

## **DHS Proposed Revisions to HIV Reporting Rules Related to Retention of Names and Expanded Laboratory Reporting — Fact Sheet and Frequently Asked Questions**

This change will assure that Oregon continues to receive its fair share of federal funding, improve disease tracking and prevention efforts, and help connect people to available services.

- 1) DHS is proposing revision to the state HIV reporting system that will retain the names of people with reported cases of HIV.
  - This would replace the current system that converts the names of patients with HIV to unique identifier codes. The name-to-code process has been in place since 2001, when mandatory reporting of HIV-infected individuals was implemented in Oregon.
  - Oregon stands to lose 30 to 40 percent—3 to 4 million dollars—of federal Ryan White Care HIV-prevention funds if it does not convert to a named reporting system by June of 2006. These funds provide lifesaving treatment and other services to people infected with HIV.
  - Oregon's future Ryan White Care funding will likely be based on the number of the state's HIV and AIDS cases officially counted by the federal Centers for Disease Control and Prevention (CDC). CDC will not count Oregon's HIV cases unless individual names are retained at the state level, to assure double counting of cases does not occur.
  - Although CDC requires that states collect names in order to ensure the quality of data, no names or other personal information will be shared with CDC.
  - This change does not affect HIV anonymous testing—that option will still be available throughout Oregon.

Revisions to HIV Reporting in Oregon

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- This change only affects people whose HIV infection has not yet progressed to AIDS. DHS already retains the names of people whose infection has progressed to AIDS.
  
  - There are other benefits of a system that retains the names of people with HIV:
    - Ability to gather more complete and accurate information on cases, which helps Oregon advocate effectively for its fair share of federal funding for HIV and AIDS care;
    - A more accurate, comprehensive and timely portrayal of the epidemic in Oregon that guides public health efforts to prevent new cases and identify those with the greatest need;
    - Reduced disease transmission through improved client access to available services and more timely partner counseling, testing and referral, if the patient desires;
    - Opportunities for confidential public health investigations when new or unusual disease transmission patterns emerge or variations in the HIV virus are suspected;
    - Accurate estimates of the number of people with HIV and AIDS who are getting regular medical care for their infection;
    - Ability to identify categories of HIV-infected people who may have limited health care access.
- 2) DHS also proposes expanding its laboratory reporting requirements to enhance prevention efforts.
- Currently, labs only report results of tests performed that define HIV infection or AIDS, such as evidence of severe immune deficiency or presence of the virus in the blood. The proposed expansion will require labs to report all of these tests, whether positive or negative.
  - Enhanced laboratory testing will help us better assist people who need more frequent health care. It will also provide information on testing

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patterns, which will help us more effectively ensure the availability of HIV testing in Oregon.

- 3) DHS will need to revise Oregon Administrative Rules (OAR 333-019-031) in order to convert to an HIV name-retention system.
- No change to Oregon statutes is required, nor is any change required for AIDS case reporting.

### **Potential questions:**

**Q:** What is the impact of losing \$3 to \$4 million—how many people does this affect and what does the money buy?

**A:** Oregon spends approximately \$8,500 per patient per year to support medical care and treatment for people with HIV and AIDS. Most of these funds are supported by the Ryan White CARE Act. Therefore, the loss of \$3–\$4 million means that 350–470 people would lose this assistance.

**Q:** When will the new system will go into affect?

**A:** After an initial period of discussion with health care providers, the HIV/AIDS community, community-based organizations, and public officials, administrative hearings will take place in March, and implementation will ensue in late March or early April.

**Q:** How will communities be informed about this proposed change?

**A:** During January and February, DHS will engage legislators, community representatives and community based organizations, local health departments, and medical providers in discussion about the changes necessary to avoid loss of federal funding.

**Q:** How will you guarantee that the names of HIV-positive cases are kept confidential under this proposed new system?

**A:** DHS has safely guarded the names of people with AIDS over its 20-year history of named reporting. We have had no breaches of confidentiality in the

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collection and retention of HIV (not having progressed to AIDS) case reports since mandatory reporting began in 2001.

The HIV and AIDS case reporting systems operate under particularly rigorous confidentiality standards:

- A limited number of public health personnel have access to HIV and AIDS data.
- Data are kept in a locked facility on a computer that cannot be linked to other computer networks.
- Removal of identifiable data from the facility is forbidden.
- Staff must review security procedures and sign strict confidentiality statements annually.

In addition, public health officials who improperly disclose the identity of any person with a reportable health condition, knowingly misuse confidential information or fail to adhere to established policies on information security of information are subject to criminal prosecution and fine. Furthermore, health care providers, health plans, billing companies and the people who work for them are subject to substantial fines and imprisonment for improper use or disclosure of identifiable health information under the Federal Health Insurance Portability and Accountability Act (HIPAA) of 1996.

**Q:** Are you concerned that this change may dampen people's willingness to go in for an HIV test?

**A:**

- For those who wish to be tested but might be dissuaded by fear of reporting, anonymous testing is available as an alternative to confidential testing by name. A person testing anonymously does not provide name or other identifying information to the testing center and cannot be identified or reported if the test is positive.
- Since HIV reporting was implemented in 2001 under the current name-to-code system, the average annual number of HIV tests done in Oregon has increased, suggesting that mandatory reporting does not deter people from testing. Similarly the numbers of people seeking HIV testing have not declined in other states after implementation of named HIV reporting.

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- Since mandatory reporting began in 2001, there has been no shift from confidential name-based HIV testing to anonymous testing. In fact, proportions of people testing anonymously have declined since 2001.

**Q:** Do other states have name-to-code systems? Are they converting to a name-based system?

**A:** Forty-one other states have HIV systems that retain the names of HIV patients. Seven other states, including Washington, have HIV reporting systems that encode the names of HIV patients. All of these states are exploring transition to name-retention systems.

**Q:** Will there be a financial impact to the name-based system or the enhanced lab testing?

**A:** Aside from helping to assure that Oregon retains its fair share of federal funding for HIV treatment and prevention, no substantial financial impact is anticipated. DHS may even experience some cost reduction as a result of simplification of reporting procedures.

**Q:** Will names be used for other purposes?

**A:** Oregon statute (433.008) prohibits disclosure of personal information from case reports except to other public health agencies for enforcement of public health rules or laws, or when the individual signs authorization for release of records. The statute further protects public health officials from being compelled to disclose such information in administrative or judicial proceedings.