Naming Names

Will the squabble over HIV reporting tear us apart?

March 1, 1999 By Annette Fuentes

Eric Sawyer is fond of recalling one of ACT UP's first public actions back in June 1987, at the Gay Pride march in New York City. Activists set up a mock concentration camp on the back of a flatbed truck and hoisted signs reading "Test blood, not people." The message was directed at conservatives who were calling for testing and detention of people with HIV. "With all the draconian policies being discussed, it was only natural that people fought a policy that might lead to quarantine," says Sawyer, a founder of both ACT UP/New York and the HIV/AIDS Human Rights Project.

Today, ACT UP no longer opposes HIV testing and even encourages people to learn their status, a position that—with the advent of new HIV drugs—virtually all AIDS organizations now share. But the controversy over HIV testing hasn't disappeared. It has morphed into a different, more complicated debate over whether positive HIV test results should be reported to public health agencies and how such reporting should be done. Schisms over HIV surveillance aren't the first fault lines to divide AIDS advocates. But they've erupted in the past year as conservative politicians flex their muscles in state legislatures with increasingly punitive approaches to HIV prevention.

As 1999 began, 30 states had laws requiring that positive HIV tests be reported by name to public health departments, and 11 of those eliminated their anonymous testing sites. New York's law, passed in 1998, is one of the most far-reaching; it even includes a partner notification provision. Three states require reporting by a confidential system of codes, and three other states, including California, introduced HIV reporting bills in the 1998 legislative session that did not become law.

At the federal level, the Centers for Disease Control and Prevention (CDC) has, for the first time, put its imprimatur on a names-reporting system, releasing proposed guidelines in December that triggered a furious response by opponents. The Coburn-Ackerman bill in Congress, called the Partner Notification Act, would make names reporting the law of the land without addressing access to health care.

Since the early 1980s, all states have required reporting of diagnosed AIDS cases by name. In recent years, though, epidemiologists have put the emphasis on tracking HIV infection because such data offers a more accurate picture of tomorrow's epidemic. Most AIDS advocates oppose

names reporting as a violation of privacy that will only deter risk groups from seeking tests and treatment, and instead back an alphanumerical unique identifier (UI) code to protect an individual's identity. Others question the need for any widespread surveillance system without a commitment of more targeted resources for prevention and treatment. A tiny minority supports names reporting of HIV prevalence as the best way to collect data on the epidemic's growth.

Advances in medical understanding and treatment of HIV explain in part the evolution in advocates' thinking on tracking HIV. "In the beginning, GMHC [Gay Men's Health Crisis] did not support HIV testing primarily because there wasn't anything to do with the information except drive yourself crazy," says Ron Johnson, GMHC's policy director. "But as treatments became more effective and prevalent, there was a medical reason for individuals to know their status." Passage of the Federal Americans with Disabilities Act and its protections for people with AIDS also influenced advocates. "It makes many of us more comfortable with surveillance of any kind," says Daniel Zingale, executive director of AIDS Action in Washington, DC.

But there is a gap the size of the Grand Canyon between a policy of encouraging HIV testing in the interests of early treatment and a policy that supports HIV test surveillance by public health officials. In the last two years, major AIDS advocacy organizations—including GMHC and AIDS Action—have crossed that divide. In the case of GMHC, the leap to a policy supporting HIV test reporting was more Evel Knievel–style crash than graceful jeté. In reversing its opposition to test reporting last year, GMHC clearly said it supported unique identifiers but failed to explicitly oppose names reporting. Many took the omission as tacit support for the controversial policy usually associated with right-wing politicians, not AIDS activists. After a *New York Times* article drew attention to its position, GMHC quickly backpedaled, reasserting the agency's opposition to names reporting. But the damage was done.

"If you believe what [GMHC] said after their public relations fumble, regardless of whether it was backtracking or just poor handling of an important public policy announcement, the fact is it happened," Sawyer says. "GMHC went out on a limb before anyone else went public with their position, wanting to be seen as number one. Some people were put on the spot and forced to take a position by this almost-names-reporting stance." When journalists called him for comment, Sawyer said he didn't support any reporting—but he remembers feeling pressured to take a stand on unique identifiers.

GMHC's public statement set new parameters for the debate on HIV surveillance, especially in the agency's base of New York City, where unique identifiers—rather than zero surveillance—quickly became the progressive alternative to reporting names. In fact, many advocates say they believe GMHC helped to pass Assemblymember Nettie Mayersohn's names-reporting bill in July by suddenly making the unthinkable a possibility, and by choosing not to aggressively fight the bill. But there is still an alternative approach, says Catherine Hanssens of Lambda Legal Defense and Education Fund, and that's to make use of other kinds of data, such as blinded seroprevalence studies. "I disagree with the notion that at this stage we have to cut our losses and take one position or the other," she says. "We do not support surveillance through unique identifiers because there is no evidence to say it will accomplish the goals offered in its support. Information

on the incidence of HIV could be incredibly useful, but it is incorrect to suggest that we don't have enough data right now to make targeted allocation of funds for prevention."

Last fall in California, a bill to establish a unique identifier system highlighted the splits over HIV reporting: While some AIDS activists championed its passage as a progressive achievement, hardliners applauded when then Gov. Pete Wilson, a Republican, vetoed the bill. Proponents of the measure expect newly elected Democratic Gov. Gray Davis to support it in round two this year. "We lobbied heavily for the bill," says Regina Aragon, public policy director for the San Francisco AIDS Foundation. "It would be helpful in our state to have better data [to target resources], and a UI system will get us good data without the risks to people's privacy." Aragon says that though the science to date is equivocal on whether names-reporting systems discourage people from testing for HIV, "we believe high-risk groups will be deterred."

Studies exist to both support and refute this deterrent effect. In the October 28, 1998, issue of the *Journal of the American Medical Association*, two studies of HIV testing systems offered very different findings. One asserted that anonymous testing was tied more closely to earlier diagnosis and treatment for HIV than confidential testing, which requires individuals' names. The other study, by the CDC, found that the number of HIV tests did not decrease in six states after names-reporting systems were enacted. But the CDC study has been criticized as having a flawed design and predictable conclusions—and a survey released December 23 by the same agency showed that 35 percent of gay men in names-reporting states had avoided getting tested because of privacy concerns. Activists across the country say the CDC has been lobbying service providers to support names-based surveillance, sometimes using not-so-subtle threats to link funding to that position. Perhaps the most powerful incentive for AIDS agencies to back HIV reporting is the carrot of more federal dollars for counting high infection rates, not just AIDS cases.

"The CDC came up here and said openly that Congress was clamping down and told us, 'You ought to support names reporting,'" says Jeffrey Reynolds, policy director of the Long Island Association for AIDS Care and a member of the New York State AIDS Advisory Council. "I said, 'How much would you give us for a unique identifier system?' and they said, 'Nothing.'" AIDS service providers, including GMHC, are scrambling for funding as private sources dry up, making them especially vulnerable to the CDC's brand of arm-twisting, advocates say. "The CDC has been threatening to base federal funding on HIV-reporting figures," Hanssens says. "Many [AIDS agencies] are doing a good job, and continuing to do that work is contingent on getting Ryan White money. So they think, 'If we don't support names reporting, we won't get the money.'"

One of the few prominent AIDS advocates to publicly support names reporting is Michael Isbell, a member of GMHC's board and of the Presidential Advisory Panel on HIV/AIDS. Isbell notes that as an attorney at Lambda in the 1980s, he was a vociferous opponent of names-based reporting. But today, he believes that as long as anonymous testing sites are maintained, names reporting is a useful tool for tracking the epidemic, just as it is for tuberculosis and syphilis. "If the motto in the '80s was 'Silence = Death,' now the motto seems to be 'Ignorance = Bliss,'" Isbell says. "Our message still places too much emphasis on the risk of HIV tests. The opposition to a more standard HIV surveillance system is part of an anachronistic approach to the disease."

Some advocates see such an about-face on names reporting as further evidence that the changing demographics of the AIDS epidemic are triggering profound political realignments. Now, as HIV makes inroads among communities of African Americans, Latinos and youths, the rules of engagement are being rewritten.

“When the epidemic was prevalent in the gay male community, Mike Isbell was opposed to names reporting,” says Dennis deLeon, executive director of the Latino Commission on AIDS in New York City. “Now that the epidemic has moved into the black and Latino community, he’s for it. It’s an example of someone else’s ox being gored.” DeLeon and many frontline service providers predict that under New York’s new law, people will test later for HIV and infection will increase.

The splits over HIV reporting policies won’t be mended so easily, and there are more contentious battles ahead. Laws to criminalize HIV transmission, for example, may be introduced in various state legislatures, including New York, in the coming year. “I think activists are less united than ever before,” says Reynolds, who sits on the state’s AIDS Advisory Council. “There’s a need for the AIDS community to go on a mountain somewhere and figure out where the hell we’ve gone wrong. We’ve gotten so caught up in medical advances, we’ve kind of lost the focus that HIV is far more than a medical issue.”

© 2026 Smart + Strong All Rights Reserved.

http://beta.docker.poz.com/article/Naming-Names-7736-2223