

# Tracking the HIV Epidemic: Current Issues, Future Challenges

## ABSTRACT

The emergence of a new infectious disease, AIDS, in the early 1980s resulted in the development of a national AIDS surveillance system. AIDS surveillance data provided an understanding of transmission risks and characterized communities affected by the epidemic. Later, these data provided the basis for allocating resources for prevention and treatment programs.

New treatments have dramatically improved survival. Resulting declines in AIDS incidence and deaths offer hope that HIV disease can be successfully managed. However, to prevent and control HIV/AIDS in the coming decades, the public health community must address new challenges. These include the defining of the role of treatment in reducing infectiousness; the potential for an epidemic of treatment-resistant HIV; side effects of treatment; complacency that leads to relapses to high-risk behaviors; and inadequate surveillance and research capacity at state and local levels to guide the development of health interventions.

Meeting these challenges will require reinvesting in the public health capacity of state and local health departments, restructuring HIV/AIDS surveillance programs to collect the data needed to guide the response to the epidemic, and providing timely answers to emerging epidemiologic questions. (*Am J Public Health*. 2000; 90:1037–1041)

Patricia L. Fleming, PhD, MS, Pascale M. Wortley, MD, MPH, John M. Karon, PhD, Kevin M. DeCock, MD, and Robert S. Janssen, MD

At the start of the 21st century, the United States has witnessed 2 decades of the AIDS crisis. More than 400 000 lives have been taken prematurely by HIV<sup>1</sup>; more than 800 000 Americans are currently living with HIV.<sup>2</sup> Despite steady advances in prevention science and in medical treatment to improve survival among infected persons, HIV remains a major public health threat in this country. In this report, we summarize the current status of the epidemic in the United States and identify emerging issues that may challenge future progress in preventing HIV infection, disease, and death. To meet these challenges, reinvestment in the public health capacity of state and local health departments to monitor the epidemic is urgently needed.

### **Current Status of the National Epidemic**

Beginning in 1981, the US Centers for Disease Control and Prevention (CDC) and state and local health departments set up a surveillance system to track a new disease phenomenon, AIDS. During the early 1980s, through surveillance and epidemiologic research, it was evident that a new disease agent was being transmitted sexually and through contaminated blood. AIDS surveillance data tracked an epidemic that was spreading rapidly throughout the United States. We now know that HIV incidence peaked in the mid-1980s, reflecting successful prevention strategies such as blood screening and donor deferral, counseling and testing programs, and behavioral risk reduction.<sup>2</sup>

During the 1990s, the nation's investment in the AIDS clinical trials infrastructure yielded tremendous gains in effective treatments, contributing to the first declines in the AIDS-related death toll in 1996<sup>3</sup> as well as to dramatic declines in perinatal HIV transmission.<sup>4</sup> Treatment-associated declines in AIDS incidence and deaths meant, however, that many people with HIV who needed treatment and care were free of AIDS and therefore not counted in the national AIDS statistics that serve as the basis for funding HIV services through the Ryan White Care Act.

Recently, the CDC published recommendations for a nationwide system for reporting cases of HIV infection.<sup>2</sup> The expansion of the AIDS surveillance system to

include all persons who have been diagnosed with HIV will greatly enhance knowledge of the scope and impact of the epidemic at state and local levels. Characterizing persons who have been diagnosed with HIV as well as those who have AIDS can improve the allocation of needed prevention and treatment resources to communities.

Although declines in the number of AIDS cases and deaths have occurred in recent years among men and women, all racial/ethnic groups, and all behavioral risk categories, the rates of decline have not been uniform (Table 1). Proportionate declines in AIDS incidence and deaths have been smaller among Blacks than Whites and among women than men.

Interpreting trends is more complicated now than in the "natural history era" of the 1980s and early 1990s. Many of the populations that historically have had poorer access to care and treatment are also those that experienced relatively higher HIV incidence rates in more recent years. AIDS incidence rates now reflect a combination of factors, including differences among at-risk populations in recent and remote HIV incidence trends and in access to testing and treatment, adherence to treatment, and the emergence of drug-resistant HIV strains<sup>5-7</sup> (also CDC, unpublished data, 2000). Women, Blacks and Hispanics, and persons infected via heterosexual transmission represent increasing proportions of AIDS cases. Blacks and Hispanics continue to have population AIDS incidence rates 8 and 3 times higher than Whites, respectively.<sup>1</sup> Men who have sex with men comprise the majority of prevalent AIDS cases and have the highest infection rates among all risk groups.

The dramatic declines in AIDS incidence and deaths that occurred in 1996 and 1997 showed signs of leveling in 1998 (Figure 1). As effective treatments enable HIV-infected persons to survive longer free of AIDS, indications that new AIDS cases in-

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The authors are with the Division of HIV/AIDS Prevention—Surveillance and Epidemiology, National Center for HIV, STD, and TB Prevention, Centers for Disease Control and Prevention, Atlanta, Ga.

Requests for reprints should be sent to Patricia L. Fleming, PhD, MS, Centers for Disease Control and Prevention, Mailstop E-47, 1600 Clifton Rd, NE, Atlanta, GA 30333 (e-mail: pfleming@cdc.gov).

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**TABLE 1—Estimated Aids Incidence and Deaths in 1998 Among Persons With AIDS Aged ≥13 Years, by Sex and Exposure Category, Race/Ethnicity,<sup>a</sup> and Percentage Change From 1997 to 1998—United States**

	AIDS Incidence			AIDS Deaths		
	n	%	% Change 1997–1998	n	%	% Change 1997–1998
Sex and exposure category						
Men	33 857	76	–12	13 242	78	–21
MSM	18 152	42	–11	6 467	38	–23
IDU	9 028	20	–14	4 241	25	–19
MSM–IDU	2 195	5	–13	1 142	7	–16
Heterosexual	4 017	9	–5	1 190	7	–16
Women	10 446	24	–9	3 807	22	–15
IDU	3 784	9	–14	1 778	10	–16
Heterosexual	6 344	14	–5	1 924	11	–15
Race/ethnicity						
White	13 836	31	–13	5 435	32	–22
Black	23 176	48	–9	10 062	49	–17
Hispanic	8 812	20	–12	3 114	18	–21
American Indian/Alaska Native	143	<1	–15	64	<1	–13
Asian/Pacific Islander	339	<1	–11	107	<1	–24
Total <sup>b</sup>	44 303	100	–11	17 050	100	–20

Note. MSM = men who have sex with men; IDU = injection drug users; heterosexual = person having had sex with a partner with HIV/AIDS or at risk for HIV/AIDS.

<sup>a</sup>Persons of Hispanic ethnicity may be of any race. The small number of estimated AIDS diagnoses and deaths among Asian/Pacific Islanders and American Indians/Alaska Natives makes it difficult to interpret small fluctuations from year to year. All estimates are based on data reported to CDC through June 30, 1999, and adjusted for delays in reporting cases, deaths, and exposure category. Point estimates are presented for reproducibility of the data.

<sup>b</sup>Totals include persons with missing sex or race/ethnicity data and with other/unknown risk exposure.

creasingly represent previously untested persons are provided by interviews of persons with AIDS. The proportion of persons with AIDS whose diagnosis represented the first time they were tested for HIV increased from 25% in 1993 to 42% in 1998.<sup>8</sup>

To continue to decrease AIDS incidence will require expanded efforts to increase access to HIV testing among high-risk populations and to reduce the interval between the first positive test and entry to care.<sup>9</sup> This will be a difficult challenge. HIV-infected persons who are first diagnosed when they have AIDS represented a stable proportion of all new HIV diagnoses from 1994 through 1998 (range = 22%–25% in the 25 states that conduct HIV case reporting<sup>8</sup>). These “late-testers” likely represent the hardest-to-reach populations, as evidenced in a recent study of HIV-infected mothers. Those who were at highest risk of transmitting HIV perinatally were less likely to have been tested prior to pregnancy or to have received prenatal care and more likely to have used drugs during pregnancy.<sup>10</sup> To sustain reductions in perinatal HIV transmission rates, special outreach efforts to bring disenfranchised and substance-abusing women into prenatal care and to get them to accept testing and treatment are needed.

Surveillance data have provided reliable measures of cumulative AIDS incidence (more than 700 000) and cumulative deaths among persons diagnosed with AIDS (more than 400 000) through 1999.<sup>1</sup> The number of people

living with AIDS (AIDS prevalence) surpassed 300 000 in 1999. The CDC recently revised its estimates of HIV prevalence upward; as of December 1998, between 800 000 and 900 000 persons were estimated to be living with HIV/AIDS.<sup>2</sup> Data from multiple sources suggest that HIV incidence was relatively stable overall during most of the 1990s (CDC, unpublished data, 2000). The composite picture of the epidemic suggests that the population of infected persons is slowly increasing in size as a result of sustained levels of HIV transmission associated with high-risk sex and drug-using behaviors, especially among young racial/ethnic minorities, in concert with increased survival among treated persons.

### *Emerging Issues in Surveillance and Epidemiology*

Recent innovations in testing technology provide the ability to measure HIV incidence in blood samples from persons newly diagnosed as having HIV.<sup>11</sup> However, accurately estimating HIV incidence more broadly in the untested population remains a challenge. Data from multiple sources—including documented seroconversions, case reports, and seroprevalence data for young adults (who by definition are recently infected) and longitudinal studies of seroincidence—need to be synthesized. Perhaps the best means of obtaining population-based incidence estimates

in the future will be to conduct incidence testing on specimens from all newly infected persons and to give priority to those persons in epidemiologic follow-up. Characterizing newly infected persons should enable rapid identification of populations in need of enhanced prevention interventions. HIV testing and diagnosis early in the course of disease, together with referrals to long-term support for prevention and treatment, will enhance efforts to reduce HIV incidence, especially if most transmission occurs prior to knowing one’s infection status. Follow-up surveys of these persons will enable rapid assessments of access to, adherence to, and the impact of treatment and care guidelines.<sup>12–15</sup>

Does early treatment reduce infectiousness? Indirect evidence comes from 2 studies of heterosexual transmission in Africa, which showed that low viral loads were directly correlated with lower risk of HIV transmission.<sup>16,17</sup> Data from perinatal prevention trials support the hypothesis that treatment reduces transmission by reducing viral load.<sup>18</sup> Among adults, direct evidence has been lacking. If early testing and treatment reduce the risk of HIV transmission, there is the hope that “treatment as prevention” can decrease infection rates. However, a difficult dilemma may lie ahead. Any potential public health benefits of early treatment could be outweighed by the advisability of delaying initiation of therapy to reduce risks of viral resistance or side effects of treatment in individual patients.

Highly active antiretroviral therapy (HAART) poses the threat of transmission of treatment-resistant HIV. Studies of recently infected persons have documented that treatment-resistant phenotypes are being transmitted.<sup>19</sup> Many patients have difficulty adhering to complex dosing regimens. Identifying mutations that predict a poor clinical course or are transmitted efficiently is important. At the population level, surveillance systems will need to detect an emerging threat and guide efforts to prevent an epidemic of treatment-resistant HIV.

Recent reports of deaths due to mitochondrial dysfunction among infants born to treated, infected women in France have raised concerns.<sup>20</sup> To date, no evidence to support this observation has emerged in the United States, despite an exhaustive review of available data.<sup>21</sup> However, numerous reports describe a variety of metabolic side effects of HAART in adults, ranging from lipodystrophy to liver and renal dysfunction.<sup>22,23</sup> Current and future guidelines for standard of care will need to evolve as epidemiologic measures of the risk-benefit ratios of early testing and treatment interventions emerge. To inform this process, there should be monitoring of the incidence and prevalence of adverse effects of treatment in the population.

To identify how HIV was being spread early in the epidemic, the CDC developed a hierarchical risk assessment based on the relative probabilities of transmission via different behaviors among persons with multiple risks for infection. An estimated 200 000 or more HIV cases will be reported in the next few years. Assessing risk behaviors in a sample of cases will enable estimation of current transmission dynamics in the population. Today, however, not just risk, but testing and care-seeking behaviors are of particular interest for determining whether new infections represent lack of knowledge or lack of access to prevention programs, and whether new AIDS cases represent lack of access to testing or treatment or poor adherence and resistant virus. Behavioral surveys in infected and at-risk populations are currently conducted in few states. They are needed in many more areas for assessment of the penetration of educational messages and intervention programs in the targeted populations.

In an era when treatment offers hope, efforts to prevent HIV transmission through behavioral risk reduction may be threatened. Anecdotal reports of relapses to high-risk behaviors among gay men who may be less concerned about an HIV diagnosis in light of effective treatment are supported by data from a multistate interview study.<sup>24</sup> These self-reported increases in risk behaviors occurred concurrently with increased rectal

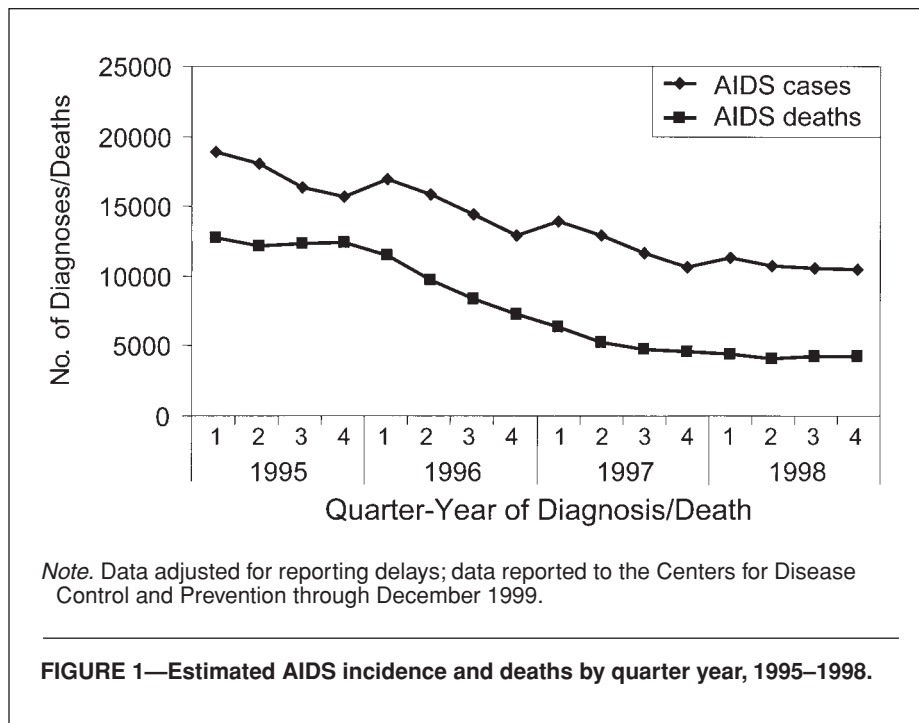


FIGURE 1—Estimated AIDS incidence and deaths by quarter year, 1995–1998.

gonorrhea rates among gay men in several cities.<sup>25</sup> Without renewed attention to primary HIV prevention, we risk an upsurge in HIV infection rates, particularly among teenagers and young adults, as they enter their most vulnerable years of initiating sexual activity.

Economic factors will increase demands to demonstrate that the nation's investment in HIV prevention, treatment, and services yields results. The current surveillance system provides only indirect evidence of these successes, because HIV/AIDS case reports do not include data on access to and use of prevention and treatment services. In the future, HIV/AIDS surveillance systems will need to contribute more directly to efforts to measure the impact and outcomes of interventions. Today, over \$2 billion is allocated annually for HIV-related services by the CDC, the Health Resources and Services Administration, and the Department of Housing and Urban Development on the basis of AIDS surveillance data. Upcoming and potentially divisive battles will define the future basis for allocation of resources. Agencies, states, cities, and communities have much at stake, because AIDS surveillance data alone are now a less reliable indicator of the size and scope of the HIV epidemic.

### *Restructuring HIV/AIDS Surveillance to Meet the Challenges of the Next Decade*

Since the mid- to late 1980s, the CDC and state health departments have tracked the

epidemic by using a variety of surveillance and research strategies, such as anonymous HIV seroprevalence surveys, seroincidence studies in high-risk settings, AIDS surveillance, mortality surveillance, behavioral surveys, interview studies of infected and at-risk persons, observational cohorts to track HIV-related morbidity, and statistical modeling to estimate HIV/AIDS incidence and prevalence and to forecast future trends. These tools have provided demographic, clinical, and behavioral risk data to identify populations at greatest risk of HIV infection and to estimate the size and distribution of the epidemic at the national level. Although AIDS and mortality surveillance data are available nationwide, most of the other strategies are available in only a few states, compromising the states' abilities to adequately characterize their local epidemics. New cases of HIV or AIDS now represent missed opportunities for counseling, testing, and care; barriers to obtaining these services; or denial of HIV risk and avoidance of health-seeking behaviors. To address unmet needs for data, enhanced surveillance and epidemiologic capacity in many more state and local health departments are needed to determine which factors contribute to ongoing transmission and disease progression. In the absence of such data, it will be difficult to target effective intervention strategies, even with nationwide HIV case reporting.

At the state and local level, programs and services must necessarily be prioritized on the basis of local needs. In concert with the CDC's recommendation for national HIV



case surveillance, the agency has proposed a comprehensive restructuring of its surveillance systems to enable more states to conduct HIV/AIDS surveillance and research to provide locally relevant data.<sup>26</sup> The CDC envisions a multitiered data collection infrastructure. First, at a minimum, all states should require that health care providers report cases of HIV infection and AIDS. Demographic, laboratory, clinical, treatment, and behavioral risk data should be collected on all or a representative sample of reported cases and deaths. Ensuring the completeness and quality of such data through standard case definitions and surveillance practices will improve local, state, and national understanding of the epidemic and provide an equitable basis for distribution of resources and services. However, funding deficits for public health surveillance threaten the ability of state and local health departments to rectify current data gaps.

Second, areas that have large numbers of cases or high HIV/AIDS incidence rates need more comprehensive surveillance data to target interventions efficiently and to assess how well they achieve the goals of reducing HIV risks and improving access to testing and care. Self-report data (i.e., interviews of at-risk and infected persons) can improve the accuracy of race/ethnicity, education, and socioeconomic status data. In addition, in-person interviews can provide data on factors such as reasons for seeking testing, where testing and care are being sought, barriers to obtaining services, unmet needs such as for substance abuse treatment, and comorbid conditions such as sexually transmitted diseases, tuberculosis, and mental illness.

To monitor the changing spectrum of HIV disease and the emergence of resistant virus and side effects of treatment, as well as to assess the prevalence of standard of care among eligible persons, more comprehensive data should be collected on a representative clinical laboratory and behavioral sample of persons diagnosed with HIV or AIDS. The CDC currently supports supplemental surveillance projects that collect these data in about 10 states, but it will extend this capacity to 15 to 20 additional states during the next few years. These studies should be combined with focused laboratory, epidemiologic, and clinical follow-up on persons newly diagnosed with HIV to obtain minimum population-based estimates of rates of HIV transmission.

Third, areas with the highest incidence rates should conduct seroincidence surveys and respond rapidly with intensive prevention interventions if clusters of HIV infection are identified. Rapid dissemination of aggregate public health data through estab-

lished reporting channels will facilitate a timely public health response.

Finally, public health surveillance itself must reexamine its role in a changing world. Communities expect public health to protect them against disease threats in the shrinking world of the 21st century. Surveillance must identify such threats, characterize populations at risk, determine causes of disease and routes of transmission, help to control the spread of disease, and promote good health. To maintain the trust, respect, and confidence of health care providers and affected communities, public health data must be collected and maintained under strict safeguards and assurances of privacy and confidentiality. However, the recent debate over names vs codes for reporting HIV cases<sup>2</sup> diverted attention from the real underlying issues that concern vulnerable populations when health departments hold sensitive, personal data: public health information should be used not to harm individuals or communities but to promote good health. In the next decade, public health experts must assume a leadership role in defining appropriate uses of surveillance data and in defending against inappropriate uses.

## Conclusions

The purpose of public health surveillance is to provide data for action promoting good health. In the next few years, an expanded surveillance system should ensure that, nationally and at state and local levels, we can track a changing epidemic, measure HIV/AIDS incidence and prevalence, and enhance planning to prevent HIV and its sequelae. A major commitment to vaccine research and development is under way. Sustained investments in prevention and treatment research continue to hold promise. Surveillance can guide these efforts, measure their successes and failures, and refocus interventions to help those persons most in need.

The first 2 decades of the epidemic witnessed an explosive growth in knowledge of the virus, how it affects the immune system, how to prevent it, and how to treat it. These advances occurred at the same time that the HIV epidemic was reaching catastrophic levels in many countries in Africa and Asia. In the next decade, we will have the opportunity to make a difference, at home and abroad. To do so at home, state and local health departments need an increased investment in their surveillance, research, and program capacities. A renewed national sense of resolve is needed to further reduce the number of new infections each year and to ensure that people with HIV/AIDS have access to testing, care,

and treatment so they may live longer, healthier lives.

Will we accomplish these goals at home, and will we reach out to other countries to contribute to the control and prevention of HIV worldwide? Whether we see this as our national obligation will ultimately determine how history will record our actions during the next decade of the HIV/AIDS pandemic. □

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