

WHAT'S IN A NAME?

Oregon health officials want to hear from the public about a topic that has sparked great debate nationwide by Inga Sorensen

It's a hot button issue that keeps resurfacing. Should the names—as well as ages, genders, races, risk behaviors and areas of residence—of all people who test positive for HIV be reported to state and county health departments?

Or should health officials implement a unique-identifier system, which utilizes a code of numbers and letters instead of the names to track the spread of HIV?

Fueled by a push from the federal Centers for Disease Control and Prevention, the Oregon Health Division is pondering expanding its disease-reporting system, and is seeking input via a series of community meetings throughout the state.

Currently each state must report AIDS cases. Traditionally, many states, including Oregon, have refrained from widespread reporting efforts for people with HIV.

However, in the fall of 1997, the CDC requested that all states and territories conduct HIV tracking as part of their AIDS surveillance programs. (Twenty-nine states currently require the reporting of all HIV cases as well as AIDS cases.)

Many agree the advent of more promising treatments for HIV disease makes it imperative to track HIV infections more effectively and link people with HIV to appropriate care.

They note that because fewer people are progressing to AIDS, AIDS data is no longer an accurate gauge of HIV prevalence.

In the October 1997 issue of *The New England Journal of Medicine*, Dr. John W. Ward, chief of the CDC's HIV/AIDS surveillance branch, wrote: "Without revisions in surveillance systems, health authorities will not have reliable information about the prevalence, incidence, and future directions of HIV infection, the kinds of behavior that currently increase the risk of HIV transmission, or the heightened impact on specific subpopulations, such as racial and ethnic minorities and women."

The major point of controversy is how to track HIV—through names reporting or unique identifiers?

Many advocacy groups favor unique identifiers instead of names reporting. They say such a system would preserve confidentiality and provide better epidemiological data by encouraging testing and minimizing duplicate names.

Names reporting proponents, meanwhile, say that particular system would paint a more accurate portrait of HIV's reach, as well as provide an opportunity to get more people who test positive the care they need via follow-up services, which could include education, treatment and partner notification.

But opponents outline myriad concerns about names reporting.

The American Civil Liberties Union has published a document titled *HIV Surveillance and Name Reporting: A Public Health Case for Protecting Civil Liberties*, which argues such a plan would undermine both public health and civil liberties.

The report concludes that HIV names reporting would discourage a significant portion of the public from being tested, thereby hampering HIV tracking efforts.

The ACLU says it recognizes that the emergence of promising new medical treatments and improved legal protections have shifted the focus of epidemiological surveillance to the "front end" of the AIDS epidemic—HIV infec-

tion—and that the benefits of early medical intervention, which didn't exist just years earlier, have placed greater emphasis on learning the HIV status of people.

The group also notes that proponents of names reporting argue the Americans with Disabilities Act has strengthened the legal protections for people with HIV, easing concerns that names reporting will expose individuals to discrimination by employers, insurance companies or government agencies.

The ACLU says that while these developments may warrant better HIV tracking, they do not justify names reporting.

According to one of the nine comprehensive studies cited in the ACLU's report, more than 60 percent of individuals tested anonymously would not have tested if their names were reported to public health officials. The group says similar conclusions were reached by the other studies, strongly suggesting names report-

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ing would obstruct efforts by public health officials to track HIV cases.

The ACLU's report also found legal protection against HIV discrimination to be far from secure, despite the ADA.

The Gay and Lesbian Medical Association, a San Francisco-based national medical organization with 2,000 members, has come out strongly against HIV names reporting.

And the Human Rights Campaign, the nation's largest lesbian and gay political organization, has said the need for an expanded HIV surveillance system must be fully explained and justified. The campaign is calling on the CDC to demonstrate that the benefits of expanded surveillance will outweigh the costs both in terms of resources and increased risk of confidentiality breaches.

Even if confidentiality is guaranteed under names reporting, some say the perception alone of a possible slip is enough to deter people from getting tested.

Critics say some people within ethnic minor-

ity populations are already distrustful of bureaucratic institutions or harbor strong fears of ostracism within their own communities.

Others say immigrants and undocumented workers may also balk at getting tested or seeking treatment for fear of deportation.

There are many populations greatly impacted by HIV and AIDS—notably, minorities and drug users—who are distrustful of the public health system, says longtime consumer advocate Jack Cox, who tested positive for HIV more than a dozen years ago.

Had names reporting been the order of the day back then, Cox says, he probably would not have sought testing. It was, he recalls, a time when the gay community held such distrust toward public institutions.

In 1994, Cox organized the HIV Advisory Council of Oregon and Southwest Washington, which works to improve HIV/AIDS services and give voice to consumers.

Though he's stepping back from HIV-related work, he remains outspoken on the issue of names reporting.

"I think there is a need for expanded reporting," he tells *Just Out*. "But I believe unique identifiers is the way to go."

Cox says he believes input from supporters of the unique-identifiers system at the public forums could be effective.

"I think we can influence the direction of this," he says.

Tom Eversole, HIV/STD/TB program manager for OHD, says at this juncture his agency has no specific proposal on the table.

"We want to hear the concerns and values of the people of Oregon before we come out with a proposal," he says, adding that the public meetings, which have been organized by the Council of Local Health Officials HIV Committee, should provide important insight.

Currently in Oregon, people can be tested for HIV without giving their names. And they can be tested confidentially, meaning their names are protected under state law.

For more than a decade, those who have tested positive for HIV have been anonymously reported to OHD. Anonymous testing has been available since

1986, and Eversole stresses anonymous testing will always be an option.

Currently, labs and health care providers confidentially report symptomatic HIV-positive people by name to local health departments and OHD.

Oregon already has limited names reporting for HIV-positive people with special circumstances, as well as pediatric reporting.

■ The PUBLIC MEETINGS, held from 6 to 9 p.m., are slated for April 20 at the Rogue River City Council, 133 Broadway in Rogue River; April 21 at Lutheran Inner-City Ministries, 4219 N.E. Martin Luther King Jr. Blvd. in Portland; April 22 at the Linn County Fairgrounds, 3700 Knox Butte Road in Albany; and April 27 at the Petersen Barn and Community Center, 870 Berntzen Road in Eugene.

Other meetings are in the works. For more information, call the toll-free expanded-reporting comment line at 1-800-777-2437.

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