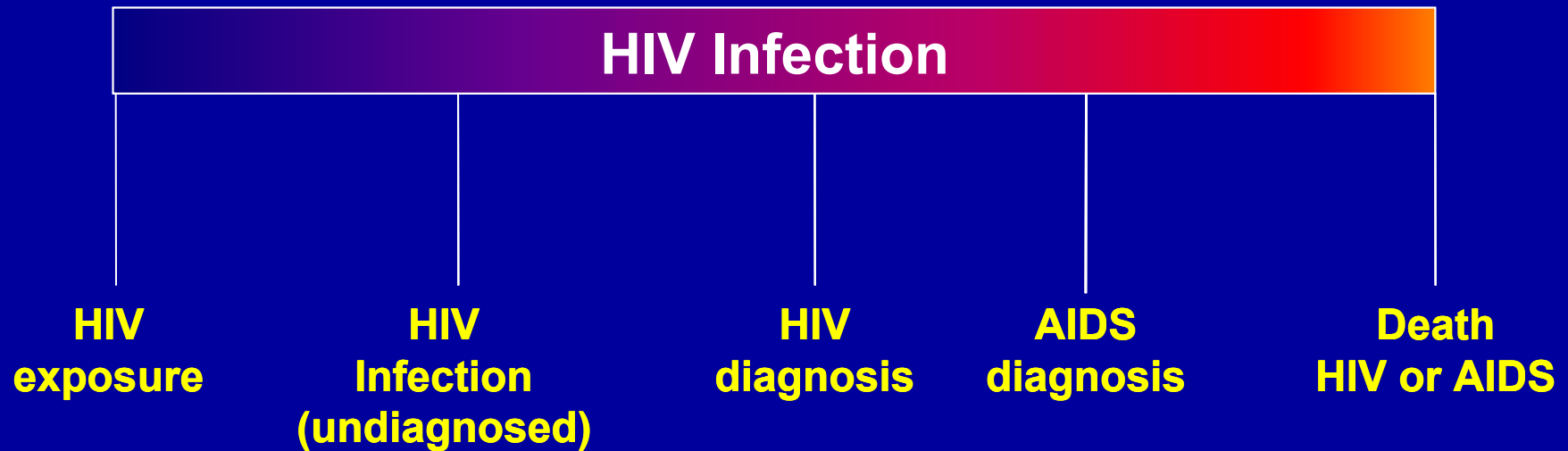


Understanding HIV/AIDS Surveillance Data in the United States: A Crash Course

**Federal AIDS Policy Partnership,
Community Forum on HIV/AIDS Surveillance,
April 14, 2008**

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Understanding HIV as a Continuum



Source: Glynn MK and Rhodes P, "Estimated HIV Prevalence in the United States at the end of 2003." Presentation, National HIV Prevention Conference; June 2005.

Disease Surveillance in the U.S.

- Authority to require disease notification and reporting in the U.S. resides with the states
- Based on individual state legislative and regulatory decisions
- In other words, disease reporting is not federally mandated but, rather, voluntary on the part of states
- Federal government can influence reporting through recommendations and guidelines, and by tying federal funding decisions to disease counts
- Surveillance systems take time to become standardized and to mature

Some Particular Challenges for HIV and AIDS Surveillance in the U.S.

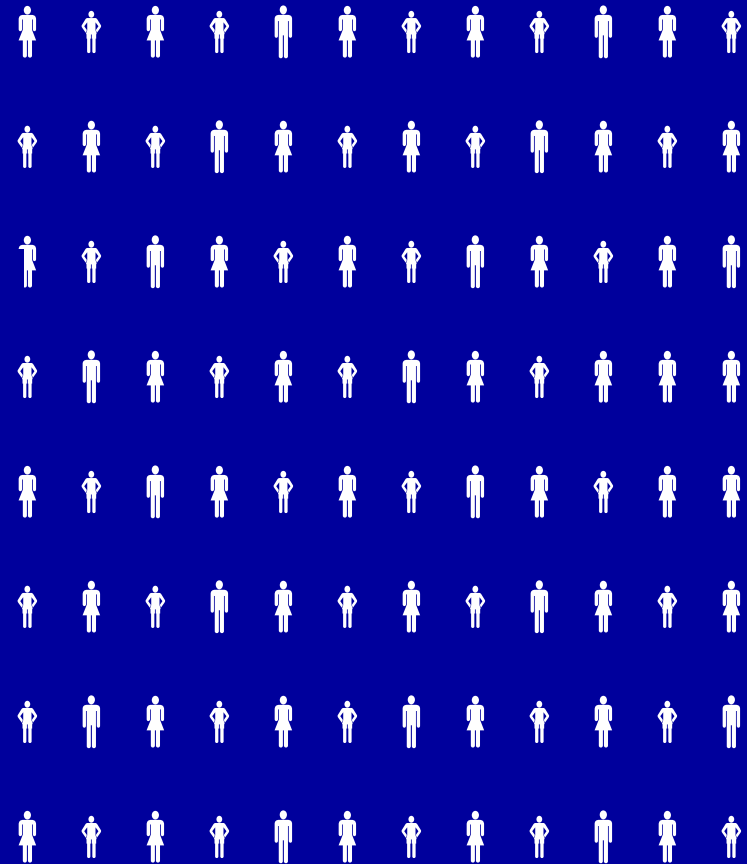
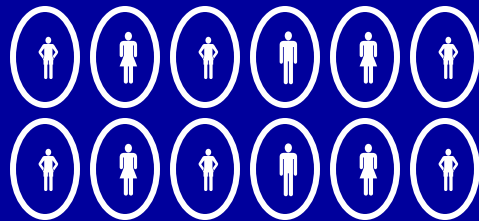
- Many people with HIV do not know their status
 - Stigma
 - Long incubation period with no symptoms
 - Testing rates
- AIDS case reporting is more complete than HIV case reporting but increasingly offers a picture of the past
- HIV case reporting is becoming more complete but still needs time to mature *and* HIV case reporting is of *diagnoses, not new infections*
 - Standard diagnostic tests cannot determine when someone became infected; this is a challenge worldwide

Key Terms & Concepts

Incidence & Prevalence

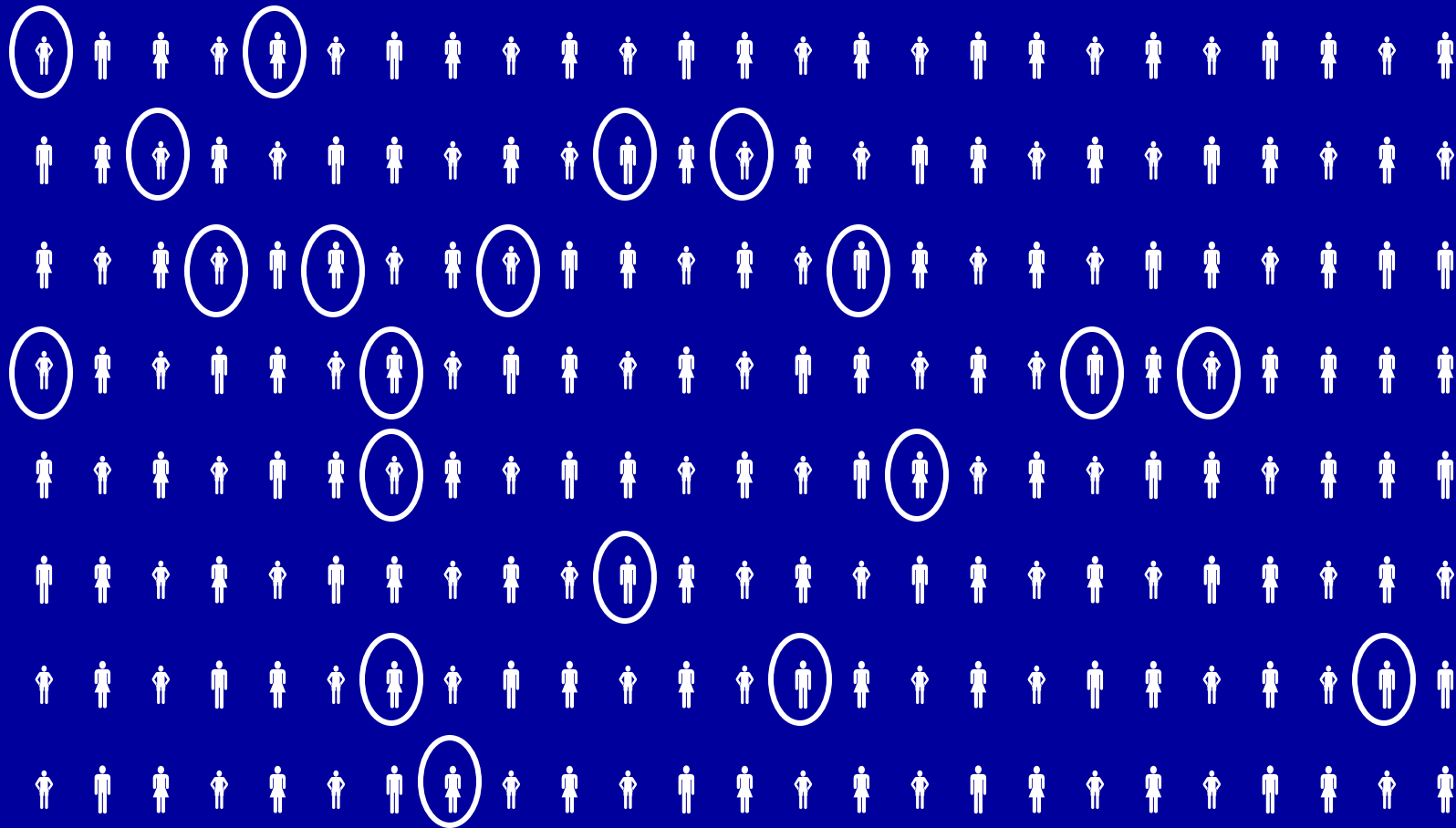
- Incidence: The number or proportion of new cases/people with a disease within a specific population during a specific period of time—e.g., the number of new HIV infections occurring in the last year. The denominator is the population at risk and the numerator is the number of new cases during the specified period of time.
- Prevalence: The number or proportion of cases/people with a disease or condition at a specific point in time—e.g., the number of people living with HIV, at any disease stage, including AIDS. Often expressed as the percent of a population infected with HIV at a point in time.

Incidence



Adapted from Schoenbach VJ, "Epidemiologic measures: Incidence & Prevalence", www.unc.edu/epid600.

Prevalence



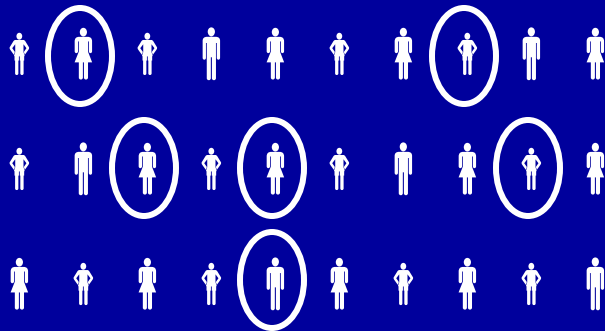
Adapted from Schoenbach VJ, "Epidemiologic measures: Incidence & Prevalence", www.unc.edu/epid600.

Why Case Rates/Proportions Are So Important for Comparing Impact

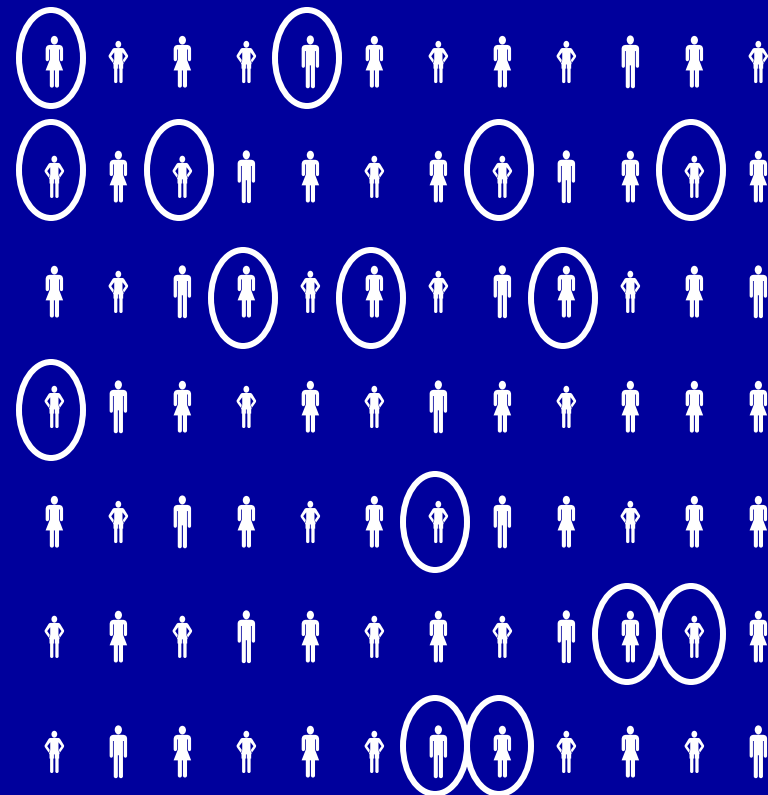
- Using rates, or proportions, to assess the impact of disease (or some other measure of interest) is important for comparing across time and between subgroups.
- A case rate (per 100,000) for example, standardizes the number of cases by population size. It effectively says, for every 100,000 people of the population of interest, how many are infected? And how does this compare to another group of 100,000 people?
- Without a rate, it may be difficult to determine which group has the highest concentration of disease.

Example: Which Population has the Highest Concentration of HIV?

Population A:
6 out of 30 infected



Population B:
15 out of 84 infected



Answer

- Population A: $6 / 30 = 20\%$
- Population B: $15 / 84 = 18\%$
- Population A has a greater *concentration* of HIV
- Population B has a greater *number* of people infected with HIV and who may be in need of services at a given point in time
- Bottom line: both measures are important but provide different kinds of information

Incubation & Window Periods

- Incubation (or Latency) Period: The time from infection to the onset of symptoms. Infection may be detectable through diagnostic tests during this period but not be apparent to the infected individual. For example, someone with HIV may be infected for years before any symptoms develop.
- Window Period: The time from infection to detection of infection. This is highly dependent on the types of diagnostic tools available. For example, standard diagnostic tests for HIV cannot detect whether someone is infected for several weeks after infection. While there are other tests available that can detect infection earlier, they are not generally used for diagnostic efforts.

New HIV Infection ≠ New HIV Diagnosis ≠ New HIV Report

- Year of Infection: year in which person becomes infected. May be difficult to determine, depending on the disease, the diagnostic capabilities available, and whether or not people come forward or are encouraged to come forward to learn about their status; may not be determined until some time after infection. For a person infected with HIV in 2000, the year of infection is 2000.
- Year of Diagnosis: year in which the health provider or laboratory diagnoses the case, regardless of when the person was infected. For a person who is infected with HIV in 2000 but not diagnosed until the end of 2004, the year of diagnosis is 2004.
- Year of Report: year in which the report was officially made to state/federal health official, regardless of when the person was infected or when the case was diagnosed. For a person who is infected with HIV in 2000, diagnosed at the end of 2004, but whose case is not reported to the state or CDC until early 2005, the year of report is 2005.

Risk/Transmission Classification in the U.S.

- Standardized categories of risk used
- Categories are listed in a hierarchy *by probability* of transmission
- Why a Hierarchy?
 - The challenge of ascertaining risk in the context of a disease that involves stigma, in which people may not know how they became infected or may not want to share that information
 - System started early on based on what was becoming known about HIV
 - Follow-up is important
 - Supplementary data collection, sources, and estimation techniques help to paint fuller picture

The Hierarchy of Risk Classification for Adults/Adolescents

1. Male-to-male sexual contact
2. Injection drug use
3. Male-to-male sexual contact and injection drug use*
4. Hemophilia/coagulation disorder
5. High-risk heterosexual contact
 - a. Sex with injection drug user
 - b. Sex with bisexual male
 - c. Sex with person with hemophilia
 - d. Sex with HIV-infected transfusion recipient
 - e. Sex with HIV-infected person, risk factor not specified
6. Receipt of blood transfusion, blood components, or tissue
7. Other/risk factor not reported or identified

The Risk Classification System, continued

- For surveillance purposes, individuals categorized once, in the category listed *first* in the hierarchy even if they fall into multiple categories*
 - Example: a man who has sex with men and with women will be categorized as “msm”
 - Example: a woman who injects drugs and has sex with men will be categorized as “IDU”
- What about “Other/risk factor not reported or identified”
 - Initially quite a high share falls into the unreported and unknowns. Example, 46% of cases reported among women are categorized as “heterosexual”, 36% as “other”
 - CDC estimates the risk for these cases and re-allocates them using information from population-based samples and models
 - After re-allocation, 80% of cases among women estimated as “heterosexual, 1% as “other”

*There is an exception to this rule for men who report sex with men and injection drug use, for which there is a unique category used

A “Walk Through” of An HIV/AIDS Surveillance Report



Some guiding principles:

Note: reports issued annually, and based on data provided by states to CDC (see case reporting form)

Note: most of the data in report are presented at national level, with some breaks by major subgroup/region. For additional data by state, see Kaiser Family Foundation's statehealthfacts.org site

Steps for getting started:

1. First, make sure you have the most recent report and its most current version
2. Read the Commentary
3. Read the Technical Notes
4. When reviewing a table, check its title, dates, and all notes

Surveillance Report: Section 1

- Presents HIV and AIDS cases in the United States; national level data and major subgroup distributions.
- These are *estimated* cases, not actual reports.
 - CDC adjusts reported cases to account for reporting delays and to redistribute cases initially reported without an identified risk factor
 - Because they have been adjusted, they are important tables for tracking the epidemic over time and by subgroup
- Where HIV cases are presented, only from states/areas that have had confidential HIV name-based reporting for sufficient length of time (4 years) to allow for these adjustments.
- Even where HIV cases are presented, these are *NOT* the same as new HIV *infections*

Surveillance Report: Section 2

- Presents estimated deaths among people with AIDS
 - Not the same thing as deaths due to HIV, although most are. Deaths due specifically to HIV are available through other CDC reports.
- Estimates derived from adjustments made to reported data to account for reporting delays and to redistribute cases reported without identified risk factor
- Because they have been adjusted, these estimates are useful for tracking trends over time and by subgroup

Surveillance Report: Section 3

- Presents estimated HIV and AIDS prevalence (number estimated to be living with HIV and AIDS)
- Estimates derived from adjustments made to reported data to account for reporting delays and to redistribute cases reported without identified risk factor
- Because they have been adjusted, these estimates are useful for tracking trends over time and by subgroup
- *Important note:* these estimates are adjustments of reported cases only, and do not represent the estimate of all people living with HIV/AIDS in the U.S., since significant shares do not know their status and have not been diagnosed/reported

Surveillance Report: Section 4

- Presents a “survival” analysis
- Takes the number of people who were diagnosed with AIDS in 2002, and looks forward to see what share have survived for different periods of time.
- Very useful for looking at differences, for example, in survival time for different subgroups; if one subgroup is less likely to survive as long as another, it could indicate differential access to care or later diagnosis for that subgroup.

Surveillance Report: Section 5

- Presents HIV and AIDS data by year of report
- Not adjusted for reporting delays or to reallocate cases reported without identified risk factor
- Useful for understanding reporting across the country but not for tracking the epidemic
 - For example, knowing how many states are now reporting HIV cases
- Also, only section that includes state-level data and metropolitan level data
 - Because the AIDS case reporting system is relatively complete, some of these data can be used to look across areas (for AIDS only)

HIV Data in Section 1 “vs.” Section 5

- Section 1: includes only those states/areas that have been conducting confidential name-based HIV reporting for sufficient time to allow for needed adjustments
 - 33 states and 5 areas in current report
- Section 5: includes all states/areas that conduct confidential name-based HIV reporting
 - 45 states and 5 areas in 2006
 - Not adjusted for delays or risk reallocation
- HIV data in Section 1 and Section 5 CANNOT be compared
- HIV data in Section 5 in 2006 CANNOT be compared to prior report years since fewer states reported HIV cases in past and these data are not adjusted to allow for such comparisons
- The increase in HIV cases REPORTED in 2006 as shown in Section 5 (compared to last year’s report) is due to an increase in the number of states providing these data, not increasing cases

Resources & Links

- Latest CDC Annual HIV/AIDS Surveillance Report:
<http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2006report/default.htm>
- Prior CDC HIV/AIDS Surveillance Reports:
<http://www.cdc.gov/hiv/topics/surveillance/resources/reports/past.htm#surveillance>
- Additional state-level data at Kaiser's www.statehealthfacts.org
- You can also obtain state-level and sometimes local level data from your state health department. See NASTAD directory at:
http://www.nastad.org/About/res_state_Directory.aspx.
 - be aware that these data are not necessarily comparable to data from other locations since they have not be adjusted