

Chapter

1

## INTRODUCTION

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- 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

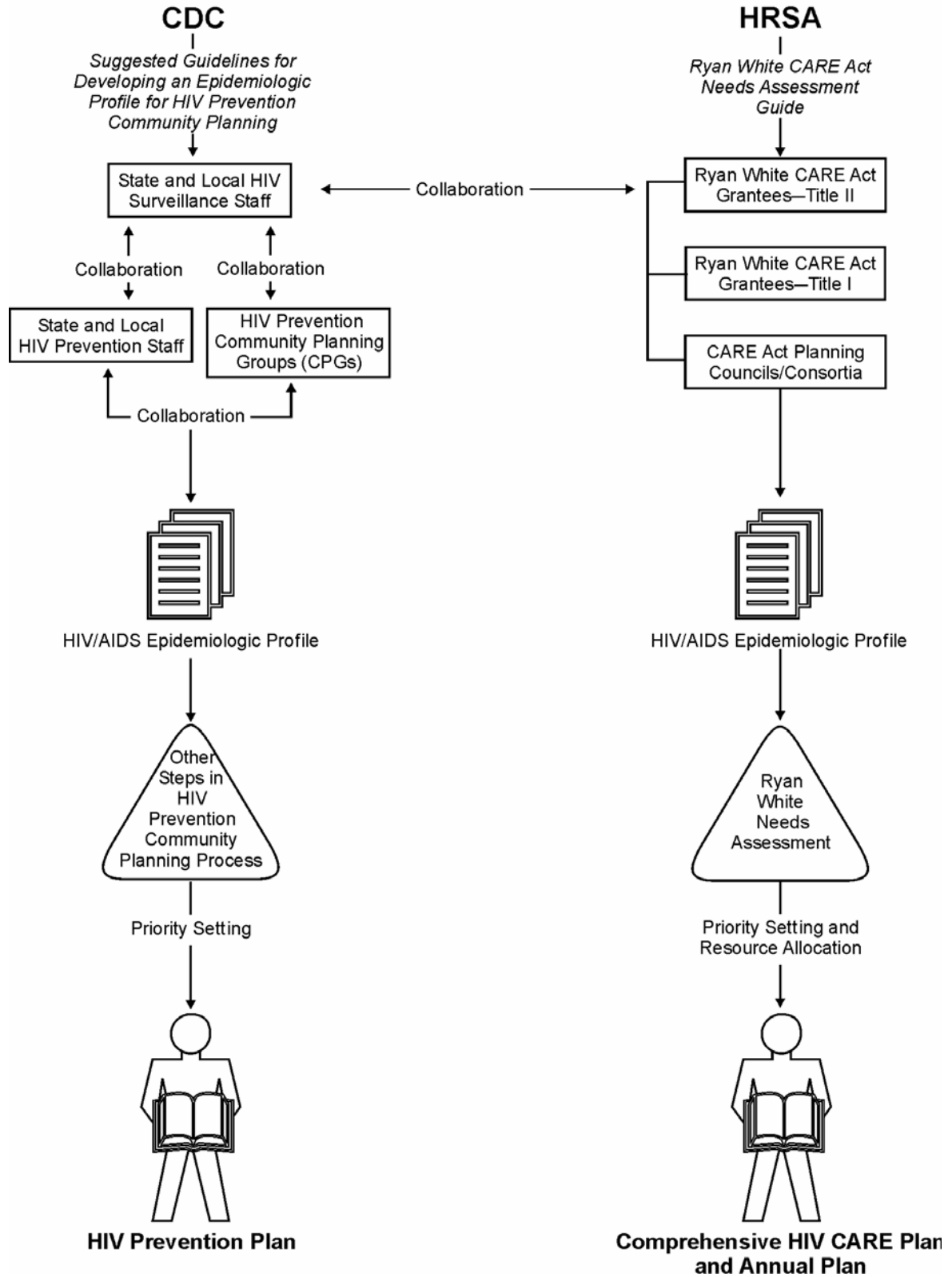
You will learn a number of specific skills, including

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

## 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 <ul style="list-style-type: none"> <li>• Community planning groups</li> <li>• State and local health departments</li> <li>• Community-based organizations</li> </ul>	<ul style="list-style-type: none"> <li>• Preventing and intervening to reduce transmission of HIV/AIDS</li> </ul>	<ul style="list-style-type: none"> <li>• Prioritize target populations and identify appropriate interventions for each priority population</li> <li>• Develop HIV prevention plan</li> </ul>
HRSA <ul style="list-style-type: none"> <li>• Ryan White CARE Act grantees</li> <li>• Ryan White planning bodies</li> <li>• Community-based organizations</li> </ul>	<ul style="list-style-type: none"> <li>• Providing services and care for people living with HIV/AIDS</li> </ul>	<ul style="list-style-type: none"> <li>• Set priorities and allocate resources for care</li> <li>• Serve as source document for applications to HRSA's HIV/AIDS Bureau</li> </ul>

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