

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 one 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, and 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 five 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 include the following:

- Chapter 1
 - Describes the purpose of the guidelines, identifies the audience for the document, and outlines what end users will learn
- Chapter 2
 - Describes three core epidemiologic questions and two 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 seven appendixes consist of the following:

- Appendix A: Data Sources
- Appendix B: Data Sources by State
- 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 G: 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. They were developed to enable writers of epidemiologic profiles to streamline the gathering, analysis, and presentation of prevention and care data to describe the HIV epidemic for planning groups and other end users. 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.