Better Data On HIV Sought As Naming Debate Lingers

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In late 1997, HIV/AIDS activists killed a state proposal to collect the names of everyone in Connecticut with the human immunodeficiency virus. The idea is still controversial today, but even opponents agree now that Connecticut needs better information on the spread of HIV.

“There is a consensus in the community that we need better data,” said Laurie Sylla, executive director of the Hartford-based HIV Action Initiative. She has been talking quietly to HIV/AIDS organizations around the state in recent months in an effort to find out how they think the state should collect additional data.

Here’s the problem: HIV is becoming invisible in Connecticut. It may be on the rise, but no one really knows. The numbers are spotty and unreliable, and they say little about who might be swept up in a new wave of infection.

In the years before effective HIV treatment, infection led to AIDS and to death in a way that was statistically predictable. With the advent of highly effective HIV drugs in the mid-1990s, many of the people infected have been able to stay healthy. The number of reported AIDS cases in Connecticut dropped from 1,197 in 1997 to 608 last year. It’s no longer possible to infer HIV infection rates from reported AIDS cases.

Connecticut is one of a handful of states that do not have a system for comprehensively reporting adult HIV cases. Newborns are screened for HIV exposure during pregnancy or at birth. In addition, pediatric HIV cases - in children under 13 - are reported to the state Department of Public Health. These numbers are small. Last year, only two HIV cases in children were reported - both in newborns. HIV infection in people with tuberculosis is reported (47 cases between 1996 and 1999).

In addition, medical labs have been required for the past two years to alert the state to any positive HIV tests - without names. Last year, 1,054 positive tests were reported. In addition, 233 positive test results were reported from public clinics.

But lab results often don't have personal data, such as age, gender, race and town of residence, so these figures are incomplete. There is no way to screen out duplicate tests.
The result is a mix of figures that tell little about infection trends.

**Knowing Where To Aim**

Naturally, it's difficult to target prevention and treatment when you don't know where to aim. What's more, millions in federal funds for HIV/AIDS prevention and treatment in Connecticut are at stake. The state is receiving $19.3 million this year, of which $12.8 million is for treatment. Within five to seven years, the federal government plans to directly link its allocations to states for treatment to the number of residents infected with HIV. States with bad HIV figures are going to lose out.

“There is a lot of energy being put out by [the Centers for Disease Control and Prevention] and others to identify the real numbers in each state, because they have a limited amount of funding and they want to know where they are going to put that funding,” said Dr. Joxel Garcia, the state’s commissioner of public health.

In addition, other health priorities are competing for state money, so it's important to have a good grip on HIV in Connecticut, Garcia said. He wants to decide by June how to proceed.

The simple answer is to make HIV a "reportable" infection, creating a confidential list of people who test positive - as is done with many other illnesses. But when the previous health commissioner floated such a proposal in 1997, the HIV/AIDS community lobbied passionately against it. A compromise resulted in the current patchwork.

The proposal on names reporting fell flat because people with HIV fear being stigmatized. Activists worried that such a fear would keep many HIV-positive individuals away from testing and treatment. Some still believe names reporting won't fly here - although 33 other states collect names and other personal information on HIV-infected residents.

Luz Gonzalez, executive director of Hispanos Unidos, a New Haven HIV/AIDS organization, said she believes that the state needs better HIV information, but that names reporting isn't a good idea.

“This is scary for some people, especially if you're living longer and trying to work and have insurance,” she said.

"Look at the people getting infected," she added, referring to the growing proportion of AIDS cases among Latinos and African Americans. "They've been discriminated against all along."

Ruth Rodriguez of Hartford, who is HIV-positive and has had full-blown AIDS, said that she's not against names reporting but that people getting tested must be given the option to remain anonymous. "Everyone has the right to choose whether they want their name on a piece of paper," she said.

One alternative to names reporting is called "unique identifier" reporting. Instead of taking names, the state would take personal data useful for tracking HIV, but use a code or unique identifier instead of name. Six states and Puerto Rico use this system, and Maine and Washington use a system in which names are converted to unique identifiers over time,
so the states don't end up with a huge storehouse of names. But the CDC is not convinced that these alternatives prevent duplication and is still studying their effectiveness.

'A Twisted System'

As Connecticut weighs its choices, a larger question remains: How good are any of them at predicting the direction of the epidemic, or at making it possible to create programs to prevent new infection? A September report from the Institute of Medicine concluded that the current surveillance systems are flawed.

"What you have with HIV reporting is sort of a twisted system," said Edward Kaplan of Yale University, who was on the IOM panel that produced the report on HIV prevention. "You learn about infections as people test for them, not as they happen," he said, noting that people tend to get tested when they feel sick. Kaplan is a professor of management sciences at the Yale School of Management, a professor of public health at the Yale School of Medicine and director of the law, policy and ethics core of the Center for Interdisciplinary Research on AIDS.

Kaplan and his colleagues on the IOM panel suggested a different approach involving random, anonymous blood tests performed at high-risk sites, such as drug treatment centers. Community surveys would have to be done to make it possible to extrapolate the results of such tests to specific risk groups - injection drug users, for example - and to the general population. A newly developed follow-up test, called a "detuned assay," would make it possible to find out which infections happened in the previous four to six months. This would give researchers a sense of who is being infected - and where.

Some local activists hope that this kind of population research could make HIV reporting obsolete, but the CDC, whose opinion may be paramount, has its doubts. Dr. Robert Janssen, director of the CDC's division of HIV/AIDS prevention, surveillance and epidemiology, said names reporting is most likely to provide the best foundation for good state and national data. The blind surveys would be used to track HIV among people who aren't getting tested. The CDC also favors giving everyone the option of remaining anonymous.

Kaplan said it's possible to track the HIV trend without names reporting, but it's also hard to provide treatment and other services to those who test positive unless there are names. If people are being linked to care, they may be more willing to accept names reporting, he said. Activists have asked the same question: What's in it for us?

"If you say, 'We want better data,' what are you going to do with it?" said Sylla. "What kind of commitment of resources is going to go along with this? State funding for prevention has not increased in seven years. Are you going to increase it?"

Garcia said he is not proposing any new money for HIV/AIDS services in the state, in part because the poor data on HIV makes it hard to justify. Services for HIV/AIDS make up one of his department's largest programs, accounting for nearly 16 percent of the annual budget. But the number of AIDS cases has been cut in half in the last four years.
He said that in conversations with community groups, he's found that the attitude toward names reporting has shifted. The state has been found to be trustworthy with personal information in reporting other diseases, and the experiences of other states that conduct names reporting has been good. He said, however, that he's keeping an open mind and that his conversations with advocacy organizations have been cordial.

"I have not met one person so far that has come here in an adversarial way," he said.