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## **Kaiser Family Foundation Tutorial Understanding Data July 21, 2008**

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**JEN KATES:** Statistics are really tricky and a lot of the mistakes or challenges that reporters come into or face when they are reporting on HIV are very common for anything where you are talking about Epi data and data in general. But, there are some specific ones related to HIV. What I see is that, the most common things, reporters really confuse the data that they are trying to talk about.

**RENATA SIMONE:** They are all estimates. The numbers we see on UNAIDS and the other, very reliable sites are extrapolations from small samplings of data and so they are estimates. And over the last 25 years, we have seen the estimates go up, then we see them go down, then we see oops, we overestimated by several million or perhaps we underestimate. So, bearing in mind always that it is an estimate is a good idea.

**BRENDA WILSON:** It is one of those things of which statistic do you choose to use, do you use the one that is most dramatic because you could say that the overall rate of infection in South Africa is around 10-percent. If you look only at women who are child-bearing age, you would say 20-percent.

Now, I am sure most reports, what we generally do, is go for the 20-percent figure because we figure it is more representative, it gets people's attention more and

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epidemiologist do believe it is representative of a really serious situation, what is going on the country and the lower number can be misleading. So, it is a question of what is most representative, what gives you a clearer picture of what actually is going on.

**RENATA SIMONE:** Check hard, as hard as we can. We do our own math in some cases. We call the National Councils on AIDS in different countries. We try to triangulate the numbers and see if they make sense. If the numbers look too fuzzy, we do not report them. We say figures are not reliable, but something like that.

And the other thing we do is we make our research transparent. If you can find good numbers that you triangulate that you source three times and you are comfortable. But, if not, what we found useful is to say this is what this agency says, this is what we hear from these people, on the ground, the people at the AIDS service organization told us a different story. Just be completely transparent.

**JEN KATES:** In a news report, I think the basic data that a reporter should understand and be able to talk about with all of the right qualifications that you can do in a short story and I recognize that there are limitations, are incidents and prevalence. And those are two terms that you might not see in a story, but are really important for

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reports to understand before they go reporting.

**CZERNE REID:** One thing that happened relatively recently was when I got some data from the health department and I was playing around with it in Excel and trying to do some graphs. Then I got a second data set and I noticed that some of the numbers were off. So, I contacted the analyst at the department and realized that there were numbers under cumulative cases of HIV.

I did not even think about it, but I was reading cumulative to mean prevalence. So, that is something that you have to pay attention if it says incidents or if it says prevalence or if it says cumulative because cumulative of course, includes people who are dead. Whereas, prevalence is just people who are still living with the disease and incidents is people who are newly diagnosed in a given period. So, I think just paying attention to the headings on those tables when you are looking at the data is very important.

**JEN KATES:** HIV incidents, for example, is the number of new infections that are occurring. So, if we want to know the most recent trends, how many new infections were there in a country, that is incidents? On this graphic here, there is a visual depiction of this and it shows on the left side of it, people that are infected. The circles there are supposed to symbolize people who have HIV.

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And on the right side, is the population that is not infected. As those people move in, let us say this is in a one year period that is incidents. Those are the people that are newly infected. So, this is trying to show that that group of new people are the newly infected people.

Prevalence, the number of people with the disease, tells us what the current burden is in a place. What this graphic shows for prevalence is a population and within that population, you see circles around some of the people. That is the number of people with the disease at a given point in time. That is your prevalence.

**JOHN DONNELLY:** Incidents is going to be more important to understand and that is because there are new models being developed that will try to measure who are the last thousand people who were infected with the disease. What is the incidence rate in the population? So, more and more reporters are going to be hearing these different terms, incidence and prevalence.

And the thing to look out for, it will be very important in terms of how different prevention techniques are working, is to understand incidents, to ask questions about incidents. Who is infected in the last six months? What is the incidents rate? And that way you can measure whether these efforts to prevent the spread of the disease are working.

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The prevalence is a general way of looking at it that does not really tell you too much about whether prevention techniques are working.

**JEN KATES:** The best thing to do when you are going to report on an HIV story and you need to use data, is to go to an official source like a Health Department. If it is global data, UNAIDS or WHO. If it is country-specific data, those sources as well as potentially the country that you are talking about, to start there. It does not mean you would end there, but to start there.

Because the official data, even if they are estimates, even if they have some limitations, they have at least been vetted and they have also been looked at from a comparative sense. So, when you are talking about one country and you want to look at two countries or three countries, if you go to that official larger source, it is more secure in your comparisons.

**CZERNE REID:** I found the Health Department to be a good source of information and another thing too is, if they are not short-staffed and they have people who have the time to help you, they can help you get lots of raw data, rather than just looking for reports that are done in a preset manner. They can give you raw data that you can then play around with the way you want.

So, if you want to calculate proportions of women

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verses men or Blacks verses Whites or any kind of thing that you want to do yourself that is not necessarily required for a report they are sending to the CDC, then if they give you the raw set of data then you can play around with that. And I find the people at my Health Department are willing to help me with that.

**JACKIE JUDD:** And you have to seek that out, you have to ask for that?

**CZERNE REID:** Right, right. And it comes with building a relationship. And this is what I have found; I did not necessarily set out to build a relationship with people in the community. But, in showing up to the different places and writing the stories then everyone started paying attention to the work I was doing and then people would recognize my name. They would not necessarily know me.

But then I would go to the Health Department and I would ask for something and they would know my name and so people would be willing. And they do not always have time, but when they do have time, they are generally willing to help me.

**RENATA SIMONE:** Think about what the numbers mean and what they are saying. Sometimes the numbers themselves are not as important as what does it say about the situation. So, what is the context of, what does the number mean in the context of that community or that family or that specific

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story that you are trying to tell?

**JEN KATES:** It is a very complicated territory and reporters need to know that that is just a common thing, it is not about their reporting. It really is complex even for people working in it day-to-day and that is why we at Kaiser, as well as other organizations, are there to try to help walk people through.

I think the biggest thing is if you do not understand something, chances are it is because it is complicated, so find someone who can help but do not just report on it because it probably is complicated and nuanced and it is important to understand that.

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