

HIV REPORTING BEGINS OCTOBER 1, 2001

IT WILL PROBABLY be no surprise to readers of the *CD Summary* that the HIV Program of the Department of Human Services (DHS) is in the process of implementing changes to reporting requirements for HIV infection. While this has been a controversial decision, it was made after a four-year-long process of discussion and community input. This includes recent outreach activities which gathered input from communities of color and hard-to-reach populations on how to best address fears about the reporting changes and how to encourage testing by high-risk individuals. In response to this discussion and input, the reporting rules have undergone substantial changes. This issue of the *CD Summary* describes the reasons for the reporting changes and the new reporting system, and contains some answers to questions you may be asked by your patients about these changes.

WHY CHANGE REPORTING FOR HIV?

AIDS has been reportable in Oregon since 1984, but HIV infection has not, except in some very limited circumstances (such as when a unit of blood tests positive for HIV). Since 1995, Oregonians living with HIV have experienced remarkable improvements in health due to the availability of effective medication for this disease. The result has been a dramatic decrease in deaths due to AIDS, and in the incidence of new AIDS cases. Because of this dramatic drop in AIDS cases, AIDS case reporting is no longer adequate for tracking the evolution of the HIV epidemic, which is necessary in order to optimally allocate and target prevention and treatment resources. In addition, the availability of life-saving therapy creates an opportunity for public health to help assure that patients receive appropriate drug therapy as soon as possible after infection with HIV. Without reporting of new HIV infections, it is impossible for public health to carry out this assurance function. The Centers for

Disease Control, the Surgeon General and many community partners have advocated expanding reporting to include persons with HIV.

So where's the controversy? There is still substantial stigma associated with HIV infection. Some members of the community and a few health care providers have expressed concerns about reporting the names of HIV-infected people to a government agency. These concerns are primarily centered on fears that many persons at risk for HIV will refuse to go for testing out of fear that their names might leak out or be reported to other government agencies, such as the Immigration and Naturalization Service.

Forty-seven other states have adopted an HIV reporting system. These systems generally can be divided into two groups: "unique identifier" (UI) systems, and "name-based" systems. In a "name-based" system infected persons are reported to the public health system in the same way that other reportable disease cases are reported—that is, by name. In a UI system, the medical care provider converts the patient's name into a UI using a specific algorithm. The UI is then reported to the public health system.

In designing the new reporting rules, the HIV Program carefully considered the public's concerns, the experience of other states with HIV reporting, and the logistics of the new system. A UI system was not adopted because it imposes a large burden upon providers, and also requires that the public health system undertake extensive and expensive efforts to assure that the UI is being created correctly. In addition, there was concern that providers would need to keep records to allow them to translate the unique identifier back to a patient name, and that this would actually increase the risk of a violation of patient confidentiality. Instead, the HIV Program has opted for a hybrid

system that uses the best features of a UI system at much lower burden to providers and cost.

KEY COMPONENTS OF THE NEW SYSTEM

- Anonymous testing will continue to be available through all publicly-funded HIV Counseling and Testing sites, and all persons seeking testing at these sites will be offered the option of anonymous testing.
- Confidential testing is available through health-care providers in addition to county HIV testing sites.
- Laboratories will report all positive HIV test results with the patient's name to the HIV Program via a secure, confidential mechanism. Of course, the name of a person who tests anonymously will *not* be reported. For clients with heightened confidentiality concerns, providers sometimes chose to use a pseudonym on the lab form ("Ronald Reagan" had thousands of HIV tests in the 1980s). If "Ronald Reagan" tests positive, the clinician will be required to provide the patient's real name, or enough information to create an accurate Unique Identifier.
- HIV Program staff will contact the medical care provider who ordered the test and obtain information needed to complete the HIV/AIDS case report form. This is identical to the process currently in place for AIDS case reporting.
- The reporting provider will be asked to assure that the patient will be informed of the HIV care and prevention resources available in the community, and that the patient's medical care will conform to HIV treatment guidelines published by the U.S. Department of Health and Human Services. Providers who wish additional training on those guidelines will be offered that training.



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- As soon as the case report is completed and the referral assurances are given, the patient's name will be converted to a Unique Identifier (UI) code, and the name erased permanently from HIV Program records. In no instance will a person's name be held for more than 90 days. The UI will allow the HIV Program to make sure that HIV-positive persons are recorded in the system only once.

FREQUENTLY ASKED QUESTIONS

Here are some answers to questions that the HIV Program is already receiving from providers and the general public:

What if my client wants to test anonymously?

Anonymous testing will continue to be available, and should be offered to all persons requesting an HIV test. Persons wanting to test anonymously can do so at their local county health department or at several community-based organizations.

If a client tests anonymously, what happens when he or she goes to a doctor for HIV-related care?

When that person seeks care the infection will be reported, as described above. After the case report is completed and the provider has assured that the patient will be made aware of available community resources and will be treated according to national guidelines, the patient's name will be converted to a UI. In no case will the name be held more than 90 days by the HIV Program.

What if a provider does not have a long-term relationship with the patient, and so cannot make the patient aware of community resources or assure that the patient will be appropriately treated?

If the provider can't contact the patient, HIV Program staff will work with the local health department to contact the patient and carry out these assurance functions.

Will those who test negative for HIV infection be reported by name?

No.

Will the state or the local health department ever provide names of HIV-positive persons to insurance companies or to the Immigration and Naturalization Service?

Absolutely not. Names of persons who are HIV-positive or who have AIDS are never shared with any other agency or individual. This is true for all reportable diseases.

How is the security of HIV data maintained at the HIV Program? Who will have access to the names or to the codes?

The HIV/AIDS database is maintained on a stand-alone computer within the HIV Program. This computer is located behind locked doors, and the computer containing data is physically secured within a locking metal cabinet. The data are password-protected, and only two staff members have access to the system.

What if my client wants confidential testing, but insists that he/she does not want his/her full name given to the state?

If you are not able to reassure your patient with the data security information above, you only need to give enough information so that the HIV program staff can create a Unique Identifier number. The staff will then check the HIV/AIDS database to see if the UI is present, indicating that the patient has been reported previously.

What about breaches of confidentiality? How will they be handled?

All breaches or suspected breaches of confidentiality that are reported to DHS will be investigated according to DHS's authority, and appropriate sanctions imposed. In addition, affected individuals may contact the state ombudsmen (800/442-5238) who can advise them of their rights and the availability of legal remedies, if appropriate.

Providers and laboratories who want additional written information or specific training about changes in HIV-reporting rules, please contact the HIV/STD/TB Program at 503/731-4029.

FLU SURVEILLANCE OPENS

BEGINNING OCTOBER 1, 2001 the Oregon State Public Health Lab will begin accepting specimens of suspected epidemic catarrh for viral culture to "rule out influenza" without charge. Throat wash kits will be available from the OSPHL (503/229-5882), or from your local health department. Lab slips should be well marked with "**rule out influenza**" and include a legible provider name and correct ten-digit phone number.

Specimens should be collected within 3 days of clinical onset and not later than 5 days after onset from patients who present with compatible illness, viz., temperature of 38.3°C or more, cough, myalgia, and two or more of the following: headache, sore throat, rhinorrhea, malaise, chills, prostration. Specimens should be kept cool (but not frozen). If they will be more than 24 hours in transit, use a cold pack.