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HIV REPORTING IN OREGON: ONE YEAR LATER

ALTHOUGH AIDS has been reportable in Oregon since 1984, reporting of HIV infection has been a “hot button” issue since the beginning of the epidemic. This was not a problem early in the HIV epidemic, because AIDS cases accurately reflected the overall epidemiology. Anti-viral therapy changed all that in the mid-1990s, and since then, the dramatic change in the natural history of HIV infection means that AIDS cases don’t represent the characteristics of more recently infected individuals.¹ In 1997, the Centers for Disease Control and Prevention (CDC) recommended that all states implement HIV reporting and formalized this recommendation into its HIV surveillance guidelines.² Oregon’s HIV program sought to comply with federal guidelines, but understood the delicate balance between the public health need for accurate epidemiologic data and the concern on the part of HIV-positive or at-risk persons that this information might be used in damaging ways. On October 1, 2001, after four years of community dialogue, advisory input and community education, a compromise “name-to-code” reporting system was put into effect in Oregon [OAR 333.019.0031 (2)]. As a result, all existing (prevalent) and new (incident) HIV cases are now reportable to the state by laboratories and clinicians. We present the data from the first twelve months of HIV reporting (October 1, 2001 through Sept 30, 2002) in this issue of the *CD Summary*.

DESCRIPTION OF THE NAME-TO-CODE HIV CASE REPORTING SYSTEM

Oregon’s “name-to-code” HIV reporting system is fundamentally similar to the well-tested, name-based AIDS reporting system. The key difference is that as soon as all reporting requirements are met, a unique identifier (UI) “code” is constructed from letters in the person’s first and last name, the numbers in the birth date

and the person’s gender, and the individual’s name is permanently removed from the database. Laboratories report any test result indicative of HIV infection (positive serology, detectable viral load, positive p24 antigen) to the state within one day. The UI is created by the HIV staff and checked against all previously reported HIV and AIDS cases. If there is no matching UI in the database and it is a new case, the reporting physician is contacted and asked to fill out the case report form. In addition, the provider is asked to assure that a newly-diagnosed person is given information on HIV case management, medical care, and prevention services in the community. The provider is encouraged to discuss partner notification with the patient, and to offer the services of disease intervention specialists (DIS) in notifying partners and offering HIV testing. When the case report is complete, the name is removed; only the UI remains in the database.

HIV CASES

From Oct 1, 2001, to Sept 30, 2002, 823 cases of HIV were reported. Most (81%) of these were prevalent cases who had been previously diagnosed and had established health care relationships; 158 were new cases. In the same time period, 314 cases of AIDS were reported. The demographic characteristics of these two groups are displayed in the Table (right).

Compared to AIDS cases reported in the same period, new HIV cases tended to be younger. A slightly higher proportion of HIV cases were women, although the trend is much less dramatic than in other parts of

the country. There were no striking differences in the races or ethnicities of the two groups. African-Americans represented a disproportionately large proportion of both HIV and AIDS cases. Male HIV cases usually identified sex with another man (MSM) as their primary risk factor. The data do not reveal any trend towards an increase in the percentage of injection drug users (IDU) among HIV cases. Of the 29 female HIV cases, 9 were apparently infected through heterosexual sex, and 7 as a result of injection drug use; 13 did not know or did not report their HIV risk. As an added bonus, the HIV reporting system identified additional AIDS cases (30–35) that had not been previously reported by the existing system.

HIV TESTING

Before HIV reporting was implemented, there was concern that any such reporting, especially if the person’s name were used, would make at-risk people wary of having their name reported to public health so that many would avoid HIV testing altogether. Evidence from other states has demonstrated that HIV reporting produces no long-term reduc-

Demographics of new Oregon HIV and AIDS cases reported between Oct 1, 2001 and Sept 30, 2002

Demographics		HIV Cases		AIDS Cases	
Age Range	0–19	7	4%	5	2%
	20–29	34	22%	35	11%
	30–39	56	35%	123	39%
	40–49	39	25%	88	28%
	50+	22	14%	63	20%
Race/Ethnicity	African American	17	11%	21	7%
	American Indian	3	2%	7	2%
	Asian/Pacific Islander	2	1%	3	1%
	Hispanic	12	8%	31	10%
	White	124	78%	252	80%
Risk Behavior	MSM	93	59%	181	58%
	MSM/IDU	10	6%	17	5%
	IDU	18	11%	46	15%
	Hetero sex	11	7%	31	10%
	Other	26	16%	38	12%
Gender	Male	129	82%	272	87%
	Female	29	18%	42	13%
Total		158		314	



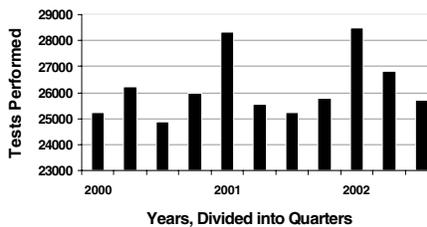
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tions in the numbers of clients who seek HIV testing.² However, these conclusions were based primarily on data from publicly funded HIV testing sites, and there was concern about the impact of reporting changes on testing behavior in the private sector. Oregon's HIV program was uniquely positioned to clarify this issue. Since 1989, both public and private providers have been required to fill out a form on every client who receives an HIV test in Oregon. This system is anonymous, but it does allow for estimates of the numbers of people being tested along with some basic demographic information. In the first year of HIV reporting, 106,763 HIV serologic tests were performed on persons in Oregon. Rather than indicating that people had become reluctant to come in for HIV testing, this actually represented a 1.6% increase from the previous twelve-month period (10/1/00 to 9/30/01).

As a proportion of all tests, African-Americans (5.1%), Hispanics (11.0%), and Asian/Pacific Islanders (6.0%) were tested out of proportion to their percentages of the population, and actually showed increased testing numbers over the last year. Women received 74% of the HIV tests (64,041), with a large number performed as part of prenatal screening. County health department HIV counseling, testing and referral (CTR) sites funded by the state HIV Prevention Program did 19.9% (21,333) of all HIV tests, up 1.3% from the previous 12 months. In the CTR sites, there was actually an increase in testing among men who have sex with men (12.3%) and injection drug users (15.0%). CDC recommends that all states give clients the option of anonymous HIV testing, and Oregon counties are now

Total number of HIV serologic tests performed in Oregon, by quarter, 2000-2002



required to offer this option to all clients at CTR sites. As a result, there was a 19.1% increase (6,295 tests) in anonymous tests performed, representing 29% of all HIV tests performed in county health departments.

WHAT HAVE WE LEARNED?

The HIV case reporting system has revealed several interesting points about the HIV epidemic in Oregon.

- The characteristics of HIV cases are remarkably similar to AIDS cases, suggesting that there is no dramatic shift in the epidemic to new populations in Oregon.
- The primary risk behavior associated with HIV cases is unprotected sex with a male partner.
- HIV testing in Oregon did not decrease due to fear of name-based HIV reporting, but actually increased in several target populations.
- There was an increase in anonymous testing, in part due to efforts at CTR sites to assure that everyone was aware of this option.
- It is very important to take the time to carefully plan implementation of the reporting system and provide extensive education for healthcare providers and the community.

The long road to HIV testing created a system that balanced the concerns of the community with the need for accurate information on a disease of immense public health importance. With this system in place, Oregon is now better situated to fight the HIV epidemic in the coming decade.

REFERENCES

1. CDC. Update: trends in AIDS incidence—United States 1996. *MMWR* 1997;46:861–7.
2. CDC. Guidelines for national human immunodeficiency virus case surveillance, including monitoring of human immunodeficiency virus infection and acquired immunodeficiency syndrome. *MMWR* 1999;48:1–32.

Smallpox Vaccination, the Military, and Adverse Events

ALTHOUGH vaccination of Oregon's smallpox response teams in public health and in hospitals was postponed until several important issues are clarified, vaccination is being given to active-duty members of the military in some places. Reservists may also be vaccinated at some point. If that occurs, you may see some adverse reaction to smallpox vaccine in your office, clinic, ER or hospital. Information on the management of adverse events after smallpox vaccination can be found on CDC's website (<http://www.cdc.gov/mmwr/preview/mmwrhtml/di52cha1.htm>).

If you should run across someone with an adverse event please be sure to report it immediately to your local health department. For further assistance, including requests for Vaccinia Immune Globulin or Cidofovir for the treatment of some adverse reactions, please contact your local health department or Oregon Public Health Services (503/731-4024).