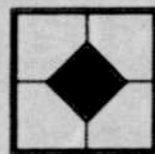


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NATIONAL news

THE NAME GAME

Controversy continues to bubble over HIV names reporting,
but the boiling point is yet to be reached by Bob Roehr

Mandatory names reporting is bad science, bad public health policy and a waste of funds that should be directed to real AIDS prevention and health care," argues Catherine Hanssens, an attorney with the Lambda Legal Defense and Education Fund, which opposes policies that call for the names of people with HIV to be reported to government health departments.

Hanssens isn't alone in her opposition.

"By requiring me to report the names of those who test positive, the government drives a wedge between me and my patients. This is dangerous public health policy," charges Dr. Robert Cohen, the former vice president of the New York City Health and Hospitals Corporation.

Meanwhile Steve Morin, director of the AIDS Policy Research Center at the University

of California at San Francisco, opposes names reporting "because there is significant evidence of a deterrent effect" on people getting tested for HIV, he says.

The effect is minimal for heterosexuals, he adds, and very high for gay men. "It is more of a psychological issue, they don't want their name on a government list," he concludes.

Many AIDS advocates agree the current reporting system, based upon an AIDS-defining illness, is of little value in an era of combination therapy that keeps many people from becoming sick. Many believe that a system recording incidence of HIV infection is needed to better understand the changing demographic nature of the epidemic in order to guide prevention and service delivery.

The sharpest disagreement comes over the way those records should be gathered. One faction supports use of a coded system known as "unique identifiers." They say the data collected will be just as good, individual privacy will be better protected, and as a result, people will be less fearful of getting tested.

The national Centers for Disease Control and Prevention studied the unique-identifier systems in use in Texas and Maryland and concluded there are operational and structural flaws that compromise the data gathered. Texas is moving to a names-reporting system.

Furthermore, a unique-identifier system is more costly to implement, and there is conflicting evidence regarding the long-term effect of names reporting on whether people get tested.

In October 1997, CDC officials told *The New York Times* the agency had no immediate plans to require states and cities that receive its funding to keep records on individuals who test positive for HIV. However, they did not rule out the possibility that the CDC would eventually institute such requirements.

The CDC has already invited public comment on a draft proposal that promotes the idea of mandatory names reporting. (It is believed that the agency, which funds most AIDS sur-

veillance efforts, will begin to include names reporting as a condition of receiving federal funds. The belief was fueled several months ago when the CDC asked state health officials across the country how and when they intended to implement HIV names reporting.)

Meanwhile, the comment period for the draft is winding down, thus prompting the issue to heat up once again.

Lambda Legal Defense and Education Fund circulated a letter of opposition to the CDC position; it was signed by supporters of Lambda's stance and released to the press Feb. 21.

The letter says the CDC "has trivialized the serious concerns raised by community members regarding the harmful impact of names reporting on populations disproportionately affected by the epidemic."

The epicenter of opposition is New York.

Last year the state Legislature enacted a law requiring names reporting. It was supposed to be implemented on Jan. 1 but was pushed back to April 1.

"It is turning out to be more complicated and more expensive than the proponents indicated," says Morin. "Where will the money come from? Will they eliminate prevention in order to record names?"

Some AIDS heavyweights are backing Lambda. The

list includes Gay Men's Health Crisis in New York, AIDS Project Los Angeles, the San Francisco AIDS Foundation, the AIDS Action Committee of Massachusetts, and the national AIDS Action Council.

But at least as interesting are the names that are not on the list. They include large service providers such as the Whitman-Walker Clinic in Washington, D.C., and the National Association of People with AIDS.

Also missing from the list are organizations in states that already have adopted names reporting as their standard. Those states—almost 30 in all—are home to about a third of the nation's people with HIV and AIDS.

It isn't so much that people are embracing the CDC position, but they see the spirited opposition to names reporting as a distraction from more important concerns, says Alexander Robinson, who has served as an AIDS lobbyist for the American Civil Liberties Union. "It is somewhat disingenuous to argue that somehow HIV names reporting is going to be more intrusive" than existing programs, he adds.

Robinson says lower-income people "give up all sorts of information in order to have access to entitlement programs. They are more concerned about whether there is going to be something available in terms of care than whether or not you are going to take their name."

He notes the limitations of either reporting system, saying they record only those who show up to be tested.

"The real effort should be put into making sure that individuals know their status," Robinson says.



PHOTO BY BOB ROEHR
HIV/AIDS activist Alexander Robinson