questionnaire will capture information on the participant's experience with HIV testing, exposure to HIV prevention materials, discrimination, violence, perceived exposure to HIV or high-risk situations, history of life events, religiosity, mental health, intentional behaviors, coping skills, and HIV therapy. In addition, medical records of all participants will be abstracted.

Population: Persons aged ≥ 19 years with a recent HIV infection as defined by STARHS are classified as cases. Controls are persons aged ≥ 19 years who are HIV-negative and have been recruited from locations comparable to those where cases were recruited.

Strengths: CHIP offers information on behavioral risk factors, health status, perceived HIV risk, mental and psychosocial health, and life experiences among persons recently infected with HIV. Because the CHIP questionnaire includes questions about participants' prevention experiences, the effect that prevention messages have had on them, their HIV testing history, and their perceived need for services, CHIP data are valuable for prevention planners who are focusing services on persons at high risk and those who are already infected. The statistical power of the study will enable researchers to detect differences between cases and controls.

Limitations: CHIP interview data are self-reported, and the accuracy of the information cannot be validated with another source of information. The study is not population based; thus, inferences about findings from CHIP cannot be made to all persons recently infected with HIV. In addition, cases may be misclassified because of errors in analyzing test results when STARHS is applied, very recent infections may remain undetected if the antibody level is not detectable by the less sensitive test used with STARHS, or an older infection may inadvertently be classified as a recent infection.

Where available: Chicago, Dallas, Los Angeles; and North Carolina

Contact person(s): Local CHIP principal investigators; CDC, Division of HIV/AIDS Prevention, Prevention Research Branch

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 coterminous 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, or to achieve 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.

Available at http://www.samhsa.gov

Enhanced Perinatal Surveillance (EPS)

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/AIDS trends, provide a data collection system that enables states to respond to selected requirements of the Ryan White CARE Act, and assist with timely evaluation of perinatal prevention efforts. The project collects data by the use of the HIV/AIDS 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/AIDS 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 1999 or later years 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. Data from population-based areas are complete. In a study that included data from 4 population-based project areas (Louisiana, Michigan, New Jersey, and South Carolina), 90% ascertainment of infants born to HIV-infected women was found when data were compared with data from the Survey of Childbearing Women. 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/AIDS, 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 1999 and later.

Where available: Chicago, District of Columbia, Houston, Los Angeles, New York City, Philadelphia; Alabama, California, Connecticut, Florida, Louisiana, Maryland, Michigan, Mississippi, North Carolina, New Jersey, New York, Ohio, Pennsylvania, South Carolina, Tennessee, Texas, Virginia; and Puerto Rico

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator or EPS site coordinator; CDC, Division of HIV/AIDS Prevention, HIV Incidence and Case Surveillance Branch

Expanded HIV Risk Assessment Project (EHRAP)

Overview: EHRAP was designed to evaluate the ability of HIV/AIDS reporting areas to collect indicators of behavioral risk factors from existing records, compare indicators of behavioral risks across HIV/AIDS Reporting System (HARS) risk groups, evaluate the best source of data for indicators of behavioral risks and current definitions, and develop standard definitions of high-risk heterosexual behaviors. EHRAP specifically focuses on persons who are reported in HARS as men who have sex with men (MSM), injection drug users (IDUs), persons with heterosexually acquired infection, or persons with no identified risk. CDC provides each project area with a random sample of HIV cases reported during a 12-month period, stratified by gender and risk. Risk information is extracted from numerous medical records (e.g., case report form, sexually transmitted disease records, tuberculosis records, inpatient and outpatient records, counseling and testing records, hepatitis registry, autopsy records) for each case onto a standardized abstraction form.

Population: All persons in an HIV reporting area who are reported as having HIV infection

Strengths: Population-based estimates of behavioral risk factors for persons reported as HIV infected are available because EHRAP reviews the behavioral information in records from numerous sources. EHRAP informs areas of data sources with the most complete behavioral risk information about persons reported as having a case of HIV infection.

Limitations: Risk information from different record sources may be difficult to locate, and risk information may be incomplete. The project relies on the documentation of risk by health care providers.

Where available: Mississippi and South Carolina conducted a pilot study of EHRAP and extracted data from 1999 HARS information. FY 2000 funds were awarded to Alabama and Virginia, and FY 2001 funds were awarded to New Jersey and Houston to conduct EHRAP.

Contact person(s): State or local health department, HIV/AIDS surveillance 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 in 25 cities, regional laboratories, and CDC. Each month, *N. gonorrhea* isolates are collected from the first 25 men with urethral gonorrhea at 25 STD clinics in the United States. Patient demographics, sexual orientation, history of gonorrhea, reason for clinic visit, and gonorrhea treatment received are abstracted from the medical chart. At regional laboratories, the susceptibilities of these isolates to a panel of antimicrobials are determined by agar dilution and minimum inhibitory concentration techniques according to criteria recommended by the National Committee for Clinical Laboratory Standards.

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, Anchorage, Atlanta, Baltimore, Birmingham, Chicago, Cincinnati, Cleveland, Dallas, Denver, Fort Bragg (North Carolina), Honolulu, Kansas City (Missouri), Long Beach, Miami, Minneapolis, New Orleans, Philadelphia, Phoenix, Portland (Oregon), San Diego, San Francisco, Seattle, and St. Louis; and Orange County (California).

Contact person(s): 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 US territories

Contact person(s): 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(No. RR-19):1–39.

CDC. *Guidelines for Viral Hepatitis Surveillance and Case Management*. Atlanta: CDC; 2002. Available at: http://www.cdc.gov/ncidod/diseases/hepatitis/resource/pubs.htm.

HIV Counseling and Testing System (CTS)

Overview: All states, territories, and selected cities receive funding to support HIV counseling, testing, and referral programs as part of HIV prevention cooperative agreements with CDC. To monitor these programs, the CTS collects information to quantify and characterize services delivered at CDC-funded sites. Data include information on demographics and on counseling and testing (testing history, test result). Personal identifying information is not collected. Several locations collect client-based counseling and testing data by using a nonidentifying client code to link the tests of a person who repeatedly seeks HIV services.

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

Strengths: Standardized data on clients who are tested for HIV are available at the local level. Data may offer insights into HIV infection rates for a high-risk population in that area. CTS testing data may highlight the effect of a prevention program upon the populations being targeted and the effect of prevention programs upon routine HIV/AIDS surveillance.

Limitations: In most areas, the CTS collects test-based, rather than person-based, data and collects information only from persons who seek counseling and testing services at a CDC-funded site. However, areas using a system with a nonidentifying client code can estimate client-based data. Population estimation of HIV seroprevalence is not possible at sites where CTS data are test based. However, at sites where client-based estimates are used, HIV positivity may be used to estimate HIV prevalence for that population. In test-based systems, because a person can repeatedly seek testing, it is not possible to distinguish persons who have been tested multiple times; however, an estimate of the number of persons may be made by using the self-report of a previous HIV-positive test result on the client abstract form. Because the CTS gathers data on prevention activities, changes may reflect changes in program priorities rather than testing patterns of individuals.

Where available: Test-based counseling and testing projects are conducted in 50 states, 6 city health departments, and US territories. Client-based systems are available in California, Colorado, Florida, Louisiana, Maryland, Michigan, Texas; and Houston, San Francisco, and Seattle.

Contact person(s): State, territorial, or city health department HIV program manager or AIDS director

Reference: Report of 1997–1998 data available at http://www.cdc.gov/hiv/pubs/cts98.pdf

HIV Epidemiology Research Study (HERS)

Overview: A cohort study of HIV-infected women and women who were not infected but who reported injection drug use or sexual behaviors that placed them at high risk for HIV infection. Women aged 16–55 years were enrolled at participating sites, interviewed, and given a physical examination every 6 months. The HERS interview collected information on medical history, medications, reproductive history, contraceptive use, drug use, health care utilization, pyschosocial health, functional abilities, life events, sexual behavior, social behavior, and HIV-related beliefs. The physical exam focused on weight, skin, breast, oral, abdominal, and pelvic findings. Blood, oral, vaginal, cervical, and rectal samples were obtained for a variety of laboratory tests. In addition, medical records were abstracted for all hospitalizations and AIDS-related outpatient visits.

Population: Women aged 16–55 years who were HIV infected or who reported injection drug use or high-risk sexual behavior were eligible for enrollment.

Strengths: HERS collected detailed information on a cohort of HIV-infected women and noninfected women who were at high risk for HIV. Data from the study can be used to measure the effects of HIV infection on the physical, emotional, and social health of women and identify intervention components that may improve the quality and duration of the lives of HIV-infected women.

Limitations: HERS data are not representative of all HIV-infected women in a service area because enrollment took place at a participating study site. Loss to follow-up may have compromised the precision of study findings.

Where available: Baltimore, Detroit, Providence (Rhode Island), and New York City

Contact person(s): CDC, Division of HIV/AIDS Prevention, Epidemiology Branch

HIV Incidence Surveillance

Overview: The goals of HIV incidence surveillance are to (a) collect and test diagnostic blood specimens from all persons with newly diagnosed HIV infections who have been reported to HIV surveillance, (b) collect the HIV testing history needed for the statistical estimates of incidence, and (c) link incidence test data and testing history data in order to make population-based estimates of HIV incidence. The serologic testing method that will be used to distinguish between recent and long-standing HIV infection is the serologic testing algorithm for recent HIV seroconversion (STARHS).

Population: All persons with newly reported HIV infections who do not have advanced disease, such as AIDS, and who are not taking antiretroviral medications for HIV prevention or hepatitis B

Strengths: The comparison of incident and prevalent infections will allow monitoring of emerging trends in the epidemic, targeting and evaluation of prevention programs, and population-based estimation of HIV incidence.

Limitations: Currently, a less sensitive HIV enzyme immunoassay, the serologic test that will be used to detect newly diagnosed HIV infections, is not licensed by the Food and Drug Administration; thus, consent is required if it will be linked to personal identifiers. For population-based estimates of incidence, the testing history must also be obtained from the persons tested. Estimates of the number of persons who are HIV-positive and do not know their status must still be derived from information on persons who are tested. STARHS is currently available only for blood tests. However, oral testing is often used in interventions that target populations thought to be at high risk because of their behavior; therefore, high-risk persons may not be tested with the less sensitive HIV enzyme immunoassay. Although STARHS cannot be applied to analyze the results of their tests, statistical modeling can be used to account for these persons in estimates of incidence.

Where available: Pilot sites funded 2001—Alabama, Colorado, Michigan, New Jersey; and Seattle. Funded 2002—Arizona, Florida, Indiana, Louisiana, Maryland, Massachusetts, Mississippi, Missouri, New York State, Ohio, Oklahoma, South Carolina, Tennessee, Texas, Virginia; Chicago, Houston, New York City; and Puerto Rico

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

HIV Prevalence and Incidence and Associated Risk Behaviors among Incarcerated Illicit Drug Users

Overview: Survey to assess HIV prevalence, trends, and related risk behaviors and estimates of HIV incidence among illicit drug users booked into a correctional facility. Systematically sampled persons booked into the correctional facility and determined, during a brief interview, to be IDUs are referred for HIV counseling and testing (C&T) according to standard health department and C&T protocols for correctional facilities. The persons who are referred and all other IDUs who seek C&T in the health clinic are invited to participate in the survey by completing a brief supplemental standardized interview about drug use, travel patterns, and related risk behaviors.

Population: All IDUs referred for HIV C&T and other IDUs who seek HIV C&T in the health clinic of the correctional facility

Strengths: This observational study is a cross-sectional face-to-face interview survey of risk behaviors among IDUs booked into correctional facilities. Interview data are linked to HIV antibody test results obtained through standard HIV C&T according to local protocols. A non-name identifier, which protects the confidentiality of study enrollees, allows linkages between data from participants who are repeatedly booked and re-enrolled in the survey, so that HIV incidence and changes in drug-use behaviors can be monitored and assessed.

Limitations: Volunteer bias may affect results. Potential participants intercepted in the booking area may be hesitant to reveal information about drug-use history because of fear of self-incrimination.

Where available: Chicago, Philadelphia, Seattle; and California, Colorado, and New York State

Contact person(s): Local study site coordinator; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

HIV Seroprevalence Surveys

Overview: From 1988 through 1999, CDC monitored HIV seroprevalence through a national serosurveillance system. As part of this system, anonymous unlinked surveys (AUSs) were designed to estimate the prevalence of HIV infection among selected populations, such as patients attending sexually transmitted disease (STD) clinics and persons entering drug treatment centers. Residual sera, originally collected for other purposes and which otherwise would have been discarded, were tested for HIV after all personal identifiers were permanently removed from the specimens. All sites that conducted AUSs offered voluntary counseling and testing, allowing anyone who participated in the surveys the opportunity to learn his or her HIV status. In addition to AUSs, CDC monitored HIV prevalence in 3 other populations in which HIV testing is routinely performed. Data were provided by the US Department of Labor (Job Corps entrants), the US Department of Defense (military applicants), and the American Red Cross (blood donors).

Populations: Populations included in the AUS component of the surveillance system through 1997 included MSM and high-risk heterosexuals at STD clinics, IDUs entering drug treatment programs, and clients of adolescent medicine clinics. Earlier surveys included the Survey of Childbearing Women and sentinel hospital surveys (emergency department and outpatient services).

Routine HIV screening results are provided for youth (16–21 years of age) entering the Job Corps, military applicants (all persons applying for active duty or reserve military service, the service academies, or ROTC), and American Red Cross first-time blood donors.

Strengths: AUSs allow estimates of HIV infection without the participation bias that results from a person's decision to seek or not seek HIV testing. Because testing behavior may differ considerably in racial and ethnic, socioeconomic, and behavioral risk groups, AUSs are especially important in providing data that are representative of specific subgroups of the population. Demographic and risk information, linked to the residual specimens through a unique study number, were abstracted from routine medical records and intake forms. Data from these surveys have been instrumental in describing populations with the greatest need for preventive services and future care. Results from the Survey of Childbearing Women (discontinued in 1995) could be used to infer the magnitude of HIV in the general childbearing population.

Results from routine HIV screening of military applicants, Job Corps entrants, and first-time blood donors provide important additional information on the epidemic. Each of these geographically diverse groups is composed of persons with particular demographic and socioeconomic characteristics.

Limitations: Persons attending the participating AUS clinics may not be representative of the selected population. For example, persons attending STD clinics are likely at higher risk for HIV than are MSM or heterosexual persons who do not attend the clinics. Also, because of the nonrandom selection of venues, results cannot be generalized to persons who do not attend these venues. However, trend data are less subject to bias within a particular group.

HIV prevalence among Job Corps entrants may not be indicative of prevalence among other economically and socially disadvantaged youth because applicants with current drug addictions or serious medical or behavioral problems and those on supervised probation are not accepted into the program. Applicants who are HIV-positive or who use drugs are not accepted into the military; therefore, self-selection bias among persons at high risk is likely.

Where available: CDC funded AUSs through 1999. In 1997, 16 metropolitan areas conducted surveys at STD clinics, 12 conducted surveys in drug treatment centers, and 4 conducted surveys in adolescent medicine centers. Some areas continue to support local AUSs. Since 1987, all Job Corps entrants have been tested, and since 1985, all military applicants have been screened through serosurveys.

Contact person(s): State or local health department, HIV/AIDS seroprevalence coordinator

References

CDC. *HIV Prevalence Trends in Selected Populations in the United States: Results from National Serosurveillance, 1993–1997*. Atlanta: CDC; 2001:1–51. Also available at: http://www.cdc.gov/hiv/pubs/hivprevalence/hivprevalence.htm.

CDC. *National HIV Prevalence Surveys: 1997 Summary.* Atlanta: CDC; 1998:1–25. Also available at: http://www.cdc.gov/hiv/pubs/hivsero.htm.

Copies of both documents are available from the National Prevention Information Network (NPIN), 800-458-5231.

HIV Testing Survey (HITS)

Overview: Established to monitor HIV testing patterns by assessing reasons for seeking or avoiding testing, examining knowledge of state policies for HIV surveillance, and assessing HIV testing patterns among persons at high risk for HIV infection. In addition, HITS collects behavioral risk information from persons at high risk for infection and can be used to evaluate the representativeness of HIV surveillance data.

HITS is an anonymous cross-sectional survey of populations at high risk for HIV infection. The core populations are men who have sex with men (MSM), injection drug users (IDUs), and high-risk heterosexual adults. Areas have the option of sampling a population of local interest. To recruit participants, the study is conducted in several cities in a state (generally) at 3 venues: gay bars, street locations in areas of heavy drug use, and sexually transmitted disease (STD) clinics. At a minimum, 100 persons in each population group are interviewed; thus, states have a minimum sample of 300 persons. Persons who are not tested or who self-report as HIV-positive are interviewed. Persons who are HIV-negative may be interviewed as well.

Native American HITS: A special project of HITS was conducted in 2000 in Portland, Oregon. HITS methods were used for this project; however, focus groups of Native Americans were used to modify the general HITS questionnaire so that the questionnaire content was culturally appropriate.

In 2002, HITS was conducted on 3 reservations in Idaho, Oregon, and Washington. An additional Native American project was conducted in Houston, Texas.

Population: Regardless of the venue, persons who are at least 18 years of age, able to give informed consent, and have been a resident of the state for at least 1 year are eligible for a HITS interview. In addition, the following behavioral criteria apply for each risk group: men at MSM venues are eligible if they have had sex with a man within the past 12 months; IDUs must have injected within the past 12 months; and high-risk heterosexual adults who seek care at an STD clinic are eligible if they are at the clinic because of a suspected STD, have not been treated during the past 90 days, are not at the clinic because of referral or follow-up, and have not had homosexual sex within the past 12 months.

Native American HITS: Native Americans living in Portland, Oregon, were sampled at venues identified through formative research. Participants were recruited by the use of social network sampling (participants are asked to recommend other persons like themselves who could be recruited to participate).

Strengths: The survey collects valuable public health information about HIV testing attitudes, history and behaviors, as well as knowledge about testing, and risk behaviors from population groups at high risk for HIV.

Limitations: HITS is a cross-sectional survey and relies on a convenience sample for participation. Information collected is self-reported and may be subject to recall bias. Further, HITS data may not represent the entire high-risk population of an area.

Where available: HITS-I (1996)—Arizona, Colorado, Maryland, Mississippi, Missouri, New Mexico, North Carolina, Oregon, Texas. HITS-II (1998)—Arizona, Colorado, Mississippi, Missouri, New Mexico, Oregon, Texas. HITS-2000—Florida, Illinois, Kansas, Nevada, New York State, Texas, Washington; New York City. HITS-2001—California, Louisiana, Vermont; Philadelphia. HITS-2002—Florida, Illinois, Michigan, New Jersey, Washington; Los Angeles County; Houston, New York City, Philadelphia. Asian/Pacific Islander HITS (2002)—Seattle/King County (Washington). Migrant Farm Worker HITS (2002)—California. Native American HITS 2002—Houston and Portland (Oregon). Transgender HITS (2002)—San Francisco.

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator or HITS site coordinator; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical 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 person(s): Local study investigators; CDC, Division of HIV/AIDS Prevention, Epidemiology Branch

Impact of Ryan White CARE Act Title I Funding on HIV Services Utilization and Health Outcomes in Newly Eligible Metropolitan Areas

Overview: The objective of the Ryan White Evaluation Project is to evaluate the impact of Ryan White Title I funding on the availability, accessibility, quality, and continuity of HIV care in 2 communities newly designated Ryan White Title I eligible metropolitan areas (EMAs) as of March 1, 1999. This project will determine whether Ryan White funding improves adherence to treatment guidelines for HIV.

The project is divided into 2 periods (Phase I and II) and involves a 1-year medical chart review of eligible HIV-infected patients. Phase I is defined as the period before Ryan White funding and includes patients whose HIV diagnosis was made during September 1996 through November 1997. Medical chart review of patients included in Phase I includes the period March 1998 through February 1999. Phase II refers to the period after Ryan White funding and includes patients whose diagnosis was made during April 1998 through November 1999. Phase II patient chart review took place during March 2000 through February 2001. The data include demographic characteristics, vital status, insurance coverage, AIDS-defining conditions, laboratory data, antiretroviral and prophylactic therapies, immunizations, access to health care, mental health, substance abuse, dental care, and case management.

Population: Persons ≥ 13 years of age with a diagnosis of HIV infection

Strengths: The evaluation study collects information on HIV care among populations of interest to Ryan White EMAs (e.g., persons who are homeless, abuse substances, or are mentally ill). The project examines information documented by health care providers to determine whether HIV-infected patients who are known to surveillance programs are receiving standards of care for HIV. One can infer that persons with no identified source of health care have not sought care.

Limitations: The cross-sectional design of the study does not allow the comparison of changes in the quality of health care delivered to HIV-infected patients over time as a result of Ryan White funding. The quality of the data depends upon the completeness of chart documentation by providers and the ability of staff at the study sites to locate the medical records. Consequently, the study may underestimate the amount of HIV care received. As is true of any project that uses surveillance to identify persons, the data will not reflect persons whose infection has not been reported to surveillance programs.

Where available: Las Vegas, and Norfolk (Virginia), and Ryan White EMAs

Contact person(s): CDC, Division of HIV/AIDS Prevention, HIV Incidence and Case Surveillance Branch; HRSA, HIV/AIDS Bureau, Office of Science and Epidemiology

MSM Interview Project

Overview: A one-time study focused on men who have sex with men (MSM) who have a recent diagnosis of HIV infection. The purpose of the study is to assess the usefulness of the serological testing algorithm for recent HIV seroconversion (STAHRS) in identifying recent HIV infection among MSM who have a new diagnosis and who have been reported with HIV infection through the national HIV/AIDS Reporting System and to characterize behaviors, including risky sexual behaviors during the likely time of infection, HIV testing behaviors, and health-care-seeking behaviors. In addition, the study will determine the prevalence of sexually transmitted diseases (STDs) through self-report, matching of HIV and STD registries, and medical record review. HIV/AIDS surveillance data and laboratory and demographic criteria will be used to identify MSM who may be recently infected with HIV: (a) recently documented HIV seroconversion (within 18 months), (b) younger age (18–29 years), (c) higher CD4 count or percentage (>700 or >36%). MSM meeting any 1 of these criteria are eligible for the study. After informed consent is obtained, eligible participants will be interviewed, and attempts will be made to retrieve the stored HIV diagnostic blood specimen for testing.

Population: All HIV-infected men newly reported to HARS in Alabama and New York City who have had sex with men and who meet any 1 of the 3 criteria for recent infection. Approximately 100 eligible men per site will be enrolled.

Strengths: The MSM Interview Project will allow sites to use STAHRS to identify recently infected MSM (within 180 days of infection). The project makes it possible to compare the behaviors of those who have been infected most recently (past 6 months) and the behaviors of those who have been infected longer.

Limitations: The interview data are self-reported and therefore subject to recall bias. Data from this project may not represent all recently infected MSM because of either refusal to participate or the lack of availability of the diagnostic blood specimen. In addition, there may not be a sufficient number of MSM from the Alabama site.

Where available: New York City and Alabama

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator or MSM interview project site coordinator; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

MSM Prevalence Monitoring Project

Overview: Created to monitor trends in STDs, TB, and HIV risk behaviors among men who have sex with men (MSM). The project aims to improve data collection, data management, and reporting of sexually transmitted diseases (STDs), tuberculosis (TB), and HIV risk behaviors among MSM. Approximately 90% of the project data have been collected at STD clinics; data have also been collected at bathhouses, HIV care clinics, and HIV counseling and testing sites.

Population: MSM with a diagnosis of an STD, TB, or HIV infection at a public STD clinic or venue selected by the project as a place frequented by MSM

Strengths: Provides project sites with additional resources to conduct active surveillance of STDs, TB, and HIV risk behaviors among MSM. This surveillance enables projects to monitor the prevalence of infections and coinfections among MSM in order to evaluate the effectiveness of current programs and to anticipate prevention needs.

Limitations: Data, currently collected mostly in STD clinics, may not reflect STDs in the general population of MSM.

Where available: 1999—Chicago, District of Columbia, Long Beach (California), Philadelphia; 2000—Boston, Denver, Houston, San Francisco, Seattle; 2001—New York City

Contact person(s): Local or state STD program manager; CDC, Division of STD Prevention, Epidemiology and Surveillance Branch

National Death Index (NDI)

Overview: This national database of state death record information cannot be accessed directly; however, NCHS does perform 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 US state of death, and the death certificate number. For an additional fee, an enhanced service, named NDI-Plus, may be used, which additionally 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 US Virgin Islands

Strengths: NDI is a nationwide, population-based index in which the causes of death are properly classified according to the rules of the NCHS and the ICD-9 or ICD-10.
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. The most recent data are usually added to the NDI 15 months after the end of the calendar year. Use of this service can be expensive, particularly if NDI-Plus is used to find the causes of death. Before investigators use either the routine NDI or the NDI-Plus services, they should first search for matches in the death-certificate database of the Office of Vital Statistics of their state or local health department. Records, for which good matches are found, need not be submitted for a search for matches in the NDI database.

Where available: National Center for Health Statistics

Contact person(s):
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 US 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 US 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: http://www.samhsa.gov

National Neighborhood Indicators Project (NNIP)

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

All local partners have built locally self-sustaining information systems with integrated and recurrently updated information on neighborhood conditions in their cities. These systems facilitate the direct use of information by local government and community leaders to build the capacities of distressed urban neighborhoods. Current NNIP activities are sponsored by the Annie E. Casey Foundation and the 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 geo coded. 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, Cleveland, Denver, District of Columbia, Indianapolis, Miami, Milwaukee, Oakland (California), Philadelphia, and Providence (Rhode Island)

Reference: http://www.urban.org/nnip

Outcome Assessment through Systems of Integrated Surveillance (OASIS)

Overview: Promotes the integrated use and interpretation of state and local surveillance data. Depending on the jurisdiction, these may include surveillance data for sexually transmitted disease (STD), HIV/AIDS, and tuberculosis; vital statistics; behavioral surveys; and other enhanced surveillance. OASIS includes an examination of comorbidity through geographic mapping of disease and through registry matching of surveillance data.

Population: Persons reported to a surveillance system

Strengths: Through an examination of multiple surveillance data sources, OASIS may provide a description of morbidity and risk in the community, including geographic patterns of morbidity and comorbidity.

Limitations: Analyses of data from multiple sources differ by jurisdiction. Analyses are limited by limitations inherent in each surveillance system.

Where available: California, Indiana, Massachusetts, Michigan, Missouri, New York State, North Carolina, Ohio, Oregon, Texas, Virginia, Washington; and Baltimore, New York City, San Francisco

Contact person(s): State or city health department or state or city STD surveillance staff; CDC, Division of STD Prevention, Epidemiology and Surveillance Branch

Pediatric Spectrum of Disease (PSD)

Overview: The PSD study is an active surveillance project designed to increase understanding of the pediatric HIV epidemic by providing epidemiologic data on the characteristics, magnitude, pattern, and spread of HIV exposure or disease in children; follow trends in disease characteristics, patterns of recognition, and treatment; and follow response to national guidelines for prevention and treatment. All HIV-infected children and children born to HIV-infected mothers are eligible for enrollment and are ascertained by participating health care providers. Data are abstracted from medical records every 6 months.

Population: All HIV-infected children and children born to HIV-infected mothers

Strengths: PSD is a population-based source of data describing the spectrum of HIV disease documented in the medical charts of children infected with HIV or born to an HIV-infected mother. The project has been conducted since 1988, and more than 14,600 children have been enrolled. Data from PSD have been used to design and revise the pediatric AIDS definition, estimate the prevalence of HIV disease in US children, establish guidelines for prophylaxis for opportunistic infections, and understand the natural history of HIV infection in children.

Limitations: PSD relies upon both the amount of morbidity information available in the medical chart, which may not be complete, and upon the thoroughness of diagnostic testing and recording. Loss to follow-up may occur.

Where available: District of Columbia, Los Angeles, New York City, San Francisco; Massachusetts, North Carolina, Texas; and Puerto Rico

Contact person(s): PSD study site coordinator; CDC, Division of HIV/AIDS Prevention, Epidemiology Branch

Pregnancy Risk Assessment Monitoring System (PRAMS)

Overview: A population-based survey that collects perinatal information, including information on prenatal HIV prevention through counseling and testing. Each month, a random sample (from state birth certificate files) of state-resident mothers are mailed a standardized 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 HIV prevention and HIV testing with them during a prenatal care visit. In 15 states, all mothers are 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 prevention and 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. For states collecting actual HIV testing information (an elective question), the level of HIV testing can 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, the data are less representative of mothers at high risk for HIV infection or HIV-positive mothers. 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: 31 states (Alabama, Alaska, Arkansas, Colorado, Florida, Georgia, Hawaii, Illinois, Louisiana, Maine, Maryland, Michigan, Minnesota, Mississippi, Montana, North Carolina, North Dakota, Nebraska, New Jersey, New Mexico, New York, Ohio, Oklahoma, Oregon, Rhode Island, South Carolina, Texas, Utah, Vermont, Washington, West Virginia); and New York City

Contact person(s): PRAMS coordinator for your state. Additional background and information on whom to contact in your area available at: http://www.cdc.gov/nccdphp/drh.

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.

Project One

Overview: Project One is a multicomponent project designed to estimate the incidence of HIV infection among men who have sex with men, injection drug users, and high-risk heterosexual adults, and to characterize persons with recent HIV infection. The project components consist of multiple incidence studies, behavioral characterization of persons with a recent diagnosis of HIV infection, and a study of drug-resistant strains and subtyping of new cases.

Population: Persons ≥ 18 years of age residing in the study area whose HIV infection was diagnosed within the past 6 months

Strengths: For 3 important population segments, this study provides key information on HIV incidence and, among those found to be HIV infected, the extent of exposure to prevention services and missed opportunities for HIV prevention; behavioral, individual, and contextual factors associated with HIV transmission; and the viral characteristics of recently transmitted HIV infection.

Limitations: This study has limited generalizability beyond the 3 US metropolitan areas in which it is conducted.

Where available: Chicago, Dallas, Los Angeles

Contact person(s): Project One research managers; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

Rapid Assessment and Response and Evaluation (RARE) – Crisis Response Team Initiative

Overview: Local crisis response teams work in partnership with local community, public health and community leaders to describe the local HIV/AIDS epidemic and its effect upon vulnerable populations. The teams use rapid assessment methods such as focus groups and street intercept surveys during a period of 8 to 10 weeks. The process, conducted at the microlevel, complements surveillance and data-gathering systems by providing data describing the epidemic from the perspective of the neighborhood and the individual. After focus groups and surveys are completed, the findings are presented to the community so that prevention strategies can be identified and prioritized for its specific geographic area.

Population: Persons in community groups of interest in participating cities

Strengths: Provides limited information about prevention and care needs in the defined geographic area

Limitations: Results from this project cannot be generalized to the entire geographic area.

Where available: Phase I cities—Atlanta, Baltimore, Chicago, Detroit, District of Columbia, Miami, New Haven (Connecticut), Newark, Oakland (California), Philadelphia, West Palm Beach; US Virgin Islands

Phase II cities—Birmingham, Cleveland, Columbia (South Carolina), Corpus Christi (Texas), Dallas, Houston, Jacksonville (Florida), Memphis, Mercedes (Texas), Phoenix, Portland (Oregon), St. Louis (Missouri), San Antonio; Puerto Rico

RARE projects have been conducted in conjunction with municipal governments (typically the mayor's office and the health department) in Atlanta, Chicago, Detroit, District of Columbia, Los Angeles, Miami, Newark, New Haven (Connecticut), Oakland (California), Philadelphia, and West Palm Beach.

Contact person(s): Local health department or office of the mayor

Reference: Trotter RT, Needle RH, Goosby E, Bates C, Singer M. A methodological model for rapid assessment, response, and evaluation: the RARE program in public health. *Field Methods* 2001;13:137–159.

Note: A variety of manuals of rapid assessment methods are available: for example, the University of Texas Southwestern Medical Center's *Community-Based Assessment: A Guide for HIV Prevention Workers* is available at http://www3.utsouthwestern.edu/preventiontoolbox/assess/assess.htm.

School Health Education Profiles

Overview: The profiles monitor characteristics of health education in middle or junior high schools and at senior high schools in the United States. The profiles are surveys conducted by state and local education agencies to collect representative data on schools serving students in grades 6–12. The survey includes questions about required health education classes, content of health education, coordination of health education, qualifications of health educators, and parental involvement in health education. Questions about health education content include HIV prevention, substance use, pregnancy prevention, alcohol and tobacco use, diet, physical activity; and violence. Data from states with overall response rates of ≥ 70% were statistically weighted, enabling population-based inferences.

Population: High school and middle or junior high schools in a state or city are eligible for sampling. The profiles use a systematic equal-probability sampling strategy. At a sampled school, the principal and the lead health educator complete a survey. Profile surveys have been conducted biennially since 1996 (1996, 1998, and 2000).

Strengths: The project provides population-based information on the provision of health education offered to students in school, collecting information on whether HIV education is required, whether teachers are trained to teach HIV prevention education, the extent to which parents are informed about HIV prevention education, and other broad topics pertaining to HIV prevention. The profile serves as a springboard for developing community-wide prevention activities or enhancing activities in the school system or both. 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 health education provided and are applicable only to students in school. In addition, the unit of analysis is the schools, not the students.

Where available: States with weighted 1998 data—Alabama, Alaska, California, Delaware, Georgia, Hawaii, Idaho, Illinois, Iowa, Louisiana, Maine, Massachusetts, Michigan, Minnesota, Missouri, Montana, Nebraska, New Hampshire, New Mexico, New York, North Dakota, Ohio, Pennsylvania, South Carolina, Utah, Virginia, West Virginia, Wisconsin, Wyoming. Local areas with weighted 1998 data—Dallas, Fort Lauderdale, Los Angeles, Miami, New Orleans, Philadelphia, San Diego, and San Francisco

Contact person(s): State department of education. CDC, Division of Adolescent and School Health

Reference*:* http://www.cdc.gov/mmwr/PDF/SS/SS4908.pdf

Sentinel Surveillance for Variant and Drug-Resistant Strains (SSVRS)

Overview: SSVRS was conducted to describe the prevalence of mutations associated with reduced drug susceptibility among antiretroviral drug–naïve persons with a recent diagnosis of HIV infection. Genotypic resistance testing and HIV subtyping were conducted for all eligible persons. These data may help guide recommendations for baseline (before therapy) antiretroviral resistance testing in a given area.

Population: Persons with a diagnosis of HIV infection during the past 12 months, antiretroviral drug–naïve, at HIV counseling and testing sites, in HIV care clinics, and other clinical settings

Strengths: To date, SSVRS is the largest and most diverse study to monitor the prevalence of antiretroviral drug resistance in the United States.

Limitations: Because the sample was not a random sample of persons with a recent diagnosis, the data may not be representative of all HIV-infected persons in the United States. Also, the study may underestimate the prevalence of mutations among the chronically infected group of persons with a recent diagnosis because some mutations do not persist in the absence of drug pressure.

Where available: Denver, Detroit, Grand Rapids (Michigan), Houston, Miami, Newark, New Orleans, New York City, San Diego, San Francisco

Contact person(s): State or local health department, SSVRS coordinator; CDC, Division of HIV/AIDS Prevention, HIV Incidence and Case Surveillance Branch

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 US 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 epidemic 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 and US territories

Contact person(s): State or city STD program manager

Reference: CDC**.** Case definitions for infectious conditions under public health surveillance. *MMWR* 1997;46 (No. RR-10):1–56.

Supplement to HIV/AIDS Surveillance (SHAS)

Overview: SHAS is a cross-sectional interview study that collects self-reported characteristics and behaviors of persons ≥ 18 years of age who have been recently reported with HIV infection or AIDS through routine surveillance to state or local health departments. SHAS was developed to collect information supplemental to routine HIV/AIDS surveillance. The SHAS interview module gathers information on demographic and socioeconomic characteristics; substance use; sexual behavior; access to medical and social services; use of, and adherence to, therapies for HIV and HIV-related opportunistic illnesses; disability related to HIV infection; and reproductive or child health (women only).

Eligible persons are recruited by using population-based or facility-based sampling methods, depending upon the area's HIV/AIDS case load. In areas with <500 persons eligible for interview, all persons are interviewed. Areas conducting population-based or facility-based sampling use 3 strategies in recruiting patients for interviews: (a) all persons reported to surveillance, (b) 30% random sample of HIV-infected men who have sex with men (if male-to-male sex is the predominant mode of HIV transmission) and 100% of HIV-infected persons from other risk groups, or (c) 50% random sample of all persons for whom male-to-male sex is not the primary mode of transmission.

Population: HIV-infected persons ≥ 18 years of age reported to state or local health departments are eligible for a SHAS interview. Persons who are medically or mentally unstable are excluded.

Strengths: Enhanced behavioral and social information collected from persons reported as having HIV/AIDS can be compared with information from routine surveillance. A standardized questionnaire is used to gather self-reported information on use of HIV care services and adherence to therapies. In some areas, the information is representative of all or nearly all persons reported as having HIV/AIDS. Additional gynecologic information is available. Sampling methods are flexible to accommodate local and state needs.

Limitations: SHAS gathers self-reported data; thus, the data are subject to recall bias, particularly for questions concerning injection drug use and sexual history, and cannot be validated by another source of information. SHAS is a cross-sectional survey, so changes in behavior over time cannot be examined. In project areas without HIV reporting, SHAS information may be less useful for prevention activities than it is in areas where HIV infection is reportable. SHAS is based upon a sample of convenience that is not entirely population based; project sites rely upon the cooperation of providers who have reported HIV infections to HARS to approach their patients about the project.

Where available: Since 1990, the following areas have conducted population-based SHAS: Arizona, Delaware, New Mexico, South Carolina (Richland and Charleston Counties, Edisto Health District), Washington State; Los Angeles County; and Tampa.

The following areas conduct facility-based SHAS: Atlanta, Denver, Detroit, Jacksonville (Florida), Jersey City (New Jersey), Miami, and Hartford and New Haven (Connecticut).

Since 2001, Kansas, Maryland, Minnesota, and Texas (Austin) have received funding to conduct SHAS. As of 2002, Chicago, Houston, and Philadelphia have received funding to conduct SHAS.

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator or SHAS site coordinator; CDC, Division of HIV/AIDS Prevention, HIV Incidence and Case Surveillance Branch

Reference: Buehler JW, Diaz T, Hersh BS, Chu SY. The Supplement to HIV/AIDS Surveillance project: an approach for monitoring HIV risk behaviors. *Public Health Reports* 1996;111(suppl 1):133–137.

Survey of HIV Disease and Care (SHDC)

Overview: SHDC, a cross-sectional survey of HIV-infected persons reported to the HIV/AIDS Reporting System (HARS), was developed to obtain population-based estimates of the clinical characteristics of persons receiving medical care for HIV infection. SHDC collects demographic and clinical information, including the proportion of patients receiving therapy as recommended by current treatment guidelines and the proportion of patients receiving preventive services. The medical records of sampled patients are reviewed for the preceding 12 months, and the information is documented on a standardized abstraction form.

Population: Health care providers who have reported an HIV-infected person(s) to HARS are eligible for sampling. A listing of the health care providers' HIV-infected patients is prepared and then sampled systematically with a random start. Women and members of racial/ethnic minority groups are oversampled.

Strengths: SHDC is designed to collect data on a representative sample of patients receiving HIV care so that population-based estimates of the proportion of HIV-infected persons receiving recommended standards of care can be made. Women and members of racial/ethnic minority groups are oversampled to ensure that population-based estimates in these populations are valid. SHDC extracts information from a variety of records in order to capture information on prescription of HIV antiretroviral therapies, receipt of medical care and social services, and laboratory testing history.

Limitations: SHDC is a cross-sectional study, and medical records are the source of the data. Estimates of care cannot be assessed over time, and the quality of the data depends upon the completeness of documentation in the patient's medical record. Because the sampling frame is patients who have sought medical care, population-based inferences cannot be made about HIV-infected persons not receiving care for HIV infection. SHDC does not collect behavioral information; therefore, self-reported adherence to therapies documented in the medical chart is not known. In addition, data from SHDC may underestimate the amount and type of medical care a patient received if the patient received medical care from more than 1 provider; for example, gynecologic care may be underreported because women may seek a non-HIV care provider for this service.

Where available: Since 2000, Florida, Louisiana, Maryland, Michigan, Ohio, Washington; and Houston

In 2001, New Jersey and Virginia, Philadelphia, and Puerto Rico received funding to initiate SHDC.

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator or SHDC site coordinator; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

Survey of HIV Disease and Care Plus (SHDC+)

Overview: SHDC+, a cross-sectional survey of HIV-infected persons reported to the HIV/AIDS Reporting System (HARS), was developed to obtain population-based estimates of clinical outcomes among persons receiving medical care for HIV infection and self-reported behavioral determinants of clinical outcomes. Using medical record abstraction, SHDC+ collects demographic and clinical information, including the proportion of patients receiving therapy recommended by current treatment guidelines and the proportion of patients receiving preventive services. In addition, participants are interviewed in person about HIV risk behaviors and adherence to treatment. The medical records of sampled patients are reviewed for the preceding 12 months, and the information is documented on a standardized abstraction form.

Population: Health care providers who have reported an HIV-infected person(s) to HARS are eligible for sampling. A listing of the health care providers' HIV-infected patients is prepared and then sampled systematically with a random start. Women and members of racial/ethnic minority groups are oversampled.

Strengths: SHDC+ is designed to collect data from a representative sample of patients receiving HIV care so that population-based estimates of the proportion of HIV-infected persons receiving recommended standards of care can be made. Women and racial/ethnic minorities are oversampled to ensure that population-based estimates of these populations are valid. SHDC+ extracts information from a variety of record sources in order to capture information on prescription of HIV antiretroviral therapies, receipt of medical care and social services, and laboratory testing history; in-person interviews are conducted to collect information on adherence to HIV therapy and behavioral risks. Data from SHDC+ are useful for estimating the proportion of persons who received appropriate standards of care for HIV disease and learning whether they adhere to their therapy. SHDC+ also offers an opportunity for methodologic research; interview data will also be used to assess the validity of selected data from chart abstraction and vice versa.

Limitations: SHDC+ is a cross-sectional study, and medical records are the source of the data. Estimates of care cannot be assessed over time, and the quality of the data depends upon the completeness of documentation in the patient's medical record and the validity of the self-reported information. Because the sampling frame is for patients who have sought medical care, population-based inferences cannot be made about HIV-infected persons who are not receiving care for HIV infection. In addition, data from SHDC+ may underestimate the amount and type of medical care a patient received if the patient received medical care from more than 1 provider.

Where available: In 2001, Michigan, New Jersey, and Washington (Seattle/King County) received funding to conduct SHDC+.

Contact person(s): State or local health department, HV/AIDS surveillance coordinator; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

Tuberculosis Surveillance

Overview: All reporting areas (the 50 states, the District of Columbia, New York City, Puerto Rico, and other US jurisdictions in the Pacific and Caribbean) report tuberculosis (TB) cases to CDC by using a standard case report form, the Report of a Verified Case of Tuberculosis. 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 additional data to better monitor and target groups at risk for TB disease, to estimate and follow the extent of drug-resistant TB, and to evaluate outcomes of TB cases. The Report of a Verified Case of Tuberculosis form was revised to obtain 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.

Population: All persons whose case of TB meets the public health surveillance definition

Strengths: The level of active TB disease reporting is more than 95% complete. As a result of the 1993 expansion of surveillance activities, jurisdictions have been able to evaluate the success of TB control efforts and monitor the status of the TB epidemic. TB surveillance data provide areas with a minimum estimate of the level of HIV comorbidity.

Limitations: Data on HIV infection status of reported TB cases should be interpreted with caution because these data are not representative of all TB patients with HIV infection. HIV testing is voluntary, and some TB patients may decline HIV testing. In addition, TB patients who have been tested anonymously may not share their HIV test results with their health care provider. Further, testing may be influenced by other factors, such as the extent to which testing is focused on, or routinely offered to, specific groups.

Where available: All 50 states, the District of Columbia, New York City, Puerto Rico, and other US jurisdictions in the Pacific and Caribbean

Contact person(s): State or territorial health department TB coordinator: http://www.cdc.gov/nchstp/tb. Select "Contact us" for a list of coordinators.

Reference: CDC. *Reported Tuberculosis in the United States, 2001.* Atlanta: CDC; 2002. Available at: http://www.cdc.gov/nchstp/tb

US 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: US population

Strengths: A wide range of online statistical data on the US 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 US jurisdictions

Contact person(s): http://www.census.gov/main/www/contacts.html

References: http://www.census.gov

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 (US Standard Certificate of Live Birth) to collect birth data and report this information to NCHS annually. As of 2003, states will adopt a revised standard form. The 2003 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 US territories. Tabulated state birth tables are available at the Web site.

Strengths: Vital records include all births in an area. Reporting is approximately 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

Contact person(s): State vital records registrar; CDC, National Center for Health Statistics

Reference*:* http://www.cdc.gov/nchs

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. As of 2003, states will adopt a revised death certificate that 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 US 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 AIDS may be missing. Death records are less timely than AIDS case reports.

Where available: All states and local areas maintain death registries

Contact person(s): State vital records registrar; CDC, National Center for Health Statistics

Reference: http://www.cdc.gov/nchs

Young Men's Survey (YMS)

Overview: YMS was established in the early 1990s to enumerate, sample, and estimate prevalence outcomes of a population of young men who frequent public venues and have sex with other men. YMS, a cross-sectional, multisite, venue-based survey, was conducted in 2 phases. In Phase I (1994–1998), young men aged 15–22 years were enrolled in 7 US metropolitan areas. In Phase II (1998–2000), men aged 23–29 years were enrolled in 6 US metropolitan areas. Before the phases of the survey were implemented, formative research was conducted to identify all potential venues and the times those venues were frequented by young men who have sex with men (MSM). Venues include street locations, dance clubs, bars, businesses, social organizations, bathhouses, health clubs, and other public places. Venues and associated time periods that were estimated to yield enough young MSM were included in monthly sampling frames. Each month, sampling events were conducted at 10–15 venues, and their associated time periods were randomly selected from the time frame. During sampling events, participants responded to an anonymous standardized questionnaire, and a blood specimen was obtained. The YMS questionnaire captured information on client demographics; venue attendance and frequency; HIV-related risk behaviors, including condom use, use of alcohol, drugs, and needles; medical history; and psychosocial factors. Blood specimens were tested for HIV antibody, evidence of past or current hepatitis B infection, and syphilis.

Population: Young men aged 15–29 years who frequent a public venue in the sampling frame and who have sex with other men. Eligible men must be residents of the county in which the study is being conducted.

Strengths: The YMS sampled a large population of young MSM and collected baseline measures of HIV infection and risk factors that can be used to allocate resources to meet HIV-related medical care, social services, and HIV/AIDS prevention needs for young MSM. Although YMS used venue-based sampling, 2 population-based surveys have found that most young MSM attend 1 or more public venues that are included in the YMS sampling frame. Further, because many types of venues (in addition to bars) are included in the YMS sampling frame, it is likely that most young MSM are eligible for sampling.

Limitations: YMS data are generalizable only to the population of young MSM who attend venues included in the YMS sampling frame. Young MSM who frequent low-volume or unidentified venues or do not frequent venues are not represented. In addition, YMS data are self-reported and thus subject to recall bias.

Where available: Miami (1995-2000); Baltimore (1996–2000), Dallas (1994–2000), Los Angeles (1994–2000), New York City (1997–2000), San Francisco Bay Area (Phase I only, 1994–1995), Seattle (1997–2000)

Contact person(s): Local YMS study coordinator; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

Reference: MacKellar D, Valleroy L, Karon J, Lemp G, Janssen R. The Young Men's Survey: methods for estimating HIV seroprevalence risk factors among young men who have sex with men. *Public Health Reports* 1996;111(suppl 1):138–144.

Youth Risk Behavior Surveillance (YRBS) among Native Americans

Overview: Conducted to monitor 6 priority high-risk behaviors that contribute to the leading causes of mortality, morbidity, and social problems among Native American youth living in the Navajo Nation and in the continental United States. The Native American YRBS projects are conducted by (a) the Navajo Nation in collaboration with the Indian Health Service and CDC, (b) South Dakota, (c) Montana, and (d) the Bureau of Indian Affairs.

Using a self-administered questionnaire, the Native American 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 pregnancy history.

Population: The Navajo Nation YRBS methods included a sample of students attending public high schools on the Navajo Nation reservation and Navajo students attending public high schools (bordering the reservation) with ≥ 50% Navajo student enrollment. South Dakota sampled middle schools (grades 6–8) receiving funding from the Bureau of Indian Affairs (BIA) or with ≥ 25% Native American enrollment (public and private), as well as high schools receiving funding from the BIA or with ≥ 25% Native American enrollment (public and private). Montana sampled self-identified Native Americans attending public high schools outside Montana Indian reservations and high school students enrolled in schools within a reservation or bordering one. The BIA nationwide survey of high school and middle school students was implemented in all schools receiving BIA funding, except Alaska.

Strengths: The Native American YRBS is a population-based survey that samples Native American adolescents enrolled in public schools. The questionnaire is administered anonymously to students during school. Inferences from the Navajo, South Dakota, and Montana YRBS results can be drawn about the behaviors of adolescents in school, making the information useful for developing community-wide prevention programs aimed at adolescents in the Navajo Nation or Native American adolescents living in South Dakota and Montana. The estimates from the BIA survey can be generalized to Native American students attending BIA-funded schools in the continental United States. The YRBS questionnaire is a standardized instrument.

Limitations: Limitations of the YRBS conducted in 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 BIA survey samples students attending BIA-funded schools; thus, survey estimates cannot be generalized to students who attended schools not funded by the BIA.

Where available: 1997 and 2000—Navajo Nation and selected bordering high schools; 1997 and 2000—South Dakota middle and high school surveys; 1999—Montana high school survey; 1994, 1997, and 2001—BIA nationwide survey of high school students (excluding Alaska); 1997 and 2000—BIA nationwide survey of middle school students (excluding Alaska)

Contact person(s): Navajo Nation Department of Health and Indian Health Service, 505-368-6308 for Navajo YRBS. South Dakota, 605-773-6898. Montana, 406-444-1963. For National Native American YRBS, call the BIA at 202-208-3601, or go to http://www.oiep.bia.edu

Youth Risk Behavior Surveillance System (YRBSS)

Overview: Established to monitor 6 priority high-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. CDC conducts national surveys among students in high schools and alternative high schools. In addition, state, territorial and local school-based surveys are conducted by education and health agencies.

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 pregnancy history.

Population: YRBSS surveys a representative sample 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 states 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 thereafter. In 1990, 23 states participated in YRBSS; as of 1999, 41 states participated, 22 of which achieved a minimum overall response rate of 60% (Alabama, Alaska, Arkansas, Delaware, Hawaii, Massachusetts, Michigan, Mississippi, Missouri, Montana, Nevada, New York, North Dakota, Ohio, South Carolina, South Dakota, Tennessee, Utah, Vermont, West Virginia, Wisconsin, Wyoming). In 1999, the 14 cities that conducted YRBSS achieved the minimum overall response rate of 60% (Boston, Chicago, Dallas, Detroit, District of Columbia, Fort Lauderdale, Houston, Miami, New Orleans, New York City, Palm Beach, Philadelphia, San Diego, and Seattle).

Contact person(s): State department of education; CDC, Division of Adolescent and School Health, Surveillance and Evaluation Research Branch

References: CDC. Youth Risk Behavior Surveillance—United States, 2001. *MMWR* 2002;51(SS-4):1–64. Also available at: http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5104a1.htm

Appendix B: Data Sources by Jurisdiction

Table 1: Alabama – Maryland

Jurisdiction	AIDS Surveillance	HIV Surveillance	Adult/ Adolescent Spectrum of Disease (ASD)	AIDS Progression	Antiretroviral Drug Resistance Testing (ARVDRT)	Arrestee Drug Abuse Monitoring (ADAM)	Behavioral Risk Factor Surveillance System (BRFSS)	Care Act Data Report (CADR)	CDC/HRSA Demonstration Project (CDP)	CDC National HIV Behavioral Surveillance	CDC Wide Ranging Online Data for Epidemiologic Reporting (WONDER)
Alabama	X	X				Birmingham	X	X			X
Alaska	X	X				Anchorage	X	X			X
Arizona	X	X				Phoenix Tucson	X	X			X
Arkansas	X	X					X	X			X
California	X	CBR				Sacramento San Diego San Jose	X	X	X		X
Chicago	X	CBR		X			X	X		X	X
Colorado	X	X	Denver	Denver	X	Denver	X	X			X
Connecticut	X	ORS		Hartford			X	X			X
Delaware	X	NTC					X	X			X
D.C.	X	CBR					X	X		X	X
Guam	X	X					X	X			X
Florida	X	X				Miami	X	X	X	Ft Lauderdale Miami	X
Georgia	X	X	Atlanta			Atlanta	X	X	X	Atlanta	X
Hawaii	X	CBR					X	X			X
Houston	X	X	X				X	X		X	X
Idaho	X	X					X	X			X
Illinois	X	CBR			X		X	X	X		X
Indiana	X	X				Indianapolis	X	X			X
Iowa	X	X				Des Moines	X	X			X
Kansas	X	X					X	X			X
Kentucky	X	CBR					X	X			X
Los Angeles	X	CBR	X	X			X	X		X	X

Table 1: Alabama – Maryland, *continued*

Jurisdiction	AIDS Surveillance	HIV Surveillance	Adult/ Adolescent Spectrum of Disease (ASD)	AIDS Progression	Antiretroviral Drug Resistance Testing (ARVDRT)	Arrestee Drug Abuse Monitoring (ADAM)	Behavioral Risk Factor Surveillance System (BRFSS)	Care Act Data Report (CADR)	CDC/HRSA Demonstration Project (CDP)	CDC National HIV Behavioral Surveillance	CDC Wide Ranging Online Data for Epidemiologic Reporting (WONDER)
Louisiana	X	X	New Orleans			New Orleans	X	X			X
Maine	X	NTC					X	X			X
Maryland	X	CBR			X		X	X		Baltimore	X

Note. HIV case surveillance in areas is based on the status of reporting as of April 2003.

CBR: Code-based reporting: conducted by HIV case surveillance using coded identifiers.
NTC: Name-to-code: HIV cases initially reported by name. After public health follow-up and collection of epidemiologic data, names are converted to codes.
ORS: Other reporting system: another system that may be a variant of name- and code-based reporting.
RNR: Reporting not required: HIV reporting currently not required or a surveillance system has not yet been implemented.
X: For AIDS surveillance and for HIV surveillance, X indicates that the area conducts name-based reporting. For other data sources, X indicates participation by the area in the listed study or project.

Table 1: Massachusetts – South Carolina

Jurisdiction	AIDS Surveillance	HIV Surveillance	Adult/ Adolescent Spectrum of Disease (ASD)	AIDS Progression	Antiretroviral Drug Resistance Testing (ARVDRT)	Arrestee Drug Abuse Monitoring (ADAM)	Behavioral Risk Factor Surveillance System (BRFSS)	Care Act Data Report (CADR)	CDC/HRSA Demonstration Project (CDP)	CDC National HIV Behavioral Surveillance	CDC Wide Ranging Online Data for Epidemiologic Reporting (WONDER)
Mass.	X	CBR		Boston			X	X	X	Boston	X
Michigan	X	X	Detroit				X	X			X
Minnesota	X	X				Minneapolis	X	X			X
Mississippi	X	X					X	X			X
Missouri	X	X					X	X			X
Montana	X	NTC					X	X			X
Nebraska	X	X				Omaha	X	X			X
Nevada	X	X				Las Vegas	X	X			X
New Hampshire	X	ORS					X	X			X
New Jersey	X	X					X	X	X	Newark	X
New Mexico	X	X				Albuquerque	X	X			X
New York	X	X					X	X	X		X
New York City	X	X	X			X	X	X		X	X
North Carolina	X	X					X	X			X
North Dakota	X	X					X	X			X
Ohio	X	X				Cleveland	X	X			X
Oklahoma	X	X				OK City	X	X			X
Oregon	X	NTC				Portland	X	X			X
Pennsylvania	X	X					X	X			X
Philadelphia	X	RNR				X	X	X		X	X
Puerto Rico	X	X	Bayamon				X	X		San Juan	X
Rhode Island	X	CBR					X	X			X

Table 1: Massachusetts – South Carolina, *continued*

Jurisdiction	AIDS Surveillance	HIV Surveillance	Adult/ Adolescent Spectrum of Disease (ASD)	AIDS Progression	Antiretroviral Drug Resistance Testing (ARVDRT)	Arrestee Drug Abuse Monitoring (ADAM)	Behavioral Risk Factor Surveillance System (BRFSS)	Care Act Data Report (CADR)	CDC/HRSA Demonstration Project (CDP)	CDC National HIV Behavioral Surveillance	CDC Wide Ranging Online Data for Epidemiologic Reporting (WONDER)
Samoa	X	X					X	X			X
San Francisco	X	CBR		X			X	X		X	X
South Carolina	X	X					X	X			X

Note. HIV case surveillance in areas is based on the status of reporting as of April 2003.

CBR: Code-based reporting: conducted by HIV case surveillance using coded identifiers.
NTC: Name-to-code: HIV cases initially reported by name. After public health follow-up and collection of epidemiologic data, names are converted to codes.
ORS: Other reporting system: another system that may be a variant of name- and code-based reporting.
RNR: Reporting not required: HIV reporting currently not required or a surveillance system has not yet been implemented.
X: For AIDS surveillance and for HIV surveillance, X indicates that the area conducts name-based reporting. For other data sources, X indicates participation by the area in the listed study or project.

Table 1: South Dakota – Wyoming

Jurisdiction	AIDS Surveillance	HIV Surveillance	Adult/ Adolescent Spectrum of Disease (ASD)	AIDS Progression	Antiretroviral Drug Resistance Testing (ARVDRT)	Arrestee Drug Abuse Monitoring (ADAM)	Behavioral Risk Factor Surveillance System (BRFSS)	Care Act Data Report (CADR)	CDC/HRSA Demonstration Project (CDP)	CDC National HIV Behavioral Surveillance	CDC Wide Ranging Online Data for Epidemiologic Reporting (WONDER)
South Dakota	X	X					X	X			X
Tennessee	X	X					X	X			X
Texas	X	X	Dallas			Laredo San Antonio	X	X		Dallas	X
Utah		X				Salt Lake City	X	X			
Vermont							X	X			
Virgin Islands							X				
Virginia	X	X					X	X			X
Washington	X	ORS	Seattle		Seattle	Seattle Spokane	X	X			X
West Virginia	X	X					X	X			X
Wisconsin	X	X					X	X			X
Wyoming	X	X					X	X			X

Note. HIV case surveillance in areas is based on the status of reporting as of April 2003.

ORS: Other reporting system: another system that may be a variant of name- and code-based reporting.

Table 2: Alabama – Mississippi

Jurisdiction	Collaborative Injection Drug Users Study (CIDUS)	Context of HIV Infection Project (CHIP)	Drug Abuse Warning Network (DAWN)	Enhanced Perinatal Surveillance	Expanded HIV Risk Assessment Project (EHRAP)	Gonococcal Isolate Surveillance Project (GISP)	Hepatitis C Surveillance
Alabama				X	X	Birmingham	x
Alaska						Anchorage	X
Arizona			Phoenix			Phoenix	X
Arkansas							X
California			San Diego	X		Long Beach Orange County San Diego	X
Chicago	X	X	X	X		X	X
Colorado			Denver			Denver	X
Connecticut				X			X
Delaware			X				X
D.C.			X	X			X
Guam							X
Florida			Miami	X		Miami	X
Georgia			Atlanta			Atlanta	X
Hawaii						Honolulu	X
Houston				X	X		X
Idaho							X
Illinois							X
Indiana							X
Iowa							X
Kansas							X
Kentucky							X
Los Angeles	X	X	X	X			X
Louisiana	New Orleans		New Orleans	X		New Orleans	X
Maine							X
Maryland	Baltimore		Baltimore	X		Baltimore	X
Mass.			Boston				X

Table 2: Alabama – Mississippi, *continued*

Jurisdiction	Collaborative Injection Drug Users Study (CIDUS)	Context of HIV Infection Project (CHIP)	Drug Abuse Warning Network (DAWN)	Enhanced Perinatal Surveillance	Expanded HIV Risk Assessment Project (EHRAP)	Gonococcal Isolate Surveillance Project (GISP)	Hepatitis C Surveillance
Michigan			Detroit	X			X
Minnesota			Minneapolis			Minneapolis	X
Mississippi				X	X		X

Note. HIV case surveillance in areas is based on the status of reporting as of April 2003.

X: For AIDS surveillance and for HIV surveillance, X indicates that the area conducts name-based reporting. For other data sources, X indicates participation by the area in the listed study or project.

Table 2: Missouri – Wyoming

Jurisdiction	Collaborative Injection Drug Users Study (CIDUS)	Context of HIV Infection Project (CHIP)	Drug Abuse Warning Network (DAWN)	Enhanced Perinatal Surveillance	Expanded HIV Risk Assessment Project (EHRAP)	Gonococcal Isolate Surveillance Project (GISP)	Hepatitis C Surveillance
Missouri			St. Louis			Kansas City St Louis	X
Montana							X
Nebraska							X
Nevada							X
New Hampshire							X
New Jersey			Newark	X	X		X
New Mexico						Albuquerque	X
New York			Buffalo	X			X
New York City	X		X	X			X
North Carolina		X		X		Fort Bragg	X
North Dakota							X
Ohio				X		Cincinnati Cleveland	X
Oklahoma							X
Oregon						Portland	X
Pennsylvania				X			X
Philadelphia			X	X		X	X
Puerto Rico				X			X
Rhode Island							X
Samoa							X
San Francisco			X			X	X
South Carolina				X	X		X
South Dakota							X
Tennessee				X			X
Texas		Dallas	Dallas	X		Dallas	X
Utah							X
Vermont							X

Table 2: Missouri – Wyoming, *continued*

Jurisdiction	Collaborative Injection Drug Users Study (CIDUS)	Context of HIV Infection Project (CHIP)	Drug Abuse Warning Network (DAWN)	Enhanced Perinatal Surveillance	Expanded HIV Risk Assessment Project (EHRAP)	Gonococcal Isolate Surveillance Project (GISP)	Hepatitis C Surveillance
Virgin Islands							X
Virginia				X	X		X
Washington			Seattle			Seattle	X
West Virginia							X
Wisconsin							X
Wyoming							X

Note. HIV case surveillance in areas is based on the status of reporting as of April 2003.

X: For AIDS surveillance and for HIV surveillance, X indicates that the area conducts name-based reporting. For other data sources, X indicates participation by the area in the listed study or project.

Table 3: Alabama – Los Angeles

Jurisdiction	HIV Counseling and Testing	HIV Epidemiology Research Study (HERS)	HIV Incidence Surveillance	HIV Prevalence & Incidence & Associated Risk Behaviors among Incarcerated Illicit Drug Users	HIV Seroprevalence Surveys	HIV Testing Survey (HITS)	Hospital Outpatient Study (HOPS)	Impact of RWCA Title I Funding on HIV Services Utilization and Health Outcomes	MSM Interview Project	MSM Prevalence Monitoring Project
Alabama	X		X		X				X	
Alaska	X				X					
Arizona	X		X		X	Phoenix				
Arkansas	X				X					
California	X			X	X	Oakland Sacramento San Diego	Oakland			Long Beach
Chicago	X		X	X	X	X	X			X
Colorado	X		X	X	X	Denver	Denver			Denver
Connecticut	X				X					
Delaware	X				X					
DC	X				X		X			X
Guam	X				X					
Florida	X		X		X	Ft Lauderdale Jacksonville Miami Orlando Pensacola St Petersburg	Tampa			
Georgia	X				X	X				
Hawaii	X				X					
Houston	X		X		X	X				X
Idaho	X				X					
Illinois	X				X	Rockford				
Indiana	X		X		X	X				

Table 3: Alabama – Los Angeles, *continued*

Jurisdiction	HIV Counseling and Testing	HIV Epidemiology Research Study (HERS)	HIV Incidence Surveillance	HIV Prevalence & Incidence & Associated Risk Behaviors among Incarcerated Illicit Drug Users	HIV Seroprevalence Surveys	HIV Testing Survey (HITS)	Hospital Outpatient Study (HOPS)	Impact of RWCA Title I Funding on HIV Services Utilization and Health Outcomes	MSM Interview Project	MSM Prevalence Monitoring Project
Iowa	X				X					
Kansas	X				X	Kansas City Wichita				
Kentucky	X									
Los Angeles	X				X	X				

Note. HIV case surveillance in areas is based on the status of reporting as of April 2003.

X: For AIDS surveillance and for HIV surveillance, X indicates that the area conducts name-based reporting. For other data sources, X indicates participation by the area in the listed study or project.

Table 3: Louisiana – Oregon

Jurisdiction	HIV Counseling and Testing	HIV Epidemiology Research Study (HERS)	HIV Incidence Surveillance	HIV Prevalence & Incidence & Associated Risk Behaviors among Incarcerated Illicit Drug Users	HIV Seroprevalence Surveys	HIV Testing Survey (HITS)	Hospital Outpatient Study (HOPS)	Impact of RWCA Title I Funding on HIV Services Utilization and Health Outcomes	MSM Interview Project	MSM Prevalence Monitoring Project
Louisiana	X		X		X	Baton Rouge Monroe New Orleans				
Maine	X				X	X				
Maryland	X	Baltimore	X		X	Baltimore				
Massachusetts	X		X		X					Boston
Michigan	X	Detroit	X		X	Detroit Grand Rapids				
Minnesota	X				X					
Mississippi	X		X		X	Jackson				
Missouri	X		X		X	Kansas City Springfield St Louis				
Montana	X				X					
Nebraska	X				X					
Nevada	X				X	Las Vegas Reno		Las Vegas		
N. Hampshire	X				X					
New Jersey	X		X		X	Jersey City Newark				
New Mexico	X				X	Albuquerque				
New York	X		X	X	X	Buffalo Rochester				
New York City	X	X	X		X	X	X		X	X

Table 3: Louisiana – Oregon, *continued*

Jurisdiction	HIV Counseling and Testing	HIV Epidemiology Research Study (HERS)	HIV Incidence Surveillance	HIV Prevalence & Incidence & Associated Risk Behaviors among Incarcerated Illicit Drug Users	HIV Seroprevalence Surveys	HIV Testing Survey (HITS)	Hospital Outpatient Study (HOPS)	Impact of RWCA Title I Funding on HIV Services Utilization and Health Outcomes	MSM Interview Project	MSM Prevalence Monitoring Project
North Carolina	X				X	X				
North Dakota	X				X					
Ohio	X		X		X	Columbus Cleveland Dayton				
Oklahoma	X		X		X					
Oregon	X				X	Eugene Portland				

Note. HIV case surveillance in areas is based on the status of reporting as of April 2003.

X: For AIDS surveillance and for HIV surveillance, X indicates that the area conducts name-based reporting. For other data sources, X indicates participation by the area in the listed study or project.

Table 3: Pennsylvania – Wyoming

Jurisdiction	HIV Counseling and Testing	HIV Epidemiology Research Study (HERS)	HIV Incidence Surveillance	HIV Prevalence & Incidence & Associated Risk Behaviors among Incarcerated Illicit Drug Users	HIV Seroprevalence Surveys s	HIV Testing Survey (HITS)	Hospital Outpatient Study (HOPS)	Impact of RWCA Title I Funding on HIV Services Utilization and Health Outcomes	MSM Interview Project	MSM Prevalence Monitoring Project
Pennsylvania	X				X					
Philadelphia	X			X	X	X	X			X
Puerto Rico	X		X		X					
Rhode Island	X	Providence			X					
Samoa	X				X					
San Francisco	X				X	X				X
South Carolina	X		X		X					
South Dakota	X				X					
Tennessee	X		X		X					
Texas	X		X		X	X				
Utah	X				X					
Vermont	X				X	Battleboro Burlington Rutland				
Virgin Islands	X				X					
Virginia	X		X		X			Norfolk		
Washington	X		Seattle	Seattle	X	Seattle Tacoma Yakima County				X
West Virginia	X				X					
Wisconsin	X				X	Milwaukee				
Wyoming	X				X					

Note. HIV case surveillance in areas is based on the status of reporting as of April 2003.

X: For AIDS surveillance and for HIV surveillance, X indicates that the area conducts name-based reporting. For other data sources, X indicates participation by the area in the listed study or project.

Table 4: Alabama – Montana

Jurisdiction	National Death Index (NDI)	National Household Survey of Drug Abuse (NHSDA)	National Neighborhood Indicator Project (NNIP)	Outcome Assessment through Systems of Integrated Surveillance (OASIS)	Pediatric Spectrum of Disease (PSD)	Pregnancy Risk Assessment Monitoring System (PRAMS)	Project One	Rapid Assessment and Response and Evaluation (RARE)
Alabama	X	X				X		
Alaska	X	X				X		
Arizona	X	X						
Arkansas	X	X				X		
California	X	X	Oakland	X				Oakland
Chicago	X	X					X	X
Colorado	X	X	Denver			X		
Connecticut	X	X						New Haven
Delaware	X	X						
DC	X	X	X		X			X
Guam	X	X						
Florida	X	X	Miami			X		Miami West Palm Beach
Georgia	X	X	Atlanta			X		Atlanta
Hawaii	X	X				X		
Houston	X	X						
Idaho	X	X						
Illinois	X	X				X		
Indiana	X	X	Indianapolis	X				
Iowa	X	X						
Kansas	X	X						
Kentucky	X	X						
Los Angeles	X	X			X		X	X
Louisiana	X	X				X		
Maine	X	X				X		
Maryland	X	X	Baltimore	Baltimore		X		
Massachusetts	X	X	Boston	X	X			

Table 4: Alabama – Montana, *continued*

Jurisdiction	National Death Index (NDI)	National Household Survey of Drug Abuse (NHSDA)	National Neighborhood Indicator Project (NNIP)	Outcome Assessment through Systems of Integrated Surveillance (OASIS)	Pediatric Spectrum of Disease (PSD)	Pregnancy Risk Assessment Monitoring System (PRAMS)	Project One	Rapid Assessment and Response and Evaluation (RARE)
Michigan	X	X		X		X		Detroit
Minnesota	X	X				X		
Mississippi	X	X				X		
Missouri	X	X		X				
Montana	X	X				X		

Note. HIV case surveillance in areas is based on the status of reporting as of April 2003.

X: For AIDS surveillance and for HIV surveillance, X indicates that the area conducts name-based reporting. For other data sources, X indicates participation by the area in the listed study or project.

Table 4: Nebraska – Wyoming

Jurisdiction	National Death Index (NDI)	National Household Survey of Drug Abuse (NHSDA)	National Neighborhood Indicator Project (NNIP)	Outcome Assessment through Systems of Integrated Surveillance (OASIS)	Pediatric Spectrum of Disease (PSD)	Pregnancy Risk Assessment Monitoring System (PRAMS)	Project One	Rapid Assessment and Response and Evaluation (RARE)
Nebraska	X	X				X		
Nevada	X	X						
N. Hampshire	X	X						
New Jersey	X	X				X		Newark
New Mexico	X	X				X		
New York	X	X		X		X		
New York City	X	X		X	X	X		
North Carolina	X	X		X	X	X		
North Dakota	X	X				X		
Ohio	X	X	Cleveland	X		X		
Oklahoma	X	X				X		
Oregon	X	X		X		X		
Pennsylvania	X	X						
Philadelphia	X	X	X					X
Puerto Rico	X	X			X			
Rhode Island	X	X	Providence			X		
Samoa	X	X						
San Francisco	X	X		X	X			
South Carolina	X	X				X		
South Dakota	X	X						
Tennessee	X	X						
Texas	X	X		X	X	X	Dallas	
Utah	X	X				X		
Vermont	X	X				X		
Virgin Islands	X	X						

Table 4: Nebraska – Wyoming, *continued*

Jurisdiction	National Death Index (NDI)	National Household Survey of Drug Abuse (NHSDA)	National Neighborhood Indicator Project (NNIP)	Outcome Assessment through Systems of Integrated Surveillance (OASIS)	Pediatric Spectrum of Disease (PSD)	Pregnancy Risk Assessment Monitoring System (PRAMS)	Project One	Rapid Assessment and Response and Evaluation (RARE)
Virginia	X	X		X				
Washington	X	X		X		X		
West Virginia	X	X				X		
Wisconsin	X	X	Milwaukee					
Wyoming	X	X						

Note. HIV case surveillance in areas is based on the status of reporting as of April 2003.

X: For AIDS surveillance and for HIV surveillance, X indicates that the area conducts name-based reporting. For other data sources, X indicates participation by the area in the listed study or project.

Table 5: Alabama – Mississippi

Jurisdiction	School Health Education Profiles	Sentinel Surveillance of Variant and Drug-Resistant Strains (SSVRS)	STD Surveillance	Supplement to HIV/AIDS Surveillance (SHAS)	Survey of HIV Disease and Care (SHDC)	Survey of HIV Disease and Care Plus (SHDC+)	Tuberculosis Surveillance	US Census Bureau	Vital Records – Births and Deaths	Young Men's Survey (YMS)	Youth Risk Behavior Surveillance System (YRBSS)
Alabama	X		X				X	X	X		X
Alaska	X		X				X	X	X		X
Arizona			X	X			X	X	X		
Arkansas			X				X	X	X		X
California	X	San Diego	X				X	X	X		San Diego
Chicago			X	X			X	X	X		X
Colorado		Denver	X	Denver			X	X	X		
Connecticut			X	Hartford New Haven			X	X	X		X
Delaware	X		X	X			X	X	X		X
DC			X				X	X	X		X
Guam			X				X	X	X		
Florida	Ft Lauderdale Miami	Miami	X	Jacksonville Miami Tampa	X		X	X	X	Miami	X
Georgia	X		X	Atlanta			X	X	X		
Hawaii	X		X				X	X	X		X
Houston		X	X	X	X		X	X	X		X
Idaho	X		X				X	X	X		
Illinois	X		X				X	X	X		X
Indiana			X				X	X	X		
Iowa	X		X				X	X	X		X
Kansas			X	X			X	X	X		
Kentucky			X				X	X	X		X
Los Angeles	X		X	X			X	X	X	X	
Louisiana	X	New Orleans	X		X		X	X	X		X
Maine	X		X				X	X	X		X
Maryland			X	X	X		X	X	X	Baltimore	

Table 5: Alabama – Mississippi, *continued*

Jurisdiction	School Health Education Profiles	Sentinel Surveillance of Variant and Drug-Resistant Strains (SSVRS)	STD Surveillance	Supplement to HIV/AIDS Surveillance (SHAS)	Survey of HIV Disease and Care (SHDC)	Survey of HIV Disease and Care Plus (SHDC+)	Tuberculosis Surveillance	US Census Bureau	Vital Records – Births and Deaths	Young Men's Survey (YMS)	Youth Risk Behavior Surveillance System (YRBSS)
Massachusetts	X		X				X	X	X		X
Michigan	X	Detroit, Grand Rapids	X	Detroit	X	X	X	X	X		X
Minnesota	X		X	X			X	X	X		
Mississippi			X				X	X	X		X

Note. HIV case surveillance in areas is based on the status of reporting as of April 2003.

X: For AIDS surveillance and for HIV surveillance, X indicates that the area conducts name-based reporting. For other data sources, X indicates participation by the area in the listed study or project.

Table 5: Missouri – Washington

Jurisdiction	School Health Education Profiles	Sentinel Surveillance of Variant and Drug-Resistant Strains (SSVRS)	STD Surveillance	Supplement to HIV/AIDS Surveillance (SHAS)	Survey of HIV Disease and Care (SHDC)	Survey of HIV Disease and Care Plus (SHDC+)	Tuberculosis Surveillance	US Census Bureau	Vital Records – Births and Deaths	Young Men's Survey (YMS)	Youth Risk Behavior Surveillance System (YRBSS)
Missouri	X		X				X	X	X		X
Montana	X		X				X	X	X		Navajo Nation
Nebraska	X		X				X	X	X		X
Nevada			X				X	X	X		X
New Hampshire	X		X				X	X	X		X
New Jersey		Newark	X	Jersey City	X	X	X	X	X		X
New Mexico	X		X	X			X	X	X		X
New York	X		X				X	X	X		X
New York City		X	X				X	X	X	X	X
North Carolina			X				X	X	X		
North Dakota	X		X				X	X	X		X
Ohio	X		X		X		X	X	X		X
Oklahoma			X				X	X	X		
Oregon			X				X	X	X		
Pennsylvania	X		X				X	X	X		
Philadelphia	X		X	X	X		X	X	X		X
Puerto Rico			X		X		X	X	X		
Rhode Island			X				X	X	X		
Samoa			X				X	X	X		
San Francisco	X	X	X				X	X	X	X	
South Carolina	X		X	X			X	X	X		X
South Dakota			X				X	X	X		Navajo Nation
Tennessee			X				X	X	X		X
Texas	Dallas		X	Austin			X	X	X	Dallas	Dallas
Utah	X		X				X	X	X		X
Vermont			X				X	X	X		X

Table 5: Missouri – Washington, *continued*

Jurisdiction	School Health Education Profiles	Sentinel Surveillance of Variant and Drug-Resistant Strains (SSVRS)	STD Surveillance	Supplement to HIV/AIDS Surveillance (SHAS)	Survey of HIV Disease and Care (SHDC)	Survey of HIV Disease and Care Plus (SHDC+)	Tuberculosis Surveillance	US Census Bureau	Vital Records – Births and Deaths	Young Men's Survey (YMS)	Youth Risk Behavior Surveillance System (YRBSS)
Virgin Islands			X				X	X	X		
Virginia	X		X		X		X	X	X		
Washington			X	X	X	Seattle	X	X	X	Seattle	Seattle

Note. HIV case surveillance in areas is based on the status of reporting as of April 2003.

X: For AIDS surveillance and for HIV surveillance, X indicates that the area conducts name-based reporting. For other data sources, X indicates participation by the area in the listed study or project.

Table 5: West Virginia – Wyoming

Jurisdiction	School Health Education Profiles	Sentinel Surveillance of Variant and Drug-Resistant Strains (SSVRS)	STD Surveillance	Supplement to HIV/AIDS Surveillance (SHAS)	Survey of HIV Disease and Care (SHDC)	Survey of HIV Disease and Care Plus (SHDC+)	Tuberculosis Surveillance	US Census Bureau	Vital Records – Births and Deaths	Young Men's Survey (YMS)	Youth Risk Behavior Surveillance System (YRBSS)
West Virginia	X		X				X	X	X		X
Wisconsin	X		X				X	X	X		X
Wyoming	x		X				X	X	X		X

Note. HIV case surveillance in areas is based on the status of reporting as of April 2003.

X: For AIDS surveillance and for HIV surveillance, X indicates that the area conducts name-based reporting. For other data sources, X indicates participation by the area in the listed study or project.

Appendix C: Web Data for Core Epidemiologic Question 1

The following Web sites may provide data that can be used to describe the general population in the epidemiologic profile:

http://www.fedstats.gov or http://quickfacts.census.gov (equivalent Web sites):
Select a state under the "MapStats" heading and click on "submit" or "go." A table with state-specific data then appears. To change it to county-specific data, select a county and click on "go." These tables provide the following data, which may be useful for the profile:

- Population, 2000
- Population, net change from 1990 to 2000, as a number and a percentage change
- Females, 2000
- White persons, 2000 (persons reporting only one race, including white Hispanics)
- Black persons, 2000 (persons reporting only one race, including black Hispanics)
- American Indian and Alaska Native persons, 2000 (persons reporting only one race, including Hispanics who are American Indians or Alaskan Natives)
- Asian persons, 2000 (persons reporting only one race, including Asian Hispanics)
- Native Hawaiian and Other Pacific Islander persons, 2000 (persons reporting only one race, including Hispanic Pacific Islanders)
- Other races, 2000 (persons reporting only one race, including other Hispanics)
- Persons reporting two or more races (including those who are Hispanic)
- Persons of Hispanic or Latino origin, 2000 (of any race)
- High school graduates among persons 25 years old or older, 1990 (but the percentage cannot be calculated because the denominator of persons 25 years or older is not given)
- College graduates among persons 25 years or older, 1990 (but the percentage cannot be calculated because the denominator of persons 25 or older is not given)
- Percentage of persons living below the poverty level, 1997 model-based estimate

http://factfinder.census.gov takes you automatically to
http://factfinder.census.gov/servlet/BasicFactsServlet :

A great variety of tables of population data can be obtained from this Web site. For example, to obtain county-specific data by sex, race/ethnicity, and single year of age; select "Census 2000 Summary File 1." On the next Web page, select "Detailed Tables." On the following page, select the type of geographic unit in which you are interested (e.g., county). Then select your state. Next, select the specific counties of interest and click on "Add"; then click on "Show Table." On the next page, scroll down the pop-down menu to select the tables of data in which you are interested. Near the bottom are the tables

"PCT12H" through "PCT120," which distinguish between Hispanics and non-Hispanics of different races, by sex and single year of age. Click on the tables of interest to highlight them, click on "Add," and then click on "Show Table." The resulting tables may then be printed, but it would be better to save them as a spreadsheet file (e.g., Excel.xls). To do that, select "Download" and download a comma-delimited table (csv file). Double click on its icon to open it in your spreadsheet application (e.g., Excel); then save it as a regular spreadsheet file (i.e., change the suffix to ".xls"). You can then analyze the data in more detail, including calculating the subtotals for specific age groups.

Similarly, county-level data on educational attainment among persons who are at least 25 years old can be obtained by going to the main factfinder page and pressing "go" under "Data Sets." Select "Census 2000 Supplementary Survey Tables" and "List All Tables." These tables are based on a survey of only 1,023 counties, so the counties in which you are interested may not be here. Table PCT034 will show educational attainment among persons ≥25 years old by sex, and Table P114 will show poverty status in the last 12 months by sex and age group. Select the table in which you are interested and press "Next." On the next Web page, select the "geographic type" (e.g., county, MSA) in which you are interested. Wait for the page to automatically change and then select the state. Not all states may be available on the selection menu. If the state in which you are interested is available, select it. Then select the named geographic subunit area in which you are interested if it is available (it may not be) and "Add." Then press "Show table."

The Web site http://www.census.gov/acs/www/index.html provides data from surveys of samples of the U.S. population, including information about educational attainment and poverty level. The "Quick Pick" choices include state-specific and county-specific data profiles. Select state and press "Go." On the next Web page, which has selections for the entire state or a county within it, select the "Social" profile. The heading "Educational Attainment," refers to the percentages of persons aged 25 years and older who have a high school degree or higher and persons who have a bachelor's degree or higher are tabulated. Return to the Web page offering the choices of profiles and select "Economic" profile. At the bottom of the table that opens next will be the percentages of the population in selected age groups who lived below the poverty level in the past 12 months. These data should be used with caution because they are based on a survey sample and thus may have a sampling error.

http://www.statehealthfacts.kff.org: This Web site from the Kaiser Family Foundation provides "health data" by state. Click on a state for data for a single state.

Click on "Health Coverage and Uninsured" to see the health insurance status of the state's population. The top subcategory, "Distribution by Insurance Status," should provide sufficient state-specific information on this topic for the epidemiologic profile. Unfortunately, a source for such information at the county or MSA level is not known.

Click on “Demographics and Economy,” and then “People in Poverty” to see the percentage of the state’s population that live under the federal poverty level. This is stratified by demographic category (e.g., sex, race, age), but not by geographic subunit (e.g., county or MSA).

http://socds.huduser.org/scripts/odbic.exe/census/screen1.htm: This Web site summarizes some MSA-specific census data in ways that may be convenient for your use, particularly for seeing trends over time. The tables containing data on race/ethnicity, educational attainment, and poverty may be useful for the epidemiologic profile.

http://www.census.gov/population/www/projections/stproj.html: This Web site provides state-level population projections into the future, based on census data. The table provides numbers of persons by age, sex, race, and Hispanic origin, which you may use to calculate the corresponding percentages. The layout is cumbersome.

http://www.samhsa.gov/oas/NHSDA/99YouthState/toc.htm: This Web site provides state estimates on youth substance use from the 1999 National Household Survey on Drug Abuse.

Appendix D: Table Formats for Mortality Data

Ranking of 10 leading underlying causes of death in 1999 among non-Hispanic whites aged 25–44 years in State X

Causes	Rank Among Causes of Death	Number of Deaths	Percentage of Total Deaths (N = 5122)
Unintentional injury	1	1157	22.6
Malignant neoplasm	2	827	16.1
Suicide	3	614	12.0
Heart disease	4	604	11.8
HIV/AIDS	5	308	6.0
Chronic liver disease	6	195	3.8
Homicide	7	192	3.7
Cerebrovascular disease	8	115	2.2
Diabetes mellitus	9	87	1.7
Pneumonia and influenza	10	47	0.9

Ranking of 10 leading underlying causes of death in 1999 among non-Hispanic blacks aged 25–44 years in State X

Causes	Rank Among Causes of Death	Number of Deaths	Percentage of Total Deaths (N = 2124)
HIV/AIDS	1	589	27.7
Heart disease	2	270	12.7
Unintentional injury	3	227	10.7
Malignant neoplasm	4	218	10.3
Homicide	5	172	8.1
Cerebrovascular disease	6	62	2.9
Suicide	7	55	2.6
Diabetes mellitus	8	39	1.8
Pneumonia and influenza	9	29	1.4
Chronic liver disease	9	29	1.4

Ranking of 5 leading underlying causes of death in 1999 among Asians and Pacific Islanders aged 25–44 years in State X

Causes	**Rank Among Causes of Death**	**Number of Deaths**	**Percentage of Total Deaths** (N = 540)
Malignant neoplasm	1	16	29.6
Heart disease	2	9	16.7
Unintentional injury	2	9	16.7
Suicide	4	4	7.4
Cerebrovascular disease	5	3	5.6

Ranking of 10 leading underlying causes of death in 1999 among American Indians and Alaska Natives aged 25–44 years in State X

Causes	**Rank Among Causes of Death**	**Number of Deaths**	**Percentage of Total Deaths** (N = 2124)
Unintentional injury	1	87	29.2
Chronic liver disease	2	38	12.8
Homicide	3	26	8.7
Suicide	4	23	7.7
Malignant neoplasm	5	17	5.7
Heart disease	6	16	5.4
Pneumonia and influenza	7	8	2.7
Diabetes mellitus	7	8	2.7
Septicemia	9	7	2.3
HIV/AIDS	10	6	2.0

Appendix E: Table with Descriptions of Ryan White CARE Act Programs

Title I	Provides emergency relief to metropolitan areas that are disproportionately affected by HIV/AIDS
Title II	Assists states and territories in improving the quality, availability, and organization of health care and support services for individuals and families with HIV disease and provides access to needed pharmaceuticals through the AIDS Drug Assistance Program (ADAP)
Title III	Provides support for early intervention and primary care services for people with HIV/AIDS
Title IV	Provides coordinated HIV services and access to research for women, infants, children, youth, and families with, or at risk for, HIV/AIDS, focusing on the development and operation of family-centered systems of primary health care and social services that benefit these population groups
Special Projects of National Significance (SPNS)	Supports the development of innovative HIV/AIDS service delivery models that have potential for replication in other areas, both locally and nationally
HIV/AIDS Education and Training Centers (AETCs)	Supports training for health care providers in counseling, diagnosis, treatment for persons with HIV infection and in helping to prevent high-risk behaviors that cause infection
Dental Reimbursement Program (DRP)	Provides support to dental schools, postdoctoral dental education programs, and dental hygiene programs for non-reimbursed care provided to persons with HIV disease

Appendix F: Planning Group Epidemiologic Profile Feedback Form

The purpose of this form is to provide the writers of HIV/AIDS 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/AIDS 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?

_____

_____

_____

Glossary

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.

AIDS (acquired immunodeficiency syndrome). The condition that results from HIV infection and is marked by the presence of opportunistic infections that do not affect persons with healthy immune systems.

bar graph (vertical). A type of figure in which categories of variables (displayed on a horizontal baseline) are compared by amount, frequency, or magnitude (labeled on a vertical axis). (Bar graphs may also be horizontal.)

behavioral data. Data collected from studies of human behavior that is relevant to disease risk. Relevant behaviors for HIV risk may include sexual activity, substance use, sharing of drug paraphernalia, condom use, or responses to primary and secondary prevention messages.

capability. The extent to which a provider's services are geographically and physically accessible, culturally appropriate, and available at convenient times.

capacity. The amount of services a provider can deliver (i.e., the number of service units and the estimated number of clients who can be served).

CARE Act (Ryan White Comprehensive AIDS Resources Emergency Act). The primary federal legislation created to address the needs for health and support services among persons living with HIV/AIDS and their families in the United States; enacted in 1990 and reauthorized in 1996.

case. A condition, such as HIV infection (e.g., an HIV case) or AIDS (e.g., an AIDS 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 planning group. 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.

community-based organization (CBO). An organization that provides services to locally defined populations, which may include persons infected with, or affected by, 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/AIDS surveillance data, confidentiality refers to the protection of private information collected by the HIV/AIDS 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. Cumulative cases can include cases in people who have died.

cumulative incidence rate. The total number of persons who experience the onset of a disease during a specified period among all people at risk for the disease. A cumulative incidence rate is calculated by dividing cumulative incidence for a specified period by the population in which cases occurred during that period. A multiplier is used to convert the resulting fraction to a number over a common denominator (often 100,000).

eligible metropolitan area (EMA). A metropolitan statistical area that qualifies for Title I funding by reaching a certain threshold of 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 HIV/AIDS epidemic 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/AIDS 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 CARE Act funds. For HIV prevention funds, the state or local health department is referred to as the grantee. For CARE Act 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 AIDS. 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 CARE Act authorizes states to use Title II funds to establish consortia in "areas most affected by HIV disease."

HIV primary medical care. Medical evaluation and clinical care that is consistent with US Public Health Service guidelines for the treatment of HIV/AIDS.

HIV/AIDS surveillance. The systematic collection, analysis, interpretation, dissemination, and evaluation of population-based information about persons with a diagnosis of HIV infection and persons with a diagnosis of AIDS.

incidence. The number of new cases in a defined population during a specific period, often a year, which can be used to measure disease frequency. It is important to understand the difference between HIV incidence and reported HIV diagnoses. Because the results of anonymous tests are not included and therefore not all diagnoses of HIV infection are included, HIV surveillance data do not represent incident cases.

incidence rate. The number of new cases in a specific area during a specific period among persons at risk in the same area and during the same period. Incidence rate provides a measure of the effect of illness relative to the size of the population. Incidence rate is calculated by dividing incidence in the specified period by the population in which cases occurred. A multiplier is used to convert the resulting fraction to a number over a common denominator (often 100,000).

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 individual values in a data set divided by the total number of values. The mean is what many people refer to as an average.

median. The middle value in a data set. Typically, approximately half the values will be higher, and half will be lower. The median is useful when a data set has 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.

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

no reported risk (NRR). Cases in which risk information is absent from the initial case report because the information had not been reported by the reporting source, had not been sought, or had not been found by the time the case was reported. Cases may remain NRR until epidemiologic follow-up has been completed and potential risks (exposures) have been identified. If risk has not been identified within 12 months of being reported as NRR, the case may be considered NIR.

percentage. A proportion of the whole, in which the whole is 100.

prevalence. The total number of cases of a disease in persons not known to have died in a given population at a specific time. Prevalence does not indicate how long a person has had a disease and cannot be used to calculate rates of disease. It can provide an estimate of risk for a disease at a specific time. For HIV/AIDS surveillance, prevalence refers to living persons with HIV disease, regardless of time of infection or date of diagnosis. Note the difference between prevalence of a condition in the population and the prevalence of cases, namely, that a case must be diagnosed according to a definition.

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 complete population or data set, usually expressed as a fraction or percentage of the population or data set.

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 largest and smallest values in a data set.

rate. A measure of the frequency of an event or a disease compared with the number or persons at risk for the event or disease.

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., ⅔), or the 2 numbers may be separated by a colon (e.g., 2:3).

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. The time between a diagnosis of HIV infection or AIDS and the receipt of the report by the health department.

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.

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. CDC jurisdictions and HRSA service areas or planning regions.

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).

Title I (CARE Act). Provides formula and supplemental grants to EMAs that are disproportionately affected by the HIV epidemic.

Title II (CARE Act). Provides formula grants to states, the District of Columbia, Puerto Rico, and eligible US territories to improve the quality, availability, and organization of health care and support services for people living with HIV and their families.

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 or AIDS was made.

year of report. The year in which a person with a diagnosis of HIV infection or AIDS was reported to the health department.

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.

References and Suggested Readings

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

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