

On hold

Plans to institute HIV names reporting in Oregon have met with a few snags

by Inga Sorensen

Oregon health officials have scrapped a plan, at least temporarily, to require the names of people who test positive for HIV to be reported to the Oregon Health Division and county health departments.

"Let's say the proposal is on the shelf for an undetermined period of time," says Steve Modesitt, manager of OHD's HIV surveillance section.

He cites pending personnel shifts at OHD and some negative community feedback on the plan as reasons for the decision.

Modesitt, along with Dr. Anthony Marfin, the state's HIV/STD medical epidemiologist, had publicly touted the proposal, speculating it would have painted a more accurate portrait of the disease's reach and provided an opportunity to get needed care to more people who test positive.

The plan generated heated opposition from many community activists, AIDS service organizations and civil rights groups, though, all of whom expressed concerns about possible confidentiality breaches and increased discrimination.

To further complicate matters, since *Just Out* first reported on the plan on Nov. 21, Marfin has announced his intentions to leave OHD. A search is currently underway for his replacement.

"[Marfin] wrote the actual proposal and he's since decided he's leaving," says Modesitt, adding that the issue will likely be placed on hold for several months until someone new is installed in Marfin's place and "can lead the way on this."

OHD had initially hoped to have a county health endorsed proposal by January, and wanted to see a plan implemented by April. Now that timeline is history.

"We still think names reporting is the way to go," says Modesitt, who nonetheless admits OHD's process in gathering community input and nurturing support was less than stellar.

"Maybe if we had talked with people earlier about why we needed this, it would have made a difference," he says. "This has been an educational process for us.... I think it's not a bad idea that we back off for a while and ask people what they want."

The issue exploded into the public consciousness back in October, following the publication of an article in the *New England Journal of Medicine* that proposed a national system of mandatory HIV names reporting. The piece was authored by Dr. John W. Ward, chief of the federal Centers for Disease Control and



Prevention's HIV/AIDS surveillance branch, along with Lawrence O. Gostin, a director of the Georgetown University-Johns Hopkins University Program on Law and Public Health, and A. Cornelius Baker, executive director of the National Association for People with AIDS, a leading constituency group based in Washington.

Each state must report AIDS cases. But until now, many states, including Oregon, have refrained from widespread reporting efforts for people with HIV.

The authors said in the article that the advent of more promising treatments for HIV disease makes it imperative to better track HIV infections and link people to care. They argued that because fewer people are progressing to AIDS, AIDS data is no longer an accurate gauge of HIV prevalence.

They wrote: "Unless we revise our surveillance system, 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. To correct these deficits, we propose all states require HIV case reporting."

The CDC reportedly planned to release recommendations early this year about whether the names of people with HIV should be reported to health departments.

The CDC can't force states and cities to comply with its recommendations, because it is not a regulatory agency. However, it provides funding for most AIDS surveillance efforts, and could

include such a requirement as a condition of receiving federal funds.

Before issuing its recommendations the CDC said it planned to study the effectiveness of unique identifier (also called coded identification) systems in two states, as well as examine public attitudes toward HIV testing in nine other states.

Many advocacy groups favor unique identifiers instead of names reporting. The former would assign a unique alphanumeric code at random to each person who gets tested for HIV. Proponents say such a system would preserve confidentiality and provide better epidemiological data by encouraging testing and minimizing duplicate names.

OHD, meanwhile, crafted its own proposal, which called for names reporting. Modesitt told *Just Out* in November that he thought creating a unique identifier system might prove administratively cumbersome and expensive.

For more than a decade, people in Oregon who have tested positive for HIV have been anonymously reported to OHD, although the state does require limited names reporting in special circumstances for those with HIV regardless of the disease's progression (the list includes convicted sex offenders and children younger than age 6).

The new plan would have exponentially expanded the scope of those required to be reported by name, and would have mandated that health providers report all newly diagnosed HIV-infected people as they do AIDS cases.

Under the proposal, counties were to use the

information to contact those with HIV to offer assistance in obtaining medical and social support.

Both in Oregon and nationally, opponents of names reporting voiced myriad concerns. For example, on the same day the *New England Journal of Medicine* article was released the American Civil Liberties Union issued a 22-page document entitled "HIV Surveillance and Name Reporting: A Public Health Case for Protecting Civil Liberties," which blasted HIV names reporting and argued that such a plan would undermine both public health and civil liberties.

The report concluded that HIV names reporting would discourage a significant portion of the public from being tested, thereby hampering HIV tracking. Additionally, the ACLU found that legal protection against HIV discrimination was far from secure, despite the passage a few years back of the federal Americans with Disabilities Act.

"In sum, the fears that drive people away from HIV testing with names reporting are not groundless. To eliminate them, we need more than education; we need solid anti-discrimination protection and real availability of treatment for the poor and uninsured," the report said.

Meanwhile the Human Rights Campaign, the nation's largest lesbian and gay political organization, called upon the CDC to fully explain and justify the need for an expanded HIV surveillance system.

It said confidentiality and privacy concerns were legitimate, and argued that the use of unique identifiers must be fully explored as an option. If names are to be used, HRC said, the CDC must demonstrate that they are an essential part of the surveillance system.

Some Oregonians echoed that sentiment, among them Susan Stoltenberg, executive director of Cascade AIDS Project.

She, along with a number of advocates for those with HIV and AIDS, said OHD provided no evidence that names reporting would lead to better data collection. Stoltenberg also criticized OHD for failing to solicit broad-based input from the public.

As for news that the state has tabled the plan, Stoltenberg says: "I guess I have mixed feelings. I would have liked for us all to continue to discuss the matter."

Despite that, Stoltenberg says a coalition of HIV/AIDS activists is forming and will continue, among other actions, to research issues related to names reporting and unique identifiers in order to be prepared when and if OHD's proposal eventually gets dusted off.

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