

National HIV / AIDS Atlas

*Executive Summary
and
Methodology*

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Introduction

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Public health surveillance data are information for action, and the HIV/AIDS Atlas – a collaborative effort of the National Minority Quality Forum and George Washington University – represents an exciting step forward in the way that we use HIV/AIDS surveillance data. Since the beginning of the epidemic, HIV/AIDS surveillance data have been the primary source of information to guide our response to the epidemic. The HIV/AIDS Atlas provides a new way to look at these data, by adding interactive functionality and by illustrating the data in way that point to the areas of greatest need in the U.S. HIV epidemic.

The Atlas is an important, next-generation complement to the traditionally available HIV/AIDS surveillance reports. In many ways, the Atlas represents a forward-looking view of how we will interact with public health surveillance data in the future. Traditionally, surveillance reports have been published once or several times per year, at different levels of public health authority (local, state and national reports). This next step forward builds on the capacity of Web tools, and eliminates the jurisdictional dividing lines that have characterized surveillance reporting – between governmental levels, and across county and state lines. The Atlas will allow the many stakeholders in HIV prevention to visualize data, use those data in prioritizing prevention efforts and deploying treatment and care resources. Periodic surveillance reports will continue to play a critical, complementary role for public health officials and researchers who require access to more detailed and quantitative information to design research and test hypotheses.

The Atlas provides new tools to consumers of local and national HIV/AIDS surveillance data. For policy makers, graphical displays of data clearly illustrate the specific geographic areas and specific populations where HIV/AIDS is occurring most commonly; graphical displays of data are an important, intuitive way for policy makers to understand how the HIV epidemic in their jurisdictions compares to other jurisdictions. Community-based organizations can use these tools to visualize the surveillance data that they already use for targeting and prioritization of their prevention programs in a new way. Community planning bodies, which strive to include representatives of diverse backgrounds, may also find the interactive tools helpful in planning local prevention priorities. Academic researchers will be able to use the Atlas to understand the specific areas and populations where research efforts should be focused, resulting in stronger research plans and more relevant research results.

A critical aspect of the Atlas methodology is the collaboration with the collectors of surveillance data, and the attention paid to confidentiality protections for people living with HIV. Advancing technology that allows more granular examination of data always carries some risk of indirect identification of individuals or small groups of individuals within specific geographic areas. Therefore, it is reassuring that the developers of the Atlas have worked with local, state and national surveillance authorities to ensure that the carefully-crafted standards for data release have been complied with, maximizing the utility of the data while protecting confidentiality.

This release of the HIV/Atlas portends new, important ways to look at the health of populations. Next logical steps include linking the maps to the locations of HIV prevention services, such as HIV testing sites, and the ability to examine co-morbidities by “overlapping” existing tools. As antiretroviral therapies have improved people with HIV and AIDS are happily living longer, and the management of co-existing problems including liver, cardiovascular and renal disease is becoming increasingly important. These co-morbidities also have significant disparities by race and ethnicity, and interactive Web tools will allow increased understandings of how HIV and other chronic diseases coexist across geographic areas and racial and ethnic groups.

Surveillance data – information for public health action – are only as powerful as our ability to use them to prevent disease and to care for those communities and populations in greatest need. The launch of the Atlas represents a leap forward in the ability of diverse stakeholders to interpret and use these data to improve our response to the U.S. HIV epidemic.

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Overview

Using cutting-edge technology, the HIV/AIDS Atlas provides a powerful new tool to the public, health care professionals, policy makers and elected officials to access and map local, state and national information to display the impact of HIV/AIDS. For the first time, the Atlas presents county-level prevalence rates, based on the reported numbers of people living with HIV (non-AIDS) and AIDS in 2006* in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands and New York City. The Atlas depicts the intensity of the disease, rather than its magnitude.

Mapping HIV/AIDS is an important step in stemming the tide of the disease. The HIV/AIDS Atlas was developed to increase awareness of and public access to HIV/AIDS information, and to enable communities to understand the reality of the disease today. The Atlas allows users to focus on available HIV/AIDS statistics by age, gender and race/ethnicity, and it allows them to see their U.S. and state legislative districts overlaid on county-level maps.

Methodology

Data Sources

In June 2008, the National Minority Quality Forum sent data requests for the numbers of persons living with HIV (non-AIDS) and AIDS at any time between January 1 and December 31 of a given year, cross-tabulated by county, age, gender and race/ethnicity, via e-mail to the HIV/AIDS-surveillance branches within the departments of health in all 50 U.S. states, the District of Columbia, Puerto Rico, the Virgin Islands and New York City for the years 2005, 2006 and 2007. Data from the year 2006 were used unless the health department was unable to provide them. Each request specified that if the department could not provide data at the county level, it should aggregate the data to a region or state level.

(The term *region* is used generically to refer to an aggregation of more than one county; the term *state* is used generically to refer to a state, the District of Columbia, a territory or New York City.)

E-mail requests were followed up with telephone calls when necessary. If a department was unable to fulfill the request, the numbers of persons living with HIV (non-AIDS) and AIDS were obtained from the Centers for Disease Control and Prevention (CDC) *HIV/AIDS Surveillance Report, 2006*.¹

*Note: While most states reported 2006 data to NMQF, Maine, Puerto Rico and Rhode Island provided 2005 data, and Kansas, Montana, New Hampshire and Washington provided 2007

Prevalence Estimation

The population in each county as reported in the 2000 U.S. censusⁱⁱ was used as an estimate for the number of persons in each county. For states that provided region- or state-level data, the census estimates were aggregated to the same geographic areas.

Prevalence is defined as the number of affected persons in a defined population at a specified time, divided by the total number of people in the population at that time.ⁱⁱⁱ Based on reported cases, the prevalence of a disease within a population is an estimate of the proportion of that population who are living with the disease. The estimated prevalence of HIV (non-AIDS), as well as that for AIDS, for each geographic area (*A*) was calculated as follows:

$$\text{prevalence} = \frac{\text{number of persons living with disease in geographic area } A \text{ at a specified time}}{\text{number of persons living in geographic area } A \text{ at that specified time}} \times 100$$

Prevalence is displayed as a percentage. For states providing data in geographic areas other than counties, prevalence in each area was estimated and applied to each county in that area.

Geographical Analysis

ArcView 9.2 software was used to produce national and county maps of HIV (non-AIDS) and AIDS prevalence, using natural breaks (Jenks' method) to define six legend boundaries for each individual map.^{iv} Several states that provided county-level data were unable to provide estimates for some counties due to small numbers of persons living with HIV (non-AIDS) or AIDS in these areas; such counties are shaded gray.

Review for Accuracy

The numbers of persons living with HIV (non-AIDS) and AIDS provided by each state were aggregated to the state level and cross-checked with the CDC *HIV/AIDS Surveillance Report*.ⁱ After the estimated prevalence from each state was calculated, the staff contacts at the participating department of health were asked to review the county-level maps for the state.

Results

Table 1 summarizes the geographic levels of data used to estimate the prevalence of HIV (non-AIDS) and AIDS in each state. Among the 54 departments from which data were requested, 29 provided data at the county level, 12 provided data at the regional or district level and eight provided data at the state level. Five states were unable to provide the numbers of persons living with HIV (non-AIDS) and AIDS; the CDC *HIV/AIDS Surveillance Report*^f was used to estimate prevalence in these states.

Table 1. Summary of Geographic Levels of Data Used to Create the Atlas (n = 54)

Summarization Level	Geographic Areas
County	AR ¹ , AZ, CA ^{2,7} , CO, CT ⁷ , DC ^{1,5a,7} , DE ⁷ , FL ¹ , GA ³ , HI ^{5a,7} , IL ^{1,7} , IN, LA, ME ^{1,4a,7} , MA ^{1,7} , MI ¹ , MO ¹ , NH ^{4b,7} , NC, NJ ¹ , NM, NV, NYC, RI ^{2,4a,5b,7} , SC ¹ , TX ¹ , VA ⁷ , WA ^{3,4b} , WY ¹
Region	AL, ID ³ , KS ^{4b} , KY ^{2,5a,7} , MD ^{3,1} , MN, MS, NY ^{1,2,3} , OH ¹ , PR ^{4a} , TN, UT ^{2,3,6}
State or territory	IA ¹ , MT ^{4b,7} , OR ^{2,3,7} , PA ^{2,7} , SD, VT ⁷ , WV ¹ , VI ⁶
CDC-published data were used	AK ^{3,6} , ND ^{3,6,7} , NE ^{3,6} , OK ^{3,6} , WI ^{3,6}

¹ Prisoners were excluded from the data (n = 17).

² The total number of persons living with HIV (non-AIDS) or AIDS by county or region was obtained from an online report on the state department of health Web site and used to determine the overall prevalence of HIV (non-AIDS) or AIDS at the county or region level (n = 7).

³ The total number of persons living with HIV (non-AIDS) or AIDS was not available by age (n = 12).

^{4a} Data were provided for 2005 only (n = 3).

^{4b} Data were provided for 2007 only (n = 4).

^{5a} The total number of persons living with HIV (non-AIDS) was not available (n = 3).

^{5b} The total number of persons living with AIDS was not available (n = 1).

⁶ The total number of persons living with HIV (non-AIDS) or AIDS was not available by race/ethnicity (n = 7).

⁷ States did not have confidential name-based HIV-infection reporting for a sufficient length of time (since at least 2003) (n = 16).

Limitations

As the surveillance departments gather more data from clinics and hospitals, the numbers of persons diagnosed with HIV (non-AIDS) and AIDS are updated. The data obtained from the health departments have not been adjusted for delays in reporting; they reflect the numbers of persons living with HIV (non-AIDS) and AIDS that the departments were able to report at the time of the request. The CDC *HIV/AIDS Surveillance Report*[†] adjusts its counts for delays in reporting; therefore HIV/AIDS Atlas maps based on the CDC data may slightly overestimate prevalence.

Although most states provided data on persons living with HIV (non-AIDS) and AIDS at any point in time during the year, some provided data on such persons who were alive as of the end of the year. Prevalence rates might be underestimated in these states due to deaths that occurred during the year; however, the likely difference is relatively small, as CDC estimates that deaths reported in 2006 among AIDS patients were less than 4 percent of total living cases.[‡] In addition, the geographic area of testing does not necessarily correspond to the geographic area of residence, which may also be a bias in the prevalence rates.

Seventeen states were able to exclude prisoners from the data (Table 1). For states that could not exclude prisoners, counties (or regions) in which prisons or other correctional facilities are located would tend to greatly elevate prevalence, which would overstate the situation in the community at large.

Estimates of HIV (non-AIDS) prevalence may not be entirely comparable among states due to transitions from code-based reporting systems to confidential name-based reporting systems.[§] In 2005, CDC recommended that states collect HIV (non-AIDS) data through a name-based reporting system, because estimates based on name-based reporting are more accurate than those based on codes. In recent reports, CDC has reported HIV (non-AIDS) data only from states and territories that have conducted confidential name-based HIV-infection reporting for at least four years. The HIV/AIDS Atlas presents prevalence estimates in areas for which states have collected data, regardless of the method of reporting or the quality of the surveillance system.

Other factors may influence the quality of state surveillance systems and, consequently, the maps of these states in the HIV/AIDS Atlas. These factors include differences in data-release restrictions for confidentiality, in the number of years that a surveillance system has been established and in funding to support the surveillance system. In addition, prevalence estimates based on small populations may not be as stable as those based on larger populations. For a county with a small population, the addition or removal of a single living case would increase or decrease the prevalence of disease in this population by a much larger percentage, and thus would have a greater impact on the estimate than in a county with a larger population.

Finally, HIV/AIDS prevalence rates are a measure of the burden of the disease on the population. They indicate relative intensity of the epidemic, regardless of population size. To express the magnitude or extent of the disease would require publication of the absolute numbers of persons living with HIV (non-AIDS) and AIDS, by county, region or state. The HIV/AIDS Atlas was developed with prevalence rates rather than numbers of cases to provide one way for users to understand the burden of infection within their communities.

Atlas Development

The National HIV/AIDS Atlas is a project of the National Minority Quality Forum, with support from Gilead Sciences, Inc. The data were collected and analyzed by National Minority Quality Forum staff in partnership with the Department of Epidemiology & Biostatistics at the School of Public Health & Health Services at George Washington University in Washington, D.C.

Notes

ⁱ Centers for Disease Control and Prevention. *HIV/AIDS Surveillance Report, 2006*. Vol. 18. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, 2008.

ⁱⁱ Census 2000 Summary File 1. Prepared by the U.S. Census Bureau, 2001.

ⁱⁱⁱ Leon Gordis. *Epidemiology*, 3rd ed. Philadelphia: Elsevier Inc., 2004.

^{iv} ArcView 9.2 software. Environmental Systems Research Institute, Redlands, California, 2006.

^v 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(RR-13);1–28.