

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**

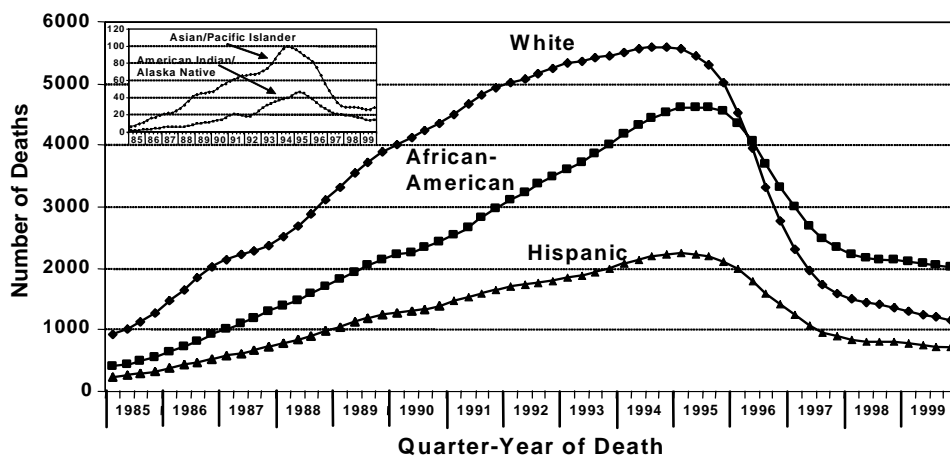
The following guidelines apply to all graphic aids:

- 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 or slices of a pie chart) will probably be difficult to distinguish. Consider using patterns (e.g., dots, wavy lines,

solid black). Shades of gray must differ at least 30%, or the gray elements will not be clearly distinguished in the original or in the copies (even if the document is professionally printed).

- Consider the preferences of your 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,<sup>a</sup> 1985–1999, United States**



<sup>a</sup>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**

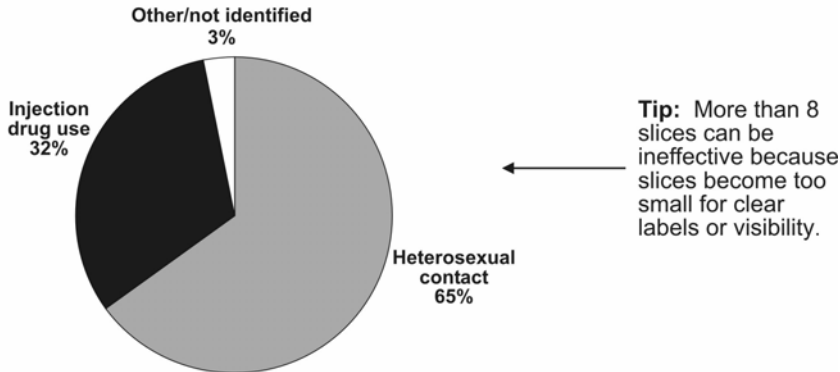
	USA, %	State X, %	County X, %
White, not Hispanic	36	40	26
Black, not Hispanic	42	34	52
Hispanic	20	26	21

## 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<sup>a</sup> among female adults and adolescents, by exposure category, County X, diagnosis in 2001



<sup>a</sup>Data adjusted for reporting delays and estimated proportional redistribution of cases initially reported without risk. Data reported through June 2002.

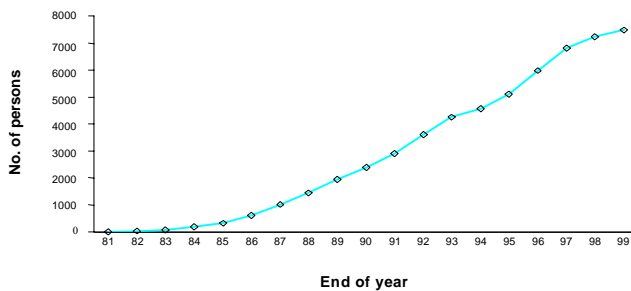
**Line graphs**

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.

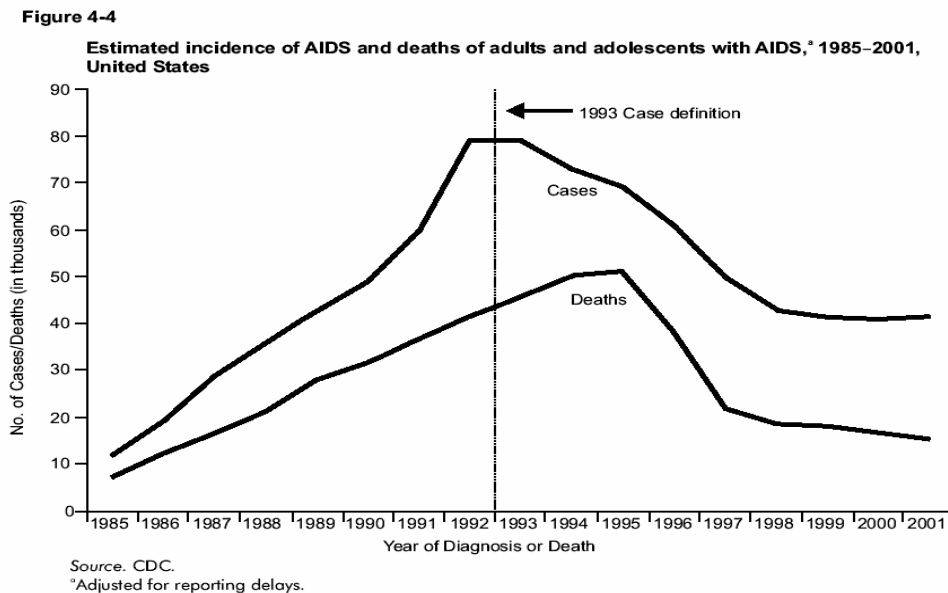
**Figure 4-3**  
**Example of line graph**  
**Number of persons living with AIDS, County X, 1981–1999**



## 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

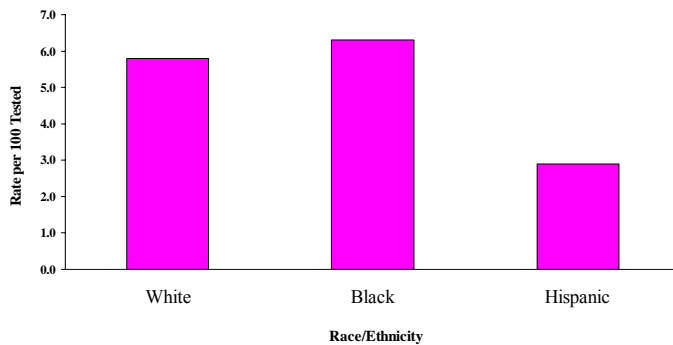


shown on the vertical axis, sometimes called the measuring axis. Categories of a variable (e.g., locations, groups) are represented by bars on the horizontal baseline. The length of each bar corresponds to a value on the measuring axis.

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**

**HIV-positive injection drug users, by race/ethnicity,  
County X STD Clinics, 1991–1998**

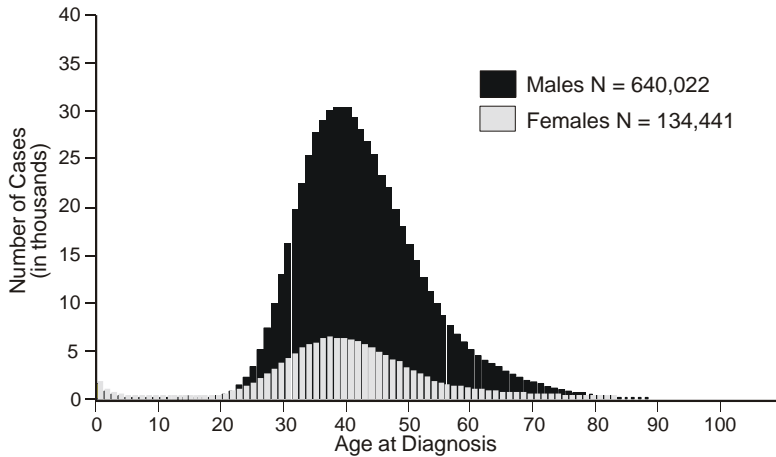


## Histograms

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**

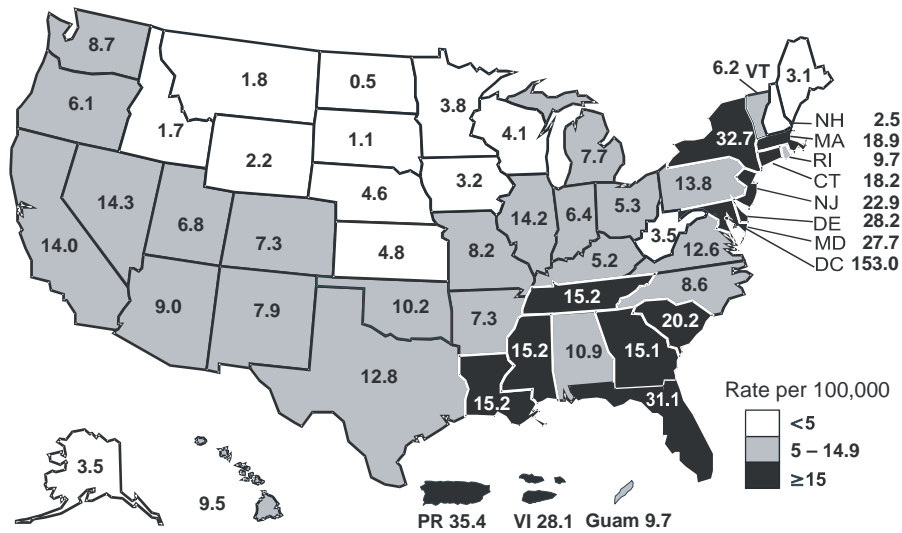


**Maps**

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.

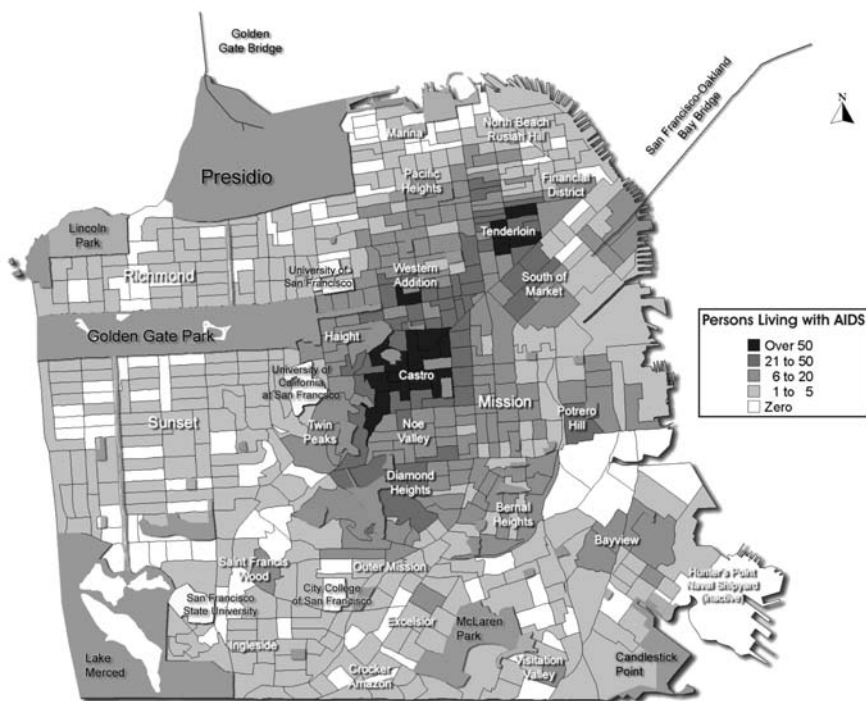
Confidentiality is also a concern when mapping data by use of GIS technology. As is true of other methods of data presentation, disclosure of information is a potential risk. However, GIS technology includes mapping techniques (e.g., spatial smoothing) that may be used to decrease the risk of disclosure 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

### Geographic Distribution of Men Living with AIDS in 2001 by U.S. Census Block Groups, San Francisco



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 <sup>a</sup>	145	8
Total	1724	100

<sup>a</sup>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