

**THE PREVENTION MARKETING INITIATIVE:**

constructing

risk profiles



**DEPARTMENT OF HEALTH AND HUMAN SERVICES**  
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# introduction.

Young people need prevention programs designed specifically for their age group. Because patterns of teen HIV risk vary across the country, program planners need the best available information about HIV risk in their local jurisdictions in order to design the most efficient, effective prevention programs. **Constructing Teen HIV Risk Profiles** is intended to help prevention service planners make effective use of epidemiologic and behavioral data as they plan and carry out interventions for adolescents in their communities.

Fortunately, since 1994, HIV Prevention Community Planning Groups in every state and territory and six major cities in the United States have worked with health departments to develop HIV Epidemiological Profiles<sup>1</sup> for a number of populations, often including youth. They have also identified unmet prevention service needs and prioritized programs for specific populations.<sup>2</sup> Because the **data necessary for targeting local HIV prevention programs for teens may have been assembled already** by your state or regional Community Planning Group, you may be able to use existing profiles, address already identified priorities, and devote all of your program resources to developing and delivering services to teens.

However, after examining available profiles, you may find that there is still a need for a special focus on data directly

relevant to adolescents. This decision was reached by the five local communities that constituted the Prevention Marketing Initiative (PMI) Demonstration Site Project, an effort to reduce sexual transmission of HIV among young people under 25 that was federally funded from 1994-1998. In order to target media campaigns and the like, the PMI sites considered it worthwhile to build on the HIV Epidemiological Profiles created by their states to compile special Teen HIV Risk Profiles.

The PMI sites learned a number of lessons as they assembled and digested the most local, in-depth available information on adolescent risk. This document uses those lessons to illustrate particular points. It complements previous technical assistance guidelines with information about newly available websites<sup>3</sup>, special databases on teens, and examples of the ways in which the PMI sites used data for planning purposes. Readers who may not have a formal background in epidemiology, but who are fairly comfortable with numbers (like volunteers with professional expertise in a field like accounting) should be able to make use of the suggestions in this document.

The PMI sites -- Nashville, Newark, Northern Virginia, Phoenix, and Sacramento -- found the Teen HIV Risk Profiles useful because they confirmed or refined impressions about local risk patterns, could be compared with inventories of services already available for teens

1. The Epidemiological Profiles follow instructions in the **1995 Suggested Guidelines for Developing an Epidemiologic Profile for HIV Prevention Community Planning Groups** prepared by the Council of State and Territorial Epidemiologists (CSTE) for the CDC.

2. See *HIV Prevention Community Planning Profiles: Assessing the Process and the Evolving Effects* published by the United States Conference of Mayors for a description of the Community Planning Process and some of the prevention activities it has fostered.

3. Website addresses change frequently. The addresses provided in this report are current as of the date of publication. However, it may be necessary to go to the organization's homepage (e.g., [www.cdc.gov](http://www.cdc.gov)) and follow the directions given.

to identify unmet service needs, and helped the PMI sites explain their program planning decisions to a variety of interested parties. However, as is mentioned several times in this document, risk profiles were among several factors that influenced PMI's ultimate planning decisions (see Appendix 1 for a chart summarizing the PMI site plans).

Decisions about programs never rest entirely on disease-relevant statistics. However, improving access to information about disease and risk behavior patterns is the first step in putting program planning on a firm scientific basis. The sponsor of PMI, CDC's Division of HIV/AIDS Prevention, and the PMI staff and volunteers hope this manual will help ground prevention programs in data and thus help guard the health of teens in the United States.

# chapter 1.

# P U Y G T U V Q D C U K E S W G U V K Q P U  
C D Q W V J K X T K U M R T Q H K N G U

## What is a Teen HIV Risk profile?

A teen HIV Risk Profile is a report that pulls together and interprets statistical information that is relevant to the risk of HIV infection in a specific population of adolescents. Such a profile is the starting point for understanding Teen HIV risk in a community.

The recommendations for developing Teen HIV Risk Profiles provided in this document are based on lessons learned by the PMI demonstration sites as they developed integrated summaries of HIV-relevant data. The data were already available from a variety of sources.

A wealth of data exists, but all data have limitations. Fortunately, the limitations of data from different sources vary, and it is often possible to balance one kind of limitation against another. When a consistent pattern of risk emerges, it can help inform decisions about programs.

## What does a basic Teen HIV Risk Profile include?

A profile should include:

- numeric information on the age, gender, ethnicity, socioeconomic status, and primary language of population members who reside within known geographic boundaries, otherwise known as **demographic information**.<sup>4</sup>
- direct indicators of HIV risk, such as the number of new HIV diagnoses reported during a specific period of time.
- indirect or **surrogate markers** of HIV risk, like STD rates.

For a really thorough profile, available information about drug use, school completion, and immigration can be added. See Chapter 3 of this document for specific data

### Box 1

#### Key Content of PMI Teen HIV Risk Profiles

- youth demographics (e.g., number of teens of various ages in the target area)
- disease epidemiology (e.g., HIV rates among local teens)
- surrogate markers (e.g., local teen pregnancy rates)
- risk and protective behaviors (e.g., reports of condom use by teens)

sources. Some planners may even have the capacity to generate sophisticated mathematical estimates of infection rates or to collect new data to fill in details, but these procedures are not needed to compile a basic risk profile and will not be discussed here.

## Who should develop the profile?

One person should assume primary responsibility for developing the Teen HIV Risk Profile. This person will have to perform or manage a number of functions including assembling data, writing, obtaining expert input and community input, editing, and securing final approvals. The person in the lead on this project should enlist the help of experts in disease and behavioral statistics. Your State AIDS Director can refer you to the individuals who can provide the best perspective on state and local data. To find how to contact your State AIDS Director, call the National Alliance of State and Territorial AIDS Director (NASTAD) at 202-434-8090. An expert advisor from state or local government may provide information in the form of standard tables. Information in this form will probably

4. Terms in bold type are defined in the text and included in a glossary (Appendix 3). A selection of other technical terms is also included in the glossary.

## Box 2

### The PMI Experience: A Team Effort Improves a Profile and Gets It Used

In each PMI site, a special coalition of volunteers was organized to represent sectors of the community that served or influenced local youth. Schools, scouting, churches, AIDS organizations, and many others were at the table. These coalitions determined that there was a need for special Teen HIV Risk Profiles.

In some PMI sites, PMI program staff assembled statistics and wrote the profile report. In other PMI sites, the report was prepared by an expert consultant. All sites found it helpful to include young people in interpreting their Teen HIV Profiles. Adult coalition members also provided useful background information. Because the numbers had been put into local context by respected community members, the profiles were more credible to the larger community.

Explaining some planning decisions to people outside PMI was a challenge, but the profiles helped. For example, in Nashville, community members were concerned that stigma could result from targeting African American adolescents. However, after PMI Staff presented compelling epidemiologic data assembled by consultants from Meharry Medical College, there was general agreement that the benefits of targeting black teens would outweigh the costs. The numbers showed that African American teens were up to four times more likely to become pregnant than white teens. Blacks were also dramatically over-represented in gonorrhea case data on males (i.e., black males comprised 48% of cases among youth under 25, whereas they constituted only 15% of the population of youth under age 25).

information feeds into an overall planning process.

Data on teen HIV risk are most likely to influence planning decisions if these data are organized to address specific questions that planners will have to answer. Before the profile is assembled, planners should set overall policies or priorities for allocating program resources, and then ask specific questions that follow from these priorities.

For example, planners could decide that their program will intervene with teens **before** they become sexually active. A specific question that would follow (and that would direct a search for data) would therefore be, “At what age do pregnancies begin to occur?”

Another example is the decision to offer Hispanic teens prevention workshops in Spanish. A related planning question would be, “How many Hispanic teens are there in each zip code in the program catchment area?”

### Will a basic Teen HIV Risk Profile provide all the information needed to make program decisions?

The data in a Teen HIV Risk Profile are interesting in themselves, but they do not provide a complete picture of local youth and their communities. Community Planning Groups compare HIV Epidemiological Profiles with lists of prevention services already in place to identify service gaps. PMI sites had additional staff and financial resources, and were able to conduct additional research through literature reviews, examinations of marketing and media databases, **focus groups**, and interviews (see box 3). This research, called “formative research” because it helps a group develop or “form” an intervention, can yield a rich understanding of the HIV-relevant risk behaviors, protective behaviors, attitudes, and lifestyles that characterize local youth.

## What resources are needed to construct a Teen HIV Risk Profile?

Assembling, organizing, and interpreting data are time-consuming activities. A basic teen HIV Risk Profile may take three months or more to complete. To guarantee this kind of time commitment, it may be advisable to pay the person responsible for keeping the work on track. Planners may also need to set aside funds to compensate an expert advisor if a lot of consultation is required.

Beyond these salary items, few resources are needed to construct a basic profile. Internet access and computer spreadsheet and graphing programs are useful, but no special statistical software is required. Some expenses for library fees and duplication can be anticipated.

Additional funding is probably necessary if planners decide to collect supplementary data through observations, interviews, **surveys**, or focus groups. Each of these data-gathering techniques has its own set of technical requirements and should be guided by expert advice. A detailed description of techniques involved is beyond the scope of this report, but some relevant references are provided in Appendix 2.

Epidemiology, the study of diseases in populations (not individuals), deals with questions about the number of cases, which groups are most affected, upward or downward **trends** in disease occurrence, and disease risk factors. An **epidemiologic profile** is a statistical description of the health of a particular group of people in a defined geographic area.

Epidemiology can be very technical. However, armed with definitions of a few key terms and straight-forward instructions and an expert advisor to answer questions, anyone who is comfortable with basic mathematics should be able to assemble a simple HIV Risk Profile. A few relevant definitions are provided below, and more can be found in Appendix 3.

To start at the beginning, epidemiologists refer to information collected for research purposes as **data**. Data from a sample of individuals are then summarized into **statistics**. For example, in the statement, "...the **mean** (or

average) test score was 75," the statistic is the mean, its **value** is 75, and it summarizes test score data from a whole classroom of individual students.

There are two major types of data:

- **Quantitative data**, which represent counts, rates, or measurements (e.g., the annual number of AIDS cases in the U.S.).
- **Qualitative data**, which are stories or themes or categories without an inherent numeric order (e.g., all the barriers to condom use mentioned by Hispanic teens in a focus group).

### Box 3

The PMI Experience: Formative Research Products Each PMI site developed:

- audience profiles, which combined Teen HIV Risk Profiles with focus group data on the situations that lead to risk behavior, the media and other information channels teens prefer, the people who influence their decisions, and the spokespeople they consider credible;
- descriptions of the social and political environments in which young people live and in which a program must function;
- lists of all the local community resources (public and private) upon which a new program can build or with which it can collaborate; and
- assessments of how accessible condoms are to youth, based on the observations of young people in different parts of the community, and surveys of outlets for free condoms (e.g., clinics and youth-serving organizations) and retail outlets.

In some cases, data are made available in untabulated form. In other instances, data are summarized or analyzed before

release to make them easier to interpret and to guard the confidentiality of those in the sample.

Epidemiologic data that are collected on a routine basis over specific time periods are sometimes referred to as **surveillance** data. Permanently maintained epidemiologic records are sometimes called **archival data**.

### How many cases are out there?

There are several ways to count the number of cases of a disease (or the number of non-disease health events like pregnancies) in a geographic area. New cases of diseases or other health events are called incident cases. In practice, the **incidence** of a disease is the number of cases identified (that is, **diagnosed** and **reported** to a disease statistics registry) during a specified period of time. Incidence is expressed as a **rate**—the number of cases per some number of people per some unit of time. For example, there were about 24 cases of AIDS per 100,000 Americans reported from July 1996 through June 1997. It is important to remember that a rate includes a **defined time period**. **Cumulative incidence** refers to the total number of new cases that have been reported, starting from the time reporting began.

**Prevalence** refers to the actual number of cases of a disease in a population at a certain time. It is estimated by a

### Box 4

#### The PMI Experience: Balancing Results of Formative Research with Other Considerations

The PMI sites found it necessary to consider the feasibility and resource requirements of their program plans along with information about the target audience and the services already in place to serve teens. This was true when they narrowed down target audiences, defined specific behavioral objectives, and chose intervention activities.

In Nashville PMI, for example, pregnancy and disease data documented sexual activity in teens as young as 12 years of age. To gain and retain support for PMI from this relatively conservative community, the community coalition included messages about delaying sexual activity in their programs for all teens, despite the fact that such messages came too late in many cases.

Sacramento's PMI coalition originally hoped to mount two kinds of interventions—one for the adolescents who had not yet become sexually active and another for the sexually active half of the teen population. Eventually, however, the site decided to narrow its focus to sexually active teens because launching two sets of programs was neither financially nor operationally feasible within the demonstration period.

# chapter 2.

MG[ GRKF GO KQNQI KE CPF 5 VCVKUVKECN VGTOU  
C S WKE M TGXKGY

complex series of mathematical equations and/or by some sort of active process for finding cases like screening. HIV prevalence studies encompass both new and previously reported cases. Diagnosing HIV usually involves a blood test. People whose blood test results are positive for HIV (indicating the presence of HIV antibodies and implying the presence of the virus) are said to be HIV seropositive. **Seroprevalence** is usually calculated as a percentage of individuals screened.

## That darned denominator!

Surveillance data are presented either as a simple count of cases or as one number divided by another number. When one number is divided by another, the first number (the number on top of the line in a fraction) is called the **numerator**. In the epidemiology context, the numerator often represents a case count, and it is usually the smaller of the two numbers. The number by which it is divided (the one under the line in a fraction) is the **denominator**. It often represents the pool or population from which cases can come, or the “population at risk”. To make comparison of rates easier, denominators are often expressed in multiples of 100 (e.g., 1,000).

It can be confusing when denominators are not expressed in the same multiple (e.g., when pregnancies are presented per 1,000 and AIDS cases are presented per 100,000) or when the time periods to which they refer differ. Transforming all rates to a common denominator can help clear up this confusion. Of course, even with a common denominator, rates that refer to time periods of different lengths cannot be compared directly.

Confusion can also occur when the populations from which cases are drawn are not the same size. The following

example shows just how tricky this denominator issue can get.

In Box 5, the expressed denominator is consistent (i.e., all rates are expressed per 1,000 women), but there is an underlying “denominator” issue. The rates still may mislead planners who are trying to determine which group has the highest number of births. A missing piece of information—how many thousand women there are in these different age subgroups—is needed. The potential confusion lies in assuming that the population subgroups referred to in each box or “cell” on the chart are of identical or similar sizes. In the example above, it is possible that there are more Hispanic women between the ages of 25 and 29. If so, they could have more births than younger women, and could require more prenatal services, even though they did not have the higher birth rate. An expert epidemiologic advisor can help clear up any confusion encountered in trying to interpret rates. To provide a complete picture, an epidemiologic profile should report rates as well as the actual number of cases.

## What are confidence intervals?

Sometimes survey results (e.g., the number of voters likely to support a political candidate, or the percentage of 15-19 year olds who used a condom at last intercourse) come with a kind of disclaimer. Just as poll results are said to be accurate within some margin of error, risk estimates are often accompanied by two other numbers: one that is higher and one that is lower than the point estimate. These two additional numbers are called **confidence limits**, and the numeric range they define is called a **confidence interval**. Confidence limits will be encountered in the national risk behavior data that are described in Chapter 3 of this

manual. For example, if 53.1 percent of U.S. teens reported condom use at last intercourse, the confidence limits might be 48.6 percent and 57.6 percent, suggesting a high degree of likelihood that the true percentage is somewhere in that range.

Confidence intervals are used because, theoretically, if the same survey procedures were used twice with the same population, the results would probably change slightly the second time. Statisticians often calculate confidence limits in such a way that the **probability** that the true figure is outside the confidence interval is less than 5 percent. ( $p < .05$ )

As previously mentioned, Appendix 3, provides definitions of other epidemiologic and statistical terms. Appendix 2 provides references to academic text books with more detailed information.

**Box 5**

**United States: Birth rates for Hispanic women, 1995 per 1,000 women**

Age	All Hispanic women
20-24	188.5
25-29	153.8

This chapter describes the major types of data used to construct Teen HIV Risk Profiles. Examples from the PMI sites are provided to illustrate how the data can be used. In some cases, the examples do not use the very latest data because the PMI profiles were compiled several years ago. However, the formats used by the data sources are fairly consistent over time, and current information can be obtained by following the directions given.

### What do Census figures say about the youth in a community?

Basic social-demographic information is a starting place for describing youth in a community. The U.S. Department of Commerce collects demographic information every 10 years through the U.S. Census. Census data can provide information on how many youth are in each age group or in each racial/ethnic group in a community. Census data also include statistics on school enrollment, educational attainment, and employment status for persons aged 16 to 19 years. Finally, the Census provides population breakdowns by poverty status and household type (e.g., the number of female-headed households with children under 18 years old). This information can help planners assess the economic situation of local youth.

Census data are available by state, metropolitan statistical area, county, census tract, and zip code and are typically presented in raw numbers. Information from **census tracts** (small areas containing 3,000-6,000 people) can be combined or aggregated into other units that are politically or programmatically meaningful in a particular community. For example, the city of Newark is divided into 5 Wards, and the PMI site in Newark was able to aggregate census tracts into Wards.

#### *1990 Census data are available from:*

- the Internet (go to [www.census.gov](http://www.census.gov), click on "Access Tools," and then "Map Stats" or "1990 Census Lookup")
- local libraries (ask for print copies)

Box 7, which contains data on white males in Essex County, New Jersey, is an example of the kind of information provided on the Census website.

It takes pages and pages in Census reports to provide information on all adolescents of all racial/ethnic categories in this detailed form. In order to see patterns in the data (e.g., **proportions** of youth in various racial/ethnic groups), it is often necessary to summarize raw Census numbers. The **pie chart** and table in Boxes 8 and 9 combine data on males and females 15-19 years old to show how summarized data are easier to interpret<sup>5</sup>.

It should be noted that race categories in Census data include White, Black, American Indian, Eskimo or Aleut, Asian or Pacific Islander, and Other Race. The Census collects information about persons with Hispanic origin, but they may be of any race and are already included in one of the race categories. As shown in the table, the number of cases totals 100% without counting Hispanics. Planners must make sure that they do not double-count Hispanics when reorganizing data.

Census data are collected only every 10 years. However, the Census website does provide updated estimates (the most recent are for 1997) for population counts by age (5-year age groups), gender, and race/ethnicity using modified race/Hispanic origin categories (see census documentation for details). These data are available at national, state, and county levels.

#### *Updated Census estimates are available from:*

- the Internet (go to [www.census.gov](http://www.census.gov), then click on "Estimates")
- most local libraries (ask for print copies)
- regional census offices (ask for print copies; see Box 10, for list of regional offices)

The Census does not include information on youth in foster care, in the criminal justice system, or living on the street. These youth may be at especially high risk for some health problems, and information about them may be available from local child welfare agencies, juvenile justice systems, and homeless organizations. The scientific literature is another good source of information about high-risk youth, but it is usually not specific to local areas.

#### *Information on high-risk youth is available in scientific articles like:*

# chapter 3.

KP HQTO CVKQP QP J KX TKUM KP [ QWP I RGQRNG

- Magura S, Shapiro JL, Kang SY. Condom use among criminally involved adolescents. **AIDS Care** 1994;6:595-598.
- Halpern-Felsher BL, Millstein SG, Ellen JM. Relationship of alcohol use and risky sexual behavior: a review and analysis of findings. **Journal of Adolescent Health** 1996;19:331-336.

Some data sources combine Census data and other information. For example, the annual **KIDS COUNT Data Book**, published by the Annie E. Casey Foundation, compiles data from various sources that measure the educational, social, economic, and physical well-being of children. This book provides detailed information about individual states and the nation as a whole.

*1998 KIDS COUNT Data Book is available from:*

- the Internet (go to [www.aecf.org/aeckids.htm](http://www.aecf.org/aeckids.htm))
- the Annie E. Casey Foundation (call 410-547-6600 for print copy)

Another place where Census data are supplemented with information from other sources is **USA Counties**. This source provides information on crime statistics by county, as well as a general profile of the area (e.g., % high school graduates, % unemployed).

*USA Counties is available from:*

- most local libraries (ask for CD-ROM)

What do disease and pregnancy statistics tell us about teen HIV risk?

As mentioned previously, there are limitations in all the sources of information about HIV risk:

- Actual AIDS cases among adolescents are

## Box 6

### The PMI Experience: Which Data to Use?

Not surprisingly, the PMI sites found that no one source of data gave them everything they needed. Combining information from a number of sources proved more helpful. The data they found most useful came from the following sources:

- U.S. Census;
- HIV/AIDS surveillance;
- STD records;
- pregnancy records; and
- Youth Risk Behavior Survey

When they compared notes, the sites found that the quality of these different indicators of local risk status varied across the country. They also found some data to be far too detailed for planners to digest. The detailed data had to be summarized to answer the questions that program planners had asked.

Some PMI sites were able to use figures already compiled by local HIV/AIDS Prevention Community Planning Groups (CPGs), but other sites constructed a Teen HIV Risk Profile and then provided it to their CPGs.

relatively uncommon, partly because of the long latency between HIV infection and the development of AIDS. However, it is likely that many individuals initially diagnosed with AIDS in their twenties were infected with HIV as adolescents (Office of National AIDS Policy, 1996).

- For several reasons, the reported number of HIV infections is an underestimate.
- Other sexually transmitted diseases and pregnancies (sometimes called surrogate markers of HIV risk) certainly reflect levels of unprotected sex, but say nothing about the likelihood of encountering a sex partner who is HIV-infected.

Although each of these indicators of HIV risk in teens is an imperfect measure, taken together, they indicate the scale of the problem in a community. They can also point to subgroups of youth who are likely to be at particularly high risk.

### Statistics on people living with AIDS

All states and territories and six high-prevalence metropolitan areas collect information on reported AIDS cases. These data are reported to the CDC after identifying information has been removed. CDC summarizes national AIDS trends twice a year in the *HIV/AIDS Surveillance Report*. The report breaks down AIDS and HIV data

#### Box 7

1990 U.S. Census Data  
Database: C90STF3A  
Summary Level: State—County

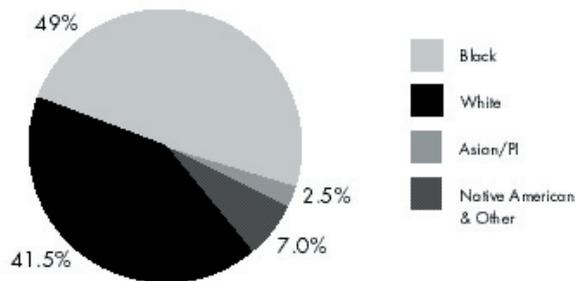
Essex County: FIPS.STATE=34,  
FIPS.COUNTY90=013  
Race by Sex by Age  
Universe: White males

Under 1 year	1969
1 and 2 years	5291
3 and 4 years	4470
5 years	2235
6 years	2010
7 to 9 years	6654
10 and 11 years	4117
12 and 13 years	4146
14 years	2017
15 years	2070
16 years	2106
17 years	2457
18 years	2284

#### Box 8

##### Essex County, New Jersey

Adolescents ages 15-19 by race, 1990 (N = 54,258)



#### Box 9

##### Essex County, New Jersey:

Adolescents ages 15-19 by race/ethnicity, 1990  
(N = 54,258)

	N	%
White	22,532	41.5%
Black	26,572	49.0%
Native American	116	0.2%
Asian/PI	1,367	2.5%
Other	3,671	6.8%
Hispanic Origin	7,920	14.6%

Source: US Census Bureau, 1990 Census

by state, mode of exposure to HIV, sex, race/ethnicity, age group, deaths, and case definition category. This last breakdown is necessary because the official AIDS case definition changed in 1993 to include more of the HIV-infected population.

#### The HIV/AIDS Surveillance Report is available from:

- the National Prevention Information Network, formerly the National AIDS Clearinghouse (call 1-800-458-5231 for a free single copy)
- the Internet (go to [www.cdc.gov/publications.htm](http://www.cdc.gov/publications.htm))

For state or local breakdowns by specific variables such as age or **exposure category**, it is necessary to contact local or state health departments. Each state has policies

5. Caution should be exercised in summarizing data because summaries can create a misleading picture. Tips for avoiding misleading presentations of data are offered in a short, entertaining book called entitled *How to Lie with Statistics* (Huff, 1993).

regarding the release of their data at state, metropolitan area, county, or health district levels. The **AIDS Public Information Data Set** contains information on the data release policies of individual states.

*The AIDS Public Information Data Set is available from:*

- the National Prevention Network (ask for print copies; inventory number D206)
- the Internet (go to [www.cdc.gov/nchstp/hiv\\_aids/software/apids/apidssof.htm](http://www.cdc.gov/nchstp/hiv_aids/software/apids/apidssof.htm))



The table above provides an example of district-level AIDS surveillance data for Davidson County, Tennessee, where the Nashville PMI site is located. Note that the number of cases in the 13-19 year age range is extremely small, even over a 6-year reporting period. Small numbers are often not released by health departments for reasons of confidentiality. Percentages are not shown for 13-19 year olds because percentages calculated from small numbers can be misleading. Statewide data should be examined if more local data contain extremely small numbers.

This table shows that at least 10 times as many AIDS cases were reported among young adults ages 20 to 29 as among teens. Among young men ages 20 to 29, most cases were attributed to male-to-male sexual contact. Among young women, heterosexual contact (57%) and injection drug use (40%) accounted for the largest portions of reported

AIDS cases. There were more males than females who were thought to have been infected by other exposures<sup>6</sup>. Like in Davidson county, the most common AIDS

Box 10 List of U.S. Census Regional Offices	
Atlanta, GA 3964	(404)730-3833/
Boston, MA 0565	(617)424-0510/
Charlotte, NC 6548	(704)344-6144/
Chicago, IL 1791	(708)562-1740/
Dallas, TX 4434	(214)640-4470/
Denver, CO 6769	(303)969-7750/
Detroit, MI	(313)259-1875/

exposure mode among adolescent and adult men nationally (45%) was male-to-male sexual contact. Among women in the U.S., the most AIDS cases (38%) were attributed to heterosexual contact. Injection drug use accounted for 22% of cases for men and 29% for women in the country as a whole (**CDC, HIV/AIDS Surveillance Report 1998;10(2)**).

**Statistics on people who test positive for HIV**

Our information on rates of HIV infection is often incomplete. Much HIV infection goes undetected altogether. In some states, cases of HIV diagnosed by private physicians and certain other health care providers (e.g., HMOs) are not reported to the health department. Other factors like the widespread availability of home test kits combine to make the reported number of HIV cases an underestimate.

Still, there is little debate about the fact that, among U.S. teens, HIV infection rates are relatively low in comparison with STD and pregnancy rates.

Recently, more states have begun to require HIV case

reporting. The **HIV/AIDS Surveillance Report** and state health departments have lists of the states that require HIV reporting at present. Box 12a gives a snapshot of HIV trends based on the data from these states.

All 50 states report data from sites that provide CDC-funded HIV counseling and testing. CDC-funded sites account for less than one third of all HIV tests in the United States each year (HIV Counseling and Testing in Publicly Funded Sites, 1996 Annual Report; [www.cdc.gov/nchstp/hiv\\_aids/pubs/cts96.htm](http://www.cdc.gov/nchstp/hiv_aids/pubs/cts96.htm)). Because people can be tested more than once, these are the numbers of counseling and testing episodes, not the number of HIV cases.

A more complete picture of HIV prevalence in certain groups of young people is provided through ongoing screening programs conducted by the Job Corps and the U.S. military. In addition, special seroprevalence studies (see box 12b for an example) are conducted periodically in geographic areas known to have extremely high HIV rates.

The following sections describe these screening programs and special serosurveillance studies.

#### HIV Screening of Job Corps Entrants

The Job Corps is a federally funded job training program for adolescents and young adults who are economically disadvantaged. It regularly tests new recruits ages 16-24 for HIV at its 106 sites around the country (before July 1, 1993, the age range was 16-21). Since 1987, about 60,000

Job Corps entrants have been screened each year.

#### *Information about national trends among Job Corps entrants is available in:*

- Valleroy LA, MacKellar DA, Karon JM, Janssen RS, Hayman CR. HIV infection in disadvantaged out-of-school youth: prevalence for U.S. Job Corps entrants, 1990 through 1996. **Journal of Acquired Immune Deficiency Syndromes and Retrovirology** 1998;19(1):67-73.

Information about the Job Corps data for some individual states is available. The source of this information varies. Some state health departments have designated contacts for local serosurveillance studies (a list of these states is provided in Appendix 4). If a state is not on the list, the state AIDS Coordinator in the State Health Department should know who to contact.

Although Job Corps data are summarized by metropolitan statistical area, sample sizes at this level of aggregation are very small. Any generalization from such small sample sizes is problematic, and descriptions of trends within local demographic subgroups are likely to be invalid. For example, a 50% increase over 2 cases is only one additional case—hardly enough to establish a pattern! Aggregation at the state level is recommended because small local sample sizes can be misleading, and because breaking statistics down by ethnicity in local areas

Box 11

Davidson County Health District, TN: Reported AIDS cases in adolescents and adults under age 30, by sex and exposure category, 1992-April, 1998

	Ages 13-19 years		Ages 20-29 years	
	Number		Number	%
<b>Male exposure category</b>				
Men who have sex with men	0		147	70%
Injecting drug use	1		32	15%
Heterosexual contact	0		7	3%
Other		1		12%
Total males	2		211	100%
<b>Female exposure category</b>				
Injecting drug use	1		23	40%
Heterosexual contact	4		33	57%
Other		0		3%
Total females	5		58	100%

Source: Tennessee State Health Department

with few Job Corps entrants could inadvertently disclose the identities of infected persons. In fact, for confidentiality reasons, state health departments will not release data if the number of cases is small.

Interesting patterns can be detected in state-level data, however, even if they have been collapsed over time. In an example from Virginia (see Box 13), ethnicity data are presented using five years of cumulative data because of the small number of entrants who tested HIV seropositive. The table shows that HIV seroprevalence in Job Corps entrants from Virginia was much higher among African Americans than among other ethnic groups. Although seroprevalence during this period was higher among female recruits than among male recruits at the national level (Valleroy et al., 1998), this was not the case in Virginia.

HIV Screening of Civilian Applicants for Military Service

The U.S. Department of Defense tracks HIV seroprevalence among civilian applicants for military service aged 17-19 and 20-24. Since the mid-1980s, all persons

applying for active or reserve duty, service academies, and the ROTC have been screened for HIV.

*Data on HIV seroprevalence among military applicants are available from:*

- state serosurveilliance studies contacts (see list in Appendix 4), where applicable.
- If a state is not on the list, state AIDS Coordinators in the State Health Department should be able to provide the proper contact information.

Although many youth are screened for HIV this way, the military applicant pool is not a perfect reflection of the general population of young people. Because youth with a known history of drug use or homosexual activity are excluded from the military, relatively few of them may apply. In addition, youth in higher income brackets tend to be under-represented among applicants for military service. HIV seroprevalence among military applicants is markedly lower than that of Job Corps entrants. A large group of applicants (at least statewide figures in most cases) would be needed to draw any meaningful conclusions from

6. Check with the health department for its definition of the “other” exposure category; this definition can vary somewhat.

military applicant data.

### Special Local Serosurveillance Studies

In several metropolitan areas with extremely high local HIV prevalence, clinic-based seroprevalence studies are conducted periodically. Findings of the studies (some of which include adolescents) are summarized in the CDC publication **HIV National Serosurveillance Summary**.

*The HIV National Serosurveillance Summary is available from:*

- the National Prevention Information Network (call 1-800-458-5231 for a print copy).
- the Internet (go to [www.cdc.gov/nchstp/hiv\\_aids/pubs/hivsero.htm](http://www.cdc.gov/nchstp/hiv_aids/pubs/hivsero.htm))

The expert consultant recommended by your State AIDS Coordinator will know whether any other special studies have been conducted in your area. This person can also explain the strengths and limitations of these studies.

The published scientific literature may also contain reports of seroprevalence studies in specific areas. One searchable online database is Medline, a comprehensive catalogue of scientific articles on health and medicine that is maintained by the National Library of Medicine at the National Institutes of Health.

*Free access to Medline is available through:*

- the Internet (go to [www.nlm.nih.gov](http://www.nlm.nih.gov); in a search use key words like “youth” or “adolescence”, “HIV seroprevalence,” and the name of the local area (region of the country))

If both general surveillance data and information about special populations of young people are available for a local area, it is wise to include both kinds of data in the Teen HIV Risk Profile. Routine surveillance data will give planners information about cases likely to be referred for treatment through the system that is already in place. Information about special groups depends on more active case finding, and is likely to generate higher estimates of HIV infection rates. Discrepancies between general surveillance and special population estimates may be useful

### Box 12a

#### What's Known About Trends in HIV

CDC recently examined trends in HIV diagnoses reported in 25 states. HIV diagnoses remained relatively stable in these states over a three year time period, but HIV diagnoses among Hispanics increased. HIV data include higher proportions of women and minorities than AIDS case data do. The HIV data also indicate a continuing toll among young people ages 13-24, with at least 2,000 young people diagnosed with HIV in these states every year.

Of the 7,200 cases of HIV reported among 13-24 year olds from January 1994 to June 1997:

- 3,203 (44%) were female
- 4,566 (63%) were African Americans
- At least 1,886 (26%) had heterosexually acquired infections
- 2,270 (31%) of the infections were in men who have sex with men
- 449 (6%) of the infections were in injection drug users

Source: Trends in the HIV and AIDS epidemic, 1998 available on [www.cdcpin.org/geneva98/trends/trends\\_2.htm](http://www.cdcpin.org/geneva98/trends/trends_2.htm).

### Box 12b

#### HIV Among Young Men Who Have Sex with Men

Recent studies of young men recruited on the street show that both HIV and HIV risk behaviors remain high among young men who have sex with men.

In a six-county sample of urban men ages 15-22 who have sex with men, between 5% and 9% were infected with HIV. Higher percentages of blacks (8%-13%) and Hispanics (5%-9%) were infected, compared with white young men who have sex with men (4%-6%).

Source: Valleroy LA, MacKeller D, Janssen R, Jacobs T. HIV and risk behavior prevalence among young men who have sex with men sampled in six urban counties in the U.S.A. Presentation at: XI International Conference on AIDS, Vancouver, Canada, 1996.

in guiding targeted outreach.

**Statistics on sexually transmitted diseases (STDs)**

There are convincing reasons to examine STD data even when the primary area of interest is HIV risk among adolescents:

- STDs are transmitted by unprotected sex, a primary route of HIV transmission.
- HIV infection risk rises when STD lesions are present.
- For gonorrhea and chlamydia, teens represent more reported cases than any other age group, and rates among female teens are highest of all.

By law, every state requires diagnoses of gonorrhea to be reported. As of 1998, 49 states required chlamydia

reporting. But without active screening, not all cases of chlamydia or gonorrhea are diagnosed. (See Box 14 for a description of how data on these diseases influenced PMI planners.)

CDCs **Sexually Transmitted Disease Surveillance Report** provides an overview of the STD situation in the United States, descriptions of STDs in selected populations that are a focus of national and state prevention efforts, and statistical information about STDs at the state, city, and national levels. At this writing, the latest report includes 1998 data.

***The Sexually Transmitted Disease Surveillance Report is available from:***

- Office of Communications, NCHSTP, CDC (write to 1600 Clifton Road, Mailstop E-06, Atlanta, GA 30333 for print copies)
- the Internet (go to [www.cdc.gov/publications.htm](http://www.cdc.gov/publications.htm) for reports dating from 1993)

Many local areas report STD cases as raw numbers, that is, a count of teens who are diagnosed with an STD. In contrast, national-level data are reported as rates. To compare local data to state or national data, rates must be calculated using appropriate demographic data for denominators.

Box 13			
Virginia: HIV seroprevalence among Job Corps entrants, by year and by ethnicity, 1993-97			
By year	Number tested	Number positive	Percent positive
1993	1,785	3	0.17%
1994	1,755	13	0.74%
1995	1,753	5	0.29%
1996	2,659	9	0.34%
1997	1,910	2	0.10%
By ethnicity			
White/Other	2829	2	0.07%
African American	7001	30	0.43%
By gender			
Male	4507	20	0.44%
Female	2494	10	0.40%
Source: CDC, Division of HIV/AIDS Prevention, Surveillance & Epidemiology, Prevention Services Research Branch			

**Statistics on teen pregnancy**  
 Most HIV infection among teens is thought to be due to unprotected sex. Pregnancy rates are considered surrogate markers for HIV risk because they indicate unprotected sex and because they have been shown to be associated with several other risk factors, including early initiation of sexual intercourse, multiple partners, STDs, and drug use (Dryfoos, 1990). Patterns of unprotected sexual behavior (at least among heterosexual youth) are fairly well reflected by pregnancy rates. They underestimate risk of HIV transmission, however, because some teens employ non-barrier forms of contraception such as contraceptive pills instead of condoms.

Teen pregnancy rates are estimated for states and the nation as a whole, and are based on recorded births and abortions,

excluding stillbirths and miscarriages.

All births in the U.S. are recorded, and county-wide teen birth rates are available from state or local health departments. Data on abortions are collected in some states and are also available from state or local health departments. CDC's **Monthly Vital Statistics Report** presents monthly and cumulative data on births, deaths, marriages, divorces, and infant deaths for states and for the United States as a whole.

***The Monthly Vital Statistics Report is available from:***

- the local library (ask for print copies)
- the Internet (go to [www.cdc.gov/nchswww/products/pubs/pubs/mvsr/mvsr.htm](http://www.cdc.gov/nchswww/products/pubs/pubs/mvsr/mvsr.htm)); a special supplement of the report that focuses on teenage birth rates (**Teenage Births in the United States: state trends 1991-1996, an Update**. 1998;46(11)) is available at [www.cdc.gov/nchswww/products/pubs/pubs/mvsr/supp/46-45/46-45.htm](http://www.cdc.gov/nchswww/products/pubs/pubs/mvsr/supp/46-45/46-45.htm)

As with STD data, local statistics on teen pregnancy are often reported as raw numbers—the number of births or abortions among young women by age and ethnicity within a county or zip code. In order to make comparisons with state or national data, it is necessary to calculate rates using census data for denominators. For pregnancy, rates per 1,000 women are usually reported.

Box 16 is an example of pregnancy data at the state level. Like national figures, it shows that the largest number of teen pregnancies occur among young white women. African Americans and Hispanics have higher pregnancy rates than whites, but this gap in rates is narrowing.

**What do behavior surveys say about HIV risk?**

While surveillance data on STDs and pregnancy clearly show that youth are having unprotected sex, it is safe to assume that young people who end up as “statistics” are not the **only** ones engaged in risky behavior. It is necessary to survey teens who do not appear in current disease or pregnancy statistics to understand the real extent of risky sexual behavior.

Surveys of the general teen population can also provide information about drug-related HIV risk and the extent of **preventive** behaviors. Data on whether youth are

abstaining from sex, refusing drugs, using condoms, and obtaining preventive health care are just as important as data on risky behaviors. They can guide interventions in building on strengths teens already have.

One useful source of behavioral data is the **Youth Risk Behavior Surveillance System** (YRBSS), a school-based survey covering six health issues. YRBSS questions that are directly related to HIV include items on:

- sexual activity
- condom and contraceptive use
- number of partners
- use of alcohol or drugs at last intercourse
- injection and other drug use
- pregnancy and STD history
- HIV education

The YRBSS is conducted during odd years (the most recent data available are from 1997) in public, private, and parochial high schools across the country and produces nationally **representative** data. State level data, grouped by grade level, gender, and ethnicity, are available, as are data on certain high prevalence cities (e.g., New York and Miami). However, not all states agree to participate in the YRBSS, and response rates in some states are low. YRBSS data are considered to be representative of all high school students in a state only if 60 percent of eligible students in a state respond.

***YRBSS national results and trends over time are available from CDC in several forms:***

- summarized in **Morbidity and Mortality Weekly Report** (a publication that is available on the Web at [www.cdc.gov](http://www.cdc.gov); the latest YRBSS results can be found in **MMWR** 1998;47(SS-3).
- in detail on a CD-ROM (free from CDC's Division of Adolescent School Health; call 770-488-3257 for a copy)

***General information about the YRBSS survey is available from:***

- the Internet (go to [www.cdc.gov/nccdphp/dash](http://www.cdc.gov/nccdphp/dash). The website also lists participating state and local educational agencies)

Box 14

The PMI Experience: Using STD Data to Support Decisions on Target Audiences

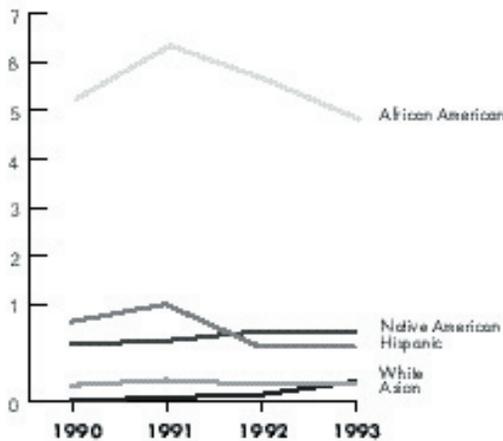
The PMI sites found that syphilis was rare among teens, so data on syphilis were not particularly useful for profiling adolescent HIV risk. In contrast, data on gonorrhea and chlamydia were useful because these diseases were widely prevalent in adolescents.

In some cases, however, gonorrhea and chlamydia painted different pictures of HIV risk among adolescents. For example, in Maricopa County Arizona, home of the Phoenix site, gonorrhea and chlamydia case data suggested different target audiences.

The graph on the left below presents gonorrhea cases among young women in Maricopa County. Taken alone, it would indicate that African Americans were the only ethnic group at very high risk. However, as shown in the graph on the right, chlamydia data from the same region indicated a comparable level of risk among Native Americans, and Hispanics also appeared to be at somewhat elevated risk compared to whites and Asians.

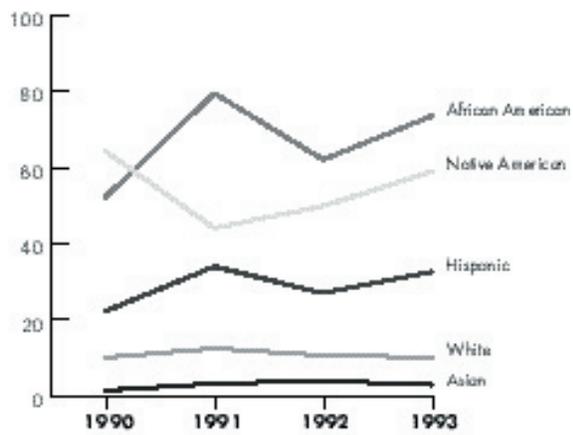
The health department told the Phoenix site that there were no active screening programs underway for either disease. Without a reason to believe that data on one disease were more accurate, and without consistent evidence that African Americans were the only young people at high risk, the site decided to target all ethnic groups.

**Gonorrhea cases\* per 1000**  
Women 15-24 in Maricopa County\*\* by Race



\*Data on STDs from the Maricopa County Department of Health Services  
\*\*Population estimates from the 1990 census of Maricopa County

**Chlamydia cases\* per 1000**  
Women 15-24 in Maricopa County\*\* by Race



\*Data on STDs from the Maricopa County Department of Health Services  
\*\*Population estimates from the 1990 census of Maricopa County

### Box 15

#### Data on Gonorrhea and Chlamydia among Youth Show Rates are Highest for Young Women

##### Gonorrhea

This disease can be silent in men and women, so their rates can be under-reported unless there is active screening. Nonetheless, according to the 1998 STD surveillance data, young women (15-19 year olds) have the highest annual rate (779.7 cases per 100,000) of gonorrhea. STD surveillance experts at state and local health departments can provide information on local screening practices and can make recommendations for data interpretation.

##### Chlamydia

Chlamydia is extremely prevalent among adolescents, and the rate of chlamydia is highest in youth aged 15-19. Young women had the highest annual rate of diagnosed chlamydia in 1998 (2,359.4 per 100,000). Although there are often no obvious symptoms of chlamydia, it can have serious health consequences such as infertility, so screening programs have been established in many areas of the country. Screening programs may not yet be active in your community. Again, STD surveillance experts at health departments can provide information on local screening practices and can make recommendations for data interpretation.

(Source: CDC, Sexually Transmitted Disease Surveillance 1998)

be adequate for your planning needs. More detailed information may not be available because it would identify individuals or require too much staff time to assemble.

Technical expertise can also be found in a school of medicine or public health, or the psychology, sociology, or anthropology department at a local university. In addition,

the expertise of people who know the target audience and who are actually part of it should be sought.

The contributions of several important players are required at a number of points in the HIV risk profile development process:

##### **The program planners**

- decide that a profile is needed
- make final decisions about priorities and planning questions
- approve the profile

##### **The profile developer**

- helps planners ask specific questions that data can answer
- manages the data collection and profile writing processes, ensuring that they are on strategy and on schedule

##### **The expert advisors**

- help locate and interpret local and national behavioral and epidemiologic data
- explain national trends and advise about their applicability to local areas
- identify strengths and limitations of data
- recommend additional data sources

##### **The community**

- identifies the important considerations for setting prevention priorities
- explains the context of information from and about specific populations
- disseminates findings
- marshals support for any decisions that the profile informs

#### How is a Teen HIV Risk Profile used?

A Teen HIV Risk Profile is combined with other information about the **target audience** and the community to make program decisions. Broadly speaking, these decisions concern which youth to target, what behavioral objectives to set, what services to mount, and where services should be concentrated. In other words, risk

Box 16

Arizona: Pregnancies, births and abortions among young women ages 15-19, by ethnicity, 1992

	White	Black	Hispanic
Number of pregnancies	14,040	980	6,500
Pregnancy rate (per 1,000)	132	196	194
Birth rate (per 1,000)	80	112	135

*Information on out-of-school youth is available in:*

- **Morbidity and Mortality Weekly Report** (Health risk behaviors among adolescents who do and do not attend school-United States, 1992. **MMWR** 1994;43(8); go to [www.cdc.gov](http://www.cdc.gov)).

**Statistics on teen drug use**

In-depth information about drug use is available from the **National Household Survey on Drug Abuse**, the primary source of information on the use of illegal drugs by the U.S. population 12 years old and older. This study is designed to be representative of the housed population in that age range; it has been conducted periodically since 1971 and annually since 1992 by the Substance Abuse and Mental Health Services Administration (SAMHSA). State-level data are available for the 1993 survey, and will be available for the 1999 survey (forthcoming). The **Monitoring the Future Study**, conducted by the University of Michigan, is another good source of national teen drug use data (see Appendix 5 for more information).

*Information and data from the National Household Survey on Drug Abuse is available from:*

- the Office of Applied Studies, SAMHSA (call 301-443-6239 for information)
- the Internet (go to [www.health.org/pubs/nhsda/](http://www.health.org/pubs/nhsda/))

[index.htm](#) for national-level data;)

**Information on high-risk youth**

Many youth at highest risk for HIV infection are not interviewed in the national behavioral surveys mentioned above. They are the young people who have dropped out of school, or who are homeless or incarcerated. Not being reachable through schools or established households, they fall outside the sampling frame—the pool from which the survey **respondents** are drawn. Researchers at local universities or health departments may have data on youth in these situations.

It is important to try to include information on high-risk youth in a teen HIV Risk profile because:

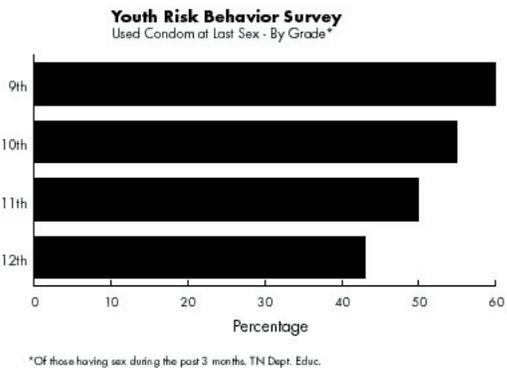
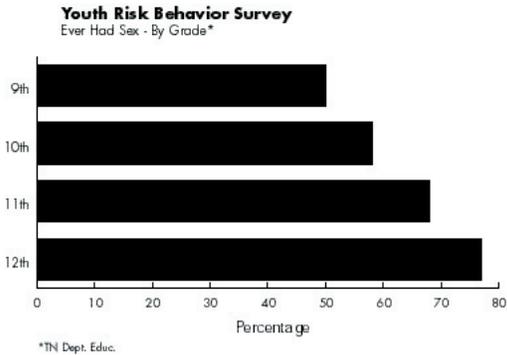
- they are likely to require intensive services;
- they often continue to interact with young people in school and thus may introduce additional HIV risk into the general population of teens; and
- they move in and out of high-risk status; one noted researcher (Dryfoos, 1990) has estimated that fully one-quarter of the young people in this country--a segment far too large to ignore--can be considered high risk at some point during their adolescence.

It is likely, however, that a search for local data on risk behavior among out-of-school youth will be unfruitful. These data are rare. Even when they are available, they may be of poor quality because they are out of date, based on poorly worded interview questions, or based on interviews with only a handful of participants who happened to be available at the time (i.e., a convenience **sample** that does not produce **generalizable** findings). Although a Teen HIV Risk Profile probably will not include behavioral data on the high-risk youth in a community, any information about how many of them there are and where they can be reached should be useful to service planners.

Box 17

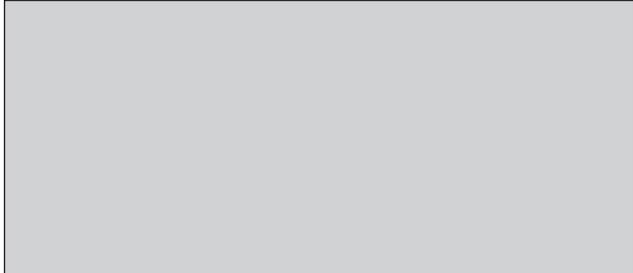
The PMI Experience: Using YRBSS Data to Understand Youth Behaviors

The Nashville site used YRBSS data from 1993 to construct the following figures on teen sexual activity and condom use for its Teen HIV Risk Profile.



The coalition saw that more youth became sexually active as they got older, but fewer and fewer used condoms as they moved through high school. Similar trends have been observed at the national level. They have been explained by the fact that young teens use condoms for contraception, and older teens move on to other forms of contraception and stop using condoms. The Nashville site decided to promote condom use for the prevention of disease and unwanted pregnancy.

In Sacramento, the PMI site found that state YRBSS data did not come up to the standard of 60% participation, were not considered representative, and thus did not have confidence limit calculations. As a result, they used a combination of national and state YRBSS data for planning purposes.



This chapter covers the major steps involved in compiling a Teen HIV Risk Profile. The chapter also includes a checklist (see page 30) that provides more detail. It should be useful in tracking progress through the steps.

**An important note:** Before plunging into the process, planners should first determine whether local organizations or the Community Prevention Planning Group have already worked with experts to assemble statistics on teens. If so, the Teen HIV Risk Profile may not need to duplicate the effort.

### Step 1. Assign lead responsibility for the profile, specify the questions the data should answer, and gather available data

The activities that lead up to actually sitting down with the data are very important. They were considered earlier in this document, and are reviewed briefly below.

Chapter 1 talks about recruiting and leading the Teen HIV Risk Profile team. It stresses the value of early input from people who will use the profile for decision making and from people who will be affected by the planning decisions. This chapter also emphasizes the importance of helping program planners ask specific questions based on their overall planning priorities.

To frame planning questions that data can answer, an organization must first clarify its overall service priorities. This is not easy, and it takes time, but it is time well spent. Remember that planning questions should be specific enough to make sure that only necessary data are collected, and yet broad enough to allow unexpected needs to become apparent. Box 19 outlines the planning priorities that one PMI site set, the HIV risk data that were most useful in answering specific planning questions, and the teen target audience eventually selected.

Chapter 3 describes the major sources of demographic, disease and risk behavior information pertinent to young people. Appendices 2 and 4 list additional sources of data that may be of interest.

Allow at least a couple of months for these preparatory

activities. Collecting all the data before beginning to analyze and write will probably save time in the long run.

### Step 2. Read, analyze, and interpret the data

The purpose of this step is to understand what the data suggest, and to determine the extent to which they reflect the status of various segments of youth in the community.

The first task is to read all the assembled data—local data, national data, and literature from scientific journals—to get a general sense for patterns of youth risk. The following questions can guide this reading:

- Are there striking differences among subgroups of youth (broken down by gender, ethnicity, age group, or area of residence) in data from each major source?
- Do the data from various sources identify the same risk groups (e.g., do certain zip codes consistently have the highest number of teen pregnancies and STD cases)?
- Are there any clear trends over time?
- Is the pattern of risk in local data consistent with state-level or national-level patterns?
- Are there gaps in the data (e.g., no information about gay youth)?

Remember that all data have limitations, and that data are often biased in one direction or another. The potential sources of **bias** are numerous (e.g., small sample sizes, unrepresentative samples, and incomplete case identification). Fortunately, in many cases, the limitations of each data set either will be described in documentation that accompanies the data or will be apparent to the expert advisors involved in creating the profile.

Imperfect data can still be useful. National figures or special studies conducted in similar localities can lead to educated guesses about what is missing in local figures. Furthermore, biased data may be good enough for planning purposes. For example, biased data collection methods (e.g., those that did not survey households without phones) can define meaningful trends if the same methods have been used consistently over time.

# chapter 4.

EQP UVT WE VKP I C VGGP

\* +8 4 KUM RT QHKNG

If state or local data are not consistent with national data, it is hard to know which information should receive more weight. Thinking about the type of area you live in can provide some perspective. For example, if the community is in an epicenter of the epidemic—one of the areas with the highest HIV incidence—then local risk indicators may be ahead of national trends.

Of course, it is advisable to obtain the most current data possible, but sometimes the most recent available data are relatively old. Remember that AIDS data and older HIV data may contain proportionally fewer cases among women, minorities and young people than recent HIV data contain.

Finally, check to make sure that all explicit planning questions have been addressed by the assembled data. Decide whether new questions should be added to the list because previously overlooked issues emerged when the data were compiled.

### Step 3. Draft the profile

The profile should begin with a brief introduction that explains the purpose of the profile and recognizes the people who have contributed to the report. Including a description of the community is a good idea. A narrative description should be accompanied by demographic data.

Next, provide data from each source, grouped by risk indicator. For example, condom use data from the state YRBSS might precede data from a local university-based researcher on teen condom use.

For all rates, denominators should be specified. It may be appropriate to transform rates to make denominators consistent. For some statistics, it may be advisable to include absolute numbers as well as rates.

Throughout the body of the report, text should contain both statistics and narrative. Statistical tables and figures allow readers to take in a lot of information at a glance, but they are not always clear to everyone, and they do not always tell the whole story. Narrative that explains the data more fully and highlights the main findings should accompany numeric and graphic presentations of statistical information. Narrative can also help readers avoid misinterpreting the data.

For example, a table estimating the number of HIV-infected teens in a large metropolitan area might provide the following statistics:

The table tells readers that most cases of HIV were thought to occur among non-Hispanic Whites, but the table is not self-explanatory. The accompanying narrative should describe:

- the time period during which these cases of HIV infection were estimated to occur
- who is included in the “Other” category, and
- how the estimates of the numbers of HIV-infected teens were derived

The text also should include facts that, while not strictly necessary in order to understand a set of numbers, help put the statistics into context. For

the table above, it would be useful to know that most Hispanic youth were second-generation Americans who spoke English.

Finally, the draft text should summarize the main conclusions about local teen HIV risk that can be drawn from the data. If possible, these conclusions should reflect consistent patterns in the data—points of agreement across data sources. In the absence of agreement across sources, the conclusions should rest on the most reliable data. Alternative interpretations should be provided where warranted, and data limitations should always be noted in the report.

**Step 4. Submit the draft to planners, revise it and update it periodically**

Have program planners and expert and community advisors review the draft profile so that their suggestions can be incorporated into the final report. If some of the original planning questions cannot be answered by available data, service providers and target audience representatives may be able to draw on their experience with the community to help fill in gaps.

Ideally, the revision process is an on-going one. Most epidemiologic and behavioral survey data are collected at regular intervals. A Teen HIV Risk Profile must be revised periodically to take new source data into account if it is to continue to provide a sound basis for program design and improvement.

Box 18

Metro area: Estimated number of HIV+ youth ages 15-19, by ethnicity, 1996

Ethnicity	Estimated number of HIV+
White, non-Hispanic	511
African American	81
Hispanic	78
Asian/Pacific Islander	2

Step 1: Assign lead responsibility for the profile, specify the questions the data should answer, and gather available data

- Assign lead responsibility for managing the development and approval of the profile.  
Contact information for person with overall responsibility \_\_\_\_\_
- Assess internal staff capacity for assembling data and writing the profile.  
Internal staff is available? Yes/No
- (If No) Find an external person to fill this role.  
Contact information \_\_\_\_\_
- Identify one or more expert advisors. Start by asking the State AIDS Coordinators for the name of the person who advised CPGs in creating their HIV Epidemiological Profiles. This person can refer you to individuals who manage surveillance data on Job Corps entrants, etc.  
Contact information \_\_\_\_\_
- Secure other resources:
  - Internet access (in-house, local library, other-specify \_\_\_\_\_)
  - Petty cash for photocopying, etc.
  - Expert advisor fees, if needed.

Box 19

The PMI Experience: Using a Teen Risk Profile in Choosing a target Audience

Before they began to assemble data, the Sacramento staff and coalition members chose criteria to guide their planning decisions. They decided that they would prioritize programs for:

- geographic areas with high rates of sexually transmitted disease, pregnancy and risk behaviors;
- settings in which a prevention program would be logistically feasible; and
- segments of the target audience that could be offered explicit programs without violating community standards.

Then the site collected data and asked for expert advice in interpreting it. Chlamydia data were found to be the most complete and accurate, and had limited gender bias. These data indicated that the highest risk group was 15-19 year olds. Based on these STD data and on teen birth rates, 15 zip codes in Sacramento and Yolo counties were designated as high-risk zip codes.

Demographic data from the Census showed that the high-risk zip codes included enough young people to warrant establishing special programs. Census data also made it clear that the teens living in these zip codes were ethnically diverse and economically disadvantaged. The Census figure for the number of 15-19 years olds in those zip codes was multiplied by the proportion of youth in that age range thought to be sexually active (a percentage that was consistent in findings from the state and national Youth Risk Behavior Surveys). According to this calculation, there were between 3,800 and 7,100 sexually active teens in the high risk zip codes.

All of this information and analysis was compiled into a Teen HIV Risk Profile. After reviewing it, planning committee members ranked several potential audience segments using the three pre-set priorities. Ultimately, sexually active 14-18 year olds living in high-risk zip codes were selected as the target audience. This age range included young people who were just below the ages at which STD risk was highest and who were accessible through high

Call a meeting to specify overall policies/priorities.  
 First policy/priority : \_\_\_\_\_

\_\_\_\_\_  Related planning question(s): \_\_\_\_\_

\_\_\_\_\_  Second (etc.) policy/priority: \_\_\_\_\_

\_\_\_\_\_  Related planning question(s): \_\_\_\_\_

Develop a preliminary schedule.

Gather data from existing sources.

Census data

Data source (website: www.census.gov or print copies at local library)

Consult regional office with questions.

Name of contact: \_\_\_\_\_

\_\_\_\_\_ Phone/e-mail address: \_\_\_\_\_

Data on AIDS cases from **HIV/AIDS**

**Surveillance Report**

Data source (website: www.cdc.gov or National Prevention Information Network [1-800-458-5231])

Consult expert advisor for guidance on interpretation.

Name of contact: \_\_\_\_\_

\_\_\_\_\_ Phone/e-mail address: \_\_\_\_\_

Data on people who test positive for HIV (use **HIV/AIDS Surveillance Report**) if reporting is required in the state

Reporting is required? Yes/No

Name of health department contact: \_\_\_\_\_

\_\_\_\_\_ Phone/e-mail address: \_\_\_\_\_

Data on Job Corp entrants

Data source: \_\_\_\_\_

Name of health department contact: \_\_\_\_\_

\_\_\_\_\_ Phone/e-mail address: \_\_\_\_\_

Data on military recruits

Data source: \_\_\_\_\_

Name of health department contact: \_\_\_\_\_

\_\_\_\_\_ Phone/e-mail address: \_\_\_\_\_

Special local serosurveillance studies

Available? Yes/No

Data source: \_\_\_\_\_

Name of contact: \_\_\_\_\_

\_\_\_\_\_ Phone/e-mail address: \_\_\_\_\_

Surrogate marker data: STDs

Chlamydia screening established in the state? Yes/No

Gonorrhea screening established in the state? Yes/No

Data source: \_\_\_\_\_

Name of health department contact: \_\_\_\_\_

\_\_\_\_\_ Phone/e-mail address: \_\_\_\_\_

Surrogate marker data: teen pregnancy

A Checklist for Constructing a Teen HIV Risk Profile

Data source (**Monthly Vital Statistics Report** available on the web at [www.cdc.gov](http://www.cdc.gov) or vital statistics obtained from the state or local health department)

Name of health department contact: \_\_\_\_\_

Phone/e-mail address: \_\_\_\_\_

**Youth Risk Behavior Survey**

60% response rate achieved in the state: Yes/No

Data source (website: [www.cdc.gov](http://www.cdc.gov) or CD-ROM available from the Division of Adolescent Health, CDC, 770-488-3257 or local educational agencies \_\_\_\_\_)

Name of contact: \_\_\_\_\_

Phone/e-mail address: \_\_\_\_\_

- (Optional) Other behavioral data from national sources (e.g., Monitoring the Future Study)

Data source: \_\_\_\_\_

Name of contact: \_\_\_\_\_

Phone/e-mail address: \_\_\_\_\_

Website: \_\_\_\_\_

- Behavioral data from local sources (e.g., a nearby school of public health)

Available? Yes/No

Data source: \_\_\_\_\_

Name of contact: \_\_\_\_\_

Phone/e-mail address: \_\_\_\_\_

Website: \_\_\_\_\_

Useful?  Yes

No: Why? \_\_\_\_\_

### Step 2: Read and analyze the data

- Note consistencies in patterns (e.g., highest risk groups) between levels of data (e.g., state and national).
- Note differences and similarities among population sub-groups.
- Look for patterns across data from various sources.
- Determine trends over time if possible.
- Examine data for gaps.
- Check that all specific planning questions have been addressed.

### Step 3: Draft the profile

- Provide data and narrative on demographics, disease, and surrogate markers.
- Make sure all denominators are specified.
- (optional) Transform rates so that they have common denominators.
- Provide rates and absolute numbers of cases.
- Describe degree of agreement among data sources.
- Describe any trends over time.
- Remind readers to be cautious in drawing conclusions when the absolute number of cases is small, data are old, etc.
- Note other limitations in the data.
- Indicate which additional data should be collected if resources allow.

### Step 4: Revise draft profile, submit to planning group, and update periodically

- Ask for and incorporate expert reviewer comments.
- Ask for and incorporate community reviewer comments.
- Submit draft profile to planners and incorporate comments.
- Submit final profile to planners.
- Update profile periodically.

Publications about youth and  
program planning

AED. **Priority setting in HIV prevention community planning.** Washington (DC): AED for CDC; July 1994.

AED and National Alliance of State and Territorial AIDS Directors. **HIV Prevention Priorities: How Community Planning Groups Decide.** Washington (DC): AED for CDC; November 1996.

Advocates for Youth. Fact sheets. Washington (DC): Advocates for Youth. Various years.

Alan Guttmacher Institute. **Sex and America's Teenagers.** Washington (DC): Alan Guttmacher Institute; 1994.

CDC. **Prevention Marketing Initiative: Applying Prevention Marketing.** Atlanta (GA): Centers for Disease Control and Prevention; February 1996.

CDC. **Prevention Marketing Initiative: Youth Involvement.** Atlanta (GA): Centers for Disease Control and Prevention; February 1997.

# conclusion.

Recent advances in communications technology have linked the public with a burgeoning scientific knowledge base. Now, for the first time, information readily available on the World Wide Web allows local prevention programs to ground their service plans in up-to-date data. The PMI demonstration sites found such data to be invaluable in planning preventive interventions for local adolescents.

The authors of this manual hope that it will help speed delivery of information relevant to HIV and AIDS to prevention service planners. The local PMI sites and their national partners hope that access to this information will help bridge the gap between good intentions and effective prevention programs for our nation's youth by encouraging the strategic use of scarce resources.

# appendix 1.

RTGXGP VKQP OCTMGVKP I KP KVKC VKXG RO K  
F GO QP UVT C VKQP UKVGU QXGT XKGY

	TARGET	BEHAVIORAL OBJECTIVE	KEY ELEMENTS	INTERVENTION ACTIVITIES
Phoenix	Sexually active 16-19 year olds who have used condoms at least once and who intend to use condoms	To use condoms consistently with steady or familiar partners	<ul style="list-style-type: none"> <li>• Reinforcing positive attitudes and beliefs about using condoms with familiar partners</li> <li>• Increasing skills to get condoms used and used correctly with familiar partners</li> <li>• Encouraging young people to always carry condoms and/or have condoms on hand</li> </ul>	<p>Skills-building workshops</p> <p>Peer outreach</p> <p>Media (transit)</p>
Northern Virginia	Sexually active 15-19 year old African Americans	To correctly and consistently use a latex condom with all partners	<ul style="list-style-type: none"> <li>• Improve condom negotiation skills</li> <li>• Improve correct condom use skills</li> <li>• Improve skills for carrying condoms (handy access)</li> <li>• Increase youth perceived risk for HIV infection</li> <li>• Improve access to condom distribution channels</li> <li>• Change normative expectations for consistent condom use among peers and in uential adults</li> </ul>	<p>Skills-building workshops</p> <p>Introductory sessions for parents</p> <p>Media</p>
	Non-sexually active 15-19 year old African Americans	To delay onset of penetrative sex	<ul style="list-style-type: none"> <li>• Improve communication and negotiation skills for refusing penetrative sex</li> <li>• Increase salience of benefits of not engaging in penetrative sex</li> <li>• Increase normative expectations among peers and in uential adults to support the delay of penetrative sex</li> </ul>	

	TARGET	BEHAVIORAL OBJECTIVE	KEY ELEMENTS	INTERVENTION ACTIVITIES
Nashville	Sexually active 12-15 year old African Americans living in low income housing who want to avoid pregnancy and STDs	To use condoms consistently and correctly	<ul style="list-style-type: none"> <li>• Increasing the salience of STDs/HIV and the intention to prevent STDs/HIV</li> <li>• Increasing perception of condom efficacy</li> <li>• Improving communication skills and refusal skills when sex is not wanted</li> <li>• Improving negotiation skills</li> <li>• Improving condom use skills</li> <li>• Improving planning and preparation for sex (having condoms on hand)</li> <li>• Increasing peer support for consistent condom use in all relationships</li> <li>• Changing gift norm (i.e., sex for gifts)</li> <li>• Increasing perception among youth that controlling their body ties in with controlling their life</li> </ul>	<p>Skills-building workshops</p> <p>Media (radio soap opera)</p>
	Non sexually active 12-15 year old African Americans living in low income housing	To delay intercourse until after high school graduation	<ul style="list-style-type: none"> <li>• Increasing connection between unsafe sex and STDs/HIV</li> <li>• Improving refusal skills</li> <li>• Improving negotiation/communication skills</li> <li>• Encouraging the norm that successful or mature relationships do not have to include sex</li> <li>• Changing gift norm (i.e., sex for gifts)</li> <li>• Increasing perception among youth that controlling their body ties in with</li> </ul>	controlling their life
Sacramento	Sexually active 14-18 year olds in high-risk areas who use condoms inconsistently	To use condoms consistently and correctly with all partners and in all situations	<ul style="list-style-type: none"> <li>• Reinforcing community norms about using condoms all the time and having condoms on hand</li> <li>• Building youths' skills and confidence in using condoms correctly and in communicating/ negotiating/refusing with partners in different situations</li> <li>• Increasing youths' access to condoms and helping youth to have condoms on hand.</li> </ul>	<p>Media (print, transit, and radio)</p> <p>Skills-building workshops</p> <p>Informational telephone line</p> <p>Parental support</p>

	TARGET	BEHAVIORAL OBJECTIVE	KEY ELEMENTS	INTERVENTION ACTIVITIES
Newark	Sexually active 13-16 year olds who want to avoid pregnancy or are concerned about HIV	To use a condom with all partners the next time they have penetrative sex	<ul style="list-style-type: none"> <li>• Improving skills (negotiation, sexual decision-making, goal setting, parent-child communication, refusal and condom use and carrying)</li> <li>• Fostering supportive norms/attitudes (condom preparedness and use with known partners is good)</li> <li>• Increasing self-efficacy (using condoms in all situations or refusing sex)</li> <li>• Increasing salience of STDs/HIV</li> <li>• Changing norms to support youth to always carry a condom</li> </ul>	<p>Skills-building workshops</p> <p>Sponsorship of events, contests, and awards</p> <p>Media support</p> <p>Parent network (workshops and meetings)</p>
	Non-sexually active 13-16 year olds	To continue to delay and use a condom the first time they have penetrative sex	<ul style="list-style-type: none"> <li>• Introducing and/or improving skills (negotiation, refusal, sexual decision-making, goal setting, parent-child communication and condom use)</li> <li>• Fostering supportive norms/attitudes around condom preparedness and delaying sex</li> <li>• Increasing self-efficacy (delaying sex, using condoms in all sexual situations)</li> <li>• Encouraging youth to carry condoms</li> <li>• Increasing salience of preventing pregnancy and STDs/HIV</li> </ul>	

# appendix 2.

UQWTEGU CPF TGHGTGPEGU

CDC. **Suggested Guidelines for Developing an Epidemiologic Profile for HIV Prevention Community Planning.** Atlanta (GA): Centers for Disease Control and Prevention; June 1995. (NAC order D875; also available on the Web at [http://www.cdc.gov/nchstp/hiv\\_aids/pubs/suggguid.htm](http://www.cdc.gov/nchstp/hiv_aids/pubs/suggguid.htm))

Center for the Study of Social Policy (CSSP). **Finding the data: a start-up list of outcome measures with annotations.** Washington (DC): CSSP Improved Outcomes for Children Project; 1995.

Children's Defense Fund. **The state of America's children: yearbook 1997.** Washington (DC): Children's Defense Fund; 1997. (Also, state-by-state data are available in *Children in the States: State-by-state fact sheets on children's status, 1997*. See website [www.childrensdefense.org/states/](http://www.childrensdefense.org/states/).)

Child Trends and the Urban Institute. **A statistical portrait of adolescent sex, contraception, and childbearing.** Washington (DC): The National Campaign to Prevent Teen Pregnancy; March 1998.

Dryfoos, JG. **Adolescents at risk: prevalence and prevention.** New York: Oxford University Press; 1990.

Institute of Medicine. **The hidden epidemic: confronting sexually transmitted diseases-summary.** Washington (DC): National Academy Press; 1997. (Also available on the Web at <http://www2.nas.edu/stdforum/>.)

League of California Cities. **Youth development planning guide: a step-by-step guide to making children and youth a priority in your city.** Sacramento: League of California Cities; 1995.

National Council of La Raza and MOSAICA. **Using data and assessing needs: a guide for community members of HIV prevention community planning groups.** Washington (DC): National Council of La Raza; June 1995.

Office of the Assistant Secretary for Planning and Evaluation. **Trends in the well-being of America's children and youth: 1996.** Washington (DC): Department of Health and Human Services.

Office of National AIDS policy. **Youth & HIV/AIDS: An American Agenda** Washington CDC; 1996.

Additional references about epidemiology, primary data collection, and data presentation

Fox JP, Hall CE, Elveback LR. **Epidemiology: man and disease.** New York: The Macmillan Company; 1970.

Mausner JS, Bahn AK. **Epidemiology: an introductory text.** Philadelphia: WB Saunders Company; 1974.

Thacker SB, Berkelman RL. Public health surveillance in the United States. **Epidemiol Review.** 10, 164-190; 1988.

*For those interested in collecting data, the following publications may be useful:*

Breakwell GM, Hammond S, Fife-Schaw C, editors. **Research methods in psychology.** London: Sage Publications; 1995.

Gorden RL. **Basic interviewing skills**. Itasca (IL): FE Peacock; 1992.

Miller DC. **Handbook of research design and social measurement**. 5th edition. Newbury Park (CA): Sage Publications; 1991.

*For those interested in presenting data, the following publications may be useful:*

Day RA. **How to write and publish a scientific paper**. 4th edition. Philadelphia: ISI Press; 1994.

Huff D. **How to lie with statistics**. New York: WW Norton; 1993.

Elifson KW, Runyon RP, Haber A. **Fundamentals of social statistics**. 2nd edition. New York: McGraw-Hill; 1990.

#### Additional useful websites about youth

**YouthInfo** ([youth.of.dhhs.gov](http://youth.of.dhhs.gov)): Website developed by the U.S. Department of Health and Human Services to provide the latest information about American adolescents. YouthInfo currently includes the following: statistical profile of teens; the latest reports and publications about adolescents; information for parents of teens; speeches by federal officials on youth topics; and links to youth-related websites at DHHS, other federal agencies, private foundations, and research organizations.

**Center for AIDS Prevention Studies HIV Prevention Fact Sheets** ([www.caps.ucsf.edu/FSindex.html](http://www.caps.ucsf.edu/FSindex.html)): Provides summaries of specific topics important to AIDS prevention, prepared by the Center for AIDS Prevention Studies at the University of California-San Francisco. Topics covered include: What are young gay men's HIV prevention needs? What are adolescents' HIV prevention needs? Does sex education work? Should we teach only abstinence in sexuality education?

The following summary definitions and explanations cover a number of terms that are often encountered in dealing with statistics and with community needs assessments related to HIV prevention. The descriptions are designed to be clear and practical and to describe terms as they are likely to be used in reference to HIV statistics; they do not attempt to provide a full technical explanation for each term. More extensive and precise definitions and descriptions can be found in several of the technical references cited in this manual. No attempt is made to include technical terms that relate specifically to HIV/AIDS; it is assumed that members of planning groups will obtain this information from other sources.

**Average:** a way of describing the typical value or central tendency among a group of numbers, such as average age or average income; three commonly used types of averages are mean, median, and mode (see each in the glossary).

**Archival data:** routinely maintained epidemiologic records.

**Bar chart or bar graph:** a visual way to show and compare scores or values for different categories of variables. For example, a bar chart might be used to show the number of reported AIDS cases that are from each major racial/ethnic group; the taller the bar, the larger the number of AIDS cases.

**Bias:** anything that produces systematic error in research findings.

**Census tract:** small areas, usually containing between 3,000 and 6,000 people, the boundaries of which are established jointly by local communities and the Bureau of the Census to achieve some homogeneity of population characteristics such as economic status and living conditions.

# appendix 3.

## INTRODUCTION

**Closed-ended questions:** questions in an interview or survey that provide a limited set of predefined alternative responses. For example, a survey might ask respondents if they have been sexually active over the past six months, and then ask, “How often in the past six months have you used a condom during sexual intercourse?” The survey would then provide the following response options: Always, Usually, Sometimes, Never.

**Coding:** the process of translating data from one format to another, usually so the information can be entered into a computer to be tabulated and analyzed. Often, coding involves assigning numbers to all the possible responses to a question, such as Yes = 1, No = 2, Not Sure = 3, No Response = 0.

**Community needs assessment:** a systematic process designed to determine the current status and unmet needs of a defined population or geographic area; may focus on a particular program topic such as HIV/AIDS, or on a broader issue area such as health.

**Confidence interval:** a numeric range around an estimated percentage that accommodates the probable margin of error (see confidence limits).

**Confidence limits:** Percentage figures that are higher and lower than an estimated result, given to indicate probable margin of error (e.g., if 53.1% of U.S. teens reported condom use at least intercourse, the confidence limits might be 48.6% and 57.6%, suggesting that the true percentage is somewhere in that range).

**Cumulative incidence:** the total number of new cases that have been reported, starting from the time reporting began.

**Data:** information collected for research purposes.

**Data analysis:** careful, rigorous study of data; usually involves studying various elements of information and their relationships.

**Decimal places:** number of digits to the right of the decimal point, which separates numbers with a value greater than one from numbers with a value of less than one. The more numbers or decimal places used, the more precise the number. For example, 34.03 has two decimal places.

**Denominator:** the number by which another number is divided (the number under the line in a fraction); in epidemiology, the denominator often represents the population from which a case count is drawn.

**Demographic information:** numeric information on the age, gender, ethnicity, socioeconomic status and primary language of individuals residing within known geographic boundaries.

**Epidemic:** the spread of an infectious disease through a population or geographic area.

**Epidemiologic profile:** a statistical description of the health of a particular group in a defined geographic area.

**Epidemiology:** the study of diseases in populations.

**Executive summary:** brief summary of a longer report, usually including the most important results or recommendations plus other information needed by policy makers or other individuals who are unlikely to read the full report.

**Exposure category:** in describing HIV/AIDS cases, same as transmission categories; how an individual may have been exposed to HIV, such as injecting drug use, sex with men who have sex with men, and heterosexual contact.

**Focus groups:** information collection method consisting of a carefully planned discussion, led by a trained moderator,

in which a small group of selected individuals give their opinions of and reactions to a concept, approach, or sample product.

**Frequency distribution:** a tally of the number of times each score or response occurs in a group of scores or responses. For example, if 20 teenagers who are sexually active provided information about how often they used condoms during intercourse over the past six months, the frequency distribution might be Always = 5, Usually = 4, Sometimes = 7, and Never. = 4

**Generalizability:** the extent to which findings or conclusions from a sample can be assumed to be the of the entire population from which the sample was drawn; findings can be generalized only when the sampling procedure and the data meet certain methodologic standards.

**Incidence:** the number of cases identified (diagnosed and reported to a disease statistics registry) during a specified period of time.

**Incidence rate:** the number of cases of a disease per population per specified time period, often expressed per 100,000 people.

**KAB studies:** knowledge, attitude, and behavior studies; in the AIDS field, studies that attempt to study people reached through specific HIV/AIDS prevention activities or messages to determine changes in knowledge and attitudes about HIV and its transmission and to assess behavior change related to risk factors such as unprotected sex and needle sharing.

**Mean:** an average calculated by adding up all the individual data values and then dividing by the number of values. For example, five teens reported having had 1, 3, 5, 5, and 6 sexual partners over their lifetimes, then their mean number of partners would be 4. The mean should not be used when a few values are very different from other values (see below).

**Median:** the central value, the one that falls in the middle of all the values when they are placed in order from highest to lowest. In the example above, the median would be 5. The median is best used when a few values are very different from other values.

**Mode:** the most frequently occurring value. For the example above, it would be 5. The mode is not a good measure to use when the number of cases

is small.

**MSM:** Abbreviation for men who have sex with men. These men, especially young MSM., may not identify themselves as homosexual.

**Numerator:** the number into which another number is divided (the number on top of the line in a fraction); in epidemiology, the numerator represents a case count and is often the smaller of the two numbers.

**Open-ended questions:** questions in an interview or survey format that allow those responding to answer as they choose, rather than having to select one of a limited set of predefined alternative responses.

**Over-representation/Under-representation:** terms often used to indicate that a particular subpopulation makes up a larger proportion or a smaller proportion of a particular group than would be expected, given its representation in the total population. For example, Hispanics and African Americans are both over-represented among AIDS cases, compared to their share of the U.S. population, while Asians/Pacific Islanders are under-represented.

**Over sampling:** a procedure in stratified random sampling in which a larger number of individuals from a particular group (or stratum) are selected than would be expected given their representation in the total population being sampled. Over sampling is done to have enough subjects to permit separate tabulation and analysis of that group. For example, minorities are often oversampled to permit separate analysis of data by racial/ethnic group as well as comparisons among racial/ethnic groups.

**Percent(age):** literally, per hundred; a proportion of the whole, where the whole is 100. A percentage is calculated by dividing the part of interest by the whole, and then multiplying by 100. For example, to find the percentage of AIDS cases among Hispanics, the number of Hispanic AIDS cases (the part of interest) is divided by the number of total AIDS (the whole), and multiplied by 100. If a community has a total of 70 AIDS cases and 14 are Hispanic, 14 is divided by 70 (0.2) and multiplied by 100. The answer is 20%.

**Percentage point:** one one-hundredth; term used to describe numerical differences between two percentages without comparing relative size. For example, if 16% of AIDS cases are Hispanic and 32% are African American, the difference is 16 percentage points (32 minus 16).

**Pie chart:** a visual way of showing and comparing different categories of variables in which a circle is divided into portions representing the percentage share of each category.

**Population count:** data that describe an entire population and that were obtained from the entire population without sampling. The U.S. Decennial Census is a population count because it attempts to obtain information from everyone living in the United States.

**Prevalence:** refers to the actual extent of a disease in a population at a certain time; it depends on some kind of active process for finding cases, and is usually estimated by screening a scientifically drawn sample of a population.

**Prevalence rate:** the total case rate of a disease or condition in a given population at a given time (compared to the incidence rate, which refers to new cases).

**Primary source data:** original data an individual collects and analyzes him or herself.

**Probability:** the likelihood that a particular event or relationship will occur.

**Probability value:** the probability that a statistical result—an observed difference or relationship—would have occurred by chance alone, rather than reflecting a real difference or relationship. Statistical results are often considered to be significant if the probability or p value is less than .05, which means that there is less than a 5% chance—5 out of 100—that the result would have occurred by chance alone.

**Proportion:** a number smaller than one that is calculated by dividing the number of subjects having a certain characteristic by the total number of subjects. For example, if 35 new AIDS cases have been reported in a community in the past year and 7 of them are women, the proportion of female AIDS cases is 7 divided by 35 or  $1/5$  ( $=0.2$ ).

**Qualitative data:** data that are expressed in words (e.g., all the barriers to condom use mentioned by focus group members).

**Quantitative data:** data that are numerical (e.g., the number of cases of a particular disease).

**Rate:** the number of cases per some number of people per some unit of time.

**Crude rates:** rates based on the actual number of events

(e.g., births or deaths) in a total population over a given time period.

**Adjusted rates:** fictitious rates constructed to permit fair comparison between groups differing in some important characteristics. For example, an age-adjusted rate is standardized for age distribution so that it is directly comparable to another rate.

**Ratio:** a combination of two numbers that shows their relative size; the ratio of one number to another is simply the first number divided by the other, with the relation between the two numbers expressed as a fraction ( $X/Y$ ) or decimal ( $X.Y/1$ ), or simply the two numbers separated by a colon ( $X:Y$ ). For example, the ratio of minority to white pediatric AIDS cases in a community with 75 total cases, 45 among Hispanic and African-American children and 30 among white children, would be  $45/30$ , or  $1.5:1$ , or  $45:30$ .

**Raw data:** data that are in their original form, as collected, and that have not been coded or analyzed. For example, if a student participating in an HIV prevention workshop is tested to determine her knowledge of HIV transmission and gets a score of 11, that is her raw score; if the score represented 11 correct answers out of 20, then the score could be converted to 11 divided by 20 times 100 or 55%, which is no longer a raw score.

**Reliability:** the consistency of a measure or question, in obtaining very similar or identical results when used repeatedly; for example, if a blood test is repeated three times on the same blood sample, it would be reliable if it generated the same results each time.

**Representative:** term used to indicate that a sample is similar to the population from which it was drawn, and therefore can be used to make inferences about that population.

**Respondent:** a person who completes or responds to a survey form or interview.

**Rounding:** presenting numbers in more convenient units; rounding is usually done so that all numbers being compared have the same level of precision (one decimal place, for example); usually numbers under 5 are rounded down while 5 and over are rounded up. For example, 3.08 which would be rounded to 3.1 and 4.14 to 4.1.

**Sample:** a group of people selected from a total population or universe with the expectation that studying the group will provide important information about the total population.

**Secondary analysis:** re-analysis of data or other information collected by someone else. For example, a planning group might obtain data on AIDS cases in their metro area from the CDC, and carry out additional analysis of those data.

**Secondary source data:** information collected by someone else, but that an individual can analyze or re-analyze

**Seroprevalence:** the ratio of seropositives per some standard number of individuals (usually a factor of 10) in a population.

**Seroprevalence report:** report that provides information about the percentage or rate of people in specific testing groups and populations who have tested positive for HIV.

**Statistical significance:** a measure of whether an observed difference or relationship is larger or smaller than would be expected to occur by chance alone; statistical results are often considered to be significant if there is less than a 5% chance—5 out of 100—that they would have occurred by chance alone (see definition of probability value).

**Statistics:** a summary of data from a sample of individuals.

**Stratified random sample:** a random sample drawn after dividing the population being studied into several subgroups or strata based on specific characteristics; subsamples are then drawn separately from each of the strata. For example, the population of a community might be stratified by ethnicity before random sampling.

**Surrogate markers:** substitute measures, used in understanding a situation where adequate direct measures are not available. For example, it may be difficult to obtain good HIV surveillance data on teenagers, but incidence rates of sexually transmitted diseases (STDs) among teenagers can be used as surrogate measures of high-risk sexual behavior because HIV is an STD, and people get STDs when they engage in unprotected sex.

**Surveillance:** epidemiologic data that are periodically collected on a routine basis to monitor the scope and impact of a particular disease or health event.

**Surveillance reports:** reports providing information on the number of reported cases of a disease or health event nationally and for specific locations and subpopulations; the CDC issues such reports on AIDS, providing both cumulative cases and new cases reported during a specific reporting period, such as each of the last two years.

**Survey research:** research in which a sample of subjects is drawn from a population and then interviewed or otherwise studied to gain information about the total population from which the sample was drawn.

**Tabulation of data:** ordering and counting of quantitative data to determine the frequency of responses, usually the first step in data analysis; typically involves entering data into a computer for manipulation through some form of data-analysis program.

**Target audience:** groups of people to be reached through some action or intervention; may refer to groups with specific characteristics (such as ethnicity, age, gender, socioeconomic status) or to specific geographic areas.

**Transmission categories:** in describing HIV/AIDS cases, same as exposure categories; how an individual may have been exposed to HIV, such as injecting drug use, sex with men who have sex with men, and heterosexual contact.

**Trend:** movement in a particular direction in the value of variables over time.

**Trend charts:** line charts that show changes or movement in the values of a particular variable over time; usually, values are recorded periodically as points on a graph, and then connected to show how the values are changing; often used to provide comparisons, such as separate lines showing reported AIDS cases among different population groups over time.

**Universe:** the total population from which a sample is drawn.

**Validity:** the extent to which a survey question or other measurement instrument actually measures what it is supposed to measure. For example, a question that asks young adults how often they use a condom is valid if it accurately measures their actual level of condom use, and it is not valid if it is really measuring the extent to which they think that they should use a condom.

**Value:** individual response or score. For example, if people responding to a survey are asked to state their age, each age is a value.

**Variable:** a characteristic or finding that can change or vary among different people or in the same person over time. For example, ethnicity varies among individuals, and income varies for the same individual over time.

**Vital statistics:** statistics about births, deaths, marriages, and divorces.

**Weighting:** a procedure for adjusting the values of data to reflect each groups percentage in the total population. For example, if a community's population were stratified by ethnicity and the minorities were oversampled so that findings for each group could be compared, a researcher would weight the data to reflect the percentage of the whole population that comes from each ethnic group in order to be able to combine findings to describe the entire population.

## California

Juan Ruiz, M.D., Dr.P.H.  
830 S Street  
P.O. Box 94234  
Sacramento, CA 94234-7320  
Phone: (916)445-0700; Fax: (916)327-3252  
E-mail: JRUIZ1@hiv1.cahnet.gov

## Chicago

James Murphy  
Chicago Department of Public Health  
333 S. State Street  
Room 2150  
Chicago, IL 60602-0000  
Phone: (312)747-9611; Fax (312)747-9663

## Colorado

Kelly O'Keefe, M.S.P.H.  
Colorado Department of Health  
4300 Cherry Creek Drive, South  
Denver, CO 80222-1530  
Phone: (303)692-2658; Fax (303)782-0904

## Florida

Marlene Lalota, M.P.H.  
Florida Department of Health  
1317 Winewood Boulevard  
Building 6, Room 401  
Tallahassee, FL 32399-0700  
Phone: (904)921-4446; Fax (904)414-0038  
E-mail: Marlene\_lalota@doh.state.fl.us

## Georgia

John Beltrami, M.D.  
Georgia Department of Human Resources  
2 Peachtree Street, N.W.  
6th Floor Tower, Room 6-412  
Atlanta, GA 30303-3186  
Phone: (404)657-2601; Fax (404)657-2586  
E-mail: JKB0600@DHRS.STATE.GA.US

## Houston

Marcia Wolverton  
Houston Department of Health  
and Human Services  
8000 Stadium Drive, 5th Floor  
Houston, TX 77054-0000  
Phone: (713)794-9441; Fax (713)794-9391  
E-mail: idnazrul@aol.com

## Louisiana

# appendix 4.

RT KO CT[ EQP VCEVU HQT NQECN  
UGTQUWTXGKNNCP EG UVWF KGU

Debbie Wendell, M.P.H.  
Louisiana Office of Public Health  
HIV/AIDS Program  
234 Loyola, 5th Floor  
New Orleans, LA 70112-0000  
Phone: (504)568-5504; Fax (504)568-8393

## Maryland

Ellen Caldeira, M.Sc., M.P.H.  
Maryland Department of Health and  
Mental Hygiene  
AIDS Administration  
500 North Calvert Street, 5th Floor  
Baltimore, MD 21202-0000  
Phone: (410)767-5143; Fax (410)333-6333

## Massachusetts

Barbara Werner, Ph.D.  
Massachusetts Department of Public Health  
305 South Street  
Boston, MA 02130-0000  
Phone: (617)983-6365; Fax (617)983-6580

## Michigan

Gerald Goza, M.S.  
Michigan Department of Public Health  
3500 North Logan Street  
Lansing, MI 48909-0000  
Phone: (517)335-8165; Fax (517)335-8121  
E-mail: GOZAG@MDPH.STATE.MI.US

## New Jersey

Helene Cross  
New Jersey Department of Health  
and Senior Services  
P.O. Box 363  
Trenton, NJ 08625-0000  
Phone: (609)984-5977; Fax (609)984-2455  
E-mail: hsg@doh.state.nj.us

## New York City

Lucia Torian, Ph.D.

New York City Department of Health  
346 Broadway #701  
New York, NY 10013-0000  
Phone: (212)442-3461; Fax (212)442-3482  
E-mail: LTORIAN@AOL.COM

## New York State

Donna Glebatis, M.S.  
New York State Department of Health  
717 Corning Tower, ESP  
Albany, NY 12237-0000  
Phone: (518)474-4284; Fax: (518)473-0118  
E-mail: dgf03@health.state.ny.us

## Puerto Rico

Sandra Miranda  
Puerto Rico Department of Health  
Rio Piedras, PR 00921-0000  
Phone: (787)763-0240; Fax (787)763-0394  
E-mail: sandram@prtc.net

## San Francisco

Willi McFarland, M.D.  
San Francisco Department of Public Health  
AIDS Office  
25 Van Ness  
Suite 500  
San Francisco, CA 94102-0000  
Phone: (415)554-9016; Fax (415)842-6959

## Washington

Dorothy Gibson  
Washington State Department of Health  
P.O. Box 47838  
Olympia, WA 98504-7837  
Phone: (360)664-4516; Fax: (360)586-5440

## Washington D.C.

Emanuel Nwokolo, Ph.D.  
D.C. Department of Human Services  
Agency for HIV/AIDS  
717-14th Street, N.W.  
Suite 600

Washington, DC 20005-0000  
Phone: (202)727-2500; Fax: (202)727-8471

# appendix 5.

C F F K V K Q P C N F C V C U Q W T E G U

To supplement a basic Teen HIV Risk Profile, planning groups may want to obtain data from the additional sources listed below. Some of the data may not be directly pertinent to HIV risk. Also, many of the national data do not allow local breakdown and/or are somewhat out of date. However, some of the information described below should be useful for filling holes in locally available information.

## National Survey of Family Growth

Description: The main function of this survey is to collect data on factors affecting pregnancy and women's health. There have been five rounds of data collection, each based on a nationally representative sample of women 15-44 years of age. The 1995 NSFG (5th Cycle) is the most recent data.

Contact: Family Growth Survey Staff, Division of Vital Statistics, National Center for Health Statistics, Centers for Disease Control and Prevention,  
Phone: 301-436-8731.

Website: [www.cdc.gov/nchswww/about/major/nsfg/nsfg.htm](http://www.cdc.gov/nchswww/about/major/nsfg/nsfg.htm).

## National College Health Risk Behavior Survey

Description: The first national survey to measure health risk behaviors among undergraduate college students aged 18 years and older. Conducted in 1995.

Contact: Division of Adolescent and School Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Phone: 770-488-3257.

Publication: Youth Risk Behavior Surveillance: National College Health Risk Behavior Survey - United States, 1995. **Morbidity and Mortality Weekly Report** 46 (SS-6). (Download **MMWR** from the CDC Web page, [www.cdc.gov](http://www.cdc.gov))

Data: To order the data set, contact National Technical Information Service, Phone: 1-800-553-6847. The item# is PB97-503528.

## National Longitudinal Survey of Youth

Description: The major purpose of the 1997 data was to determine the strength and weaknesses of the process for guiding youth (aged 12-16 on December 31, 1996) from school to work.

Contact: Bureau of Labor Statistics, Phone: 202-606-6378.

Publication/Data: Contact National Longitudinal Surveys, Phone: 202-606-7405 (Publication); 614-442-7366 (Data)

Website: [stats.bls.gov/nlsy97.htm](http://stats.bls.gov/nlsy97.htm).

### Monitoring the Future Study

- Description: Also widely known as the **National High School Senior Survey**. This study has been conducted each year since 1975 to monitor trends in drug and alcohol use among high school students.
- Contact: Survey Research Center, The Institute for Survey Research, University of Michigan, Phone: 734-764-8365.
- Publication: Contact National Clearinghouse for Alcohol and Drug Information, Phone: 1-800-729-6686.
- Data: To order data tapes, contact Inter-university Consortium for Political and Social Research, University of Michigan, Institute of Social Research, Phone: 313-763-5010.
- Website: [www.health.org/mtf/tables/index.htm](http://www.health.org/mtf/tables/index.htm)

### National Longitudinal Study of Adolescent Health (Add Health)

- Description: The first national study of adolescent health (7th-12th grade) designed to measure the effects of family, peer group, school, neighborhood, religious institution, and community influences on behaviors that promote good health.
- Contact: Carolina Population Center, University of North Carolina-Chapel Hill, Phone: 919-966-2157.
- Data: Public use data sets can be purchased from Sociometrics Corporation, Phone: 650-949-3282.
- Website: [www.cpc.unc.edu/addhealth](http://www.cpc.unc.edu/addhealth)

### National Survey of Adolescent Males (NSAM)

- Description: NSAM 1998 & 1990-91 is a two-wave longitudinal study of nationally representative, 1880 young men (aged 15-19 in 1988) conducted to determine adolescent male reproductive and sexual behaviors. The 1995 NSAM interviewed a nationally representative sample of 1729 men ages 15-19 about their reproductive and sexual behaviors.
- Contact: Freya Sonenstein, Urban Institute, Phone: 202-261-5546
- Publication: Turner CF, Rogers SM, Lindberg LD, Pleck JH, Sonenctin FL. Adolescent sexual behavior, drug use, and violence: increased reporting with computer survey technology. **Science**. 1998;280(5365): 847-8.  
Why young men don't use condoms: factors related to the consistency of utilization. In: Why some men don't use condoms: male attitudes about condoms and other contraceptives. A monograph from Sexuality and American Social Policy: A seminar series. The Henry J. Kaiser Family Foundation; 1997. ISBN0-944525-29-6.
- Data: Data sets can be purchased from Sociometrics Corporation, Phone: 650-949-3282.
- Website: [www.urban.org/family/teenmale.htm](http://www.urban.org/family/teenmale.htm)

