

HIV/AIDS REPORTING BASICS:

Who, What, When, Where, Why and How

This essay was written by Renata Simone, who began reporting on HIV/AIDS in 1985. Most recently she served as producer, reporter and writer on the award-winning documentary “The Age of AIDS.”

“The Age of AIDS” was produced in 2006 by Frontline for the Public Broadcasting Service in the United States. We are grateful to Frontline for allowing us to publish this essay, which was written as part of a reporting guide for public television reporters in the U.S.; more information can be found at www.pbs.org/wgbh/pages/frontline/aids/.

AIDS IS DIFFERENT FROM OTHER STORIES

Think of the major interdisciplinary, complex stories of our time; stories that are worldwide, ongoing and urgent. Perhaps you think of climate change, famine or nuclear proliferation. None of these is like the HIV/AIDS pandemic.

AIDS is a story of great breadth and sharp contrasts; covering it requires knowledge and sensitivity around personal issues such as sexuality, addiction and social vulnerability. At the same time, it is a global story requiring a broad understanding of international politics, economics and diverse cultural traditions. Interwoven with these strands of the AIDS story are the scientific, medical and healthcare stories, which you as a reporter must be able to “translate” for the general public. That’s what makes it complicated.

Our reporting is crucial. Ever since the first cases of a mysterious, new disease were noticed by doctors in 1981, public awareness and education has been a crucial part of the battle against the spread of HIV and its effects. As journalists, we have an opportunity—and a responsibility—to provide the public with clear, accurate, respectful reporting on the pandemic and the larger social forces that drive it forward. In the absence of a cure or preventive vaccine, information is still one of the best weapons available. With the numbers of people infected rising each day, the need today for thorough, ethical reporting is more urgent than ever.

Of course HIV/AIDS is similar to many stories but none brings so many disparate parts together. As reporters, we find ourselves challenged by the subject and inspired by the people we meet along the way. If inspiration wins, our coverage will be there for the long-term, to help our readers, listeners and viewers fight the spread of the virus.

■ Avoid Stigma and Respect Confidentiality

Unfortunately, in many communities the response to HIV is stigma and discrimination. And for too many, the cost of that stigma is literally life-threatening.

In such situations, people who are HIV-positive are unlikely to speak to you unless you assure them of confidentiality. It would be best to discuss what confidentiality means with your interview subject, as you may have very different ideas about what it is.

You may have to explain the difference between “on background and not for attribution,” “deep background” and “for guidance” on the other.

In extreme situations, he or she may expect you to keep confidential the fact that you spoke with them at all (“off the record”). Talk with your interviewee. Again, the consequences of a breach of confidentiality could be personally disastrous for your interviewee and may jeopardize your future access to that person and those around him or her.

If you plan to take photographs, film, video or plan to use your interviewees’ likenesses in any way, you must secure their permission. Make sure he or she understands where and how your work is distributed. Think of it as your responsibility to secure informed consent from your interview subjects.

Remember, many individuals at risk of HIV are women and children living in poverty; they are among the world's most vulnerable populations. It is essential that all AIDS journalism is sensitive to the circumstances of people's lives and to the impact of our reporting on our subjects.

■ **Achieving Fairness and "Balance" When Myths Are Rampant**

In the early years of the epidemic, myths were widely circulated and in some cases, the media helped spread misinformation. Because some of these early myths persist, our reporting must continuously reinforce the basic facts. For example, HIV cannot be spread by mosquitoes, through donating blood or casual social contact.

One of the most damaging and persistent myths is, "HIV does not cause AIDS". This is incorrect; HIV does cause AIDS. Despite overwhelming scientific evidence, a few "denialist" scientists question this fact, claiming a legitimate controversy exists. But this is an example of a myth masquerading as a discussion and unless handled with careful skepticism, can be very misleading.

Some journalists and editors feel obligated to cover both sides of a controversy. However, our job as journalists is to be fair and accurate. Our job is not to give equal time to all who have opinions, but to weigh the evidence based on the facts and to report the truth in our best judgment.

■ **Use Language Responsibly**

In general it is essential to exercise caution with your words. We know that scientific language is difficult to follow and can be easily misunderstood. We are prepared to insure the accuracy and clarity of our statements.

But in AIDS reporting there is an additional burden on our language. We must avoid stereotypes. Regardless of how someone encountered the virus, he or she is an individual. The words we use to characterize social and personal information can have strongly negative connotations.

Many HIV/AIDS education and service groups have created reference lists of words and phrases for reporters. We urge you to consult them before you begin. The experts, activists and positive people you approach will discern the depth of your understanding not from your questions but from the language you use to express them.

REPORTING ON HIV/AIDS USING THE SIX BASIC QUESTIONS OF JOURNALISM

Since the subject of AIDS is so complex, one way to start is to go back to basics; to look at HIV/AIDS through the lens of the first questions we are taught to ask as reporters, "Who? What? When? Where? Why? and How?"

THE FIRST QUESTION: Who?

Who Should I Think About When I Start an AIDS Story?

The short answer is "everyone." The virus does not discriminate. Since HIV/AIDS affects people from all socioeconomic groups and countries, "Who?" can be anyone. Increasingly, the most vulnerable people are young women. The best source of current global epidemiological data is the UNAIDS website (www.unaids.org).

As you begin reporting, you might want to contact grassroots organizations, and the health care workers they recommend. Many of these groups are listed on the Age of AIDS website (www.pbs.org/wgbh/pages/frontline/aids) and in this reporting manual.

Then as you move forward with your reporting, you'll need to speak directly with people involved in the epidemic. Some of those interviewees will be HIV-positive. Here are a few of the most important ideas to consider as you move forward:

■ **Your Relationship to Your Interviewees**

Aside from the importance of confidentiality and sensitivity as mentioned earlier, your relationship with your interviewee will be shaped by several other factors.

In order to establish and maintain a good reporting relationship the first rule is to do your homework. Your goal is to establish trust between you and your interviewees. In covering AIDS, you will interview people in many roles; from people with AIDS and the loved ones around them, to political leaders and community activists, caregivers and medical researchers. No matter whom you interview, you will have to earn his or her trust by showing your seriousness, professionalism, and respect.

■ **Your Editor: The Story Pitch – “Why Should I Care?”**

When there is breaking news, your pitch to your editor is clear. But if not, the question you'll have to answer is “Why should I care?” There could be as many answers to that question as stories about AIDS, but for discussion, we can identify three reasons to urge your editor to support your coverage of AIDS:

A commonly heard response from editors is, “This isn't a problem for my readers/audience.” But that is not true.

First, HIV/AIDS is a problem, visible or not, in your community. Your media outlet has a chance to be part of the solution. AIDS is a preventable pandemic and information is key to prevention.

Second, HIV/AIDS is costing your community scarce financial resources for treatment and care, while education and prevention are far less expensive.

Third, you might remind your editor that AIDS affects young people more dramatically than other groups, which is the very audience most media organizations want to capture.

Another reason to cover HIV/AIDS is pure human interest. This seemingly sad subject takes us to inspirational stories of friends and families triumphing over the worst times of their lives, of heroes, of ordinary people doing extraordinary things.

When preparing to talk with your editor you may find it useful to think of story angles beyond the health beat. For example; this is a story about religion and the role of churches; it includes topics of immigration and the workplace; basic needs such as water and food; pharmaceutical industry prices and patents; sporting events and sport celebrities; tourism; entertainment and the arts including street theater. Think laterally across disciplines and find the “pitch” that will interest him or her.

THE SECOND QUESTION: What?

What Are the Stories?

Most people think first of HIV/AIDS as a health story, but there are myriad AIDS stories embedded in specific reporting beats outside health and medicine. HIV/AIDS is a story that can be told from the perspective of business, international news and analysis, politics, law, the arts, and culture.

Here's one way to think of the range of stories about HIV/AIDS.

■ **Reporting on the Three Main Strands of the AIDS Story: Science, Society, People**

The broad tapestry of the global AIDS story is woven from many separate threads. But we can conceptualize three main strands to help organize our thoughts, our research and our reporting.

The first strand is Science. This includes medicine, research and health care. The second strand, Society, encompasses economics, cultural norms and traditions, law, politics and government and other institutions of education and social welfare.

The third strand, People, is perhaps the most important. The experiences and insights of individuals help ground your reporting and make the issues and information relevant to your readers or viewers. Part of our task is to locate the human story within the abstract ideas and crises of HIV/AIDS. One of our challenges is to imagine specific stories about people that serve to illuminate issues around economics, science, geopolitics, law.

■ **Integrating the Layers of the Story**

In the real world, science, society and the experiences of people influence each other. For example, the debate over manufacturing generic drugs for HIV involves medicine, science, economics, politics and people. Each influences the other in ways that we can describe in our reporting. The interconnections make the story interesting and sometimes surprising.

■ **The Local and Global Stories Complement Each Other**

In covering HIV/AIDS you will notice how the local and global stories reflect each other. When you're working on a local story, you can enrich your reporting with information about the same issue on the national or international level.

The reverse is true too. When you're covering a global issue, such as the high cost of treatment for HIV/AIDS, a local story can provide just the right illustration. Reporting on someone local who is struggling to pay for drugs, can lead your readers or viewers to a deeper understanding of the issue at the global level.

Other examples of local/global stories are: the role of local medical researchers and/or doctors, who set examples for care that serve as models around the world; the link between academic or medical institutions here and abroad; and the role of local churches in supporting programs, people and villages overseas.

THE THIRD QUESTION: When?

When Should We Report on HIV/AIDS?

■ **Pegging the Story to Recurring Events**

You might consider proposing and writing or producing pieces around the milestone years in the epidemic, or the yearly events around HIV/AIDS. A few of those annual events include World AIDS Day – December 1st, and in the U.S., National HIV Testing Day – June 27th, National Black HIV Awareness Day – February 7th. Aside from these national and international days of observance, there may be local milestones or events that you might use as pegs for your reporting.

■ **Timely News and Information**

Every ongoing story has occasional news hooks, which provide clear rationales for your reporting. Stay apprised of upcoming developments by staying in touch with your sources and monitoring primary research documents. Your primary research should include the major peer-reviewed scientific journals and online proceedings from medical and social science meetings.

■ **Ongoing Reporting: AIDS is Not Over**

Between the moments of news, there are long stretches when HIV and AIDS disappear from the public spotlight. But of course the epidemic continues. Complacency is very dangerous as it can lead to a false sense of security among people at risk, who may then place themselves at even greater risk.

At times when there is no news, you might suggest a straightforward prevention piece – What are the HIV/AIDS prevention programs in your area that have proven most effective? In the U.S.? In the world?

Or you might propose an investigative piece – How many people with AIDS are on waiting lists for treatment? Where are the funds earmarked for HIV/AIDS being spent and is the spending cost-effective?

Other story angles you might consider are: talking with your parents or with your children about HIV; living with HIV/AIDS and the drug regimen; taking an HIV test—what is involved, what are the costs; pre-and post counseling programs in HIV testing sites, what advice and support should be provided.

THE FOURTH QUESTION: Where?

Where Are the Stories?

The short answer, you can guess, is “Everywhere.” According to genetic studies published in the Spring of 2006, HIV emerged in southeast Cameroon between 1920 and 1935. Since then, as transportation and globalization served as “vectors” for the virus, HIV and its subtypes have been carried to every continent on earth.

Often, people are unaware of how HIV is spreading. Migration of people from place to place for work continues to play a central role in the pandemic. You might consider an investigative piece following major transport roads and routes.

As discussed earlier, finding stories may be made more difficult by the heightened issues of confidentiality and trust. But if your approach is informed and respectful, contacting your local AIDS service providers and activist groups should provide a good start.

Wherever you search for stories, on the local or global level, don’t forget to keep your curiosity alive and stay curious and open to surprises. Not only will your work be more alive, but someone seeking to prove a preconceived idea or story is not a journalist but an essayist or polemicist.

THE FIFTH QUESTION: Why?

Why Report on HIV/AIDS?

■ **Preventable Suffering**

Unfortunately, we all know or have experienced times of unpreventable suffering. But HIV and AIDS are preventable. By helping increase awareness of HIV, how it is transmitted and how to avoid it, your reporting will be part of the solution. Your work will help prevent some of the needless suffering of people at risk of HIV, their families and loved ones, and their communities.

■ **The Information Imperative**

AIDS awareness is not a one-time goal. This is true for every demographic target audience, particularly for young people. Every day, new teens and young adults are coming of age and may find themselves unknowingly at risk for HIV. So the need for reporting on basic information is constant and ongoing.

■ **The High Cost of HIV/AIDS**

Medical care and treatment of people with HIV disease is highly costly in terms of finances and human resources. Who pays for AIDS in your city or community? Are the expenditures cost-effective?

And HIV disease strikes young people in the prime of their working lives. Part of the cost of AIDS is the loss of the professional contributions of so many to the societies in which they lived.

THE SIXTH QUESTION: How?**How Can the Lessons Learned During the History of HIV/AIDS Inform Our Reporting?**

Since 1981 when the first cases were diagnosed, experts have fought many battles on all fronts and learned three broad lessons. As journalists, we can use these lessons to locate stories, and then to make our reporting better.

■ **Positive Leadership is Crucial**

How we shape our coverage can be informed by the lessons of the past. We can see clearly in the history of AIDS, in country after country around the world, that the key to the course of the epidemic is the actions, or inaction of leaders.

For example in the United States in the early 1980's and South Africa in the early 1990's, the nations' top leaders did not take aggressive action against the epidemic, and the virus spread at alarming rates. In contrast, leaders in Thailand and Uganda took aggressive action early in their countries' epidemics and were able to lower transmission rates significantly. And the recent rise in cases in Thailand and Uganda further illustrates the importance of positive leadership.

Focusing on leadership is a powerful tool in illuminating the story. Leaders in Brazil, for example, set global precedents in the fight for cheaper drugs and in the assertive prevention programs the country has in place. How and why were they able to achieve these goals is a riveting narrative about leaders who listened to their constituents and acted decisively.

Bear in mind non-governmental leaders also have a role to play. Throughout the decades of the battle against AIDS, many of the true leaders have been ordinary people who found themselves in terrible circumstances but summoned the strength to survive and the courage to lead.

■ **Denial, Stigma and Discrimination Are the Virus' Best Friends**

The long history of HIV/AIDS has shown that all around the world, when the social environment around HIV is filled with denial and silence, stigma, discrimination and fear, people at risk of HIV are not likely to get tested. If someone knows he or she is HIV-positive, they are likely to keep it hidden. This creates a tremendous risk to others.

If your reporting provides your audience with accurate, clear and thorough information about the virus and its transmission, it will help allay the fears that lead to stigma and discrimination and have a true positive impact.

■ **Prevention Works**

The transmission of HIV can be prevented by not having sex, not using contaminated syringes and not getting transfusions of tainted blood or blood products. Experts have pointed out these absolute measures work for some, but not all people at risk.

Failing total abstinence, definitive scientific studies have shown that the risk of transmission can be greatly lessened by other preventive measures such as using condoms, clean syringes and screened blood products. Other successful prevention strategies include reducing other STDs, TB and malaria. Recently, studies have demonstrated the effectiveness of male circumcision in reducing transmission.

These measures of prevention and "harm reduction" continue to be politically charged and need to be reported clearly and factually. Since medical science has not yet created a cure or a vaccine for HIV disease, the best weapon is prevention.

LAST BUT NOT LEAST – THE QUESTION PEOPLE ASK REPORTERS: Isn't Covering AIDS Depressing?

In many ways, AIDS is a sad story. Many lives have been lost and more are still at risk. There are unjust inequities and impossible choices.

But ultimately, AIDS is an inspirational story. Throughout the epidemic, there have been heroes whose actions made a difference in the lives around them. As journalists, we have the privilege and responsibility of meeting and giving voice to these people.

AIDS is not the kind of story you can “parachute” into. As one of the most complex problems humanity has ever faced, it is worth specializing to ensure you gain a deep and thorough understanding of the subject. AIDS crosses disciplines—from molecular virology, epidemiology and economics, to politics, sociology and psychology. The pandemic also crosses all geographic and socioeconomic boundaries, affecting rich and poor in developing and developed countries alike. So covering it takes time and understanding.

Another reason to specialize in AIDS reporting is the professional and personal rewards.

Our reporting does have a positive impact. Reporting on AIDS informs and inspires our readers, listeners and viewers to make positive choices in their own lives and to contribute to the ongoing battle against AIDS.

But perhaps most importantly, the people we meet along the way—from health care workers and political leaders to outreach workers, people with HIV and their loved ones—provide us and our audiences with long lasting inspiration and a deep sense of hope.

The opinions expressed here are those of the author's alone.

ADDITIONAL RESOURCES

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

UNAIDS. *Terminology Guidelines*, http://data.unaids.org/pub/Manual/2007/20070328_unaids_terminology_guide_en.pdf

Pan American Health Organization. *HIV-related Language: PAHO 2006 Update*, <http://www.ops-oms.org/English/AD/FCH/AI/HIVLANGUAGE.PDF>

ETHICS GUIDELINES

This material was developed for and endorsed by the Southern Africa Editors' Forum; more information can be found at www.journaids.org/docs/SAEF_ethical_principles.pdf. We are grateful for permission to reprint this material.

HIV and AIDS is a story of critical importance that should be covered by journalists with imagination, initiative and sensitivity to gender and the larger social forces driving the epidemic.

The story requires reporting of the highest ethical standards. The Southern African Editors' Forum (SAEF) and the Media Institute of Southern Africa (MISA) endorsed these principles to provide guidance to media councils, training institutions and media companies, as well as individual editors and journalists. The principles are not cast in stone but should be revised over time and in response to the unfolding epidemic.

- Accuracy is critical, since important personal and policy decisions may be influenced by media reports. Journalists should be particularly careful to get scientific and statistical information right. Facts should be painstakingly checked, using credible sources to interpret information, verify facts and make statistics and science accessible and relevant to wide audiences. Sources should be named as often as possible. Stories should be written in context.
- Misconceptions should be debunked, and any claims of cures or treatments should be reported with due care. Journalists should look at all stories critically.
- Clarity means being prepared to discuss sex, cultural practices and other sensitive issues respectfully but openly. Care should be taken to ensure language, cultural norms and traditional practices relating to, for example, inheritance and sex are understood and accurately reported taking into account universal human rights.
- Balance means giving due weight to the story, and covering all aspects, including medical, social, political, economic and other issues. Balance also means highlighting positive stories where appropriate, without underplaying the fact that HIV and AIDS is a serious crisis.
- Journalists should hold all decision-makers to account in their handling of the pandemic, from government to the pharmaceutical industry and advocacy groups. They should be engaged with, but not captive to, any interest group.
- Journalists should ensure that the voices and images of people living with and affected by HIV and AIDS are heard and seen. The human face of the pandemic should be shown. They should take care that the voices heard are diverse, and include those of women and men, vulnerable and marginalized people.
- Journalists should respect the rights of people with HIV and AIDS. Vulnerable people should be treated with particular care. Journalists should seek informed consent before intruding on anyone's privacy. They should seek to understand the possible consequences for individuals who participate in their report, and to ensure those individuals are clear about the consequences. Only in cases of overwhelming public interest can somebody's HIV status be reported against their wishes or should journalists hide their professional identity.
- Journalists should be aware of and seek out the gender dimensions of all aspects of the pandemic, from prevention to treatment and care, as this will add to the depth and context, as well as reveal new areas for reporting.

- Particular care should be taken in dealing with children. They experience the most extreme consequences of the epidemic, and their rights to privacy should be afforded even greater protection. They should only be identified if the public interest is overwhelming, and then only if no harm to them is foreseeable and they and any parents or guardians have given informed consent. Children have the right to participate in decisions affecting their lives. They also have the right to be heard, and journalists should ensure that the particular concerns they face are covered.
- Discrimination, prejudice and stigma are very harmful, and journalists should avoid fuelling them. Particular care should be taken not to use language, or images, that reinforce stereotypes.

ADDITIONAL RESOURCES

The Kaiser Family Foundation's *Global Health Reporting* website (www.globalhealthreporting.org/reportingmanuals) provides links to many reporting manuals which include ethics guidelines.

FREQUENTLY ASKED QUESTIONS ABOUT COVERING HIV/AIDS

Is there really a difference between reporting that someone has AIDS or is HIV-positive?

Yes, there can be a difference. HIV-positive means someone is infected with HIV, the virus that causes AIDS, but it does not necessarily mean they have progressed to an AIDS diagnosis. It is possible an HIV-positive person will not be showing any symptoms. Someone who has an AIDS diagnosis has a severely weakened immune system and typically does show symptoms. Depending on your story, it may be important to be clear about this distinction.

Who do I turn to for the most reliable numbers related to the epidemic?

There is a great deal of confusion, and sometimes controversy, about HIV/AIDS statistics. It can be difficult to find and interpret statistics, since there are so many challenges to conducting disease surveillance. One reason for that is most people with HIV do not know they are infected. Before using any statistics, be absolutely certain you understand what they mean, who collected them, how they were collected and over what period of time. If you find numbers that contradict each other, go back to your sources and ask them to explain the contradiction. UNAIDS is the best place to start for obtaining global and country-level HIV/AIDS data. You may also want to check directly with your country's health agency. There is more information on this in *Understanding and Reporting on HIV/AIDS Data*, and an explanation about how UNAIDS develops HIV/AIDS estimates at www.kff.org/hivaids/7742.cfm.

How important is confidentiality in reporting on HIV/AIDS?

The identity of a person with HIV/AIDS should not be disclosed without the explicit permission of that person. In many countries a person publicly identified as being HIV-positive or as having AIDS will be shunned and stigmatized and may even face violence—in the home, the community and at work. If a person agrees to be identified, it is a reporter's responsibility to make sure he or she understands the potential consequences of that decision. There is more information on this in *HIV/AIDS Reporting Basics* and *Ethics Guidelines*.

What are the common stereotypes that slip into HIV/AIDS reporting?

People with HIV/AIDS are a diverse population and your reporting should reflect that. The goal, of course, is to be objective and factual. Stay away from making value judgments and from reinforcing the stigma that many people with HIV already face. A common stereotype involves what types of people become infected including the common confusion between "risk group" and "risk behavior"—that is, assuming someone who is in a certain group engages in risky behavior. For example, many men who have sex with men practice safer sex and have a single partner. So, they are not at a significantly greater risk than the general population.

What words do I want to be cautious about using in the context of HIV/AIDS?

It is important to not use words that incorrectly stereotype or stigmatize people with HIV, perpetuate myths about the disease or carry value judgments. Two useful guides on suggested language are: http://data.unaids.org/pub/MediaAdvisory/2007/20070328_unaids_terminology_guide_en.pdf and <http://www.ops-oms.org/English/AD/FCH/AI/HIVLANGUAGE.PDF>

Do not use terminology that general audiences cannot easily understand. This is especially important when reporting on medical stories. The goal is to be precise without being so dense your audience will not understand what you are reporting.

What are the pitfalls when reporting on treatments for HIV/AIDS?

HIV/AIDS treatment is a complex area and there are many different treatments available for HIV/AIDS—some treat the virus itself, others treat the symptoms and illnesses caused by the virus. However, none is a cure for HIV or AIDS. It is important to be clear about the distinction between a treatment that may cure or prevent an illness *related* to HIV infection with a cure for HIV (or AIDS) *itself*. It also is important not to describe drugs used to slow the growth of the virus as cures. Again, there is no cure for HIV.

Is it accurate to say that someone died of AIDS?

AIDS is a syndrome that can be defined by any number of diseases and cancers. There is no singular disease that is called AIDS. When someone who had been diagnosed with AIDS does die, it is technically more accurate to report that he or she died of an AIDS-related illness, of HIV-related causes or due to HIV disease.

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. 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 injection 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—injection drug users, sex workers and men who have sex with men.

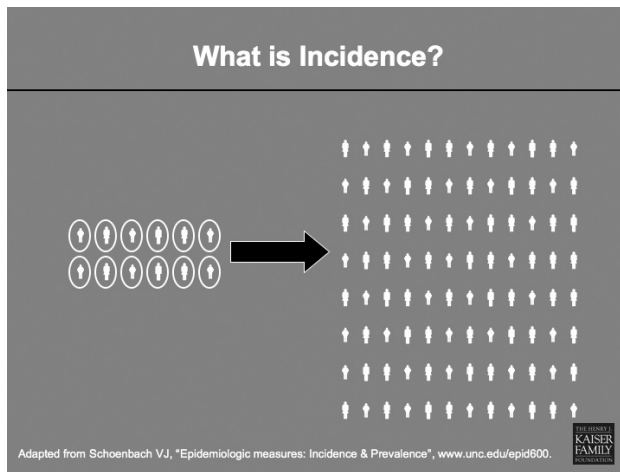
What are Key Data Issues to Consider?

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:

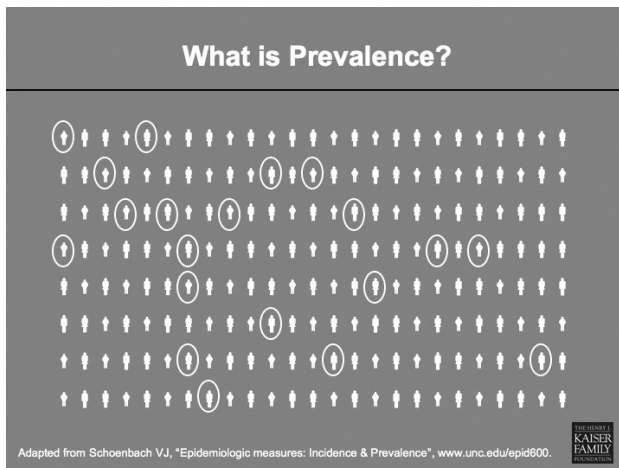
- Consult multiple types of data, compare and contrast
- Consult UNAIDS and www.globalhealthfacts.org for the latest global and country-level data
- Consult regional organizations and/or country ministries of health for surveillance reports as they may have country-specific or local data
- Indicate which 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.

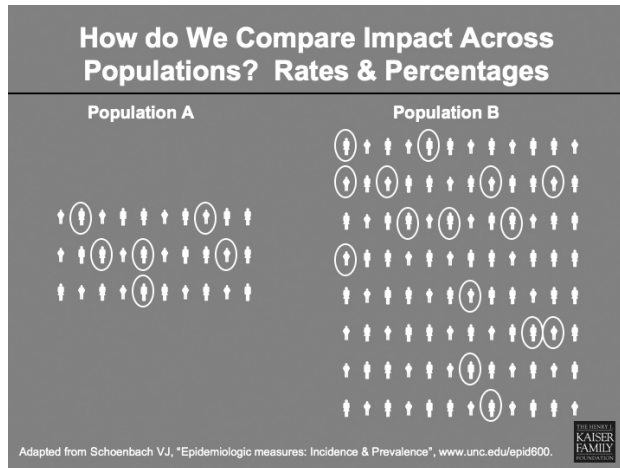
Qualification: For a disease like HIV, it is very difficult to know this number since many people do not know their HIV status and standard HIV tests used to diagnose HIV infection cannot detect when someone became infected. Therefore, HIV incidence is usually estimated. You may sometimes see "new HIV 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.



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

$$\text{Population A: } 6/30 = 20\%$$

$$\text{Population B: } 15/96 = 15.6\%$$

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* (2007), http://www.unaids.org/en/HIV_data/Methodology/default.asp

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. *Global Summary of the AIDS Epidemic*, December 2007, http://data.unaids.org/pub/EPISlides/2007/071118_epicore2007_slides_en.pdf

Kaiser Family Foundation. *Understanding the New UNAIDS Estimates*, <http://www.kff.org/hivaids/7742.cfm>

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

HIV/AIDS INFORMATION ON THE INTERNET:

How to Search and What to Look for

This information, on searching for and evaluating online information, was developed by SciDev.Net. The full multimedia training kit can be found at www.itrainonline.org/itrainonline/mmtk/mmtk_hiv aids_resources_handout.doc. We are grateful for permission to reprint this material.

Searching for HIV/AIDS information will result in different types of information, resources and links depending on whether you are using a general search engine such as Google, or searching a specialized HIV/AIDS site or database aimed at health care professionals.

- General search engine results for a search on, for example, mother-to-child transmission of HIV will yield a wide range of types of resources—ranging from news reports, to community health guides, statistical information and information aimed at medical researchers. You may get good information, bad information, and information which is not relevant to your needs.
- A search on an organization’s website may bring up information produced mainly by that organization.
- A search on a specialized portal will produce results relating to the portal’s particular focus area.

Evaluating HIV/AIDS (or any health-related) information is critically important. The specific evaluation criteria you should apply will depend in some measure on the type of information and what you intend to use it for. Unless you are writing an article on fraudulent HIV/AIDS “cures,” the quality of the information is the central evaluation criterion. Depending on the way in which you intend to use the information you might want to add additional criteria—for example, if you are looking for a good site to recommend to a grassroots organization you would also want to check that the site is easy to use and the resources targeted at an appropriate level. Key issues are:

- **Information quality:** the most important aspect of information quality is accuracy. Sometimes you will be able to assess the accuracy of the information on a website directly yourself. Very often, though, you won’t have the specialized knowledge needed to do so. In this case, you will need to ask a number of questions to help you assess the *likely* accuracy of the information. These questions include:
 - What is the source of the information, and how reliable is it likely to be? Does the provider of the information perhaps have a vested interest in promoting a particular point of view? Look for:
 - A “mission statement” or other information about the organization which maintains the site.
 - Information about individual authors.
 - Sponsorship of the site.
 - Has the information been through an editorial review process? For example, is it in a peer-reviewed journal?
 - How current is the information?
 - How comprehensive is the information?
 - Is the information based on clinical and scientific evidence?
 - Be wary of content which goes against widely held scientific beliefs without proper discussion. This could be an indication that the information is not based on scientific research.
 - When information relates to clinical trials, remember that randomized clinical trials are generally accepted as being the most reliable, followed by other study methods such as non-randomized trials and case/cohort studies.
 - Are adequate references provided, indicating the source of the information, including statistics?

Local, National and International Organizations

There is a vast range of websites produced by local, regional and international organizations around the world involved in HIV/AIDS research, treatment and care. These may be government or non-government-based organizations, who receive private and/or public funding. Websites vary in their content and resources, according to the time, money and expertise invested in production of the website and the intended users.

Information and resources on these sites generally fall into one of these categories:

- Community and media guides
- Reports
- Policy documents
- Background information (fact sheets and glossaries)
- Contact information for expert advice
- Directories
- Searchable databases
- Projects
- Funding for HIV/AIDS-related projects
- Links
- E-mail alerts