

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 directed, produced and wrote "ENDGAME: AIDS in Black America." Prior to this film, she served as producer, reporter and writer on the award-winning documentary series, "The Age of AIDS." Both films were produced for the FRONTLINE series, the flagship current affairs series shown on PBS. "The Age of AIDS" is streamed, at www.pbs.org/wgbh/pages/frontline/aids/. We are grateful to FRONTLINE for allowing us to publish this essay.

As the AIDS epidemic enters its fourth decade, reporting on the story has become a greater challenge than ever. Today, more than 34 million people live with HIV/AIDS around the world, 1.1 million people in the U.S. alone. At the same time, the success of treatment in prolonging the lives of people infected with HIV, means our editors, readers and audiences think the emergency is over—no story. Not true. The story has changed, but it is no less urgent.

There have always been what many call, "two worlds of AIDS"—those who have access to good prevention, care and treatment and those who do not. That divide persists but now the stakes are higher, because if you get the drugs, you are likely to live relatively well, for a long time. If you do not, you are at a high risk for fatal illness. Around the world, many of the most vulnerable people remain without access to prevention, care and treatment.

Similarly, stigma has become an even greater problem. According to the U.S. Centers for Disease Control and Prevention (CDC) stigma has become a major contributor to the spread of HIV. Stigma keeps people from seeking information, speaking openly, using protection and getting tested. The CDC estimates one in five of those who is positive in the U.S. does not know it. If someone does not know they are infected, they will not seek treatment or take other crucial actions to protect themselves and may expose others to the risk of transmission of the virus. The situation is urgent.

The other change is a dangerous spread of complacency among people who are at risk for HIV. In the U.S., recently, there have been shocking increases in some groups of people at risk for HIV exposure. The attitude we often hear expressed is that HIV infection is "No big deal. It's like diabetes." But it is not. The complex balance of drugs that controls HIV is not like insulin. The virus can and does outsmart the medicines and the drug regimens can have terrible side effects.

These are just a few developments in the complex global story of HIV/AIDS. As we go forward, our reporting follows these and other new dimensions of the story—but as always, it rests on the solid basics in this essay.

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 have 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 a myriad of 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 HIV's 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 authors alone.

ADDITIONAL RESOURCES

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

UNAIDS. Terminology Guidelines, www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118_terminology-guidelines_en.pdf

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