UNDERSTANDING AND REPORTING ON HIV/AIDS DATA

Reporting on HIV/AIDS is complex and sorting through the epidemiological data can be challenging. Whether using data to support a story or reporting on the data itself, the specific data chosen and how they are used, will play a large role in determining what story you tell. In addition, the data are often so complex that there is a risk of misinterpretation. For example, some reporters may use "incidence" and "prevalence" interchangeably even though they represent two different ways of measuring the epidemic (for definitions, see below). It is also important to be aware that enhancements in methodology, greater availability of data, and increasing knowledge of HIV disease have led to improved and updated estimates over time and while these provide a clearer picture of the epidemic, they often mean that current estimates may not be comparable to estimates published in prior years. Therefore, it is important to be familiar with the types and sources of HIV/AIDS data available, how they are used to characterize the epidemic, how they change over time, and their limitations in order to avoid hitting pitfalls when reporting. Included below is a brief discussion of some of these issues and suggested resources.

Where Do HIV/AIDS Data Come From?

HIV/AIDS data come from a variety of sources, including:

- Population-based household surveys
- Surveys of pregnant women attending antenatal clinics (ANCs)
- Other "sentinel" surveillance of populations at higher risk such as sex workers or injecting drug users. Sentinel surveillance is the collection and analysis of disease data from designated institutions, providers, or facilities, such as STD or ANC clinics. Such data, however, may not be representative of the general population
- Official case reports (e.g., from health departments tracking disease)
- Vital registration systems (the official recording of births and deaths)

None of these sources, however, provides a total or exact number of people living with HIV/AIDS, people newly infected, and deaths due to AIDS. This is the case for several reasons: the data cannot be obtained from direct counts since most people do not know their status, stigma surrounding HIV disease often leads to denial and underreporting, and the current reach of HIV testing services throughout the world is still relatively low. Thus, for example, the number of AIDS cases officially registered by a country will always be less than the actual size of the HIV-infected population. Despite these challenges, methods have been developed and refined over time to produce reasonable estimates at the country, regional, and global levels. These efforts are led by UNAIDS, which has a technical advisory group to help develop estimates and regularly consults with countries.

The source of HIV/AIDS data used to develop estimates depends on the level or type of HIV/AIDS epidemic within a country:

- In countries with **generalized epidemics** (countries where HIV prevalence among the general adult population is at least 1%), estimates are primarily based on blood samples from pregnant women in antenatal clinics. Surveillance of pregnant women in antenatal clinics often provide the best available data upon which to base estimates of HIV prevalence in the general population, in countries with generalized epidemics, although adjustments have to be made for doing so. Where available, population-based surveys are also used to enhance these estimates, but conducting population-based surveys is generally not feasible, at least not on a regular basis.
- In countries with **concentrated epidemics** (prevalence in the general population is less than 1% but some groups at high risk have prevalence greater than 5%), estimates are based on studies of populations at higher risk of exposure—injecting drug users, sex workers and men who have sex with men.

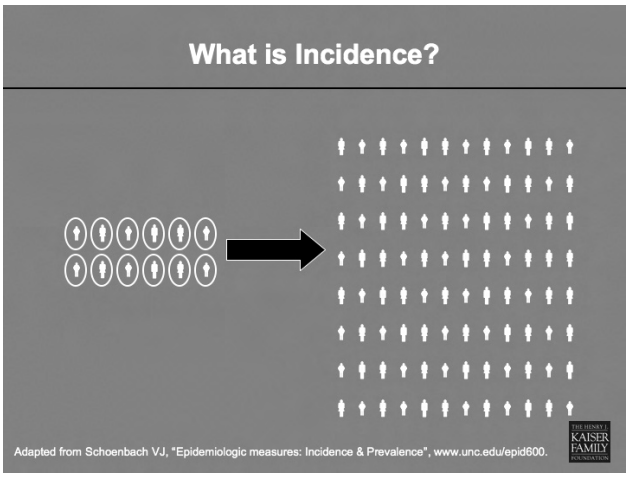
What are Key Data Issues to Consider?

Among the many issues to think about as you get ready to report on HIV/AIDS using data are the following:

- There are many sources and types of data, each telling a different story about the epidemic
- HIV/AIDS surveillance methods evolve over time, so data from the same source may not be directly comparable year to year
- The type of data available, and the lag-time in availability, may pose challenges to assessing recent impact
- There are gaps in the data
- Epidemiological measures of HIV/AIDS are numerous and each has important and distinct definitions
- Much of the data you may use are estimates only. For example, HIV incidence (new infections) is an estimate. This is true globally and in all countries, even the United States, due to the lag-time between HIV infection and the development of AIDS, the fact that many do not know their status, stigma which leads to underreporting, and surveillance systems that may not be complete
- Pay attention to ranges given around any estimate, as well as any notes that may accompany data, since these may provide important information that can help in your interpretation
- Rates/percents, not just numbers, are important—rates are standardized measures, allowing for comparison of impact or concentration of HIV/AIDS across different population groups, time periods and areas
- The story is often local and complex, so global, regional, and country averages may mask localized epidemics and trends including the impact on marginalized populations

Remember to:

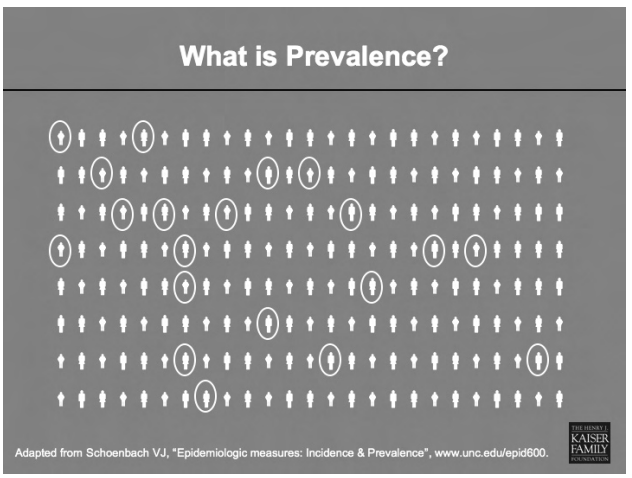
- Consult multiple types of data, compare and contrast
- Consult UNAIDS and www.globalhealthfacts.org for the latest global and country-level data
- Consult regional organizations and/or country ministries of health for surveillance reports as they may have country-specific or local data
- Indicate which type of data is being used (e.g., prevalence, incidence, rates, HIV infections or AIDS cases)
- Be clear about whether data are estimates, actual reports, representative or just a small sample from an individual study



INCIDENCE: The number of new events (e.g., of a disease or condition) occurring in a given population during a particular point in time. In this example, there are 12 people newly infected with HIV who are moving into the population. The incidence of new events, or new infections = 12.

What does it tell us: The most recent occurrence of a disease or condition; how many are newly infected with HIV.

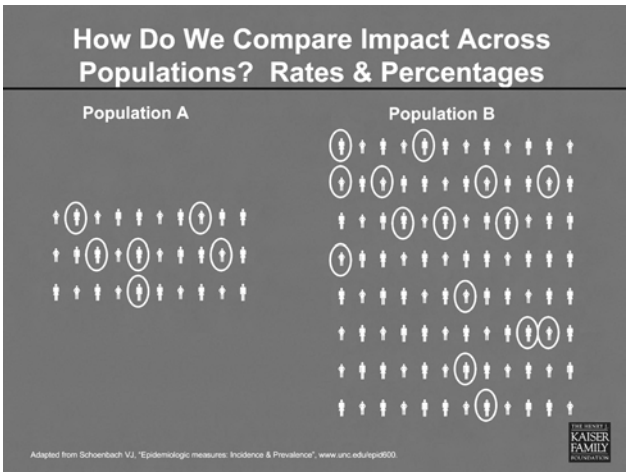
Qualification: For a disease like HIV, it is very difficult to know this number since many people do not know their HIV status and standard HIV tests used to diagnose HIV infection cannot detect when someone became infected. Therefore, HIV incidence is usually estimated. You may sometimes see "new HIV diagnosis". This is not necessarily the same thing as a new infection since people may be diagnosed with HIV at different times after they are infected, including several years after.



PREVALENCE: The number of events (e.g., of a disease or condition) in a given population at a particular point in time. In this example, there are 200 people and 20 of them have HIV. The prevalence = 20. Prevalence may also be expressed as a rate (or percent), which is the number of events (e.g., of a disease or condition) in a given population at a particular point in time divided by the population. In this example, the prevalence rate = 20/200 = 10%.

What does it tell us: The current burden of a disease in a population. It is a snapshot at a particular point in time. The prevalence rate is useful for comparing across populations or over time.

Qualification: It is important to remember that this does not tell us when someone became infected with the disease, just how many, or what share of a population has the disease at the specified time. Also, a high prevalence rate does not always signal a worsening epidemic. In fact, a high prevalence rate may occur even when incidence rates are low because people with HIV are living longer due to greater access to treatment.



RATES: In this example, there are two populations, A & B. Population A has 30 people and 6 are infected. Population B has 96 people and 15 are infected. In which population is the disease more highly concentrated? Answer: A

Population A: 6/30 = 20%
Population B: 15/96 = 15.6%

What does it tell us: A rate allows for comparison across populations or over time by standardizing for differences in population size. For example, in the case of Black Americans who make up only about 12% of the U.S. population, a rate can help us understand if HIV is more highly concentrated in this community compared to other groups.

Qualification: Whether or not you use a rate will somewhat depend on the question you are asking. If you want to know where the greatest number of people infected is located, a rate would probably not be the measure you are looking for. If, however, you want to compare across different countries or communities, or over time, a rate is very informative.

REFERENCES AND RESOURCES

UNAIDS. *HIV Data Page: Methods and assumptions for estimates* (2009), http://www.unaids.org/en/KnowledgeCentre/HIVData/Methodology/

UNAIDS. *Understanding the latest estimates of the 2007 AIDS Epidemic Update,* November 2007, http://data.unaids.org/ pub/EPISlides/2007/071118_qa_methodology_backgrounder_en.pdf

UNAIDS. *2008 Report on the global AIDS epidemic,* July 2008, http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/

Kaiser Family Foundation. *Global Health Fact*s website, www.globalhealthfacts.org