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

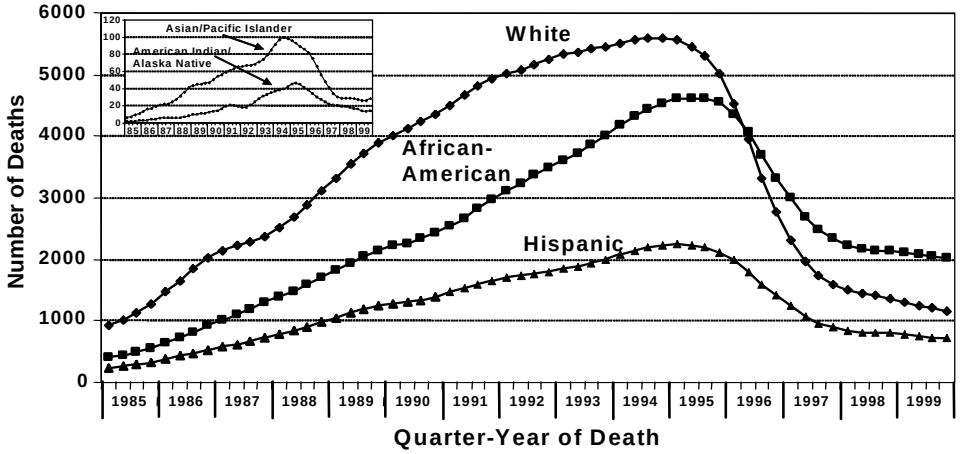
The following guidelines apply to all graphic aids:

- 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

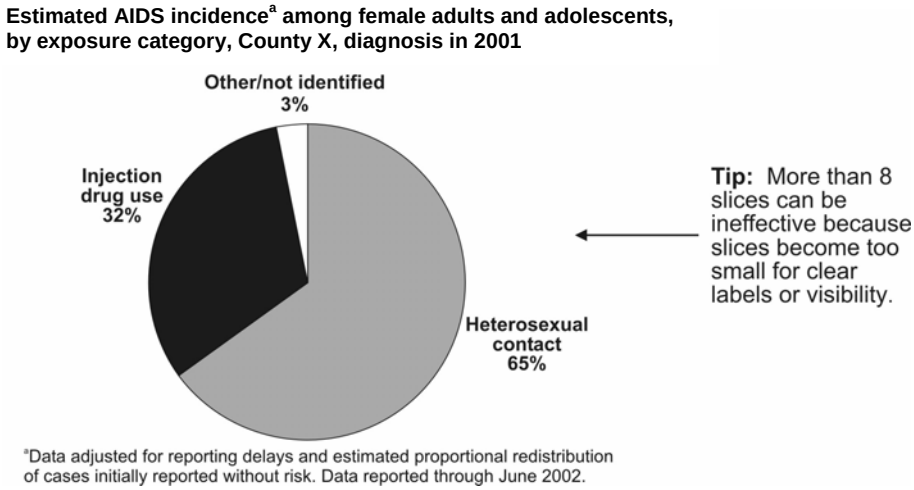
AIDS cases, by geographic unit and race/ethnicity, reported January – December, 1999

	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



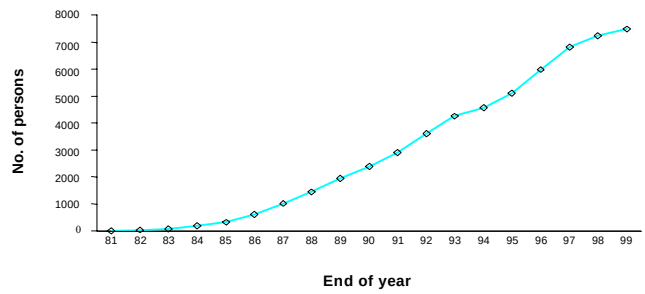
Line graphs

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.

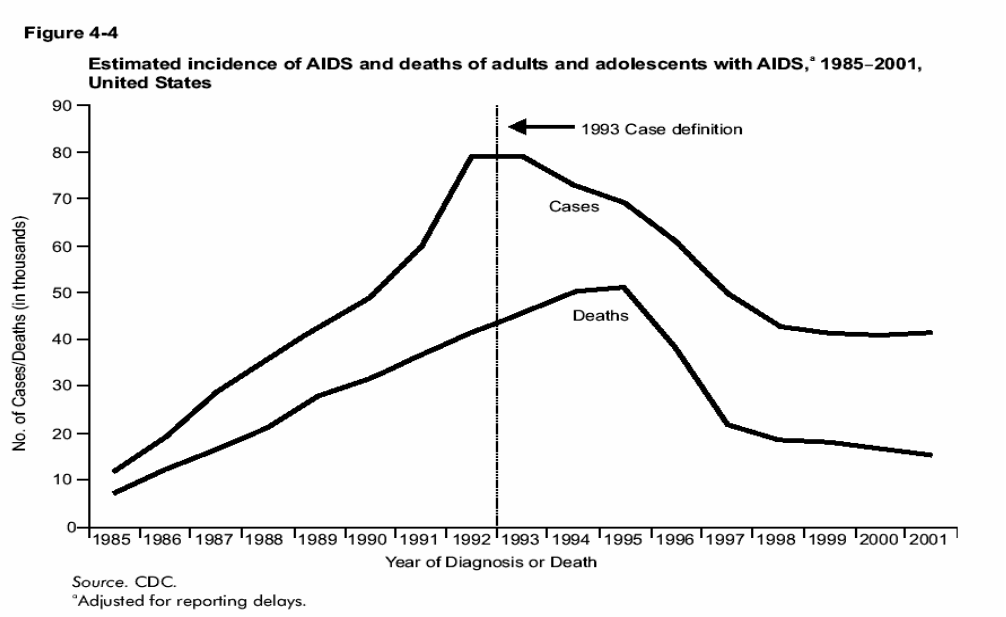
Figure 4-3
Example of line graph



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

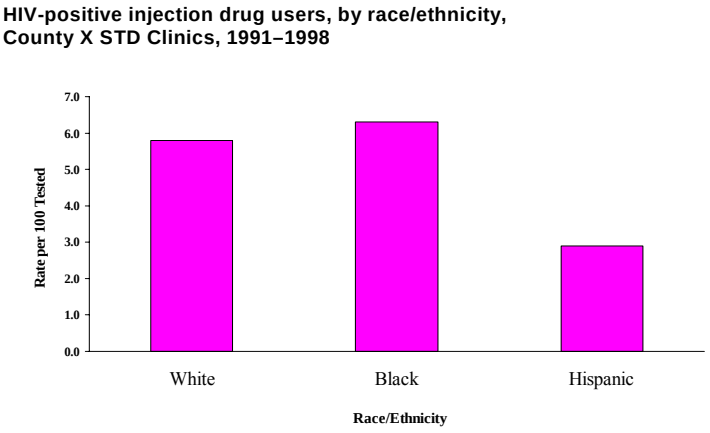
In a bar, or column, graph, data are organized so that each observation can fall into 1, but only 1, category of the variable.

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

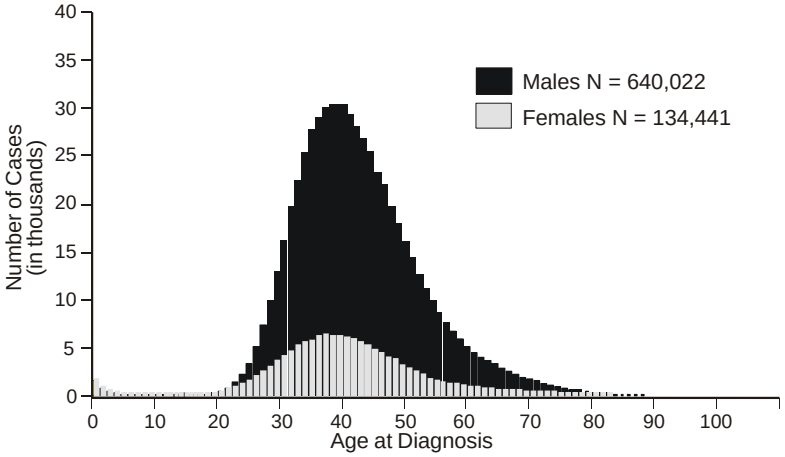


Histograms

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

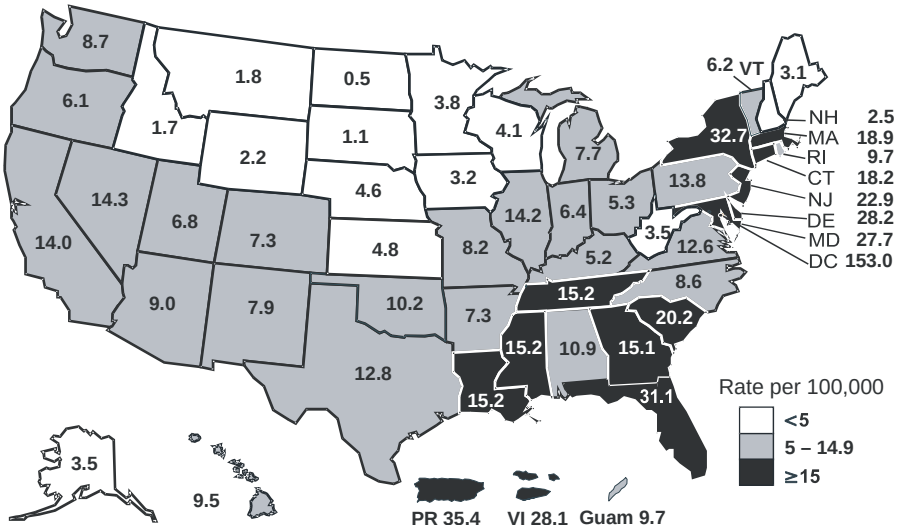


Maps

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.

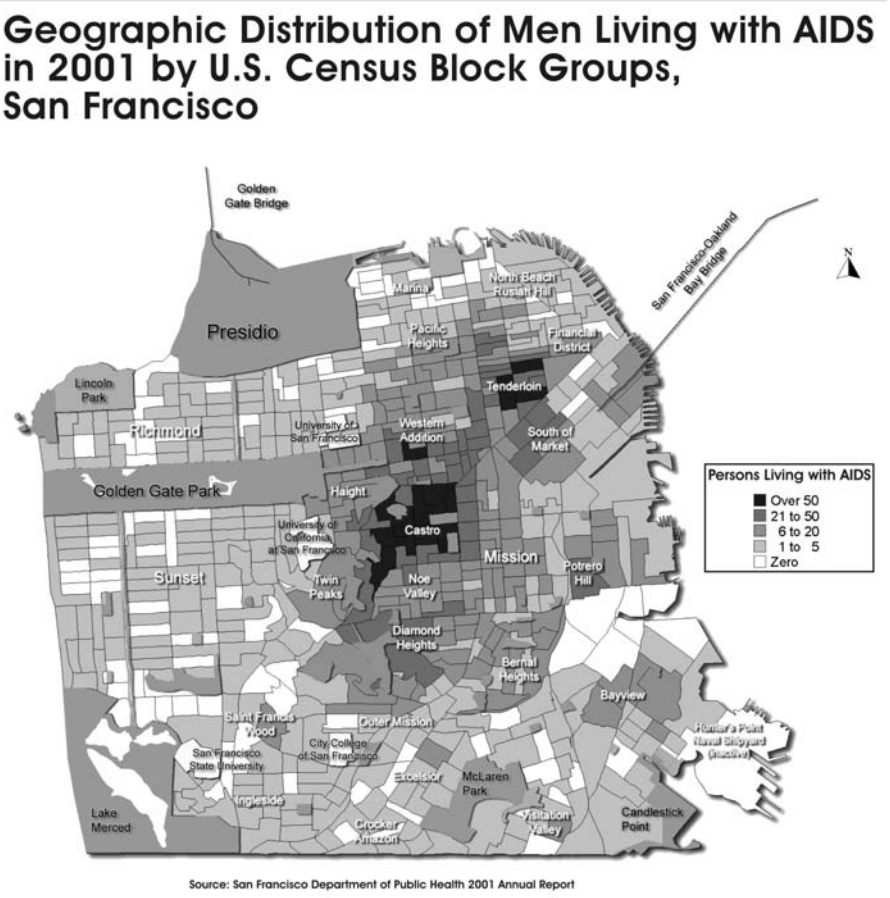
Users of GIS should be aware of the limitations before drawing conclusions based on mapping results. This is particularly important when explaining potential associations between data. For example, when one examines the distribution of persons with HIV infection by risk behavior and residence at diagnosis, 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.