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HIV Infection in Areas Conducting HIV Reporting Using Coded Patient Identifiers, 2000



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The *HIV/AIDS Surveillance Technical Report* is published by the Surveillance Branch of the Division of HIV/AIDS Prevention, National Center for HIV, STD, and TB Prevention, Centers for Disease Control and Prevention (CDC). This report describes demographic characteristics of persons diagnosed with HIV infections who were residents of states that conduct HIV infection case surveillance using coded patient identifiers during 2000. All data in this report are provisional.

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Since the early 1980's, confidential name-based surveillance has been conducted for AIDS cases; in this process, patient names associated with cases have been reported to local and state public health departments and stored in AIDS registries for ongoing surveillance activities. Since the advent of the epidemic, AIDS surveillance data have provided information critical to understanding the epidemiology of HIV and clinical conditions associated with HIV infection, have served as the backbone to evaluate the effect of treatment and prevention efforts, and have allowed population-based monitoring of the epidemic. However, with advances in treatment, such as highly active antiretroviral therapy, persons with HIV infection are living longer without progressing to AIDS. As a result, AIDS incidence has decreased, and no longer provides the most accurate population-level information on the state of the HIV epidemic. HIV infection surveillance, however, provides information on more recently infected persons, and thereby a more accurate representation of the current trends of the epidemic. Based on these facts, CDC has recommended that all states conduct HIV case surveillance as an extension of current AIDS surveillance activities (1).

As of December 2001, confidential name-based surveillance was being conducted for HIV infection that had not progressed to AIDS in 33 states, Guam and the U.S. Virgin Islands (Connecticut conducted name-based HIV surveillance for pediatric cases only). In response to community concerns regarding the confidentiality of name-based HIV reports within public health, however, several states have elected to implement HIV infection surveillance using alternative methods to confidential name-based reporting. These alternative methods utilize coded patient identifiers instead of patient names for either initial reporting to public health or for long term storage in surveillance registries. Alternative methods to confidential name-based surveillance that have been implemented and are presented here include code-based and name-to-code-based systems. In code-based systems, HIV reports are submitted to public health departments using a coded patient identifier composed of different, partial personal identifiers (e.g., date of birth, initials of patient name, portions of social security number, etc.) without patient name. In name-to-code-based systems, HIV reports are initially reported to public health departments using patient

name; after public health follow up has been conducted and patient referrals have been offered, names are converted into coded patient identifiers for storage in the surveillance registry.

As a part of the 1999 guidelines for national HIV case surveillance (1), CDC specified that states using alternative methods for conducting HIV case surveillance should evaluate the role of surveillance data in linking reported persons to prevention and care programs and determine whether alternatives to reporting of patient names would reduce confidentiality risks while meeting the needs for high-quality surveillance data. CDC is working with these areas to evaluate the proficiency and performance of the coded patient identifiers within an integrated HIV/AIDS surveillance system. The results of these evaluations will be reviewed as one aspect of a larger project being conducted by the Institute of Medicine, which will, in part, review the quality of integrated HIV/AIDS surveillance data from systems using a variety of patient identifiers (name, name-to-code, and code). Until the evaluations are complete, HIV surveillance data from states conducting alternatives to confidential name-based HIV reporting are not included in nationally accumulated HIV infection case count totals. Until the technical and logistical data management issues of data from systems using coded patient identifiers are resolved, the existing national HIV/AIDS Reporting System is unable to receive these data in the same manner as reports gathered within name-based HIV/AIDS surveillance systems. This technical report represents the first opportunity to examine demographic characteristics of persons diagnosed with HIV infections who were residents of states that conduct HIV infection case surveillance using coded patient identifiers.

As of December 2001, 12 states, the District of Columbia, and Puerto Rico had implemented alternatives to confidential name-based reporting for cases of HIV infection (without AIDS). Of these 14 areas, nine conduct code-based HIV reporting (District of Columbia, Hawaii, Illinois, Kentucky, Maryland, Massachusetts, Puerto Rico, Rhode Island, and Vermont), and five states conduct name-to-code-based HIV reporting (Delaware, Maine, Montana, Oregon, and Washington) (Figure 1). Combined, these states and territory reported 8,116 (19%) of the 42,156 AIDS cases reported to the CDC in 2000; 54,177 (17%) of the

322,865 persons living with AIDS at the end of December 2000 resided in these areas(2). In this report, we present the HIV surveillance data from the five states (Illinois, Maine, Maryland, Massachusetts, and Washington) and one territory (Puerto Rico) that had implemented alternative methods of HIV case surveillance by January 1, 2000. The coded patient identifiers implemented in these six areas include sex and date of birth in all codes, various components of last name (4 codes), the last 4 digits of the social security number (4 codes), race (2 codes), various components of first name (2 codes), zip code of residence (1 code), and health region (1 code). Aggregate data in tabular form, as reported to the state or territorial health department, were provided by respective areas for this report.

Combined, these six areas accounted for 6,327 (15%) of 42,156 AIDS cases reported to CDC in 2000 (2). In 2000, these six health departments received 8,563 reports of HIV infection (Table 1). The 35 areas with confidential name-based reporting reported 21,704 HIV infection cases during the same time period (2). Five of six areas highlighted in this report would rank in the top 10 states in the number of HIV cases reported to CDC in 2000. HIV infection was more commonly reported among males than among females in all six areas (Table 2). Of 1,191 total cases reported in Washington, 980 (82%) were male, while of 1,926 total cases reported in Maryland,

1,170 (61%) were male; these states had, respectively, the highest and lowest male-to-female case ratio among the areas. In all areas, a vast majority of all HIV infection cases (range 92% to 96%) reported in 2000 were among persons aged 20-64 years (Table 3). Within this age range, Washington cases tended to be younger, with 58% of cases among 20-34 year olds, and Maryland cases tended to be older, with 34% of cases in the 20-34 year-old age group. Areas also varied in the racial and ethnic breakdown of HIV cases (Table 4); in Maine, Massachusetts, and Washington more cases were reported for white persons (83%, 49%, and 73%, respectively) than for any other racial/ethnic group. In Illinois and Maryland, a majority of cases were among black, non-Hispanics (53% and 61%, respectively). These data continue to stress the varied face of the epidemic among different geographic areas.

References

1. Centers for Disease Control and Prevention. Guidelines for national human immunodeficiency virus case surveillance, including monitoring for human immunodeficiency virus infection and acquired immunodeficiency syndrome. *MMWR* 1999; 48 (No. RR-13):1-27.
2. Centers for Disease Control and Prevention. *HIV/AIDS Surveillance Report*, 2000; 12(2):1-45.

Table 1. HIV infection¹ and AIDS cases by area, and by 100,000 population reported to state/territory health departments in 2000, from 6 areas with HIV reporting systems using coded patient identifiers²

Area of residence (Date HIV reporting initiated)	HIV infection		AIDS ³	
	Cases	Reported cases per 100,000 population	Cases	Reported cases per 100,000 population
Code-based System				
Illinois (July 1999)	2,647	21.31	1,827	14.71
Maryland (June 1994)	1,926	36.36	1,404	26.51
Massachusetts (Jan 1999)	1,186	18.68	1,014	15.97
Puerto Rico (Oct 1998)	1,565	41.09	1,358	35.66
Name-to-code-based System				
Maine (July 1999)	48	3.76	43	3.37
Washington (Sept 1999)	1,191	20.21	476	8.08

¹Includes only those persons reported with HIV infection who have not been reported with AIDS during 2000.

²Patients identified by code in initial surveillance reports or for storage in HIV registries.

³Number of AIDS cases reported to state/territory health departments in 2000 may vary slightly from that reported by health departments to CDC in 2000 as published in the *HIV/AIDS Surveillance Report*.

Table 2. HIV infection¹ cases by sex and area of residence, reported to state/territory health departments in 2000, from 6 areas with HIV reporting systems using coded patient identifiers²

	Male	Female	Total ³
Illinois	1,923	724	2,647
Maine	36	12	48
Maryland	1,170	752	1,926
Massachusetts	786	400	1,186
Puerto Rico	1,090	475	1,565
Washington	980	211	1,191

¹Includes only those persons reported with HIV infection who have not been reported with AIDS during 2000.

²Patients identified by code in initial surveillance reports or for storage in HIV registries.

³Row totals may not equal the total of columns, reflecting cases reported with unknown sex (range 0-0.2%).

Table 3. HIV infection¹ cases by age group and area of residence, reported to state/territorial health departments in 2000, from 6 areas with HIV reporting systems using coded patient identifiers²

	Children < 13 years	13-19 years	20-34 years	35-64 years	65 years or greater	Total
Illinois	67	74	1,186	1,308	12	2,647
Maine	0	1	18	28	1	48
Maryland	26	51	660	1,160	29	1,926
Massachusetts	12	30	564	575	5	1,186
Puerto Rico	27	69	694	743	32	1,565
Washington	5	42	695	446	3	1,191

¹Includes only those persons reported with HIV infection who have not been reported with AIDS during 2000.

²Patients identified by code in initial surveillance reports or for storage in HIV registries.

Table 4. HIV infection¹ cases by race/ethnicity and area of residence, reported to state/territory health departments in 2000, from 6 areas with HIV reporting systems using coded patient identifiers²

	White, not Hispanic	Black, not Hispanic	Hispanic	Asian/Pacific Islander	American Indian/ Alaska Native	Total ³
Illinois	879	1,416	322	18	5	2,647
Maine	40	6	0	1	1	48
Maryland	186	1,176	24	6	6	1,926
Massachusetts	577	310	264	14	2	1,186
Puerto Rico	0	0	1,565	0	0	1,565
Washington	870	162	103	23	20	1,191

¹Includes only those persons reported with HIV infection who have not been reported with AIDS during 2000.

²Patients identified by code in initial surveillance reports or for storage in HIV registries.

³Row totals may not equal the total of columns, reflecting cases reported with unknown or other race/ethnicity (range 0-27.4%).

Table 5. Cumulative HIV infection¹ cases, reported to state/territory health departments through December 2000, from 6 areas with HIV reporting systems using coded patient identifiers²

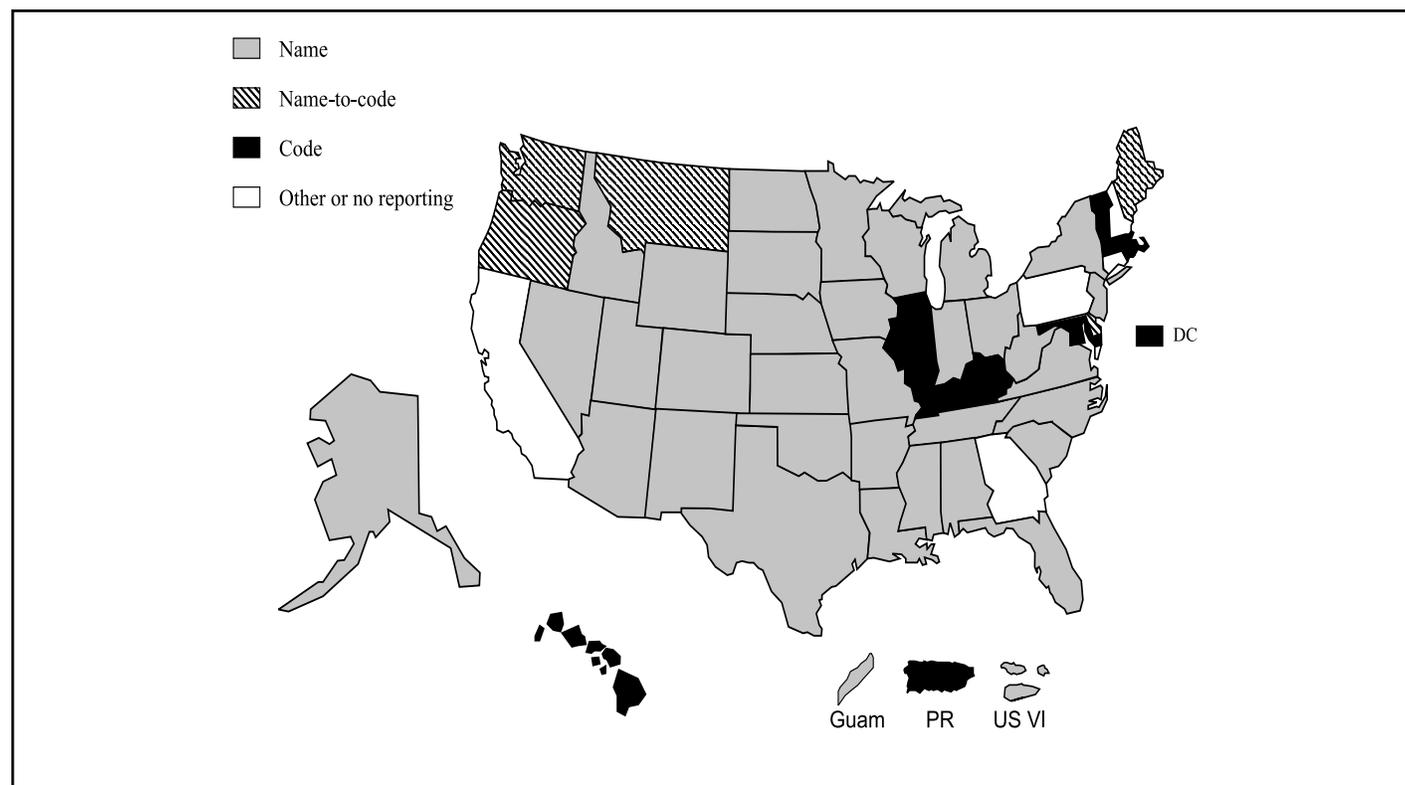
Area of residence (Date HIV reporting Initiated)	Adult/ adolescent Males	Adults/ adolescent Females	Children <13 years old	Total ³
Illinois (Jul 1999)	2,609	864	125	3,598
Maine (Jul 1999)	172	53	2	227
Maryland (Jun 1994)	7,080	4,379	152	11,647
Massachusetts (Jan 1999)	3,541	1,578	238	5,357
Puerto Rico (Oct 1998)	2,370	1,024	51	3,445
Washington (Sept 1999)	1,734	329	30	2,093

¹Includes only those persons reported with HIV infection who have not been reported with AIDS through 2000.

²Patients identified by code in initial surveillance reports or for storage in HIV registries.

³Row totals may not equal the total of columns, reflecting cases reported with unknown gender (range 0-0.3%).

Figure 1. HIV infection¹ case reporting, by patient identifier scheme and area, implemented as of December 31, 2001



¹Includes only those persons reported with HIV infection who have not been reported with AIDS.

Technical Notes

AIDS case reports, based on confidential name-based surveillance, are reported to CDC from all 50 states, the District of Columbia, U.S. dependencies and possessions, and independent nations in free association with the United States.¹ Reporting of HIV and AIDS is regulated, legislated, or otherwise mandated by state health authorities. While CDC has advised that states use the same confidential name-based approach for HIV surveillance as is currently used for AIDS surveillance nationwide, the specific implementation decision rests with the individual state or territorial health agencies. In most areas, both providers and laboratories are required to report cases of HIV and AIDS. When states elect to implement non-name-based HIV reporting, the selected coded patient identifier format is also mandated at the state level—frequently reflecting input from affected constituency groups, such as HIV infected persons and HIV/AIDS service providers. Based on differing state statutes and data collection practices, some states and territories have elected to implement coded patient identifiers constructed of portions of different personal identifiers.

HIV infection cases presented in this report are those cases reported to the participating state or territorial agencies through December 2000 and are based on the 2000 HIV case definition for public health surveillance*. Positive HIV test results for persons who tested anonymously are not included in these data.

The annual and cumulative numbers presented in this technical report are influenced by the duration of HIV reporting in each area, and the specific rules enacted in the implementation of reporting - particularly the reporting of prevalent (previously diagnosed but unreported) cases. Some states have opted to require the reporting of all persons diagnosed with HIV who are receiving care, including those initially diagnosed before the implementation of reporting. Other states have implemented systems to allow reporting of only newly diagnosed cases, and only at the time of first diagnosis. Therefore, for states that have recently implemented HIV reporting (in place

less than two years) which includes the reporting of prevalent cases, the numbers of cases may represent the reporting of both prevalent and newly diagnosed cases. This may lead to higher annual reported case counts in initial reporting years than will be observed over time; as fewer prevalent cases remain to be reported, annual case counts more accurately represent incident diagnoses. Reported cases per 100,000 population using 2000 U.S. Census data are presented to allow a standard representation of the cases being reported among the different areas, and do not represent the incidence rate of HIV infection for those areas.

Some states also require that public health agencies receive notification of all HIV infected patients receiving care, including those already reported to public health. In addition, prior to statewide HIV reporting, some areas that implemented HIV reporting using coded patient identifiers had collected reports of HIV infection from selected populations; therefore, cumulative HIV case counts may include cases reported prior to the initiation of mandated HIV reporting (Table 5). In these situations, duplicate reporting of patients can occur over time and will require accurate methods for matching the coded patient identifiers to maintain a de-duplicated HIV surveillance registry. A state with HIV infection reporting also may report persons testing positive in that state who are residents of other states. As data from the areas in this report do not undergo national de-duplication algorithms, some cases from states using coded patient identifiers may represent cases also, inadvertently, reported in other states. For these reasons, readers should not compare results between different States, and should use caution in interpreting the case counts and rates.

Reference

*Centers for Disease Control and Prevention. Guidelines for national human immunodeficiency virus case surveillance, including monitoring for human immunodeficiency virus infection and acquired immunodeficiency syndrome. *MMWR* 1999; 48 (No. RR-13):1-27.

¹Included among the dependencies, possessions, and independent nations are Puerto Rico, the U.S. Virgin Islands, Guam, American Samoa, the Republic of Palau, the Republic of the Marshall Islands, the Commonwealth of the Northern Mariana Islands, and the Federated States of Micronesia. The latter five are collectively referred to as the "Pacific Islands, U.S."