

# Summary of Changes to the National HIV Surveillance Report

CDC HIV/AIDS FACTS

JUNE 2010

The annual *HIV Surveillance Report* provides a broad overview of the current epidemiology of HIV disease in the United States and 5 U.S. dependent areas. CDC funds state and territorial health departments to collect surveillance data on persons diagnosed with HIV infection; all personal identifiers are removed from these data before being transmitted to CDC via a secure data network. Data are analyzed by CDC and then displayed, for this report, by age, race/ethnicity, sex, transmission category, or jurisdiction. As a source document, the *HIV Surveillance Report* is intended to provide a basic understanding of the HIV epidemic in the United States and is not intended to provide in-depth analyses of special populations or issues of interest. Those more specialized analyses are more suited to supplemental reports such as CDC's supplement surveillance reports, slide series, and peer-reviewed manuscripts.

Changes to the *HIV Surveillance Report* for 2008 were made in response to requests from public health partners, Surveillance Coordinators and AIDS Directors, in order to make better use of data collected through surveillance and to best characterize the HIV epidemic in the United States. This document provides a summary of and an explanation for these changes as well as general description about the report contents and format.

Additional factors contributing to the overall need to make changes to the report include:

- As of April 2008, all states had implemented confidential name-based HIV infection reporting. This is a tremendous change in the operation of our surveillance system and requires some changes to how we display our data. However, it should be noted that only 37 states have been reporting HIV infection data to CDC long enough (defined as being submitted to CDC by at least January 2005) to apply statistical adjustments to the data and be included in CDC's estimates in this report. The *HIV Surveillance Report* for 2012 (issued in 2014) will be the first time the data from all 50 states will be included in the estimates.
- In 2008, changes were made to the case definition for HIV infection. The new case definition combined the two previous case definitions for HIV and AIDS, and established a new disease staging classification. This change in the new case definition prompted our changes to the title of the report and new terminology HIV infection throughout the report.
- Advancing technologies and effectiveness of highly active anti-retroviral therapy (HAART) is changing the epidemic of HIV infection so people are living longer and healthier lives. Therefore, in order to accurately track the epidemic, growing emphasis needs to be placed on HIV surveillance rather than AIDS surveillance, a gradual process that is reflected in changes to the report.

## Terminology

### 1. New terminology for diagnoses of HIV infection with and without AIDS

- The term "HIV/AIDS"—previously used to refer to a new diagnosis of HIV infection regardless of the person's disease stage at the time of diagnosis—was replaced with the term "diagnosis of HIV infection". The use of "diagnosis of HIV infection" reflects implementation of the revised case definition for HIV infection that incorporated the previous case definition for AIDS and established a new disease staging classification (CDC. Revised surveillance case definitions for HIV infection among adults, adolescents, and children aged <18 months and for HIV infection and AIDS among children aged 10 months to <13 years—United States, 2008. MMWR 2008;57(RR-10):1-12).
- The title of the publication has been changed to reflect the new terminology; the report is now labeled: *HIV Surveillance Report*.

### 2. The term "high-risk" was removed from the "high-risk heterosexual contact" transmission category label.

- As defined in this report, these data are specific to persons exposed through heterosexual contact with a person who had a risk for HIV or was infected with HIV. However, removal of the label "high-risk" clarifies to the reader that heterosexual contact itself is the mode of transmission for HIV infection. In addition, this returns the label to as it was prior to the 2005 surveillance report and parallels the other transmission categories. The explanatory footnote will remain, as it clarifies for the reader how the data are defined.

## General Data Display

### 1. Display of data by year of diagnosis (or death), not year of report

- Data are no longer presented by the year they were reported to CDC. All data (adjusted and unadjusted) are presented by the year of diagnosis (or death). Cases reported in a given year could have been diagnosed at any time—even years earlier—and thus may not accurately reflect the current characteristics of, or trends in, the epidemic. Additionally, reported data may be more susceptible to changes in surveillance procedures and practices than diagnosis data because reported data are based on the date of report which may be delayed if surveillance practices change, in contrast to diagnosis data which depend only on date of diagnosis which will always remain the same, no matter when the case is reported.



Centers for Disease  
Control and Prevention  
National Center for HIV/AIDS,  
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TB Prevention

1-800-CDC-INFO (232-4636)  
In English, en Español  
24 Hours/Day  
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www.cdc.gov/hiv

- Most of the information from previous surveillance reports that was displayed by year of report is still included in the 2008 *HIV Surveillance Report*. These tables now contain data by year of diagnosis rather than year of report, as explained above. Tables 19-25 from the 2007 report (e.g. reported cases by sex and expanded transmission category; reported cases of infants born to HIV-infected mothers) have been removed. Those data may be better suited for display in supplemental reports and publications because of the complexity of analysis and interpretation.

## 2. Columns for data by number, estimated number, estimated rate

- Data are displayed by year of diagnosis (or death) as noted above.
- Most tables include columns for number, estimated number, and estimated rate.
  - Number refers to the unadjusted numbers of persons. These are the actual numbers of persons newly diagnosed with HIV infection during a certain period of time, without any statistical adjustments. Unadjusted numbers are provided to show the effects of the adjustments.
  - Column headings labeled “Estimated” indicate that data have been statistically adjusted to account for delays in reporting to the health department (but not for incomplete reporting) and missing risk factor information, where appropriate.<sup>1,2</sup> CDC adjusts the data for reporting delays to paint a more accurate picture of the true number of cases diagnosed during the specified time period. Adjustments improve the ability to interpret data and examine trends over time. The adjusted numbers should be used when examining trends over time, and provide readers a more accurate representation of the true number of diagnoses if they had all been reported to the state health department in a timely manner.
  - As in previous reports, rates are based on the estimated number and are calculated as estimated number per 100,000 people in a given population. Rates allow for standardized comparisons across groups, given a standard denominator (100,000 population).
- All rates presented in the 2008 *HIV Surveillance Report* are calculated using U.S. Census Bureau data for population denominators (see Technical Notes in the Surveillance Report for details).
  - As in previous surveillance reports, rates are not provided for transmission categories because the U.S. Census Bureau does not collect information on behaviors that may put people at risk for disease transmission (e.g., sexual and drug-use behaviors) and therefore, data are not available to calculate denominators.
  - CDC is in the process of developing national population estimates for risk groups. The recently released national population estimate for men who have sex with men (MSM)<sup>3</sup> was not used in this surveillance report to calculate rates for the male-to-male sexual contact transmission category because the methods used to calculate this denominator (the number of MSM in the United States) differ from all other calculations of rates in this report. A detailed description of the methods for calculating the MSM denominator and display of disease rates will be published in a separate report or publication (the recent release was through an abstract).
  - CDC currently does not provide subpopulation rates for the 5 U.S. dependent areas due to the lack of comparable population data by race/ethnicity for these areas. CDC is collaborating with the U.S. Census Bureau to develop methods for estimating rates by race/ethnicity for Puerto Rico and other dependent areas. Such rates would be reported in a separate report or publication in order to fully explain the methods for calculation.

## 3. Duplicate tables for HIV and AIDS, and for tables with and without data from 5 U.S. dependent areas

- Most data analyses are presented in two formats: The first table in each section (table a) excludes data from the dependent areas and the second table (table b) includes data from the dependent areas (American Samoa, Guam, Northern Mariana Islands, Puerto Rico, and the U.S. Virgin Islands). This makes better use of data from the dependent areas, which previously were not included in breakouts by age, race/ethnicity, transmission category or sex. It also allows users of the report to select data from the areas most relevant to them. This change was made in response to requests for these data from public health partners.

# Surveillance Report Sections

## 1. Diagnoses of HIV infection and AIDS

- Tables on diagnoses of HIV infection or AIDS present information from the most recent 4-year period, 2005-2008.
- Tables presenting diagnoses of HIV infection include:
  - Data from the 37 states and 5 U.S. dependent areas with long-term confidential name-based HIV infection reporting (i.e., since at least January 2005). As described in the Commentary in the Surveillance Report, states implemented confidential name-based reporting at different times, and inclusion of areas in the estimated (adjusted) numbers and rates of diagnoses of HIV infection is based on the date of implementation. Although all states had successfully implemented confidential name-based HIV infection reporting by April 2008, inclusion of all states in the estimated numbers and rates of diagnoses (and deaths) of HIV infection will not be possible until the 2012 *HIV Surveillance Report*, (which will be issued in 2014) when all states will have mature HIV reporting systems (to allow for stabilization of data collection and for adjustment of the data in order to monitor trends).
- As in years past, tables presenting AIDS diagnoses include:
  - Data from the United States (50 states and the District of Columbia) as well as from the 5 U.S. dependent areas.

## 2. Deaths and survival among persons diagnosed with HIV infection or AIDS

- Deaths of persons with a diagnosis of HIV infection or an AIDS diagnosis may be due to any cause (i.e., may or may not be related to HIV infection). Other sources, e.g., the National Center for Health Statistics (NCHS) mortality statistics for the United States provide data on HIV infection as a cause of death in the general population.
- Due to delays in reporting of deaths to surveillance programs, 3 years of death data are displayed which do not include data for the most recent year. For the 2008 report, data are presented for persons who died during 2005–2007. This is to allow at least 18 months for deaths to be reported.
- Previous annual HIV surveillance reports only displayed data on deaths among persons with AIDS. However, this report expands that data to include data on deaths of all persons with a diagnosis of HIV infection regardless of AIDS status in order to provide more comprehensive death information. The inclusion of the death data on persons diagnosed with HIV but not yet AIDS along with the AIDS death data provides the reader with a more accurate understanding of the number of people diagnosed with HIV who have died.
- Data on rates of death among persons diagnosed with HIV infection or AIDS have been included in this surveillance report in order to allow a more complete interpretation of the available data.
  - An increase or decrease in estimated deaths in a population may signal a true increase or decrease in deaths of persons with a diagnosis of HIV infection or AIDS, but may also be related to changes in reporting of deaths or other surveillance practices. Significant efforts have been made during recent years to improve death reporting by state HIV surveillance programs. In addition, estimation models include a degree of uncertainty, and the estimates for the most recent year are subject to the greatest uncertainty.
- Survival tables are based on 5 years of diagnosis data (HIV infection or AIDS) and present data for persons who survived 12, 24, and 36 months after an HIV or AIDS diagnosis.
  - Tables were limited to persons whose diagnosis was made during 2000–2004 to allow at least 3 years from the time of diagnosis to deaths occurring through December 31, 2007.
  - Data for each HIV reporting area were included in the survival tables beginning with the first full calendar year after implementation of code-based or name-based HIV reporting (e.g., data from New York are included for diagnoses of HIV infection that occurred during 2001-2004 only because New York implemented HIV reporting in June 2000).

## REFERENCES

1. Song R, Hall HI, Frey R. Uncertainties associated with incidence estimates of HIV/AIDS diagnoses adjusted for reporting delay and risk redistribution. *Stat Med* 2005;24:453-464.
2. McDavid Harrison K, Kajese T, Hall HI, Song R. Risk factor redistribution of the national HIV/AIDS surveillance data; an alternative approach. *Public Health Rep* 2008;123(5):618-627.
3. Purcell DW, Johnson C, Lansky A, Prejean J, Stein R, Denning P, Gaul Z, Weinstock H, Su J, Crepaz N. Calculating HIV and Syphilis Rates for Risk Groups: Estimating the National Population Size of Men Who Have Sex with Men. Abstract #22896. Presented March 10, 2010 at the 2010 National STD Prevention Conference; Atlanta, GA.

## HIV/AIDS RESOURCES

CDC HIV/AIDS  
[www.cdc.gov/hiv](http://www.cdc.gov/hiv)  
CDC HIV/AIDS resources

### CDC-INFO

1-800-CDC-INFO (232-4636)  
Information about personal risk and where to get an HIV test

### CDC National HIV Testing Resources

[www.hivtest.org](http://www.hivtest.org)  
Location of HIV testing sites

### CDC National Prevention Information Network (NPIN)

1-800-458-5231  
[www.cdcpin.org](http://www.cdcpin.org)  
CDC resources, technical assistance, and publications

### AIDSinfo

1-800-448-0440  
[www.aidsinfo.nih.gov](http://www.aidsinfo.nih.gov)  
Resources on HIV/AIDS treatment and clinical trials

## 3. Persons living with a diagnosis of HIV Infection or AIDS

- Due to delays in reporting of deaths to surveillance programs, 3 years of prevalence data are displayed which do not include data for the most recent year. For the 2008 report, data are presented for persons living at the end of each year with a diagnosis of HIV infection or AIDS during 2005–2007. This is to allow at least 18 months for deaths to be reported and those cases to be removed from displays of prevalent (living) cases.

It should be noted that data from the national prevalence estimate released in October 2008 (CDC. HIV prevalence estimates—United States, 2006. *MMWR*. 2008;57(39):1073-1076) are different from the data presented in the *HIV Surveillance Report*. The national prevalence estimate utilized an extended back-calculation method (Hall et al. Estimation of HIV incidence in the United States. *JAMA*. 2008;300(5):520-529) to estimate the number of persons living with HIV infection in the United States, including those with undiagnosed infection. The data presented in the *HIV Surveillance Report* represent the number of persons living with HIV infection that have been diagnosed, have been reported to the HIV surveillance system, and have not been reported as deceased. These data are reported annually, whereas the national prevalence estimate has been calculated periodically.

## 4. HIV infection and AIDS data for States and Metropolitan Statistical Areas (MSAs)

- These tables now include numerical rankings based on HIV diagnosis rates (by MSA only). This was done so that readers can more easily *see how areas compare* to each other.
- Tables on States and MSAs do not present data *on transmission category*. These very detailed analyses are more appropriate for supplemental reports and publications as previously mentioned.

## 5. Incidence data are not displayed in the 2008 surveillance report

- CDC will publish updated incidence estimates in a separate report later in 2010.
  - Data for incidence estimation are included up to 12 months after a diagnosis year while data on HIV diagnosis are included up to 6 months after a diagnosis year. This means that data for incidence estimates are available later than diagnosis year data and thus incidence estimates are not ready at the same time as other data displayed in surveillance reports.
  - A separate report of incidence estimates will allow for more explanation of methods and interpretation of results than is usually included in surveillance reports. In order to provide the most complete description of the incidence of HIV infection over time the next incidence estimates will include estimates based on data from 2006, 2007, and 2008.