

Diagnosis and Reporting of HIV and AIDS in States with Integrated HIV and AIDS Surveillance -- United States, January 1994-June 1997

Recent reports based on acquired immunodeficiency syndrome (AIDS) surveillance data have highlighted substantial declines in AIDS incidence and deaths. As a result of improvements in treatment and care of persons infected with human immunodeficiency virus (HIV), surveillance of AIDS alone no longer accurately reflects the magnitude or direction of the epidemic (1). Current public health and clinical recommendations promote early diagnosis and treatment of HIV disease (2). Data on persons in whom HIV infection is diagnosed before AIDS is diagnosed are needed to determine populations in need of prevention and treatment services. This report examines data for persons aged greater than or equal to 13 years in whom HIV infection was diagnosed in 25 states that conducted name-based HIV surveillance in addition to AIDS surveillance during January 1994-June 1997 *. Provisional data indicate that declines in AIDS incidence in these states were not accompanied by comparable declines in the number of newly diagnosed HIV cases. **

In late 1993, the states included in this analysis merged data from the name-based HIV and AIDS case reporting systems into an integrated HIV/AIDS surveillance system. Patient and provider names were deleted before states forwarded data to CDC and replaced by codes. Cases were divided into two mutually exclusive categories: persons in whom HIV infection was diagnosed (without an AIDS diagnosis) and persons in whom HIV infection was diagnosed only when they first had AIDS diagnosed. Data for persons aged greater than or equal to 13 years were analyzed by the earliest date of diagnosis of HIV or AIDS for January 1994-June 1997. Quarterly trends in the number of persons whose initial diagnosis was HIV infection were compared with quarterly trends in the number of persons whose initial diagnosis was AIDS. HIV and AIDS data were adjusted for delays in reporting of cases and deaths (3).

From January 1994 through June 1997, HIV or AIDS was diagnosed in 72,905 persons aged greater than or equal to 13 years in the 25 states. Of these, HIV infection was the initial diagnosis in 52,690 (72%) and AIDS was the initial diagnosis in 20,215 (28%) ([Table 1](#)). From 1995 to 1996, the number of persons in whom HIV infection was the initial diagnosis declined 2%, and the number of persons in whom AIDS was the initial diagnosis declined 9%.

Of 52,690 persons in whom HIV infection was the initial diagnosis, 28% were women, 57% were non-Hispanic blacks, and 18% were infected through heterosexual contact ([Table 2](#)). Among selected demographic groups, the number of persons in whom HIV infection was the initial diagnosis during 1995 compared with 1996 declined 3% among men (from 10,762 to 10,395) but increased 3% among women (from 4126 to 4253). The number of persons in whom HIV infection was the initial diagnosis increased 10% among Hispanics (from 971 to 1070) and decreased 3% among non-Hispanic blacks (from 8569 to 8300) and 2% among non-Hispanic whites (from 5093 to 4966). Men who have sex with men (MSM) accounted for the largest proportion of the HIV diagnoses (32%). Analysis of trends by risk/exposure category is complicated by the high proportion of HIV cases with unreported risk (28%).

Of 52,690 persons in whom HIV infection was the initial diagnosis, 7200 (14%) were aged 13-24 years. The number of HIV diagnoses per quarter-year was approximately constant in this age group, declining 4% from 1995 to 1996 (from 2066 to 1991) ([Figure 1](#)). Of persons in this age group, 3203 (44%) were female, 4566 (63%) were non-Hispanic black, and 394 (5%) were Hispanic; by risk category, 2270 (31%) were MSM, 1886 (26%) acquired HIV through heterosexual contact, and 449 (6%) were injecting-drug users; 1074 (15%) had AIDS subsequently diagnosed. An additional 653 persons aged 13-24 years had AIDS initially diagnosed.

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Editorial Note

Editorial Note: The data from these 25 states indicate that from 1994 through mid-1997, the number of persons in whom HIV infection was the initial diagnosis was stable and declines over the entire period were slight. Compared with reported declines in AIDS incidence nationally (1), these data suggest that HIV incidence was relatively stable in these states. In particular, the number of new HIV diagnoses among persons aged 13-24 years probably more closely indicate HIV incidence trends because young persons have more recently initiated high-risk behaviors.

HIV surveillance data include persons who were infected more recently than were persons reported with AIDS, and their characteristics indicate more recent trends in HIV transmission. Many of the new HIV diagnoses in these states occurred among blacks, women, young MSM, and persons infected through heterosexual contact with substantial increases observed among Hispanics. The HIV case data from

these states reflect the changing demographic and risk profile of an epidemic that disproportionately affects racial/ethnic minorities (1,3). Race/ethnicity is not a risk factor for HIV infection but is likely a marker for other factors that may be predictive of increased risk for HIV infection (e.g., low income, lack of education, and higher rates of injecting and non-injecting drug use) (4). Black and Hispanic persons who engage in high-risk sex or drug-using behaviors should be a major focus of HIV-prevention efforts, including strategies to promote knowledge of HIV status through voluntary test seeking and to facilitate entry to care and treatment.

Of persons in whom HIV infection was the initial diagnosis, 14% were adolescents and young adults aged 13-24 years, compared with 3% of persons in whom AIDS was the initial diagnosis. This age group is an important target for HIV prevention efforts because a large proportion of all new HIV infections occur among persons in this age group (5). In particular, reduction of high-risk sexual behaviors among adolescent and young adult women and MSM is needed to reduce HIV transmission in this age group.

In the 25 states, declines in the number of cases were larger among persons in whom AIDS was the initial diagnosis than among those in whom HIV infection was the initial diagnosis. Most persons with HIV had been tested in a medical facility or other clinical-care setting and had had an opportunity for early treatment interventions to delay HIV-related morbidity and mortality, contributing to declines in AIDS incidence (6). In the future, AIDS surveillance data will increasingly reflect access to testing and response to therapy in the population. Approximately one fourth of all new diagnoses in these states occurred among persons who had already developed AIDS when HIV infection was first diagnosed. AIDS surveillance data should be used to target underserved populations for early testing and prompt referrals for treatment.

HIV and AIDS surveillance data mostly reflect the characteristics of persons tested in medical care and other confidential settings. These data may not represent the characteristics of all persons with HIV infection because persons tested anonymously are not reported to the surveillance system, and some persons with HIV infection have not been tested. However, approximately 140,000 persons living with HIV have already been reported and characterized, representing most prevalent infections in these states (7). The degree to which integrated HIV and AIDS surveillance data are representative of all infected persons is expected to increase over time as the proportion of untested persons decreases.

The public health usefulness of the HIV surveillance data is affected by the performance of the system of case reporting and follow up (8). In these 25 states, most of which require laboratory-based reporting of HIV-positive test results, HIV reporting was very complete. Only 12% of persons in whom HIV infection was the initial diagnosis had not been reported to CDC as an HIV case before being reported as an AIDS case. CDC estimates that less than 2% of HIV cases are duplicates based on matching of the national coded surveillance database. CDC has developed methods for estimating the risk distribution for AIDS cases with unreported risk (3); however, similar methods for HIV cases are not yet available. In this report, the proportion of HIV cases by risk/ exposure categories is an underestimate until follow up is completed for cases reported without risks (3). Name-based HIV reporting should facilitate epidemiologic follow up to increase the completeness of risk/exposure, clinical, treatment, and other data relevant to effective HIV-prevention community planning.

This report highlights the continued need for effective HIV and AIDS prevention programs to reduce rates of HIV transmission and demonstrates the usefulness of integrated HIV and AIDS surveillance data to direct these efforts. State and local areas without such surveillance have limited ability to monitor local changes in HIV infection and disease trends. In these areas, approximately 200,000 persons have had HIV diagnosed (without AIDS) (7), but data are not available to describe trends in new HIV diagnoses. Implementing integrated HIV and AIDS surveillance in these states and local areas is necessary to provide accurate information for targeting resources to populations most affected (e.g., adolescents, women, racial/ethnic minorities, and young MSM) and for evaluating program effectiveness.

References

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- Alabama, Arizona, Arkansas, Colorado, Idaho, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, and Wyoming. ** Single copies of this report will be available until April 24, 1999, from the CDC Prevention Information Network, P.O. Box 6003, Rockville, MD 20849-6003; telephone (800) 458-5231 or (301) 519-0459.

Table_1

Note: To print large tables and graphs users may have to change their printer settings to landscape and use a small font size.

TABLE 1. Estimated number * of persons aged >=13 years in whom HIV was diagnosed, by quarter of diagnosis and disease status at initial diagnosis+ -- 25 states &, January 1994-June 1997

Quarter of diagnosis	Disease status at initial HIV diagnosis				Total
	HIV		AIDS		
	No.	(%)	No.	(%)	
1994					
1	4,038	(70)	1,723	(30)	5,761
2	4,073	(71)	1,691	(29)	5,764
3	3,809	(73)	1,430	(27)	5,239
4	3,558	(71)	1,434	(29)	4,992
Total@	15,571	(71)	6,337	(29)	21,908
1995					
1	3,904	(71)	1,568	(29)	5,472
2	3,780	(72)	1,470	(28)	5,250
3	3,711	(72)	1,421	(28)	5,132
4	3,438	(72)	1,370	(28)	4,808
Total@	14,895	(72)	5,863	(28)	20,758
1996					
1	3,889	(74)	1,366	(26)	5,255
2	3,635	(72)	1,382	(28)	5,017
3	3,619	(73)	1,310	(27)	4,929
4	3,476	(74)	1,236	(26)	4,712
Total@	14,652	(74)	5,313	(26)	19,965
1997					
1	3,762	(73)	1,376	(27)	5,138
2	3,809	(74)	1,325	(26)	5,134
Total	52,690	(72)	20,215	(28)	72,905

* Numbers are estimates after adjustments for reporting delays. Point estimates are presented for reproducibility of the data.

+ For persons who had not had an HIV diagnosis before being diagnosed with AIDS, their AIDS diagnosis date is considered their earliest HIV diagnosis date; for persons initially reported with HIV who subsequently had AIDS diagnosed and reported, they are presented by the earliest diagnosis date, which is their HIV diagnosis.

& Alabama, Arizona, Arkansas, Colorado, Idaho, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, and Wyoming.

@ Total estimates include cases with missing quarter for HIV diagnoses and AIDS diagnoses.

[Return to top.](#)

Table_2

Note: To print large tables and graphs users may have to change their printer settings to landscape and use a small font size.

TABLE 2. Characteristics of persons aged >=13 years with HIV, by disease status at initial diagnosis * -- 25 states+, January 1994-June 1997

Characteristic	Disease status at initial HIV diagnosis				Total
	HIV		AIDS		
	No. &	(%@)	No. &	(%@)	
Sex					
Male	37,996	(72)	16,866	(83)	54,862
Female	14,689	(28)	3,348	(17)	18,037
Race/Ethnicity**					
White,non-Hispanic	17,929	(34)	9,171	(45)	27,100
Black,non-Hispanic	30,229	(57)	9,127	(45)	39,356
Hispanic	3,581	(7)	1,660	(8)	5,241
Other/Unknown	949	(2)	256	(1)	1,205
Risk/Exposure category					

Men having sex with men	17,098	(32)	8,866	(44)	25,964
Injecting-drug user	9,671	(18)	3,959	(20)	13,630
Men having sex with men/ Injecting-drug user	2,088	(4)	843	(4)	2,931
Heterosexual contact	9,279	(18)	2,428	(12)	11,707
Other/Unreported	14,552	(28)	4,116	(20)	18,668
Age group (yrs)					
13-24	7,200	(14)	653	(3)	7,853
25-29	9,384	(18)	2,239	(11)	11,623
30-34	11,916	(23)	4,503	(22)	16,419
35-39	10,030	(19)	4,608	(23)	14,638
>=40	14,159	(27)	8,210	(41)	22,369
Total++	52,690		20,215		72,905

* For persons who had not had an HIV diagnosis before being diagnosed with AIDS, their AIDS diagnosis date is considered their earliest HIV diagnosis date; for persons initially reported with HIV who subsequently had AIDS diagnosed and reported, they are presented by the earliest diagnosis date, which is their HIV diagnosis.

+ Alabama, Arizona, Arkansas, Colorado, Idaho, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, and Wyoming.

& Numbers are estimates after adjustments for reporting delays. Point estimates are presented for reproducibility of the data.

@ Percentages may not total 100 because of rounding.

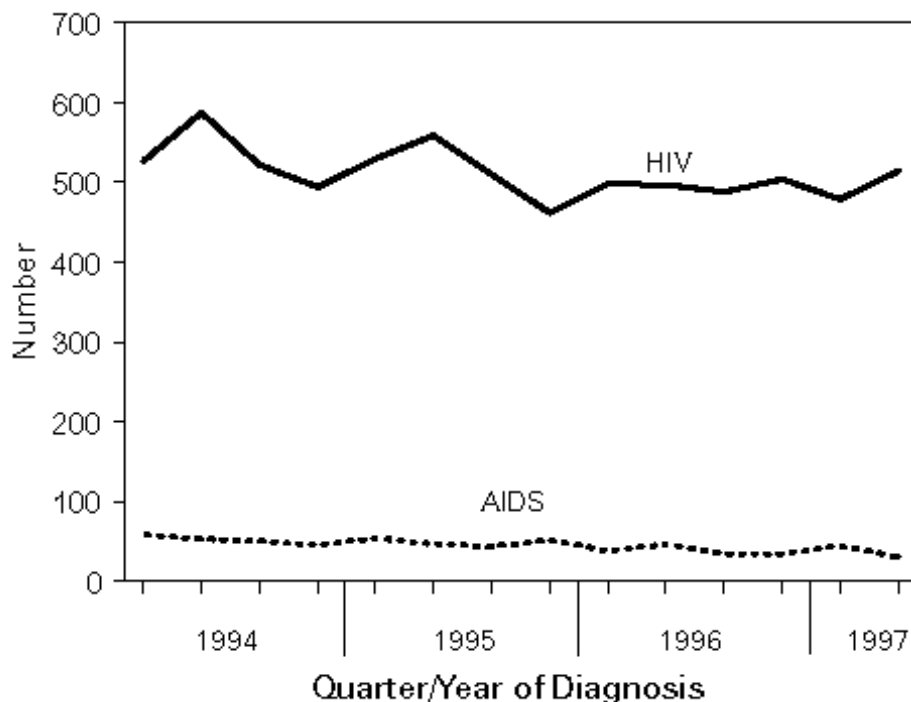
** Persons of races other than black and white were included under "other/unknown" because estimates were too small for meaningful analysis.

++ Column totals include missing/other for some categories (e.g., missing sex). Persons infected through receipt of blood or blood products are included under other/unreported risk.

[Return to top.](#)

Figure_1

FIGURE 1. Estimated number of persons aged 13–24 years with HIV infection, by disease status at the time of initial diagnosis with HIV — 25 states*, January 1994–June 1997†



*Alabama, Arizona, Arkansas, Colorado, Idaho, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, and Wyoming.

†Adjusted for reporting delays.

[Return to top.](#)

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