DESCRIBING THE EPIDEMIC

Once you have determined the scope of your profile and the process you will use to develop it, decided on the content and organization, identified the data sources you will use, and established a multidisciplinary team, you will be ready to begin preparing your HIV/AIDS epidemiologic profile. To be effective and useful, the profile should describe the epidemic from various perspectives, including
- characteristics of the general population in the geographic area covered by the profile
- characteristics of HIV-infected persons and persons engaged in high-risk behaviors
- indicators of risk
- distribution of the disease (geographically and by population)
- trends, if any

This chapter is divided into 2 sections:
- **Section 1: Core Epidemiologic Questions** presents 3 epidemiologic questions that *all* HIV/AIDS profiles should address. It describes the types of supporting data you can use to answer each question and where to find the data, presents recommended analyses, and provides caveats and explanatory notes, as appropriate.
- **Section 2: Special Questions and Considerations for Ryan White CARE Act Grantees** presents questions that are specific to epidemiologic profiles that will be used to plan HIV/AIDS care programs. Profiles focusing on care as well as prevention issues should contain the answers to the core questions in Section 1 and the questions in Section 2.

Throughout your profile, it is acceptable to conduct additional analyses or analyses different from the ones recommended here as long as you answer the core epidemiologic questions and provide an interpretation of your tables in the accompanying text. If you choose to conduct additional analyses, be sure to state in the text that you have done so.

Section 1: Core Epidemiologic Questions
Whether you are preparing an HIV/AIDS epidemiologic profile for prevention or care, you should answer 3 essential epidemiologic questions:

1 What are the sociodemographic characteristics of the general population in your service area?	**2** What is the scope of the HIV/AIDS epidemic in your service area?	**3** What are the indicators of risk for HIV infection and AIDS in the population covered by your service area?

Examining groups at risk for HIV infection and answering these core questions will help you understand the characteristics of the population in your service area, the distribution of HIV disease, and how the epidemic may look in the future. The answers provide the basis for setting priorities among populations and then identifying appropriate interventions and services. Answering these core questions is the first step in developing your comprehensive HIV

prevention and care plan. Answer the questions as completely as possible, basing your answers on the needs, available data, and resources in your area.

The remainder of this chapter presents recommended analyses that will help you answer the questions. First, however, it briefly describes the importance of changes in the epidemic and HIV/AIDS surveillance data and their potential effect on epidemiologic profiles.

Changes in the Epidemic and Data That Affect Profiles

Describing the HIV/AIDS epidemic in the United States relies heavily on surveillance data collected through the coordinated efforts of public health officials and private and public health care professionals throughout the country. States and territories collect data locally and share it with CDC. State, territory, and local health departments and CDC analyze and disseminate the data in a variety of formats for use by public health, prevention and care planning, and health communications and news organizations. The epidemiologic profile you prepare is part of the local dissemination of data to provide an understanding of the HIV/AIDS epidemic and assist in setting priorities for prevention and care in your service area.

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

To provide a balanced and accurate description of the epidemic that incorporates the strengths and limitations of the data sources, you need to be aware of the changing nature of HIV/AIDS and surveillance data.

Keep the following points in mind as you develop your epidemiologic profile. Because of the successful effects of treatment and the expansion of surveillance data to HIV infection, you may see changes in the trends of the epidemic in your service area.

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

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

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

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

- To enable us to better monitor and characterize the epidemic, CDC and the Council of State and Territorial Epidemiologists have recommended that national surveillance be expanded to include both HIV infection and AIDS cases.[3,4] Such an integrated national HIV/AIDS case surveillance system will provide information about persons whose HIV infection has been newly diagnosed, including those with evidence of recent infection, those with severe HIV disease (AIDS), and those dying of HIV disease or AIDS.

- Integrated HIV/AIDS surveillance data on new HIV and AIDS diagnoses provide a minimum estimate of persons known to be infected. HIV diagnosis data may not reflect trends in HIV incidence (new infections) because the data are affected by when in the course of disease a person seeks or is offered HIV testing. Data on new infections can reflect incidence when incidence, testing patterns, and mortality from competitive causes are constant over an extended time. In addition, these data do not represent total HIV prevalence because not all HIV-infected persons have been tested. Furthermore, because diagnoses based on anonymous tests are not reported to confidential name-based registries, these data may not represent all persons who test positive for HIV infection.

- Currently, HIV surveillance data must be interpreted with data from additional sources (e.g., behavioral surveillance) to provide a more complete picture of the epidemic. Whether a trend in the number of new HIV diagnoses is stable, increasing, or decreasing may reflect current or historical patterns in HIV incidence, changes in testing behaviors, or the maturity of the epidemic in the geographic area.[5]

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

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

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

Question **1** | What are the sociodemographic characteristics of the general population in your service area?

The general characteristics of the population in your service area provide an essential context. Supporting data will help you examine these characteristics from 2 perspectives:

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

The information you develop will help you identify the risk factors associated with HIV infection—such as poverty level and lack of health insurance—that may indicate a greater cost for providing prevention and care services.

Compile and analyze demographic and socioeconomic characteristics of the populations in your service area to determine changes during the past 5 to 10 years. Present significant changes; if no significant changes have occurred, state that.

Demographics

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

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

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

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

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

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

For collecting and reporting data on racial categories and ethnicity, the Bureau of the Census uses
- Hispanic
- non-Hispanic of one race (e.g., white, black, American Indian, Asian, Native Hawaiian or other Pacific Islander, other)
- non-Hispanic of two or more races (summation of 57 categories)

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

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

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

Recommended analyses

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

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

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

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

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

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

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

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

Data sources
- Bureau of the Census
- State census centers

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

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

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

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

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

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

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

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

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

Socioeconomic status (SES)

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

Recommended analyses

Percentage of

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

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

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

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

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

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

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

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

MSA, metropolitan statistical area.

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

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

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

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

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

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

Summary of Recommended Analyses for Question 1

- Number and percentage distribution of the population by
  - age group and sex
  - race/ethnicity and sex
  - race/ethnicity and geographic subunit (e.g., planning region, county, EMA)

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

Question **2** | ## What is the scope of the HIV/AIDS epidemic in your service area?

An examination of the extent and effect of the HIV epidemic in broad population groups in your service area provides the basis for comparison with national data and allows a closer examination of the effect on specific groups, both of which will help your planning group better focus prevention and care services. Examine this issue from the following perspectives:

- HIV and AIDS case surveillance
- HIV surveys

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

Section A: HIV and AIDS case surveillance

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

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

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

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

Recommended analyses for data from the most recently available calendar year
- Number of cases diagnosed in that year, adjusted for reporting delay. Cases with NRR should be redistributed.

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

  NIR (no identified risk). The case is considered NIR if after 12 months from report date, epidemiologic follow-up has been conducted, sources of data have been reviewed—which may include an interview with the patient or provider—and no mode of exposure has been identified. Any case that remains NRR 12 or more months after the report date will be considered NIR.

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

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

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

If adjustment for reporting delay is not available, you may use the following alternatives for your analyses:
- cases reported in the most recent year
- cases diagnosed in the most recent year without adjustment for reporting delay
- cases diagnosed in the year before the most recent year to allow time for reporting (this alternative may be helpful to allow for the lag in reporting and to allow time for NRR follow-up investigations if adjustment for NRR redistribution is not possible)

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

Data sources
- HIV surveillance data
- AIDS surveillance data

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

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

[a]Per 100,000.

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

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

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

	Males		Females		Total	
Age (yrs)	No.	%	No.	%	No.	%
0–1	7	<1	7	<1	14	<1
2–12	7	<1	12	<1	19	<1
13–24	320	8	216	12	536	10
25–44	2,725	66	1,111	64	3,836	66
45–64	984	24	363	21	1,347	23
≥ 65	64	1	22	1	86	1
Total	4,107	100	1,731	100	5,838	100

Interpretation: In 2000, a diagnosis of HIV was made for 5,838 persons in State X. Most of the diagnoses (66%) were for males aged 25–44 years.

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

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

NA, not applicable.

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

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

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

Dash indicates cell size of ≤ 3.

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

Recommended analyses for geographic areas with large case numbers
If the number of cases is large enough (>20) to stratify by geographic region (see Chapter 5 on how to handle areas with low morbidity and a small number of cases), consider developing the following tables stratified by region:
- Number and percentage distribution of cases by
  - race/ethnicity
  - age group
  - exposure category
- Case rates (cases per 100,000 population) by race/ethnicity for each geographic region
- Case rates by race/ethnicity for each sex

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

Recommended analyses for TB comorbidity
Number and percentage distribution of persons with AIDS who also have TB

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

Recommended analyses for HIV/AIDS mortality

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

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

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

Dash indicates cell size of ≤ 3.

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

Interpretation: Rates of death of persons with HIV infection or AIDS were much greater among males than among females and greater among blacks than among whites. The rate for Hispanics was intermediate between the rate for whites and the rate for blacks.

> *Note:* The denominator used in calculating death rates is the population of interest in a service area. For example, in Table 3-11, since the numbers and rates of deaths are being calculated for persons with a diagnosis of HIV infection or AIDS, the denominator is the entire population in the service area. If you wanted to calculate the rate of deaths among HIV-infected persons aged 25–44, the denominator would be limited to the population in this age group.

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

- Number of deaths by underlying cause among persons 25 to 44 years of age, based on vital statistics mortality data (see Table 3-12)
- Number and rates of death (per 100,000 population) by race/ethnicity and sex, based on vital statistics mortality data

These analyses will enable you to determine the rank of HIV infection among underlying causes of death for the most recent year for which data are available.

Data sources
- HIV and AIDS surveillance data
- Local offices of vital statistics
- National Center for Health Statistics

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

    Note: Data in death certificates on specific causes of death may be of poor quality for several reasons. Stigmatized diseases may be underreported. In addition, the causes of death may be recorded incorrectly if, for example, they were limited to symptoms or immediate causes and did not include the underlying cause (in this instance, HIV infection).

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

Cause	Ranking	Deaths, No.	Total deaths, % ($N = 934$)
Unintentional injury	1	238	25.5
Malignant neoplasms	2	139	14.9
HIV disease	3	115	12.3
Homicide	4	86	9.2
Heart disease	5	80	8.6
Suicide	6	65	7.0
Cerebrovascular disease	7	16	1.7
Chronic liver disease	8	15	1.6
Diabetes mellitus	9	7	0.7
Pneumonia and influenza	10	6	0.6

Note. Restricted to groups with at least 50 deaths from all causes and excluding causes of death that resulted in 3 or fewer deaths per group. HIV disease not listed if it either was not among the top 10 causes or caused 3 or fewer deaths. The appendixes contain additional examples of vital statistical mortality data.

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

Recommended analyses for the most recent 5-year period

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

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

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

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

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

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

Figure 3-1
Annual number of HIV (combined with AIDS) diagnoses among persons in State X, 1996–2000
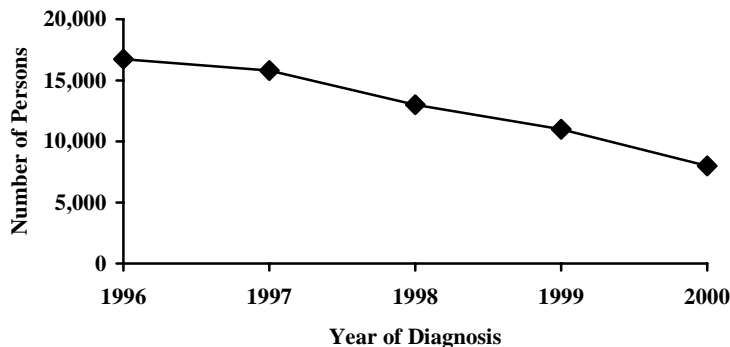
Note. Adjusted for delays in reporting.

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

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

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

Figure 3-2
Annual number of AIDS diagnoses among persons in State X,
1996–2000
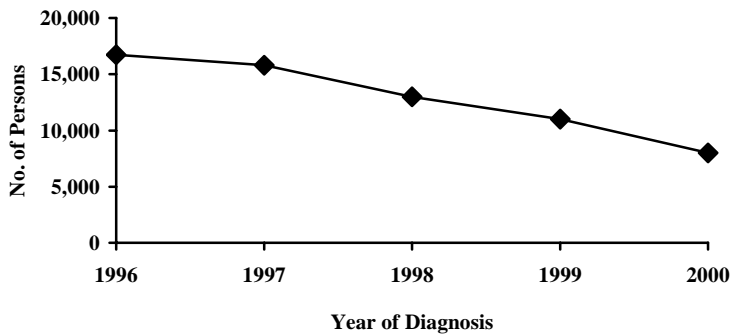
Note. Adjusted for delays in reporting.

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

Figure 3-3
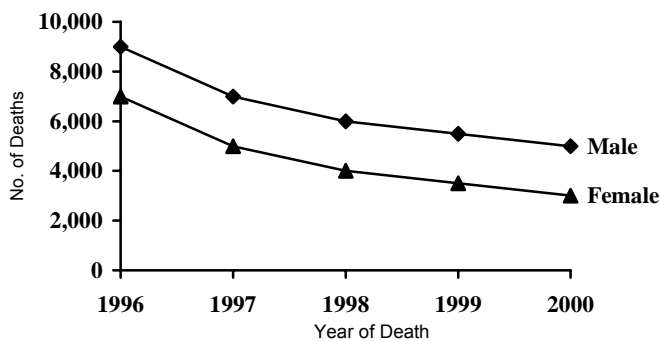**Annual number of persons living with HIV infection and AIDS in State X,**
1996–2000
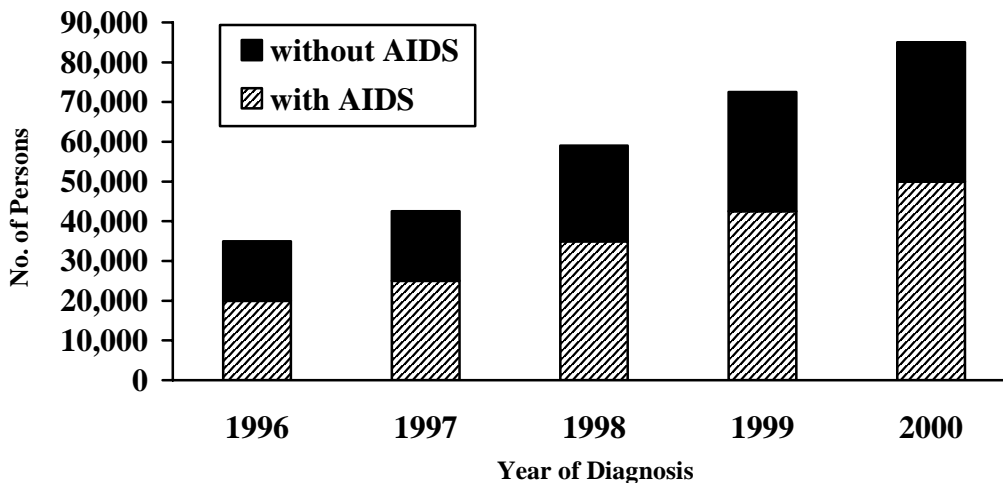
Interpretation: The number of persons living with HIV infection and AIDS has increased steadily over time. As of December 2000, an estimated 80,000 persons were living with HIV infection and AIDS in State X, representing a 129% increase since 1996. The proportion of persons living with AIDS increased from 57% in 1996 to 63% in 2000.

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

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

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

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

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

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

Method 1
a. To get the proportion of cases in your service area, divide the number of persons living with AIDS in your service area by the US total of persons with AIDS.

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

> *Example:* At the end of 2000, an estimated 323,000 persons were living with AIDS in the United States, including US dependencies, possessions, and associated nations. (Source: CDC. *HIV/AIDS Surveillance Report* 2000;12[No. 2]:1-48. Available at www.cdc.gov/hiv/stats/hasr1202.pdf .2.)
>
> At the end of the year, 35,000 persons were living with AIDS in State X. (Source: HIV/AIDS surveillance program in State X.)

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

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

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

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

Data source
HIV/AIDS surveillance data

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

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

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

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

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

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

Determine the prevalence estimate by using Method 2.

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

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

Data source
HIV/AIDS surveillance data

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

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

> *Example*
> In Table 3-13, HIV and AIDS surveillance data are used to show differences among persons for whom HIV infection was diagnosed before AIDS compared with persons for whom HIV infection was not diagnosed before AIDS. Surveillance data on persons for whom HIV infection was diagnosed before AIDS may be used to specify populations requiring prevention and treatment services.
>
> The data are from 25 states that have conducted name-based surveillance for HIV as well as AIDS since at least 1994. Patients are grouped by whether or not clinical and laboratory criteria of the 1993 case definition for AIDS were identified within 1 calendar month of the HIV diagnosis. HIV and AIDS data were adjusted for delays in case reporting and for anticipated reclassification of cases originally reported without a mode of exposure.

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

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

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

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

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

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

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

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

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

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

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

Section B: AIDS case surveillance

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

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

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

Recommended analysis for the most recently available calendar year

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

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

    NIR (no identified risk). The case is considered NIR if after 12 months from report date, epidemiologic follow-up has been conducted, sources of data have been reviewed—which may include an interview with the patient or provider—and no mode of exposure has been identified. Any case that remains NRR 12 or more months after the report will be considered NIR.

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

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

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

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

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

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

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

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

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

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

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

Dash indicates cell size of ≤ 3.

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

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

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

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

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

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

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

Dash indicates cell size of ≤ 3.

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

Recommended analyses for geographic areas with large case numbers

If the number of cases is large enough (>20) to stratify by geographic region (see Chapter 5 on how to handle areas with low morbidity and a small number of cases), develop the following tables stratified by region:

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

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

Recommended analyses for TB comorbidity

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

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

Recommended analyses for AIDS mortality

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

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

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

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

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

> *Note:* The denominator used in calculating death rates is the population of interest in a service area. For example, in Table 3-18, since the numbers and rates of deaths are being calculated for persons with a diagnosis of AIDS, the denominator is the entire population in the service area. If you wanted to calculate the rate of deaths among HIV-infected persons aged 25–44, the denominator would be limited to the population in this age group.

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

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

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

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

Cause	Ranking	Deaths, No.	Total deaths, % (N = 934)
Unintentional injury	1	238	25.5
Malignant neoplasms	2	139	14.9
HIV disease	3	115	12.3
Homicide	4	86	9.2
Heart disease	5	80	8.6
Suicide	6	65	7.0
Cerebrovascular disease	7	16	1.7
Chronic liver disease	8	15	1.6
Diabetes mellitus	9	7	0.7
Pneumonia and influenza	10	6	0.6

Note. Restricted to groups with at least 50 deaths from all causes and excluding causes of death that resulted in 3 or fewer deaths per group. HIV disease not listed if it either was not among the top 10 causes or caused 3 or fewer deaths. The appendixes contain additional examples of vital statistics mortality data.

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

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

> *Note:* Data in death certificates on specific causes of death may be of poor quality for several reasons. Stigmatized diseases may be underreported. In addition, the causes of death may be recorded incorrectly if, for example, they were limited to symptoms or immediate causes and did not include the underlying cause (in this instance, AIDS).

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

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

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

Analyze trends in the following. Stratify by sex, race/ethnicity, age group, geographic area, and exposure category and include a table for each:
- Annual number of AIDS diagnoses, adjusted for reporting delay (see Figure 3-5)

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

Figure 3-5
Annual AIDS diagnoses among persons in State X, 1996–2000
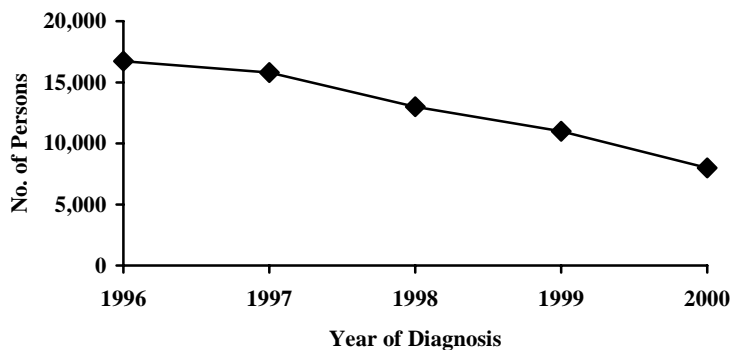
Note. Adjusted for delays in reporting.

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

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

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

Figure 3-6
Annual number of persons living with AIDS in State X, 1996–2000
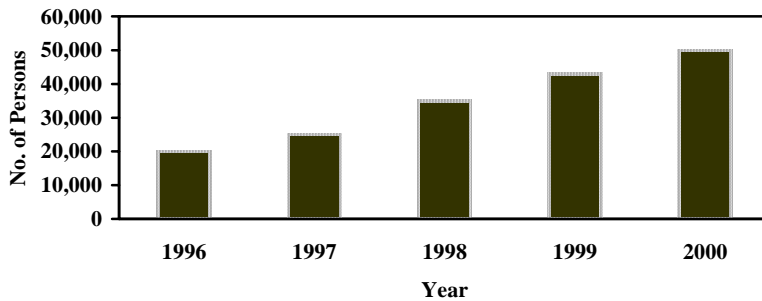
Interpretation: The number of persons living with AIDS has increased steadily over time. As of December 2000, an estimated 52,000 persons were living with AIDS in State X, representing a 160% increase since 1996.

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

Figure 3-7
Annual number of deaths of persons with AIDS in State X, 1996–2000
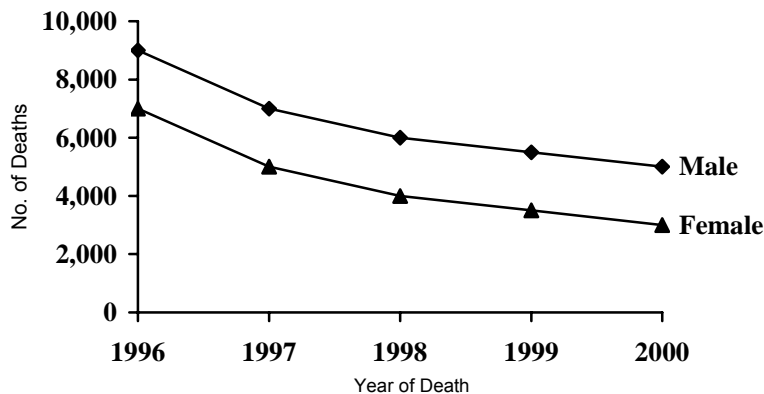
Interpretation: During 1996–2000, the number of deaths of persons with AIDS declined steadily among males and females. Among males, deaths declined 37%, from 9,500 in 1996 to 6,000 in 2000. Among females, deaths declined 43%, from 7,000 in 1996 to 4,000 in 2000.

Extrapolation Method
You may use this method to get an estimated range of the number of persons living with HIV in your area. This method is the only acceptable method for states without HIV reporting.
a. To get the proportion of cases in your area, divide the number of persons living with AIDS in your service area by the US total of persons with AIDS.

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

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

> At the end of the year, 35,670 persons were living with AIDS in State X.
> (Source: HIV/AIDS surveillance program in State X)
> a. To obtain the proportion of persons living with AIDS, divide the number of persons living with AIDS in state X by the number of persons living with AIDS in the United States
>
> 35,670/322,865 = 11.0% of the US total of persons living with AIDS.

> b. To estimate HIV prevalence for State X, multiply 11% by the lower and upper values of the national HIV prevalence estimate of 850,000 to 950,000. (Source of national prevalence estimate: Fleming PL, Byers RH, Sweeney PA, Daniels D, Karon JM, Janssen RS. HIV prevalence in the United States, 2000. In: Program and abstracts of the 9th Conference on Retroviruses and Opportunistic Infections; February 24–28, 2002; Seattle, Washington. Abstract 11.)
>
> HIV prevalence estimate for State X
> (.11 x 850,000) to (.11 x 950,000) = 93,500 to 104,500

Data Source
AIDS surveillance data

Section C: HIV surveys
HIV serosurveys
HIV serosurvey data will provide the supporting evidence you need to analyze seroprevalence rates.

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

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

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

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

HIV incidence surveillance

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

Recommended analyses for HIV incidence surveillance

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

Data source
CDC HIV incidence surveillance

HIV counseling and testing system data

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

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

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

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

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

Data source
State or local HIV counseling and testing program

Summary of Recommended Analyses for Question 2

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

HIV and AIDS case surveillance
For the most recently available calendar year
- Cases diagnosed in that year, adjusted for reporting delay (cases with NRR should be redistributed)
- Number, percentage distribution, and rates of cases by race/ethnicity and sex
- Number and percentage distribution of cases by
  - age group and sex
  - exposure category and sex
  - exposure category for each race/ethnicity

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

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

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

Recommended analyses for the most recent 5-year period
- Annual number of HIV diagnoses (combined with AIDS), adjusted for reporting delay
- AIDS cases alone (excluding cases of HIV infection that have not progressed to AIDS)
- Prevalence of HIV and AIDS cases (refers to persons living with HIV infection and persons living with AIDS)
- Annual number of deaths of persons with HIV and persons with AIDS (based on case surveillance data)
- Number of HIV cases among perinatally infected children, by year of birth

AIDS case surveillance
For the most recently available calendar year
- Cases diagnosed in that year, adjusted for reporting delay (cases with NRR should be redistributed)
- Number, percentage distribution, and rates of cases by race/ethnicity and sex
- Number and percentage distribution of cases by
  - age group and sex
  - exposure category and sex
  - exposure category for each race/ethnicity and sex

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

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

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

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

For the most recent 5-year period
- Annual number of AIDS diagnoses, adjusted for reporting delay
- Prevalence of AIDS cases (refers to persons living with AIDS)
- Annual number of deaths of persons with HIV infection and persons with AIDS (based on case surveillance data)
- Estimated total prevalence of HIV infection and AIDS (including persons with and persons without a diagnosis)

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

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

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

Question **3** | **What are the indicators of risk for HIV infection and AIDS in the population covered by your service area?**

In this section of your profile, examine data on risk behaviors and markers from 2 perspectives:

- Factors that affect the risk of acquiring HIV infection among HIV-negative persons
- Factors that affect the risk of transmitting HIV infection among HIV-positive persons

Use the data sources listed on page 78 to examine the risk for HIV infection and AIDS by exposure category, including the following:

- male-to-male sex
- injection drug use
- heterosexual contact

Note: You may also want to examine the risk for HIV infection and AIDS among populations of special interest, including incarcerated persons, homeless persons, migrant laborers, commercial sex workers, persons with mental illness, deaf and hearing-impaired persons, perinatally exposed persons, transgender persons, and any other populations in your local area at increased risk for HIV infection.

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

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

For each of the exposure categories as well as for local at-risk populations of special interest, consider not only the prevention issues for persons at risk but also the prevention and care issues for infected persons.

Direct and indirect measures of risk behavior
Direct measures of risk provide information about risk behavior that is directly associated with HIV transmission. Indirect measures do not directly describe HIV risk behaviors. Rather, they are indicators of *possible* HIV risk that may need further investigation. For example, an increase in STD or teen pregnancy rates does not directly indicate that HIV exposure is increasing but may indicate an increase in unprotected sex.

Recommended analyses for data on men who have sex with men (MSM): direct measures

- Factors that may affect the risk of acquiring or transmitting HIV, such as
  - number of sex partners (see Figure 3-8)
  - frequency of condom use or unprotected sex
  - whether partners are anonymous
  - substance use (including injection drug use)
  - information about discordant sex partners (i.e., one partner is HIV-positive and the other is HIV-negative)

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

Figure 3-8
Proportion of men who had more than 1 sex partner in the past 12 months, by risk exposure group, Supplement to HIV/AIDS Surveillance, State X, 2000
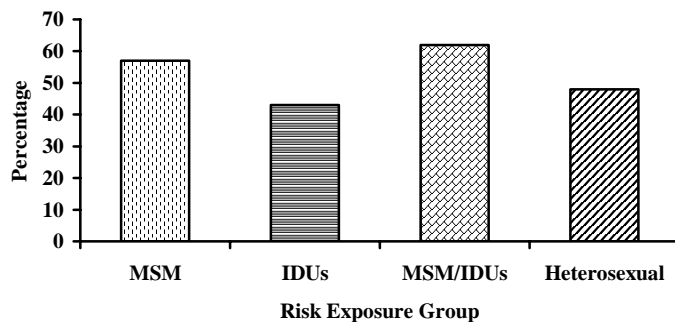
Interpretation: Having sex with more than 1 person for a defined period can indicate increased risk for the sexual transmission of HIV. Stratified analysis of this behavior by sex, race/ethnicity, or HIV exposure can indicate populations that need prevention activities. In this example, a higher proportion of men who have sex with men (MSM) and MSM who are also injection drug users, compared with other groups, reported having had multiple sex partners during the past 12 months. Local prevention planners may consider implementing prevention messages about reducing the number of sex partners, focusing on MSM and MSM who inject drugs.

Data sources

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

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

- HIV-positive persons
  - Young Men's Survey
  - Survey of HIV Disease and Care
  - Supplement to HIV/AIDS Surveillance
  - In addition, seek results from locally conducted cross-sectional studies funded by NIH and CDC, such as the Seropositive Urban Men's Study (SUMS; conducted in New York City and San Francisco). Baseline data from intervention studies such as the Intervention for Seropositive Injection Drug Users, Research & Evaluation (INSPIRE; conducted in Baltimore, Miami, New York City, and San Francisco) also may be useful. Note how the sampling frames for such studies relate to population estimates and consider the timeliness of the data and whether some studies may have more historical than contemporary value. Because of the varying applicability of such studies, they are not included in Appendix A.

Recommended analyses for MSM: indirect measures

- For data available for every state and county, trends in a service area in the male-to-female ratio for gonorrhea, syphilis, hepatitis A, and hepatitis B (an increase in this ratio may indicate increasing infections among MSM)
- For STD data available in some areas, trends in

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

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

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

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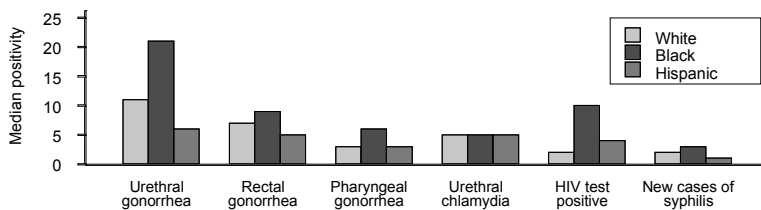

Interpretation: Among MSM at STD clinics in 2000, median positivity was higher for blacks than for other races/ethnicities for urethral gonorrhea, rectal gonorrhea, pharyngeal gonorrhea, HIV, and new cases of syphilis. The median positivity was similar for all races/ethnicities for urethral chlamydia.

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

- Factors that may affect risk of acquiring or transmitting HIV, such as
    - Injection drug use (see Figure 3-10) and other substance use
    - needle sharing
    - sharing of drug paraphernalia (cookers, cottons, water, drug solution)
    - exchanging money or drugs for sex
    - number of sex partners
    - frequency of condom use or unprotected sex

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

Figure 3-10
Injection drug use among participants in Supplement to HIV/AIDS
Surveillance, by race/ethnicity, State X, 2000
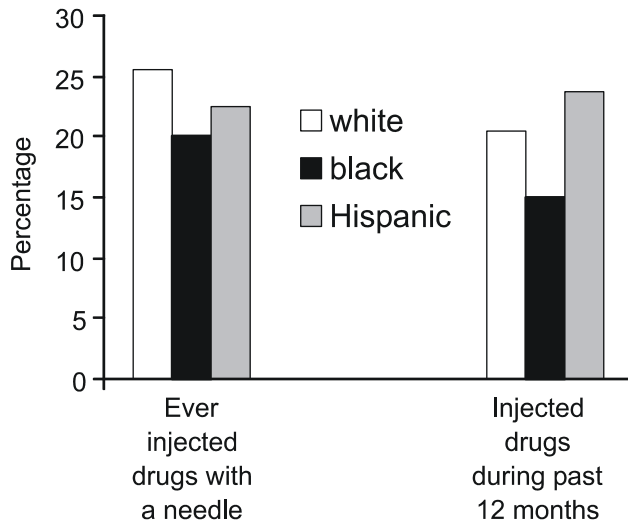
Interpretation: A history of injection drug use can provide general information on risk behavior. However, having injected drugs within the past 12 months provides a stronger indication of recent risk of acquiring or transmitting HIV. Stratified analysis of recent injection drug use by sex or race/ethnicity can indicate populations that need specific prevention activities. In the example here, the highest proportion of persons who had ever injected drugs were white; the highest proportion who had injected within the past 12 months were Hispanic. Local prevention planners may consider implementing prevention messages for current injection drug users, focusing on Hispanics who inject drugs.

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

Recommended analyses for injection drug users (IDUs): indirect measures
- Trends in the rate of hepatitis C infection
- Rates of mortality due to substance abuse
- Trends in injection drug use
- Trends in noninjection drug use (alcohol, poppers)
- Trends in recent STD history (the period examined should coincide with that of risk-behavior questions)

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

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

- Drug Abuse Warning Network
- National Household Survey on Drug Abuse
- Treatment Episode Data Set
- Community Epidemiology Work Group reports

Note: Use these sources to glean data on which drugs are prevalent in your service area, among which groups, and whether the pattern is changing. All of these factors can affect HIV risk.

Recommended analyses for data on heterosexual populations: direct measures

- Number of sex partners
- Frequency of condom use or unprotected sex
- Substance use (including injection drug use)
- Exchanging money or drugs for sex
- Information about discordant sex partners (i.e., one partner is HIV-positive and the other is HIV-negative)

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

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

Recommended analyses for heterosexual populations: indirect measures

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

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

Note: This analysis might be appropriate in an area that has a large number of syphilis cases. If your area has a small number of cases (<20), use this analysis with caution: sporadic outbreaks do not necessarily indicate changes in risk behavior in the community.

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

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

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

Recommended analyses for data on other populations of special interest
You may wish to include other populations in your profile because their members may belong to the groups already listed or because of unique factors that influence their risk. Evaluate the effect that these groups have on the epidemic in your service area. Data may be available from a variety of sources, including some of those already listed and others that are local. Analyses of case data may also suggest the need for additional studies of these populations. Take note of cases in persons reported in one state but in care in another state (common in areas of low morbidity). When routine surveillance data are not available, seek results from locally conducted cross-sectional studies funded by NIH, CDC, other government agencies, or nongovernmental organizations.

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

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

Optional analyses for HIV counseling and testing

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

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

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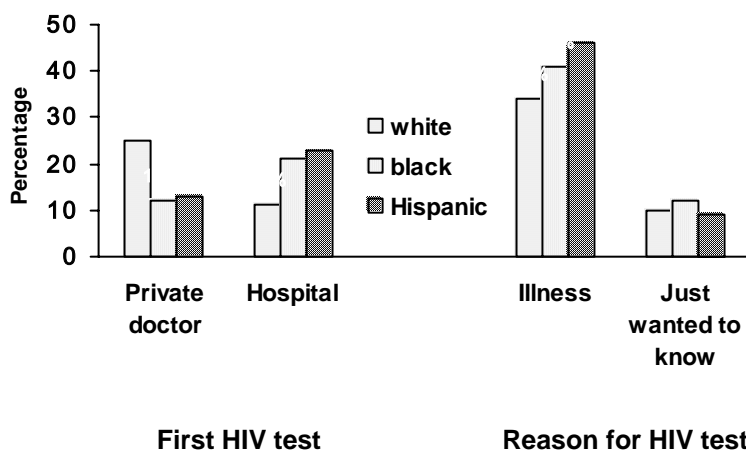
Interpretation: The location of the first test for which the result was positive, along with the main reason for seeking the test, can indicate the perception of risk for infection. Stratified analysis of location and reason for being tested can indicate populations who do not perceive themselves as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

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

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

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

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

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

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

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

Summary of Recommended Analyses for Question 3

- Examine direct and indirect measures of risk for HIV infection and AIDS by exposure category:
  - male-to-male sex
  - injection drug use
  - heterosexual contact
- If desired, examine risk for HIV/AIDS among populations of special interest, including incarcerated persons, homeless persons, migrant laborers, commercial sex workers, persons with mental illness, deaf and hearing-impaired persons, perinatally exposed persons, transgender persons, and any other populations in the local area at increased risk for HIV infection
- Conduct stratified analyses of these exposure categories by sex, race/ethnicity, and age group (including adolescents).
- Analyze HIV counseling and testing data to determine testing decisions and behaviors among specific groups at risk.

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

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

Question **1** | **What are the patterns of service utilization of HIV-infected persons in your area?**

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

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

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

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

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

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

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

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

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

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

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

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

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

Figure 3-12
Average number of visits per client, by type of Title I service, 1998–2000
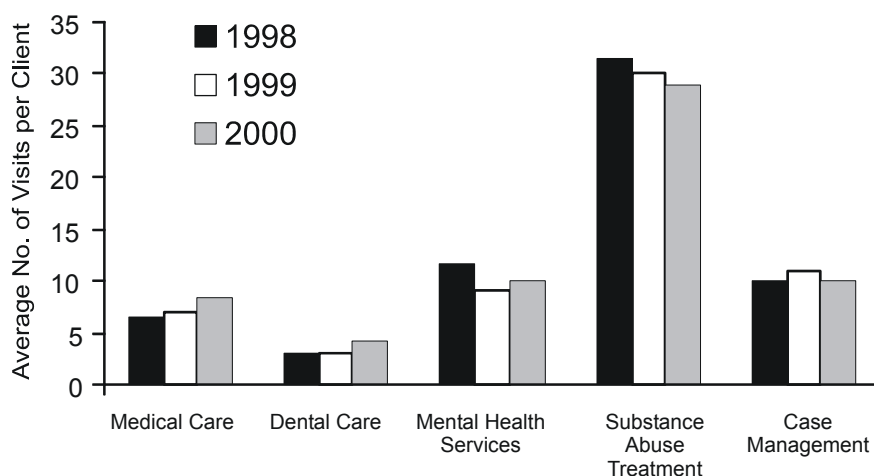
Note. Data based on valid reports only. Valid data defined as providers' reports of complete data both for the number of clients and the number of visits.

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

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

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

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

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

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

Figure 3-13
Average number of visits per client, by type of Title II service, 1998–2000
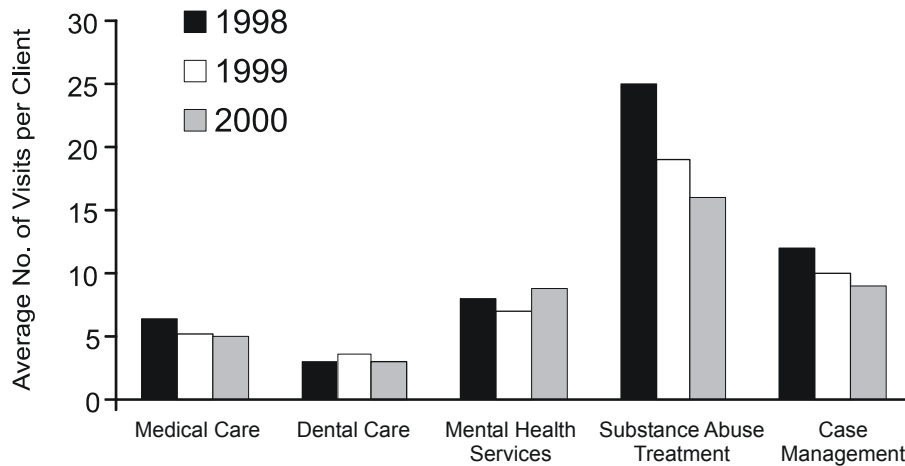
Note. Data based on valid reports only. Valid data defined as providers' reports of complete data both for the number of clients and the number of visits.

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

Other recommended analyses and possible data sources

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

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

Figure 3-14
Proportion of patients who received antiretroviral treatment late,
at the recommended time, or early, Adult Spectrum of Disease
Study—State X, 1996–2000
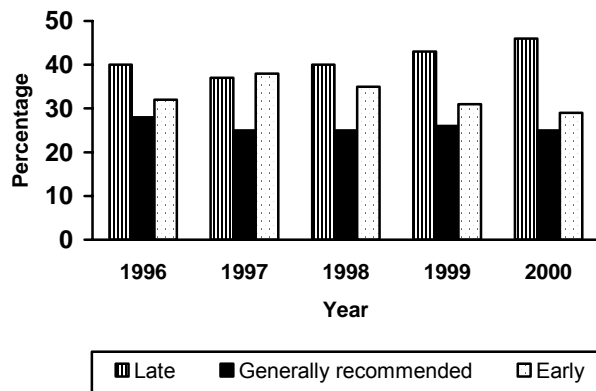
Note. Late (CD4 count of <200 cells/μL or AIDS-defining opportunistic infection), generally recommended time (CD4 count of ≥ 200, but <350 cells/μL), or early (CD4 count of ≥ 350 cells/μL).

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

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

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

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

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

Client data allow specialized analyses, including the following:

- Comparison of number and percentage of persons whose first HIV diagnosis was also an AIDS diagnosis and persons whose diagnosis was made in earlier stages of HIV infection (before progression to AIDS). This comparison shows which population groups do not have access to, or are not using, counseling and testing services early in the course of infection.

- Comparisons of persons with AIDS (and HIV where data are available) in a service area and persons receiving services through CARE Act providers may reveal which population groups are underserved. Shortfalls in services for particular populations are likely to differ by type of service.

Question **2**

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

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

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

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

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

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

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

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

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

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

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

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

Data needed are:
   c. percentage or number of PLWA that meet primary care definition
   d. percentage or number of PLWH that meet primary care definition

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

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

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

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

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

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

> *Example:* Unmet need in State X
> In state X, there were 4,291 persons living with AIDS and 3,942
> persons living with HIV. The proportion of persons living with AIDS
> who received primary medical care within the past 12 months was
> 62%. The proportion of persons living with HIV who received
> primary medical care within the past 12 months was 27%.
> a = 4,291
> b = 3,942
> c = 62%, or 0.62
> d = 27%, or 0.27
>
> Unmet need = [a X (1 − c)] + [b X (1 − d)]
>   = [4,291 X (1 − 0.62)] + [3,942 X (1 − 0.27)]
>   = [1,631 + 2,878]
>   = 4,509 persons

Summary of Recommended Analyses for Question 2

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

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