

HIV Reporting: Balancing Privacy and Public Benefit

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Reporting of HIV infection to public health authorities has been controversial since the beginning of the epidemic. Opponents of reporting fear that at-risk individuals' concern about how the data are to be used will prevent many from getting tested, and that this would hamper efforts to prevent the spread of the disease.

In Oregon in the 1980s, the balance between public health's need for these data and public concern about the possibility of their misuse resulted in a compromise. Rather than making HIV infection reportable, the state made AIDS, the potentially deadly result of HIV infection, reportable by name early in the epidemic. With information on AIDS cases, public health practitioners had some data with which to track the epidemic and plan for clinical services and prevention activities, while the larger pool of those with HIV infection short of AIDS would be protected from any possible risks of misuse of these data.

The case for HIV reporting

In recent years the case for named reporting of HIV infection has improved. Effective antiretroviral therapies make it possible for HIV-infected people to live longer, healthier lives and also decrease their infectiousness. Moreover, the epidemic is changing and moving into different demographic groups. If we allocate resources for prevention and treatment according to the profile of AIDS patients, we will be doing so on the basis of how the epidemic was transmitted several years ago when those patients got infected, rather than on the basis of how the epidemic is being transmitted today. Both of these factors strengthened the case for making HIV infection itself reportable.

In 1997 the Centers for Disease Control and Prevention (CDC) recommended that all states implement HIV reporting. Shortly afterward, Oregon's HIV program proposed that name-based HIV reporting be instituted. This was greeted with opposition by some members of Oregon's HIV advocacy community. In July 1998 the program created a task force made up of advocates, public health officials, community leaders, and medical providers to describe a set of values to form the basis for our HIV reporting methodology. Over the next year the task force elicited community input through eight "town hall" meetings, anonymous surveys, and a toll-free telephone line and identified three core values to guide the design of our HIV

reporting system: 1. anonymous testing must remain an option, 2. the confidentiality of individual reports must be protected, and 3. the system must result in improved access to HIV care and prevention services.

New reporting system developed

Based on these values, the HIV program drafted revisions to Oregon's Administrative Rules regarding the reporting of HIV infection. The revisions proposed a "name-to-code" reporting system. Reports would be submitted with names to local health departments. Public health staff would contact the reporting clinician, obtain any missing information on the reporting form, offer technical assistance regarding current treatment standards, and ensure that the patient was made aware of available contact tracing, insurance, and wrap-around services, as appropriate for their circumstances. Once this task was accomplished, the name would be stripped from the report and replaced with a unique identifier code created using a confidential algorithm. This code would enable epidemiologists to maintain an unduplicated database describing cases, but would ensure that individuals reported could not be identified. No "government database" that could identify HIV-infected individuals would be maintained, and both appropriate service provision and the data needs of the HIV program would be met. In addition to the name-to-code system, anonymous testing would continue to be available.

Although the program's original proposal for named reporting had been altered substantially based on the input from the task force, the proposed system underwent additional review, first by the Public Health Advisory Board, a Governor-appointed group of community advisors to the state public health agency, and then through four public hearings. Based on the results of these reviews, the health department administrator announced that the rule would be implemented in June 2001. Based on input from the reviews, however, he required that six benchmarks related to confidentiality and security be met before implementation. This process was overseen by another community advisory board to ensure the transparency of the process to the community. An independent consultant also conducted a series of focus groups and structured interviews to ensure that concerns of minority communities were well-

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represented in this process. The final rule change went into effect on October 1, 2001, almost four years after the initial announcement of the intent to change the reporting system by the health department.

Lessons learned

We have learned three important lessons from this process.

Maintain public trust. It is critical to take explicit steps to maintain public trust as controversial policies are developed. This trust is very fragile, and a few clumsy actions or comments can easily undo months of hard work. The community must be able to trust that its concerns have been fully solicited, heard, and addressed. The earlier this goal is achieved in the process, the better.

Engage all sides from the beginning. The community review process must be structured in such a way that all stakeholders are heard, not just those who are most vocal. One thing we discovered was that a large group in the community was amazed and concerned that Oregon had not implemented HIV reporting years ago. This group was intimidated by the vitriolic tone of the debate, and its views went largely unacknowledged until late in the process. This resulted in a very unbalanced picture of the community's opinion, with the self-reinforcing appearance that "everyone" was against changes in reporting. Articulate representatives on all sides of the debate should have been prominently included in the process from the beginning.

Ensure strong, consistent leadership. Health department leadership played an important role in standing by the HIV program through this process. Changes in agency leadership during this difficult process created doubts in the community

about whether the program would follow through on promises that had been made. We were able to overcome these doubts only because several agency leaders became highly engaged in this process and helped ensure continuity. It is critical that agency leadership be supportive of these kinds of policy changes in order to achieve an effective resolution.

Despite the difficulties encountered in developing the new system, we believe that the additional input gathered in the development process has made the system stronger and more acceptable to providers and the community. We have undertaken several new efforts to address the need for testing in minority communities as a result of input gathered in this process. Almost a year old, the new reporting system has been implemented smoothly, helping to ensure that HIV-infected Oregonians get the treatment and services they need without any breaches of confidentiality. Although a formal evaluation of the new system has not yet been completed, preliminary analyses suggest that, despite the dire predictions by opponents, testing rates have not declined. In fact, it appears that testing may even have increased in some demographic subgroups, perhaps as a result of the increased publicity about HIV testing created by the public debate. There also appear to be differences in the picture of the epidemic derived from the newly reported data, as compared to that derived from the old AIDS reporting data, which will help us better target our HIV prevention and care services. 🐾

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