

AIDS

Sexual Behavior and Intravenous Drug use

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Monitoring The Epidemic's Course

This chapter reviews the statistics and statistical systems that provide the nation with information about the current state and future course of the AIDS epidemic.¹ To conduct this review, the committee appointed a special panel on statistical issues in AIDS research. The material in this chapter constitutes the parent committee's findings after consideration of the technical panel's work.

The panel was asked to evaluate the adequacy of current statistics (and those likely to be available in the near future) for assessing the present state and monitoring the future course of the AIDS epidemic. Early on, the panel concluded that a fully adequate monitoring system must go beyond the current system for reporting AIDS cases and AIDS deaths. Rather, an adequate system of information on the current state of the epidemic must provide reliable monitoring of the prevalence and incidence of HIV infection in the population.

Developing accurate statistical systems for monitoring HIV infection is important for a number of reasons:

- Counts of AIDS cases are out-of-date indicators of the present state of the epidemic. There is a long, asymptomatic latency period between HIV infection and the development of AIDS (in most persons). Consequently, the statistics on *new* AIDS cases reflect *old* cases of HIV infection. For example, most of the adults who will be

¹ In this chapter, we focus on HIV and AIDS statistics. In [Chapter 2](#), we discuss the potential value of reliable statistics on other sexually transmitted diseases that should (other things being equal) respond to the same behavioral changes that would reduce the transmission of HIV.

counted as new AIDS cases in 1989 are likely to have been infected with HIV prior to 1986.

- Persons whose life spans are significantly shortened by HIV infection do not always manifest sufficient symptoms to be captured by the AIDS reporting system. Thus, some persons dying of HIV-related illnesses do not qualify for inclusion in the statistics on AIDS deaths.²
- HIV-infected persons without overt AIDS symptoms can transmit the virus to others.
- The future magnitude of the AIDS epidemic will be determined primarily by the current extent and future spread of HIV infection in the population.

These considerations, and the fact that the AIDS reporting system is functioning reasonably well (although not perfectly, as noted in the following paragraphs), led the panel to concentrate its attention on what is currently known about the prevalence and incidence of HIV infection in the United States.

Notwithstanding this focus, the committee notes the need for constant vigilance to ensure the efficient functioning of the AIDS case reporting system. The time lag between the diagnosis of a case and the reporting of it to the Centers for Disease Control (CDC) appears to be increasing. At present, CDC estimates that only 85 to 90 percent of AIDS cases are reported within one year of diagnosis, and

² A review of death certificates in Boston, Chicago, New York, and Washington, D.C., during 1985 found that the reporting of AIDS cases (those meeting the 1985 surveillance definition) was 89 percent complete; that is, in 89 percent of all AIDS deaths, the decedent had already been included in the AIDS case registry. However, an additional 13 percent of deaths thought to be HIV related did not meet the CDC criteria for AIDS diagnosis (Hardy et al., 1987); that is, 13 percent of all deaths originally attributed to AIDS, *Pneumocystis carinii*, or Kaposi's sarcoma on the death certificate did not meet the surveillance definition for AIDS but were judged "clinically suspicious" (p. 388) because they had an opportunistic infection included in the surveillance definition but the infection had not been confirmed by the required methods. It is also suspected that such HIV-related deaths are responsible for an epidemic of non-AIDS deaths among IV drug users in New York City. The eightfold increase in non-AIDS deaths (from 257 in 1978 to 1,607 in 1985) is presumed to be due to the fatal consequences of HIV infection in cases that did not meet the surveillance definition for AIDS. Increases in non-AIDS deaths among New York City IV drug users between 1981 and 1985 occurred in the following HIV-related categories: pneumonia (not *Pneumocystis carinii*), from 15 to 193; tuberculosis, from 3 to 35; and endocarditis, from 4 to 64 (Des Jarlais et al., 1988:155). Ultimately, some of these HIV-related deaths might be captured by the reporting system through the use of the new HIV codes for classifying causes of death from death certificates. This assumes, of course, that the physician completing the certificate is aware of the decedent's HIV status. In any event, even if this system were entirely reliable, it would count people only at the point of death.

it is thought that this percentage is declining.³ Such a decline would be a reasonable consequence of the growing demands the epidemic is making on the state and local public health departments that handle AIDS surveillance and reporting. Indeed, the increasing delays noted in the reporting of AIDS cases might be taken as direct evidence of the stresses being placed on the personnel and institutions who must cope with the epidemic. Additional resources appear to be needed now (and more will probably need to be added incrementally in the future) so that case reporting delays do not continue to increase.

The panel also identified a need for special methodological studies to assess the reliability and validity of the categorization of AIDS cases by mode of transmission. Accurate data on transmission modes are crucial because they identify the behaviors and populations that must be targeted to control the spread of infection. Although some careful work has been done to explore the accuracy with which such determinations are made, further research could provide much valuable information. Given the difficulties in obtaining accurate information on sexual behavior (particularly in some subpopulations), there is good reason to believe that some error and bias contaminate the tabulation of AIDS cases by transmission mode. Methodological studies to assess the magnitude and direction of such inaccuracies could provide useful information that would aid in the interpretation of the AIDS case data.⁴

PREVALENCE AND INCIDENCE OF HIV INFECTION

Prevalence denotes that proportion of a population that is currently infected; it is usually expressed as cases per 1,000 or per 10,000, or it may be written as a percentage (e.g., 0.4 percent, or 4 cases per 1,000). Incidence denotes the rate of occurrence of new cases of infection per unit of time (e.g., per year). Thus, an incidence of .03 per year in some population group means that new cases of infection occurred in 3 percent of the initially uninfected members of the group during the year in question. Incidence may be estimated

³ The median reporting delay (i.e., the time from diagnosis to report) has, for example, increased from 2 to 3 months in the past year (M. Morgan, Statistics and Data Management Branch, AIDS Program, CDC, personal communication, September 26, 1988).

⁴ These studies would be important to conduct even if they were to conclude that the inaccuracies themselves were, in fact, inconsequential.

directly by tracking new cases (as can be done with AIDS) or indirectly by observing changes in prevalence and adjusting for deaths (as might be done with HIV).

In November 1987, CDC transmitted a report to the President and his Domestic Policy Council that summarized in a clear, comprehensive fashion the state of present knowledge of HIV incidence and prevalence (CDC, 1987b).⁵ The report performed a great service in pulling together and organizing a massive amount of disparate information, much of which was unpublished. In summarizing current knowledge, the report highlighted the substantial gaps in our understanding of the HIV epidemic and made it quite clear that almost all that is known about HIV incidence and prevalence comes from research samples that have been recruited in a manner that precludes generalizations to well-defined segments of the population. (Such non-population-based samples are sometimes called "purposive" or "convenience" samples.)

Uses Of HIV Prevalence And Incidence Data

There are three important uses for reliable HIV prevalence and incidence data. First, such data can be used to compare population groups in terms of current HIV prevalence and, subsequently, to target prevention services to those groups that are most in need. Second, reliable HIV prevalence and incidence data can be helpful in assessing the effects of prevention services and other interventions. A third, less direct use of such data is in calibrating forecasting models. These models in turn may allow us to better anticipate the future course of the epidemic and the demands it will make on health care and other social systems.

Prevalence Data

At present, data on the prevalence of HIV infection come principally from two sources: (1) blood samples derived from programs testing special populations (e.g., military applicants and blood donors) and (2) testing of anonymous blood specimens from smaller studies of convenience samples. [Table 1-1](#) summarizes the seroprevalence data from four testing programs, two large and two small. As the table shows, there is some consistency across the estimates generated from

⁵ The "Review of Current Knowledge" section of this report has been issued as a supplement to the *Morbidity and Mortality Weekly Report* of December 18, 1987 (CDC, 1987a).

three of these programs. In particular, testing of applicants for military service, of patients in four Midwestern hospitals, and of participants in the Job Corps program all produced HIV prevalence estimates in the range of about 10 to 30 per 10,000. Estimates of HIV prevalence among blood donors, however, were an order of magnitude lower—1 to 3 per 10,000.

TABLE 1-1 HIV Seroprevalence Rates Among all Blood Donors, Military Recruits, and Samples of Hospital Patients and Job Corps Applicants

Sample	Number Tested	Year	Percentage Seropositive
Blood donors	12.6 million	1985-1987	0.02
		1985	0.035
		1987	0.012
Military recruits	1.25 million	1985-1987	0.15
Hospital patients ^a	8,668	1986-1987	0.32
Job corps applicants	25,000	1987	0.33

^a Non-self-selected samples from the general population at four hospitals in the Midwest. The actual prevalances ranged from 0.09 percent to 0.89 percent across hospitals. The prevalence among military recruits in the same four cities (adjusted for age and sex) is 0.11 percent.

SOURCE: CDC (1987a).

Despite the large number of persons screened in the four testing programs shown in [Table 1-1](#), the results are not representative of the population. Military recruits, for example, come from particular age and educational strata, and persons reporting homosexual behavior or drug use are barred from enlistment. Such selection factors introduce large and numerically unknown biases; consequently, data from the military screening program cannot be used to make inferences about HIV infection in the national population.

Similarly, residential Job Corps entrants are drawn from the disadvantaged 16- to 21-year-old population, and they overrepresent racial and ethnic minorities. Hospital samples in turn have more old and sick people than the general population, and this group may be socioeconomically biased because the patterns of health care utilization are correlated with socioeconomic status (Andersen et al., 1987; Secretary's Task Force on Black and Minority Health, 1985:194).

The operation of biasing factors in these samples may be strongest in the blood donor group because people who believe they are at high risk for HIV infection have been asked not to donate blood.

Potential blood donors at Red Cross sites are interviewed for risk factors, and they are given several opportunities to elect not to donate their blood for use in transfusions. Thus, it is not surprising that HIV prevalence among blood donors is much lower than that in other samples. The 10-fold lower prevalence rate for blood donors illustrates the problems that can arise when volunteer samples are used to make inferences about the general population.

An example of the misunderstandings that may result from the use of such samples is the reports in the popular media⁶ that the prevalence of infection detected among military recruits in the United States did not increase during the first 15 months of the military's testing program. Although this result appears encouraging, it is actually quite difficult to interpret because it is not known whether the population of military recruits was stable over time. It is possible that potential military recruits who had engaged in high-risk behaviors were discouraged from volunteering by publicity about the mandatory HIV testing of recruits. A more subtle source of possible bias may be the changes that often occur in the pool of military applicants with respect to the mix of population subgroups in the pool. These changes may be the result of a number of outside influences. For example, when the recruitment needs of the armed forces are great, the minimum educational standards for enlistment are relaxed. Similarly, when the economy fluctuates, the pool of those seeking entry to the military services may enlarge or shrink. Such changes have unknown effects on the HIV infection rates among applicants in different years.

Monitoring Trends

It is sometimes asserted that, although available HIV prevalence data are biased, they may be sufficient for following trends. Yet there are good reasons to be skeptical of this assertion. First, there is usually no assurance that the characteristics of the measurement techniques used to determine HIV prevalence have been stable over time. Given the great advances in basic knowledge and practical expertise in AIDS research since 1981, it is likely that measurement techniques have changed, although the magnitude of the differences generated by such changes is not known. Unfortunately, when comparisons are

⁶ See, for example, "AIDS Rate Remains Stable Among U.S. Military Recruits Since Testing Started in 1985; Statistics Puzzle Experts," *Washington Post*, May 15, 1987:A1.

made across studies that lack well-defined protocols,⁷ differences in measurement procedures are often impossible to recognize or control.⁸ Second, the populations being tested may not be stable over time. The CDC report notes, for example, that HIV prevalence in blood donors has decreased over time because people who tested positive dropped out of the donor pool.

Incidence Data

Measures of HIV incidence are not generally available, but they would be particularly valuable for tracking the epidemic's course, making long-term projections about its future spread, and evaluating the overall effectiveness of efforts to control AIDS. For example, reliable data on the incidence of HIV infection would make it possible to test the hypothesis that the incidence of new cases has peaked (or is now peaking) in certain population groups. In this regard, the committee notes that data included in the CDC report suggest that incidence rates may be declining among gay men (see, in particular, CDC [1987a:Table 12 and Figure 13]). It is unclear, however, how much of this peaking results from the saturation with HIV infection of small cohorts of gay men, particularly in instances in which the cohorts were selected because of their high levels of sexual activity.

Variation In Estimated Hiv Prevalence For Selected Groups

The CDC report noted substantial differences in the estimated prevalence of HIV infection on the basis of the following:

- "risk factors"—homosexual sex among men, IV drug use, hemophilia, or heterosexual sex with persons at risk;
- source of the sample—blood donors, applicants for military service, patients at clinics for sexually transmitted diseases (STDs), newborns, and so forth;
- geographic location; and

⁷ This problem frequently arises when comparisons are made across different research studies. However, data from screening programs that use highly standardized measurement procedures and careful quality control of laboratory testing (e.g., in the armed forces) are less vulnerable to this problem.

⁸ The inability to recognize or control these differences also makes it impossible to recalibrate the prevalence estimates (i.e., by replicating the two measurement procedures and observing the resulting variation in prevalence estimates).

- demographic factors—in particular, sex, age, and race.

The differences in reported prevalence estimates ranged over two orders of magnitude. It is unlikely that biases in the data could account for *all* of the observed differences. Furthermore, the reported variations in HIV prevalence often mirrored differences in the number of reported AIDS cases, suggesting that the estimates may be sufficiently accurate to provide a crude ranking of various groups in terms of HIV prevalence.

Major groups for whom HIV prevalence and incidence data are presented in the CDC report include homosexual and bisexual men, IV drug users, hemophiliacs, heterosexual partners of HIV-infected persons (or persons in recognized risk groups), patients at general care hospitals, tuberculosis patients, prostitutes, heterosexuals without identifiable risk factors, and newborn infants and their mothers. In addition, by reporting the data according to locale, CDC provides implicit information about variations in HIV prevalence across the country. The rest of this section summarizes the data presented on each of these groupings in the CDC report. The next section considers uncertainties that limit the usefulness of these data for making inferences about the prevalence and incidence of HIV infection in the overall population.

Homosexual and Bisexual Men.

In 50 surveys and studies conducted in 23 cities in 16 states, HIV prevalence rates ranged from under 10 to 70 percent, with most of the estimates falling between 20 and 50 percent. Prevalence estimates were highest in San Francisco, but the CDC report found that HIV was not concentrated in any one region of the country. It should be noted that most of the samples were drawn from patients at STD clinics, so the observed rates probably overstate prevailing rates in the population of men who have same-gender sexual contacts.

IV Drug Users.

The prevalence of HIV infection among IV drug users showed marked geographic variation ranging from 50 to 60 percent in New York City, northern New Jersey, and Puerto Rico to less than 5 percent in areas distant from the East Coast. These estimates were derived primarily from samples obtained at facilities treating heroin addicts. (Some evidence suggests that IV drug users who are not in treatment may be at greater risk of infection; see [Chapter 3](#).)

Hemophiliacs.

Prevalence rates among hemophiliacs appear to be uniformly distributed across the United States. There are indications, however, that the likelihood of infection in a given sample will be correlated with the type and severity of coagulation disorder: reported HIV prevalence rates were 70 percent for hemophilia A and 35 percent for hemophilia B.

Heterosexual Partners of Persons with HIV Infection or at Recognized Risk.

The prevalence rates for this group varied from under 10 to 60 percent in a limited number of studies. The reasons for these large differences are unclear.⁹ Recent evidence suggests that infectiousness increases with the deterioration of the immune system. The relative efficiency of male-to-female and female-to-male transmission may also be important, but there are insufficient data to assess this possibility. For heterosexual partners of high-risk persons of unknown HIV status, HIV prevalence ranged from 0 to 11 percent.

Patients at General Care Hospitals.

Non-self-selected samples of 8,668 blood specimens from the general population at four hospitals in the Midwest gave an age- and sex-adjusted prevalence of 0.32 percent. The actual prevalences ranged from 0.09 to 0.89 percent. (HIV prevalence among military applicants in the same four cities, adjusted for age¹⁰ and sex, was 0.11 percent.)

Newborn Infants and Women of Reproductive Age.

In a Massachusetts study, methods were developed to detect HIV infection in women who have borne live infants.¹¹ On the basis of 30,708 tests in 1986-1987, the weighted average prevalence was 0.21 percent (unadjusted for the mother's age and race), varying from 0.80 percent at inner-city hospitals to 0.09 percent at suburban and rural hospitals. Female military applicants from Massachusetts had a crude prevalence of 0.13 percent (adjusted for age and race). As discussed later

⁹ Subsequent to the publication of the CDC report, Peterman and coworkers (1988) reported a study of 55 wives of HIV-infected men. Ten of these women seroconverted during the course of the study. The women who seroconverted reported fewer instances of unprotected intercourse than those who did not seroconvert, suggesting that other factors in addition to exposure affect the probability of HIV transmission.

¹⁰ It should be noted that adjustment of the military sample for age introduces considerable uncertainty because the age distribution of military recruits and military personnel includes only a very small percentage of persons in older age groups.

¹¹ The risk of HIV transmission from an infected mother to her infant is estimated to range from 30 to 50 percent. However, all infants of infected mothers carry maternal antibodies to HIV—whether or not they are actually infected with the virus.

in this chapter, these prevalence estimates represent the population of childbearing women and are unbiased in terms of self-selection or exclusion related to HIV risk factors.

Prostitutes.

HIV prevalence among female prostitutes ranged from 0 to 45 percent, with the highest rates in large inner-city areas in which drug use is common, such as New York City, Miami, and Detroit. The prevalence of HIV infection was three to four times higher in female prostitutes who were also drug users, and it was twice as high in black and Hispanic prostitutes as in white and other prostitutes. The geographic pattern of HIV infection in prostitutes appeared to parallel the geographic distribution of AIDS among women in general.

Tuberculosis Patients.

HIV infection is thought to have caused an increase in the number of persons with clinical tuberculosis (TB). In one study that was not limited to self-selected groups, 19 percent of 276 TB patients in Dade County, Florida (which includes Miami) tested positive for HIV. In four studies of TB patients at high risk, the prevalence ranged from 0 to 50 percent.

Heterosexuals Without Known Risk Factors.¹²

The prevalence of HIV infection among heterosexually active persons in the absence of known risk factors in either partner appears to be low. Two small studies of seropositive military applicants found that 20 of 24 applicants in New York City who sought counseling actually had recognized risk factors, and 11 of 12 applicants in Colorado had risk factors (e.g., male homosexual contacts). In addition, 30 of 33 seropositive male active-duty military personnel revealed recognized risk factors when interviewed. Among seropositive blood donors interviewed in Los Angeles, Baltimore, and Atlanta, 153 of 186 donors (82 percent) had risk factors; of those interviewed in New York City, 97 of 109 (89 percent) had risk factors. These data suggest that as few as 15 percent of infected military applicants and blood donors acquired their infection heterosexually. This would imply that the prevalence rate for *heterosexually acquired* HIV infection was 0.021 percent for military applicants (adjusted for age, sex, and race) and 0.006 percent for blood donors.

¹² "Without known risk factors" means without histories of IV drug use, male homosexual contacts, sexual contact with persons known to be infected, or hemophilia or transfusions prior to the adoption of universal blood donation screening.

Variation by Age.

There were marked differences in the cumulative AIDS incidence and available measurements of HIV prevalence by age, sex, race, and ethnicity. For age, the available cross-sectional data indicated a differential prevalence of HIV infection that rose from the mid-teens to a peak in the early 30s, and then declined in the 40s and 50s. In theory, such a pattern might arise from two opposing age trends:

- The young have been exposed to the risk of infection for less cumulative time, which might tend to produce lower prevalence at younger ages.
- With increasing age, there may be decreased frequency of behaviors that risk infection. For example, a 20-year-old is apt to be more sexually active, to have more partners per year, and, perhaps, to be more likely to use IV drugs than a 50-year-old. Some of these patterns may be hard to verify. Nonetheless, to the degree that they apply, they suggest that, during the years since AIDS appeared, the sexual activities of older persons may have been, on average, less risky than those of their younger contemporaries.

One implication that follows from these opposing trends is that the age distribution of persons infected with HIV might be quite different in a region to which HIV came late (versus a region that was affected earlier) because the tendency on the part of the young to accumulate risky experience would exert less influence.

Variation by Gender.

The cumulative prevalence of AIDS cases (i.e., the total number of cases for each gender divided by the number of cases) was 13 times higher among men than among women. However, the cited HIV prevalence rates varied widely; the male-to-female ratio of prevalence was 5.5:1 among military applicants (adjusted by age and race), 4.6:1 among blood donors, 2.3:1 among sentinel hospital patients, and the ratio apparently approaches 1:1 among IV drug users. In theory, the variation in these ratios should reflect (1) the sex composition of the underlying risk groups plus (2) the extent to which these risk groups may be included in the population being considered. Considering the entire population, the 13:1 preponderance of men among AIDS cases reflects the fact that most AIDS cases in the United States have occurred among men who have sex with men and among IV drug users. If, however, only women and men who already belonged to one of the risk groups (e.g., IV drug

users) were considered, a different result would be expected (e.g., the approximately 1:1 ratio reported for this group).¹³

Variation Among Blacks, Whites, and Hispanics.

Although blacks constitute only 11.6 percent of the national population, approximately one quarter of reported AIDS cases in adults and one half of cases in children have been among blacks. Similarly, more than one tenth of adult cases and two tenths of pediatric cases have been diagnosed among Hispanics, who account for 6.5 percent of the national population. Estimates of HIV prevalence rates have been more variable, but the disproportion is consistent (see CDC [1988a:Table 10]). In the four hospitals studied in the Midwest, the seroprevalence rate for blacks was 3.2 times higher than that for whites. Among IV drug users, the reported seroprevalence rates for blacks were 1.7 to 5.1 times higher than those for whites; for Hispanics, the rates were 1.7 to 3.3 times higher. Similarly, seroprevalence rates among black and Hispanic military recruits were 6.9 and 3.0 times higher, respectively, than the seroprevalence rate for white recruits.

Geographic Spread of the Epidemic.

Although there is a geographic correlation between AIDS prevalence and HIV prevalence, there are also important discrepancies that suggest that the AIDS case data will have only limited usefulness as a proxy measure of HIV infection. (Indeed, it may be possible to obtain important insights about the epidemic's spread by studying the divergences between the picture of the epidemic provided by the AIDS case reports and that provided by programs monitoring HIV infection.) The AIDS statistics for a particular locale are the manifest expression of the unseen history of HIV infection in the population of that locale. The cumulative count of AIDS cases increases with the number of infections and their duration. Other things being equal, a large disparity in the ratio of AIDS cases to cases of HIV infection in two areas (given accurate data) may suggest that the time course of infection was different in the two locales.¹⁴

¹³ The roughly 1:1 ratio cited for IV drug users is inferred from the statement (CDC, 1987a:10) that "[b]y contrast, in the one principal risk group that includes women—IV drug users—the prevalence does not differ appreciably by sex." The 1:1 ratio cited for IV drug users could be produced in a number of ways, among them equivalence in needle-sharing behaviors and random mixing (by gender and HIV status) of sharing groups.

¹⁴ The disparity is not, however, definitive evidence. That conclusion would require several strong assumptions—for example, that there were no differences across the populations in the two locales in the distribution of probabilities of progressing from HIV infection to AIDS in year 1, 2, 3, 4, ..., and so on. Yet it has been suggested that the

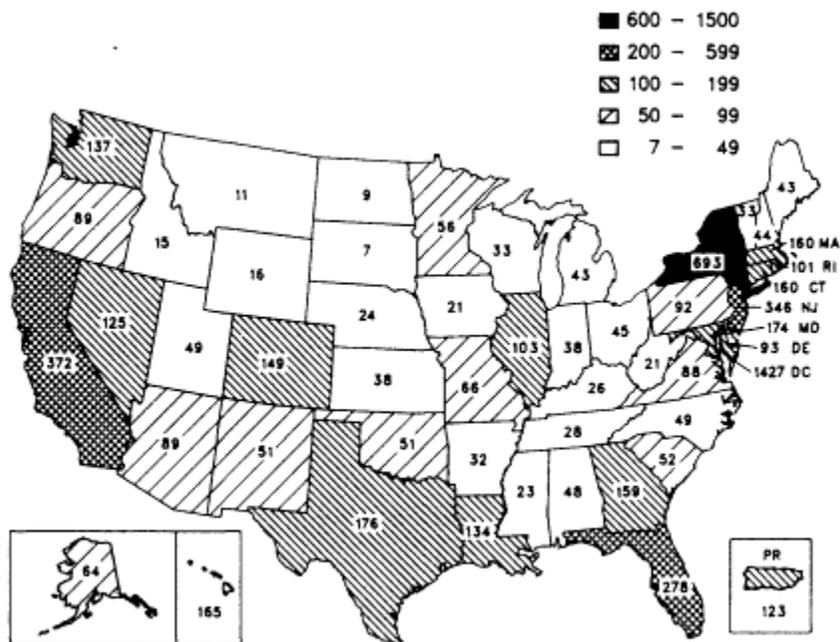


Figure 1-1 Incidence of AIDS cases (N = 44,745), by state, per million population, November 2, 1987. SOURCE: CDC (1987a).

Recognizing that there are competing hypotheses and that the available data on HIV prevalence are imperfect, it may nonetheless be instructive to consider the state-level data presented by CDC (Figures 1-1 and 1-2). As shown in Figure 1-1, the locales with the highest cumulative incidence of AIDS for the population were

1. District of Columbia	1.43 per 1,000
2. New York	0.69 per 1,000
3. California	0.37 per 1,000
4. New Jersey	0.35 per 1,000
5. Florida	0.28 per 1,000

The five locales with the highest HIV prevalence rates among military recruits (Figure 1-2) were

distribution may be different for adults and children; thus, a crude comparison of rates in two populations could be misleading if there were differences in the relative numbers of infected children. There are many other possible confounding factors for which there are no data..

Two jurisdictions that were included among the top five in the HIV rankings—Puerto Rico (no. 2) and Maryland (no. 4)—were not ranked in the top five in cumulative AIDS incidence. (Puerto Rico had a cumulative AIDS incidence rate of .12 per 1,000; the Maryland rate was .17 per 1,000.)

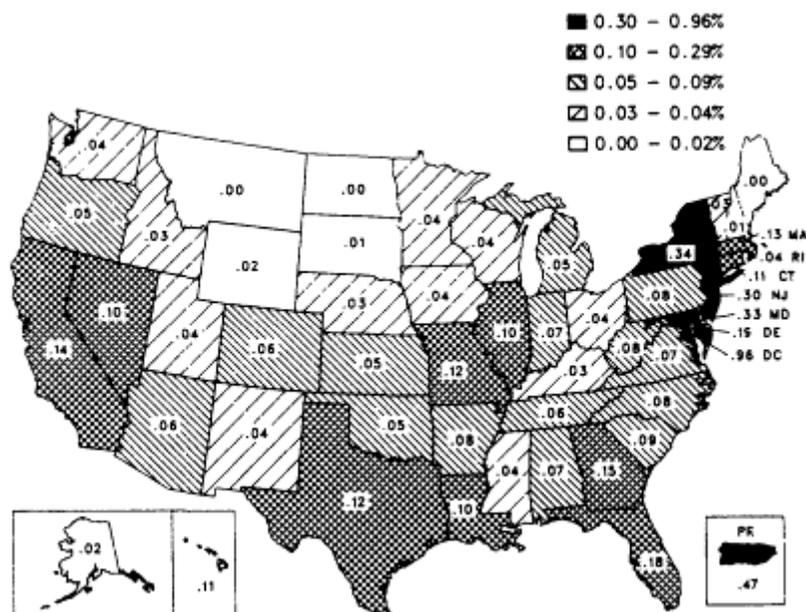


Figure 1-2 Sex-adjusted HIV antibody prevalence (percent positive) among applicants for military service ($N = 1,253,768$) by state for the period from October 1985 to September 1987. SOURCE: CDC (1987a).

1. District of Columbia	9.6 per 1,000
2. Puerto Rico	4.7 per 1,000
3. New York	3.4 per 1,000
4. Maryland	3.3 per 1,000
5. New Jersey	3.0 per 1,000

These data begin to suggest hypotheses about the timing of the geographic spread of the epidemic between adjacent jurisdictions (e.g., D.C. and Maryland) and jurisdictions that comingle segments of their population through migration and tourism (e.g., New York and Puerto Rico). Although these data can suggest hypotheses, they cannot provide a fully reliable indicator of the timing of the

geographic spread of HIV. Military recruits do not fairly represent the population; thus, data about their rates of HIV prevalence may not provide accurate rankings of jurisdictions in terms of the prevalence of infection.¹⁵

These data demonstrate the inconsistencies that can arise in using prevalence and incidence rates obtained from the testing of special populations. If another source of state-level HIV prevalence data had been used, the picture might have been different. For example, Mississippi, which has one of the lowest HIV prevalence rates among military recruits (0.4 per 1,000) would be near the top of a ranking of HIV prevalence on the basis of tests of blood donors.¹⁶

Uncertainties About HIV Prevalence

Although the above "patterns" can provide some crude guidance as to the relative prevalence of HIV infection in different groups, there are substantial difficulties in the interpretation of these data. It is clear, for example, that the various studies of HIV prevalence included in the CDC report sometimes used different exclusion criteria. Some studies compared rates based on all individuals, while other studies specifically excluded patients diagnosed with AIDS, AIDS-related condition (ARC),¹⁷ or "recognized" HIV infection. For instance, the Multicenter AIDS Cohort Study (MACS) specifically excluded AIDS patients. HIV seroprevalence rates from the MACS are based on 5,000 homosexuals who were free of AIDS at their initial visit. Other studies, such as seroprevalence studies of emergency room patients, may have included some AIDS patients in the calculation of prevalence rates. This lack of consistent criteria introduces

¹⁵ For example, to the extent that states vary in the distribution of infected individuals across risk groups (e.g., homosexual men and IV drug users) and members of these groups vary in their likelihood of volunteering for military service, the recruit data will provide a different ranking of HIV prevalence.

¹⁶ Mississippi's rate for blood donors is .25 per 1,000, which is the fifth highest rate shown in the CDC figure. Some of the states were combined, however, so the comparison is **not** precise. Nonetheless, Mississippi's rate of .25 exceeds that of New Jersey (.20 for blood donors), which ranked among the top five on both cumulative AIDS incidence and HIV prevalence among military recruits.

¹⁷ A term formerly used to describe a variety of symptoms and physical findings that may occur subsequent to HIV infection but that do not satisfy CDC's surveillance definition of AIDS (Institute of Medicine/National Academy of Sciences [IOM/NAS], 1986:353). Today, with a better understanding of the natural history of HIV infection, the term *ARC* is falling into disuse. Another IOM/NAS committee has recently recommended that use of the term *ARC* be discontinued and that HIV infection itself be considered a disease (IOM/NAS, 1988:37).

considerable uncertainty in the comparison and synthesis of findings from the studies in the CDC report.

The prevalence data also indicate, as would be expected, that there can be large differences in the results obtained from convenience samplings of what might appear to be the same population. So, for example, estimates of the prevalence of HIV infection among female prostitutes in New York City are reported as 14.3 percent on the basis of an "outreach" study conducted during 1985-1987 and 1.5 percent on the basis of a different outreach study conducted during 1986-1987.

There are also problems in using such data to target interventions to specific groups. First, there are the obvious selection biases. Prevalence estimates based on samples of gay men recruited at STD clinics will probably be higher than those that would apply to gay men in general because men recruited at an STD clinic are being treated for a disease whose mode of transmission parallels that of HIV infection. Similarly, as noted earlier, most potential blood donors in high-risk groups will presumably avoid donating blood, thereby reducing the prevalence of HIV among blood donors to a rate below that of the population in general. These biases subvert the usefulness of such data for decision making.

The committee also notes that discussions of the source, direction, and magnitude of biases in these samples are largely conjectural. Very little empirical research has been done to characterize these biases. Because HIV prevalence data will continue to be available from military recruits and blood donors, it would be valuable to explore these biases empirically. Careful studies documenting the nature of the interrelationships between trends across time in HIV prevalence in well-defined populations (estimated from probability samples) and trends in HIV prevalence found in these special groups would be especially valuable. Over time, such studies might provide an empirical basis for broadening the interpretation of trend data derived from these screening programs.¹⁸

In addition to the problems introduced by bias in the composition of the groups studied, the committee notes that other uncertainties about the data arise in the laboratory. The procedures used to determine HIV seroprevalence in the various studies cited in the CDC

¹⁸ Attempts to develop seroprevalence maps for local areas and to model HIV prevalence for regions by combining estimates from a multiplicity of screening programs and convenience samples might also be pursued. A key challenge in such efforts, however, will be providing clear and convincing rationales for the estimates of self-selection probabilities (i.e., the probability that a given member of the target population will appear in a particular convenience sample; see Manton and Singer [1988]).

report were not standardized across studies. Furthermore, HIV antibody tests may be sensitive to non-HIV infections and other biological factors that may introduce further inaccuracies into comparisons across studies. These inaccuracies are especially problematic in the study of low-prevalence populations. Finally, clerical errors (even if rare) can seriously distort already low prevalence estimates.

When the Department of Defense instituted HIV testing of applicants for enlistment in the armed forces, it established a system to standardize the HIV testing used in the program and to monitor the quality of testing done at laboratories. Similarly, CDC has established a system for testing the proficiency of laboratories conducting HIV tests as part of CDC's surveillance program. Such quality assurance programs were these agencies' responses to the widely documented experience of noncomparability of laboratory measurements performed in different places with different personnel and equipment, even on much less exacting tests than those used to detect HIV infection. Because all prevalence statistics (and clinical diagnoses) rely on test results, the level of accuracy of such results should be as high as is technically possible. What is needed is a system for monitoring the quality of HIV testing, *wherever it is performed*. **The committee recommends that an appropriate federal agency mount a continuing program to monitor HIV testing at all laboratories doing such testing.** In making this recommendation, the committee records its support for the recent recommendation on this same topic by the Presidential Commission on the Human Immunodeficiency Virus Epidemic (1988: Recommendation no. 6-33).

Principles And Methods Of Estimating Prevalence

This section begins by describing an "ideal" survey for measuring HIV prevalence in a defined group. It then identifies some of the obstacles that inevitably arise in conducting surveys and the ways in which such obstacles can be overcome. The section also offers recommendations for a realistic program to measure HIV prevalence.

An ideal survey of HIV prevalence would include four steps: (1) select a probability sample from the group of interest; (2) obtain a blood specimen from each person in the sample; (3) accurately assess the HIV serostatus of each blood specimen; and (4) combine the individual results using the statistical formulas applicable to the kind of probability sample that produced the data.

Probability Samples

The theory and practice of probability sampling—"coin of the realm" in efforts to describe a population—are well developed. The Consumer Price Index (CPI), the National Health and Nutrition Examination Survey (NHANES), and the statistics on unemployment all use this method, primarily because it yields unbiased estimates (when execution is flawless) and valid indications of the uncertainty of those estimates. When the cooperation of institutions—such as hospitals—is needed to reach the sample, however, there may be complications. Some institutions may be more cooperative than others, some may keep better records, and some may be more desirable targets because, for example, past data may exist that can provide a historical context for the new measurements. Such considerations may demand recognition and accommodation. Fortunately, the accommodation need not be to abandon probability sampling; it may instead call for giving preferred institutions large probabilities of selection (even certainty can be provided), with less preferred institutions receiving smaller selection probabilities (although the selection probability may not be zero for any institution). Much expertise regarding issues of this kind resides in the National Center for Health Statistics, which is now a component of CDC.

Full Coverage Of The Sample

Obtaining blood from each person in the sample may not be easy. Indeed, some people in a sample will not let their blood be drawn, and such refusals (nonresponse) can seriously distort prevalence estimates. Hull and colleagues (1988) report a survey in which 18 percent of a group declined to provide a blood specimen; among those 18 percent, there were more HIV positive results than among the 82 percent who did provide specimens.¹⁹ Thus, even modest nonresponse can gravely compromise the accuracy of results.

One device for coping with possible nonresponse is to assure respondents of the confidentiality (or even anonymity) of the information they are to provide—and then to ensure that such assurances

¹⁹ Every person in the group had previously given a blood specimen, and the specimens had been anonymously tested (i.e., the specimens had no personal identifiers); consequently, the total number of HIV positives was known. The number of positive results among the 18 percent who declined to give a blood specimen ($n = 9$) was more than that found among the identified specimens of the 82 percent who did not refuse the second time ($n = 8$).

are realized. Such methods as replacing names with in-house identification numbers and restricting access to files help ensure confidentiality. Provisions must also be made to forestall the possibility of "deductive disclosure." For example, a report that two 35-year-old women at hospital B gave birth to seropositive male infants on January 4 might allow the identification of the mothers from public birth records if the hospital is small (because there might have been only two male births to 35-year-old mothers in that hospital that day).

There are many ways to "coarsen" data to prevent deductive disclosure, and some methods are more effective than others. Replacing the date of birth with the month of birth introduces a 30-fold reduction in specificity and seems to lose very little useful information; removing the mother's race, however, would yield less reduction in specificity at a cost of more valuable information. Data release and reporting standards for the protection of confidentiality deserve thorough deliberation and careful policy making. Such procedures can easily develop through an ad hoc process and be suboptimal. Finding ways to safeguard confidentiality while permitting scientists to use these important data to the maximum extent feasible requires detailed study. **The committee recommends that CDC and other agencies with HIV/AIDS data gathering and reporting functions review their data disclosure practices, searching for rules and setting policies that continue to safeguard confidentiality but do so at the least practical cost in information.** It should be recognized, however, that no matter how strong the assurance of confidentiality and the measures to ensure it, some people will continue to refuse to furnish blood specimens (or other information).

A second approach to the goal of obtaining a blood specimen from each person in the sample is to use blood specimens that have no patient identifiers—that is, "blind" blood specimens that have already been obtained for some other purpose. This approach guarantees that the identity of the donor will neither be known nor be traceable to the blood specimen. Carefully considered minimal personal information such as the donor's gender, race, and age (but not date of birth) may accompany the sample. No ethical problem of violating an individual's privacy arises with this approach because no one's HIV status becomes known to anyone (including the donor, who will need another test if that knowledge is desired). The disadvantages to this approach are that individuals cannot be followed over time, and only meager information about the donor can be related to his or her HIV status. Still, a blind survey may deal

with the nonresponse bias problem quite effectively. (It is feasible to use analogous methods in studies that collect blood specimens for the specific purpose of testing for HIV. In that case, all identifying information would have to be destroyed prior to the testing of the blood specimens. For further discussion, see Turner and Fay, in this volume.)

Accurate Testing

Good laboratory tests for HIV serostatus exist, but long experience shows that it is difficult to maintain high levels of accuracy. The committee reaffirms its recommendation that an appropriate federal agency establish an effective surveillance and quality-monitoring program that includes every laboratory permitted to do HIV testing.

Combining Results

A rather subtle difficulty attends the step of combining results in a survey. Some few individuals who are not infected will nevertheless test seropositive—because of laboratory error, clerical error, or perhaps some phenomenon known only to virologists (or future virologists). In short, some false positives are inevitable, a factor that is particularly significant in the case of a low-prevalence condition such as HIV infection, for which even a small false-positive rate can be important. Thus, if I truly uninfected person in 500 gave a false-positive test result and the actual prevalence of HIV infection in the group being tested were 1 in 1,000, the list of seropositives would include three times as many individuals as it should, two thirds of whom are actually infection free. It will be impossible to tell which individuals are true positives and which are false positives. Furthermore, any change in testing error rates will appear to be a change in prevalence. This contingency can be dealt with in two steps: (1) by systematically monitoring HIV testing labs to obtain information about the magnitude of the HIV false-positive rate at each facility and (2) by using that information to adjust the observed prevalence rates.

THE 1989 HIV SURVEILLANCE SYSTEM

The present HIV surveillance system consists of six components that constitute what CDC calls its "comprehensive family of surveys." The data produced by this survey program are intended to accomplish the following objectives:

- "to obtain information on the incidence [of new cases of infection] and prevalence of HIV infection in risk groups and other defined populations" (CDC, 1987b:Appendix p. 2);²⁰
- to provide early warning of the possible emergence of HIV infection in new populations;
- to assist in targeting prevention activities and planning for future health care and other service needs; and
- to evaluate the effectiveness of AIDS prevention activities.

This surveillance program was put in place in 1987-1988;²¹ it will survey HIV prevalence (and, where possible, related behavioral risk factors) for six groups: IV drug users, patients at general hospitals, patients treated at STD clinics, patients at TB clinics, patients at clinics serving women of reproductive age, and newborn babies. These surveys are being conducted in the 20 metropolitan areas of the United States that report 75 percent of the current AIDS cases and in 10 other metropolitan areas with moderate to low AIDS prevalence. The survey program will be the nation's major source of HIV surveillance statistics for the next several years.²²

Because of the importance of this program, the committee's Panel on Statistical Issues in AIDS Research undertook a review of the six protocols that describe the individual surveys and how they will be conducted. As a result of this review, the committee has concluded that—with the exception of the screening of newborns—none of the surveys will remedy the major deficit that exists in our current knowledge: *these surveys cannot characterize (with knowable margins of error) the prevalence or incidence of HIV infection in any well-defined population.* As was true of all of the studies reported in CDC's 1987 review of HIV prevalence, five of the six components of the family of surveys program gather data from non-population-based samples that cannot be generalized to any larger population of interest.

²⁰ From the appendix entitled "Summary of HHS Plan to Determine the Incidence, Prevalence and Risk Factors for HIV Infection in the United States"; see p. 2, Point IV.

²¹ Elements of the "sentinel hospital" surveillance component (CDC, 1988c) were begun during 1986.

²² Developmental programs to test the feasibility of other strategies (e.g., HIV testing of stratified probability samples of the population) are just now beginning. However, even if preliminary testing demonstrated that these strategies were feasible, data gathering could not begin until late 1989, and the first results would probably not be available until 1990 at the earliest.

This conclusion, although strong and adverse, describes the results of a natural flow of events. Let us consider the four listed objectives of the "comprehensive family of surveys"; they serve two purposes—and those purposes are in tension. One is to help *manage* the public health problem of HIV spread at the local level. This purpose is well served by choosing study sites that have a high prevalence of infection or that are judged to be especially liable to large increases in prevalence; this purpose is also well served by selecting from among many clinics in a metropolitan area the one or two that offer the most cooperation, have the best records, and so on. Yet the second purpose (actually listed first), "to obtain information on the incidence and prevalence of HIV infection in risk groups and other defined populations," is severely compromised by the same purposive selections. Fortunately, the tension between the two purposes might be eased by suitably enlarging the surveys to become *probability samples* (i.e., involving the already chosen study sites as certainty strata). The opportunity to improve the family of surveys in this way is too important to bypass without serious investigation. To forego this opportunity would threaten the scientists and policy makers of 1995 with the same data problems that bedeviled the 1987 report on HIV prevalence: imponderable uncertainty about the prevalence and incidence of HIV infection in nearly every group of interest.

The committee recommends that efforts be made to reformulate the CDC family of seroprevalence surveys as probability samples. We believe this reformulation should be done as expeditiously as is compatible with good work.

To familiarize readers with the current family of surveys program, we describe in some detail the design and problems of two of the surveys and briefly note our concerns about three of the others. This section concludes with a description of the neonatal screening survey, the one component that is not subject to the criticisms of the other five parts of the family of surveys program. Indeed, the committee recommends that the neonatal program be expanded nationwide as soon as is practical (see the discussion later in this section).

Surveillance Of Iv Drug Users

Two kinds of cross-sectional surveys²³ will be conducted to monitor HIV prevalence among users of IV drugs: surveys of IV drug

²³ These surveys will supplement other studies by the National Institute on Drug Abuse (NIDA), which is currently supporting seroprevalence surveys in six cities of those IV
(Footnote continued on next page)

users who are currently in treatment and surveys of those who enter treatment in the future. These surveys will include clients at approximately 50 drug treatment centers in 30 metropolitan areas.

The in-treatment and entrant samples have the same stated objectives:

1. to estimate seroprevalence and correlate it with the demographic characteristics of individuals;
2. to obtain risk factor data from individuals where feasible and correlate risky behavior with seroprevalence; and
3. to establish benchmark estimates of behavior so that changes in behavior over time can be noted (see CDC/ National Institute on Drug Abuse [NIDA], 1988:11).²⁴

The reason for conducting the in-treatment surveys in addition to entrant surveys is to "rapidly ascertain HIV seroprevalence by sampling IVDUs [IV drug users] currently enrolled in drug treatment—populations that are relatively large and accessible" (CDC/NIDA, 1988:13). The in-treatment surveys are to be conducted only in situations in which seroprevalence among IV drug users is unknown and in which "relatively few IVDUs enter treatment, thus making rapid seroprevalence ascertainment from the 'entrant' survey difficult" (p. 14).

The entrant surveys will be conducted in two versions: blinded and nonblinded. In the blinded surveys, the IV drug users entering treatment will neither be informed of the survey nor of the results of their blood test. The nonblinded study will obtain informed consent prior to testing from the persons entering treatment. The nonblinded studies should be able to obtain more detailed information about "risky" behavior; in addition, trained personnel will be able to inform participants of their test results and provide counseling. The blinded studies will have higher (within-center) participation rates, however, because persons entering the center will not have the opportunity to refuse to participate. The CDC/NIDA protocol for this survey expresses the hope that "[i]deally, both blinded and non-blinded surveys should be conducted simultaneously in a treatment center. In this way, a non-biased estimate of HIV seroprevalence will be obtained . . ." (1988:16).

drug users who are either in treatment or who are reached by AIDS community outreach demonstration projects. The NIDA surveys are based on a nonrandom selection of sites.

²⁴ It should be noted that objective (3) might be accomplished without coupling the measurement of "risky" behavior to blood testing.

The estimate of seroprevalence from the blinded survey should yield an unbiased estimate of seroprevalence for that particular center. Yet unbiased estimates of seroprevalence among all IV drug users in treatment cannot be obtained under the proposed design. The major problem with the survey design is what appears to be a vaguely specified but unquestionably nonrandom selection method for choosing the drug treatment centers that will be included in the sample.²⁵ The lack of randomization is disturbing for two reasons. First, estimates of seroprevalence will be subject to biases, the magnitudes of which are unknown and most likely cannot even be estimated. Second, estimates of sampling error will miss what could be the major source of sampling variability—variability in seroprevalence across treatment centers within a metropolitan area.

A further problem with the survey design is the small number of drug treatment centers in the sample. A 50-center sample (the size proposed by CDC/NIDA) allows the surveying, on average, of only one or two centers from each of the 30 metropolitan areas. Using so few centers could make comparisons among metropolitan areas quite imprecise if there were substantial variability in seroprevalence among treatment centers in a given area. Indeed, this potentially important source of variability will not be assessed in the study. The documents that describe how local contractors should conduct the survey ignore entirely the component of sampling variability that arises in the selection of treatment centers. Thus, the protocol's specification of required sample sizes (CDC/NIDA, 1988:21ff) presumes that individual drug users are the sampling unit in a single-stage random selection. The protocol provides tables that purport to show the sample sizes necessary to detect differences with prespecified levels of statistical power. Yet the calculations that were used to produce these tables employ a statistical model appropriate for simple random sampling of individual IV drug users, which is not the type of sampling that is being used in the survey design.

If treatment centers were sampled (rather than selected), the design would be a multistage (cluster) sample of IV drug users with treatment centers defining the clusters. The (probably positive) intraclass correlation within treatment centers would imply that sample sizes larger than those envisioned in the proposal would be needed to attain the power indicated. Unequal selection probabilities for IV drug users in different centers would compound this problem.

²⁵ Some kind of stratified allocation of treatment centers is envisioned but only vaguely described in the proposal (CDC/NIDA, 1988:12).

Sentinel Hospital Surveillance

The Sentinel Hospital Surveillance program (CDC, 1988c) is intended to obtain estimates of HIV prevalence using a general hospital population sample that is not self-selected. Eight medical facilities were included in the program in 1986-1988; the survey design calls for the extension of this network to include 40 hospitals nationally, with at least 30 located in the metropolitan areas targeted by the other HIV surveys. Participating institutions must be either a short-term general hospital, a health maintenance organization, or a consortium of hospitals in the same area. They must have adult, pediatric, and emergency services, and they must receive a minimum of 17,500 annual admissions (including emergency room visits).

The general survey procedure includes a number of essentials. Infection is indicated by serologic positivity, which is established by a positive ELISA²⁶ confirmed by a Western blot test.²⁷ Only blood specimens that have already been collected for other purposes are eligible for testing. These specimens must be drawn from patients on hospital clinical services with little recognized association with AIDS.²⁸ An aliquot (0.5 milliliter minimum) will be drawn off from the blood specimen and labeled with the patient's sex, race or ethnic group,²⁹ age in years, and the month and year of collection. The clinical service will be indicated on a separate label.

Each month a random subsample of 300 specimens will be selected independent of clinical service according to a specified age/sex stratification. The stratification ensures that equal numbers of men and women are selected within each age group, and it counteracts

²⁶ Enzyme-linked immunosorbent assay, a test used to detect antibodies against HIV in blood specimens (see the 1986 and 1988 IOM/NAS reports).

²⁷ The Western blot technique involves the identification of antibodies against specific protein molecules. It is believed to be more specific than the ELISA in detecting antibodies to HIV; it is also more difficult to perform and considerably more expensive. (For further information, see IOM/NAS [1986, 1988].)

²⁸ Eligible services include cardiovascular, endocrinology, obstetrics, ophthalmology, orthopedics, pediatric ear-nose-throat (excluding middle-ear infection), adult ear-nose-throat (except patients hospitalized for cancer or biopsy), emergency (except patients hospitalized for infectious diseases), gynecology (except patients hospitalized for infections, STDs, cancer, or biopsy), general surgery (except patients hospitalized for cancer or biopsy), and pediatric surgery (except patients hospitalized for cancer or biopsy). Also eligible are patients hospitalized for accidents, poisoning, burns, trauma (excluding gunshot and stab wounds), drowning, asthma, cerebrovascular accidents, and hernias.

²⁹ The coded race and ethnic groups are "white (not Hispanic)," "black (not Hispanic)," "Hispanic," "other," and "not specified." If at least 10 percent of the blood specimens are from an identifiable racial or ethnic group (other than black, white, or Hispanic), that group is to be coded.

the overrepresentation of the aged in hospital populations. In addition, the design requires that hospitals with fewer than 50 percent nonwhite patients oversample blood specimens from these patients.

Seroprevalence rates will be calculated by age group, sex, and race. Composite rates adjusted by age and sex for each hospital, for the region, and for the nation will also be calculated. Data for individual hospitals and cities will not be published; instead, ranges of values for institutions and regions will be offered. State and local authorities and participating hospitals will receive summaries of data for their own specimens, as well as regional and national results.

Because the surveillance uses blind testing of blood specimens with no personal identifiers retained, self-selection biases will be avoided. However, once again, the hospitals themselves will be selected rather than sampled. In selecting the participating hospitals, CDC (1988c:45) states that "weight will be given to the offeror's breadth of representativeness and the probable consistency of representativeness." To this end, potential sites are asked to provide information on the geographic and socioeconomic characteristics of the population they serve and the "approximate proportion" of non-whites among their patient populations. Although such data may guide the survey designers to choose hospitals with particular types of population diversity, it does not overcome the major inadequacy of the design.

Like the survey of IV drug users, the sentinel hospital surveillance system eschews the sampling of hospitals within the 30 metropolitan areas. Because only 40 hospitals will be chosen to participate, in most cities this surveillance system will be monitoring prevalence in one hospital, HMO, or consortium. If there is considerable variation in seroprevalence rates for hospitals within the same metropolitan area, there must be doubts about the ability of this system to meet its explicitly stated objective "to obtain information to indicate current prevalence of HIV infection in the United States, and more importantly, changes in prevalence over time" (CDC, 1988c:1). This does not imply, of course, that the resultant data would not be suggestive or that this type of surveillance system would not provide information that could be obtained rapidly and economically. Yet the value of this information would be immeasurably enhanced if the study design were altered so that prevalence data could be projected to the entire hospital population and not merely to the 40 hospitals included in this sample.

Surveys Of STD And TB Clinics And Clinics Serving Women Of Reproductive Age

In its review of the other components of the CDC family of surveys program (CDC, 1988a,b,d), the committee's statistical panel determined that these components (with the exception of neonatal screening) shared the deficiency in sampling that characterizes the surveys of IV drug users and sentinel hospitals. Consequently, we do not describe these components of the survey in detail but instead raise certain other issues that pertain particularly to them.

For the surveys targeted at clinics serving women of reproductive age, the committee is concerned about the substantive justification for including all of the different types of clinics: family planning, prenatal, abortion, and the Special Supplemental Food Program for Women, Infants, and Children (WIC). We find little reason to conduct blinded surveys in prenatal clinics. The screening of newborns (discussed later in this chapter) will provide better information on the HIV status of women giving birth, and such a screening captures the entire population of these women. However, representative data on the serostatus of women who have abortions would be extremely valuable. Unfortunately, as with the other components of the survey program, the study of women attending abortion clinics will not be generalizable to the population of women using such clinics.

The panel was surprised to find that the survey designers did not stratify their selection of clinics by type (e.g., prenatal, abortion, etc.). Without controlling the mix of clinics in different geographic areas, it becomes difficult to make comparisons across areas.

In reviewing the protocol for the blinded HIV prevalence surveys of patients at TB clinics, the committee felt that further consideration might be given to the use of *confidential* rather than *anonymous* testing. Current standards of medical practice dictate HIV testing for all TB patients because preliminary evidence suggests that TB patients with HIV infection require a modification of the standard antituberculosis therapy. Thus, both CDC and the American Thoracic Society have recommended a more aggressive approach to the treatment of TB in HIV-infected patients. It might reasonably be argued that if it is good medical practice to test for HIV infection in all TB patients, then clinics should perform such tests and patient permission should be sought to use these data for statistical purposes. If so, confidentiality, rather than anonymity, would be important.

One cannot rule out the possibility, of course, that such testing would lead to substantial rates of nonresponse, but it is also possible

that people who come to a clinic for treatment of a major disease will be less likely to refuse to participate. They may be even less likely to refuse when they learn that HIV testing is necessary for the effective treatment of their condition. In any event, a small amount of anonymous testing could be used as a check on selection bias.

While we do not wish to recommend unequivocally a confidential (nonblinded) survey of TB patients, we do believe that CDC should reconsider this option if the major purpose of this survey is to assess the prevalence of HIV in patients of public TB clinics. In this reconsideration, it would be desirable for CDC to pilot-test a nonblinded screening procedure to determine whether it produces high levels of nonresponse. The committee recognizes, however, that the data gathered from TB clinics may have other uses (see the discussion later in this chapter) and these uses may legitimately influence the data collection strategy.

Data Management

A final area of concern to the committee regarding the family of surveys program involves the program's proposed data management plan. This plan seems to ensure that some data will be discarded to ensure confidentiality.³⁰ This outcome would result from the requirement that there be a minimum number of persons per stratum (e.g., black men aged 20-24), which is applied to the smallest possible group by month and by site. Considering that yearly (or half-yearly) trends are likely to be the data of interest, it should be possible to wait until a year's worth of data has accumulated before transmitting it to the central data collection site. Alternatively, some central facility within each metropolitan area could aggregate data for that area, and restrictions could be placed on the availability of results for specific clinics.

Neonatal Screening

The neonatal screening (CDC/NIH, 1988) is unique among the surveys planned for the 30 target cities included in the family of surveys

³⁰ Discussions with CDC staff indicate that this aspect of the plan probably resulted from attempts to guarantee anonymity *at the clinic level* in the blended surveys. Because HIV test results will be identifiable by clinic, the data disclosure possibilities are great (particularly since some of the clinic samples will be small). Although the committee has no solution to propose, it does believe further study of this issue is warranted. Among the alternative strategies that might be considered are relaxation of the requirement that *all* HIV test results be identifiable by clinic.

program. It is the only survey to provide seroprevalence data that, by design, can be generalized to an identifiable population.

The CDC/National Institutes of Health (NIH) neonatal survey will perform HIV tests using the dried blood specimens that are routinely collected from all (hospital-born) newborns (to test for metabolic disorders). Because children born to HIV-infected mothers carry the mother's antibodies (without necessarily being infected themselves),³¹ the HIV seroprevalence rates derived from this screening can be projected both to the population of newborns and to the population of childbearing women. (Estimates of the number of newborns who are actually infected, as opposed to the number who are passively carrying the mother's antibodies without infection, will require ancillary studies; these studies might be performed on small subsamples, however.) The statistics derived from this survey will provide a basis both for projecting future AIDS cases among infants and, perhaps most importantly, for monitoring the prevalence of infection among an important part of the population of heterosexually active women.

Although the neonatal survey is unique in its ability to provide seroprevalence estimates that reflect rates of infection in an important, identifiable population, it is not perfect. The group of women represented by these statistics will not include all women who may be at risk of infection. For example, the group does not include women who choose not to bear children, women who abort or miscarry prior to delivery,³² or women who have ceased childbearing. Because serostatus may influence a woman's decision to avoid pregnancy or to abort after conception, biases of uncertain magnitude may occur when these data are generalized beyond the operational definition of the population studied (i.e., all women who delivered a live child in a hospital during a particular time period). The magnitude and direction of one of these biases may be estimated, however, by conducting ancillary studies of the serostatus of probability samples of, in particular, women who abort. Consequently, **the committee recommends instituting a continuing anonymous probability survey of the HIV serostatus of women who are clients of clinics that provide abortion services.**

³¹ All newborns of HIV-seropositive women carry the maternal antibody to HIV, even though the infants themselves may not be infected. It is estimated that there is a 30-50 percent risk of perinatal HIV transmission from an infected mother to her child and subsequent diagnosis of AIDS in the infant (IOM/NAS, 1988:35).

³² The draft protocol (CDC/NIH, 1988:20) notes that attempts will be made in another program to monitor seroprevalence in aborted fetuses; no details are given of this effort.

Other aspects of the neonatal survey also require attention. Interpretation of the seroprevalence statistics derived in this survey will require that analysts grapple with the systematic differences between women who bear children (particularly those who bear many children) and those who do not. For example, the seroprevalence rates that are obtained in the newborn screening survey will be affected by childbearing women in proportion to the number of children they bear. Obtaining and recording information on the birth order of the infant may permit estimation of the size of this bias so that the HIV seroprevalence estimates for childbearing women can be adjusted to correct for it. Interpreting the results of the neonatal screening will be greatly assisted by the various reliable sources of statistical data on the characteristics of childbearing women already in existence (e.g., the National Survey of Family Growth and the registry of births).

The newborn survey will be conducted statewide in all of the states that encompass the 30 cities included in the family of surveys program. These blinded surveys will be conducted by the states' public health departments; CDC/NIH is also urging state health departments in the rest of the nation to participate in this survey. The survey protocol calls for a quarter-inch "punch" to be removed at the processing laboratory from the filter paper containing blood obtained from a newborn heel stick. This small sample will be tested for HIV; the remainder of the filter paper will continue to be used in tests for neonatal metabolic disorders. The protocol asserts that "virtually 100 percent of babies born in the United States are screened [in this manner] for phenylketonuria and congenital hypothyroidism" (CDC/NIH, 1988:6).

The protocol also describes various alternatives for sampling the blood specimens. We believe it would be best to include all infants in the sample. First, it is not an impracticably large task because every baby is already tested (from the same specimen) for other purposes. Second, a large sample is helpful because of the low prevalence of HIV infection. Seroprevalence in women is in the .001 to .01 range; let us use .003 for the purposes of this example. In a county with a population of 1 million, about 16,000 births can be expected annually. Of those, approximately 48 will be seropositive. Even with 100 percent HIV testing, as soon as subgroups are considered (e.g., "older white mothers" or "younger Hispanic mothers"), there will be only a dozen or so cases annually that will provide evidence about HIV prevalence in such subgroups. Moreover, comparisons of year-to-year changes in the number of cases will be less precise than the rates themselves. In this instance, the opportunities for

economy through the use of samples are not large; furthermore, administrative simplicity, lower costs, and greater effectiveness can probably be attained by routinely treating all births in exactly the same fashion.

Basic demographic information to be collected in the newborn survey includes the month and year of the infant's birth, the county (or parish) of the mother's residence, and the county (or parish) in which the hospital is located. The protocol notes that, for counties with few births or for those with only a single hospital, data should be aggregated to ensure that there will be no inadvertent disclosure of the mother's or infant's identity. In addition to the basic demographic information, the protocol specifies that "when available and provided that inadvertent disclosure [of identity] cannot occur, the zip code of mother's residence and hospital locations, and/or mother's race and age should be included" (CDC/NIH, 1988:11). The committee believes these provisions provide good illustrations of the need for a carefully considered policy on the collection of identifying data (which is already the subject of a recommendation appearing earlier in this chapter).

Because CDC's proposed neonatal screening will provide unbiased estimates of HIV prevalence for a population of great interest, **the committee recommends that the newborn infant seroprevalence survey be extended to include all children born in the United States.**

It should be recognized, however, that the interpretation of trends in the prevalence rates obtained through this survey will lead immediately to questions about transmission. High (or rising) rates of infection will prompt the question of whether such increases are due to infection through IV drug use and needle-sharing among women of childbearing age, whether they are a consequence of heterosexual transmission of HIV infection, whether they are the result of increased childbearing among female IV drug users, or whether they arise from still other factors. As it is presently constructed, the neonatal survey can pose such questions effectively, but it will not provide answers regarding the causes of any trends that are observed. To provide such answers will require a different sort of data gathering (which might build on the neonatal survey). These data gathering efforts might target areas with high prevalence rates (or with rapid changes in prevalence rates); targeted follow-up surveys would then be needed to establish the causes of transmission in these areas. One strategy might regard the neonatal survey as a "screener" to identify

areas in which more specialized studies should be conducted to answer questions of causality. This type of strategy would not be overly difficult to implement after some experience is gained with the basic neonatal survey.

ESTIMATES OF NATIONAL HIV PREVALENCE AND INCIDENCE

There are three methods of estimating the current extent of HIV infection in the United States.

1. Divide the population into groups or strata, and for each stratum estimate both the size of the group and its rate of seroprevalence. Combine these estimates for an estimated number of infected persons in the stratum; obtain a national total estimate by adding the estimates for all strata.
2. Exploit the necessary mathematical connections among three time series: $A(t)$, the number of AIDS cases seen by time t ; $H(t)$, the number of HIV infections that have occurred (mostly unseen) by time t ; and $l(x)$, the probability distribution for the "latency," the length of the interval between acquiring HIV infection and being diagnosed with AIDS.
3. Conduct a sample survey of the population of the United States, collecting and testing blood specimens.

This section considers each of these methods in turn, calling them (1) the components model, (2) the epidemiological model, and (3) the sample survey method.

The Components Model

The components model was used to derive the most widely quoted estimate of HIV prevalence in the United States (see [Table 1-2](#)), which was presented in the Public Health Service's 1986 "Coolfont Report" (Public Health Service, 1986). That report concluded: "[B]y extrapolating all available data, we estimate that there are between 1 and 1.5 million infected persons in those groups [IV drug users and homosexual men] at present" (p. 343). Although explicit calculations were not shown in the original document, the Coolfont report indicated that its authors estimated that 2.5 million American men between the ages of 16 and 55 are "exclusively homosexual" throughout their lives and that 5-10 million more have some homosexual

contact.³³ Similarly, they estimated (without explicit reference to a source) that 750,000 Americans inject heroin or other drugs at least once a week and that similar numbers inject drugs less frequently. These estimates of population size were then multiplied by estimates of the prevalence of HIV infection among these groups³⁴ to generate the widely quoted estimate that there are from 1-1.5 million infected persons in these two groups. Changes in estimates of population size and HIV prevalence led CDC (1987a) to revise its estimate for 1987 (see Table 1-2) to 945,000-1.41 million infected individuals.

TABLE 1-2 Estimates of the Number of Persons Infected with HIV in the United States

Source	Population	Date	Estimate
PHS Coolfont report ^a	IV drug users and homosexual men	June 1986	1.25 million ^b
CDC Domestic Policy Council report ^c	IV drug users and homosexual men	Nov. 1987	1.17 million ^d

^a Public Health Service (1986:341-348).

^b Estimated as the interval 1.0 million to 1.5 million; the midpoint of the interval is shown in the table.

^c CDC (1987b).

^d Estimated as the interval 945,000 to 1.41 million; the midpoint of the interval is shown in the table.

Estimates derived using the components model are vulnerable to errors of unknown magnitude in both multiplicands. For example, the 1986 Coolfont estimate used data collected by Kinsey and colleagues (1948) in the 1940s to estimate the *current* number of male homosexuals in the United States. Even 30 years ago, the Kinsey data were widely regarded as unreliable for making such estimates because the research that produced them did not use probability sampling and because the respondents in the Kinsey studies were disproportionately drawn from the Midwest and from the college-educated segment of the population (e.g., Terman, 1948; Wallis, 1948; Cochran et al., 1953). Today, a further leap of faith is required

³³ The subsequent CDC report (1987a) provides the explicit breakdown used in the 1986 calculations.

³⁴ The prevalence rates used in these calculations were not published in the original report (Public Health Service, 1986), but the report states that HIV prevalence estimates range from 20-50 percent for homosexual men and from 10-50 percent for users of IV drugs.

to assume that the relative size of the (self-reported) homosexual population has not changed since the 1940s (see [Chapter 2](#) and Fay and colleagues [in press]). Furthermore, the committee notes that estimates of the prevalence of HIV infection among homosexual men were not derived from probability samples. Identical problems afflict the estimates of HIV infection among IV drug users (see Spencer [in this volume]).

The Epidemiological Model

The epidemiological model depends on a necessary mathematical relationship among these three time series:

$A(t)$, the (cumulative) number of AIDS cases that have appeared by time t ;

$H(t)$, the (cumulative) number of cases of HIV infection that have occurred (mostly unseen) by time t ; and

$l(x)$, the probability³⁵ that a person will be diagnosed with AIDS after the passage of x years from time of infection with HIV.³⁶

Before discussing the mathematical relation, let us note what is known about these series. First, from CDC statistics, $A(t)$ is known for the period since 1981. The data are not quite exact because revisions must and do occur. (For example, a major revision of the AIDS case definition was adopted in 1987 [CDC, 1987c]). Because of reporting delays, the most recent portion is most susceptible to revision. Second, almost nothing is known about $H(t)$ because there are such meager data about HIV prevalence. Third, $l(x)$ can be known only for x from 0 up to about 10 years, for there has been no opportunity to see the relative frequency of latencies longer than 10 years. What is known about this latency distribution comes largely from studies of hemophiliacs, transfusion recipients, and a few other

³⁵ The function $l(x)$ is a probability density function that ordinarily sums to 1.0 if integrated from 0 to infinity. However, because not all of those infected with HIV may eventually be diagnosed with AIDS, the integral of $l(x)$ from 0 to infinity may be less than 1.0.

³⁶ Implicit in this definition of $l(x)$ is the assumption that latencies (intervals between time of infection and time of AIDS diagnosis) have had the same probability distribution over time; thus, the definition tacitly assumes that changes in the ratio of men to women among infected individuals or in the relative proportions of IV drug users, homosexuals, and blood product recipients are all immaterial with respect to the distribution of latencies. (With the exception of latencies for newborns, we are not aware of convincing information that contradicts—or supports—these assumptions.) Also involved is the assumption that diagnostic practices have not altered in a way that shortens or lengthens latencies.

special groups. By assuming that $l(x)$ has a specific functional form, such as that of the Weibull distribution, it is possible to extend our estimate of $l(x)$ beyond $x = 10$ years.

The epidemiological model sets out to estimate the curve $H(t)$ by using $A(t)$, which is approximately known, and $l(x)$, which is somewhat known. The relation among these three series is

$$A(t) = \int_0^t H(t-x)l(x)dx. \quad (1)$$

Thus, if any two of $A(t)$, $H(t)$, and $l(x)$ are known exactly, the other can be calculated exactly. We do know $A(t)$ more or less exactly and $l(x)$ can be estimated; thus, it is possible to produce an *estimate* of $H(t)$, the cumulative incidence of HIV infection up to time t . An estimated solution of equation (1), then, consists of two estimated series, $H(t)$ and $l(x)$; the adequacy of this solution can be judged by how closely the resulting $A(t)$ (from the solution) corresponds with the observed $A(t)$. Unfortunately, quite different pairs of estimates of $H(t)$ and $l(x)$ provide equally good fits to $A(t)$ but carry very different values for the cumulative incidence $H(t)$ and for the latency distribution $l(x)$.

In practice, using equation (1) to estimate $H(t)$ is fraught with difficulties. In particular, $l(x)$ is very small for the first two or three years. Thus, as equation (1) shows, AIDS cases that have been diagnosed by, for example, 1988, are primarily a function of the number of HIV infections through 1985. Therefore, even a perfectly accurate count of the AIDS cases diagnosed through the previous year provides little reliable information on new HIV infections during the past three or four years. Because HIV incidence may be growing rapidly and because it is not possible to estimate precisely the number of new cases of HIV in the past few years, estimates of the cumulative incidence $H(t)$ could be far off the mark. This imprecision does not matter very much for predicting the number of new AIDS cases in the short-run because such predictions do not depend heavily on the incidence of HIV infection in the past few years (Brookmeyer and Gail, 1986). In terms of predicting current HIV prevalence, however, and for estimating trends in prevalence over time, this imprecision can be costly.

Clearly, the epidemiological and the components models approach the estimation of HIV prevalence quite differently. Each has its problems, but they are of quite different kinds. Both produce estimates of HIV prevalence of "about 1,000,000"—meaning, within the range of 0.5-2 million infected persons. Confidence in this rough

estimate is strengthened by the fact that the uncertainties affecting the two methods of estimation are quite different.

Sample Survey Method

The Public Health Service recently embarked on a developmental program to test the feasibility of obtaining direct estimates of HIV infection by means of a survey that would seek blood specimens (and associated questionnaire data on risk) from a probability sample of the national population. This undertaking is necessarily complex and difficult, and it cannot be foreseen whether such a survey will produce the desired estimates.

Among the most important of the attendant difficulties will be ensuring a sufficiently high rate of response to the survey. Because less than 1 percent of the population is thought to be infected with HIV, nonresponse could have a debilitating impact if it were to come disproportionately from population subgroups with elevated prevalence rates. In that case, the estimates produced by such a survey program could be seriously biased, even if the initial sample of designated respondents were unbiased. (Turner and Fay [in this volume] explore in greater detail the complexities involved in such a survey.)

The committee commends the exploratory spirit in which the Public Health Service has begun the development of this survey, and it applauds its strategy of using experiments to test whether or not such a survey might provide useful direct estimates of prevalence (and, ultimately, trends in prevalence). The outcome of these experiments should play a decisive role in the ultimate decision of whether to go forward with such a survey.

CONCLUSION

The committee believes that there is a pressing national need for better statistical systems to monitor the spread of the AIDS epidemic and, more particularly, the spread of its precursor, HIV infection. The development of such systems will require time and adequate resources—both in dollars and in appropriately trained scientific staffs. If the nation is to have a better understanding of the HIV/AIDS epidemic in 1999 than it has in 1989, the investment *must* be made. Delays in committing resources to the development of these systems would be false economy. Such a policy would only postpone unavoidable expenditures while forcing scientists and policy makers

to continue to "make do" and work without accurate information on the current magnitude and future course of the epidemic.

The development of a more reliable system for tracking the spread of HIV infection is a prerequisite for mounting a fully effective and efficient national response to AIDS. Without better information on the incidence of new HIV infections in the population, the nation will lack adequate means to determine whether current strategies for controlling the spread of HIV are working. Without better information on the prevalence and spread of infection in the population, it is difficult to prepare adequately for future demands for hospital beds and other health care services. Without better data, it is easy to anticipate endless debates about whether the disease is spreading "rapidly" or "slowly." To the extent that opposing sides in these debates produce "evidence" from convenience samples, inconsistency in conclusions is to be expected, and there is thus no basis for an informative scientific debate.

What we require for more informative debates, for better planning for future health care needs, and for improved evaluation of the effects of national AIDS-control strategies are *data derived from research designs that can provide reasonably unbiased estimates of the prevalence and incidence rates for HIV infection in well-defined populations of substantive interest.*

Attributes Of An HIV Monitoring System

Such designs for monitoring HIV would have two characteristics that set them apart from the procedures ordinarily used for tracking epidemics. These attributes follow directly from the nature of the disease under consideration. A *passive* reporting system is not adequate to monitor the spread of a fatal infection that is asymptomatic (for almost all infected individuals) for a long period of time. This fact requires a conceptual departure from the way in which epidemic diseases have traditionally been monitored. Traditionally, such diseases have been classified as "reportable" by public health officials. After such a determination, health care workers (physicians, testing laboratories, etc.) were legally required to report all new cases of the disease to the local department of public health. These reports, when aggregated by federal disease control officials, provided crucial information for monitoring the course of many past epidemics. Part of the reason for the success of this type of system followed from the fact that many of these infections quickly caused symptoms that required medical attention. The outcome (in a substantial fraction

of cases) was swift, and the size of the public health problem posed by the spread of the infection could be monitored by counting the number of new cases reported to health authorities.

Unfortunately, a passive reporting system does not work as well for diseases that in most infected individuals are slow to require medical attention. These diseases do not provide sufficient motivation to the infected person to seek medical care quickly and thereby be captured by the statistical reporting system; consequently, the statistical system must actively "ferret out" information on new cases. This more active method of case gathering and reporting is the first way in which an HIV monitoring system would differ from more traditional case-reporting systems.

A second difference is that an adequate measurement system for HIV cannot rely exclusively on the routine functioning of the medical infrastructure to count infected persons. This requirement has important institutional consequences because it mandates the organization of surveillance outside of traditional medical settings.

Other Uses Of Data On HIV

This committee has listened with interest to arguments that population-based estimates of HIV incidence and prevalence are unnecessary from a public health perspective. Rather, it has been suggested that targeted samples of convenience could suffice to provide "sentinels" that could be used to guide the nation's response to the AIDS epidemic.

The committee recognizes that there may be public health uses of prevalence data whose purposes can be served by other methodologies. In reviewing the protocol for HIV testing of patients at TB clinics, for example, the committee was initially perplexed by the choice of blind testing; reasonable standards of medical treatment would dictate routine HIV testing of all TB patients because preliminary evidence suggests that standard antituberculosis therapy should be modified for persons infected with HIV. After discussions with CDC staff, the committee came to understand that a major purpose of the blind testing was to convince reluctant clinics to begin routine HIV screening of TB patients. The evidence from the blind screening was intended to stimulate local clinic staff to recognize the extent of HIV prevalence in their clinic and to adopt the Public Health Service's recommendation for routine HIV screening of all TB patients.

In this case, there was a clear public health use for numerical information on prevalence in particular clinics. That purpose could be well served without attempting to estimate accurately the true prevalence of HIV among all patients at TB clinics. While recognizing this important public health use of such data, the committee would observe that the *stated objectives* of this survey, as with other components of the family of surveys program, were to determine HIV prevalence and monitor trends in prevalence.³⁷ These more demanding objectives require a survey design appropriate to these tasks.

It is the opinion of this committee that the public health mandate to monitor the spread of HIV *requires* that reliable statistical data be gathered on HIV infection. Gathering such data necessitates the use of methods that ensure (to the extent technically possible) that the resultant estimates will reflect, with known margins of error, the actual incidence and prevalence of infection in specific populations. *The committee concludes that it would be a serious mistake for the Public Health Service to continue to "make do" with estimates derived from convenience samples.*

The committee would also emphasize that much of the information needed to understand and cope with the spread of HIV is obtainable only with the consent of a person who may be harmed if test result confidentiality is not maintained. Thus, maintaining confidentiality serves not only fairness but also society's interest in access to information to help combat the disease. Two steps can help: (1) confidentiality can be buttressed with legal penalties in the event of its breach, and (2) legal protection against discrimination can be established for persons infected with HIV. In this regard, the committee wishes to note that it endorses the approaches to protecting confidentiality and opposing discrimination proposed by the Presidential Commission on the Human Immunodeficiency Virus Epidemic (1988).³⁸

The Presidential Commission has provided the President and the American people with 35 specific recommendations on the steps that should be taken to halt discrimination against persons with HIV infection and AIDS and to guarantee the confidentiality of

³⁷ The protocol (CDC, 1988a:4) states: "The objectives of this survey are the following: (1) to determine the prevalence of HIV antibodies among persons with confirmed or suspected tuberculosis by age, sex, race, ethnicity, metropolitan area, TB clinic site, country of origin, clinical status (confirmed or suspected TB), anatomic site of infection (pulmonary, extrapulmonary, or both) and (in the non-blinded surveys) AIDS risk factor; and (2) to monitor trends in infection levels over time. Implementation of a standard protocol will facilitate comparison of data from different clinics."

³⁸ See Chapter 9, Sections I and II.

information about individuals' HIV status. The committee believes that the approaches recommended by the commission could serve the nation well by improving the climate in which future research and interventions will be conducted.

Finally, the committee and its Panel on Statistical Issues in AIDS Research wish to end this chapter by offering two observations: one about the past and one about the future.

The Public Health Service has met an unexpected, challenging, and complicated epidemic with vigor and ingenuity and has much to be proud of. Moreover, its achievements have been accomplished in the face of considerable adversity on a number of fronts—physical, diplomatic, political, and administrative. As always, however, the past must give way to the future. The HIV/AIDS problem is not going to disappear soon, if ever. Its most visible component, AIDS, will surely increase for years to come. Now is the time to prepare for the future, and good data will be indispensable in future efforts to control this epidemic. No postponement should be accepted in implementing the clearly necessary steps to markedly improve the data on this disease. CDC should be given the resources needed to promptly initiate the appropriate steps to improve the nation's HIV/AIDS information base.

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