

## Evaluation of Active versus Passive AIDS Surveillance in Oregon

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**Abstract:** We searched for unreported AIDS cases in Oregon through death certificate and medical record review, and enhanced infection control practitioner and physician surveillance. Fifty-six AIDS cases diagnosed between February 1, 1986 and January 31, 1987 were reported passively. Twenty-nine additional cases diagnosed during this time were retrospectively identified by active methods. Ninety percent of those 29 cases were diagnosed by physicians and cared for in hospitals that had previously reported cases. Completeness of reporting under the passive system was 64 percent. (*Am J Public Health* 1990; 80:463-464.)

### Introduction

Since the acquired immunodeficiency syndrome (AIDS) was first described in 1981, surveillance for AIDS cases has served to define the modes of transmission and to characterize the populations most affected. To date, there have been little data to assess the need for these active surveillance systems, that seek AIDS case reports through a variety of methods rather than passively depending on physician reporting. This study assesses the need for active AIDS surveillance systems. The HIV (human immunodeficiency virus) program of the Oregon Health Division initiated prospective active surveillance for AIDS in February 1987. We applied the methods used for active surveillance to retrospectively determine the number and characteristics of AIDS cases that had gone unreported under the previous passive system. We report here the results of that evaluation.

### Methods

We used four active surveillance methods to identify unreported cases diagnosed between February 1, 1986 to January 31, 1987, the year before active surveillance began.

- All physicians in Oregon were sent a letter reviewing AIDS reporting requirements and soliciting case reports. Physicians who had previously reported at least one AIDS case were provided with a list of all these cases for review and asked to report additional unreported cases under their care.
- Infection control practitioners at hospitals where previous AIDS cases had been diagnosed were asked to compile a list of previous AIDS admissions and

maintain a log of subsequent admissions for comparison with our central AIDS registry. Those from hospitals without reported cases were asked every six months to confirm that no AIDS-related admissions had occurred.

- At all hospitals statewide where at least one case had been diagnosed, medical records of all potential AIDS admissions were reviewed. Admissions were pulled if they contained any of five International Classification of Diseases, Volume 9 (ICD-9) codes (042, 043, 279.19, 136.3, 173.9) previously shown to be reliable in identifying persons with an AIDS diagnosis.<sup>1</sup> Cases were matched with reported cases in the central registry and physicians of possible unreported cases were queried.
- Death certificates designating AIDS or listing a cause of death potentially AIDS-related (including all deaths related to known opportunistic conditions and deaths from infectious or immunosuppressive causes in persons under age 60) were reviewed. Physicians of potential unreported cases were queried.

A case diagnosed during the year before active surveillance began was considered to be discovered by **active surveillance** if it was reported by any reporting source after the start of active surveillance and more than 6 months after diagnosis. All other cases were classified as reported by passive surveillance. All cases met the 1985 CDC surveillance case definition.<sup>2</sup>

### Results

#### Completeness of Reporting

Fifty-six AIDS cases diagnosed between February 1, 1986 and January 31, 1987 were reported under the passive system. Using active surveillance methods an additional 29 cases diagnosed during this time were found retrospectively. The completeness of reporting before active surveillance began was 64 percent (95% confidence interval = 54, 74). For cases reported under the passive system, the median time between diagnosis and report, or lag time, was one month. Lag time ranged from 7 to 19 months for cases found by active surveillance only (median = eight months).

#### Characteristics of Cases and Reporting Sources

Cases reported by passive surveillance did not significantly differ from those identified by active surveillance by age, race, county of residence, risk factors, disease at diagnosis or mortality status at time of report, although our power to detect significant differences was limited by the relatively small sample size (Table 1).

Characteristics of physicians who reported cases by passive surveillance did not differ from physicians whose cases were identified under active surveillance by specialty,

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**TABLE 1—Characteristics of Cases Reported by Passive or Active Surveillance**

| Characteristics            | Passive (n = 56) |      | Active (n = 29) |      |
|----------------------------|------------------|------|-----------------|------|
|                            | No.              | %    | No.             | %    |
| Age (mean)                 | 35.6yrs          |      | 35.2yrs         |      |
| Race                       |                  |      |                 |      |
| White                      | 53               | 94.6 | 28              | 96.6 |
| Non-White                  | 3                | 5.4  | 1               | 3.4  |
| County of residence        |                  |      |                 |      |
| Multnomah (urban Portland) | 38               | 67.9 | 23              | 79.3 |
| Other                      | 18               | 32.1 | 6               | 20.7 |
| Mortality status           |                  |      |                 |      |
| Alive at report            | 38               | 67.9 | 19              | 65.5 |
| Dead at report             | 18               | 32.1 | 10              | 40.0 |
| Disease at diagnosis       |                  |      |                 |      |
| PCP                        | 33               | 59.1 | 20              | 68.5 |
| Other disease w/o PCP      | 14               | 25.2 | 3               | 10.3 |
| KS alone                   | 9                | 16.1 | 6               | 20.4 |
| Mode of transmission       |                  |      |                 |      |
| Homosexual/bisexual men    | 45               | 80.4 | 22              | 75.9 |
| Homosexual/bisexual IVDA   | 5                | 8.9  | 5               | 17.2 |
| Hemophilic (adult)         | 3                | 5.4  | 1               | 4.0  |
| Other                      | 3                | 5.4  | 1               | 4.0  |

PCP = Pneumocystis carinii pneumonia; KS = Kaposi's sarcoma; IVDA = Intravenous Drug Abuse.

city of practice, or previous reporting history. Ninety percent (26/29) of cases identified by active surveillance were cared for by physicians who had reported at least one case before the start of active surveillance.

Characteristics of hospitals from which cases were reported passively did not differ from hospitals where cases were identified under active surveillance by previous reporting history, bed size, or location. Ninety percent (26/29) of cases identified by active surveillance were diagnosed in hospitals that had cared for at least one case before the start of active surveillance.

#### Efficacy of Active Surveillance Components

We compared the relative effectiveness of each component of active surveillance in identifying previously unreported cases. The initial reporting source for cases identified actively was physicians for 14 percent, infection control practitioners 31 percent, medical record review 31 percent, and death certificate review 24 percent. We estimated the completeness of the surveillance system using the capture-recapture methodology (Chandra Sekar and Deming method).<sup>3</sup> Our surveillance system was divided into two independent reporting components: unsolicited (physician or infection control practitioner reporting) and solicited (medical record review or death certificate review). The percentage of cases found by unsolicited means was 80 percent. The percentage of solicited reports was 95 percent. Seventy-seven percent of cases were found by both methods. The estimated completeness of reporting was 99 percent of the estimated case population.

#### Discussion

Relative to active AIDS surveillance, the completeness

**TABLE 2—Characteristics of Physicians Reporting by Passive or Active Surveillance**

| Physician Characteristics | Passive |      | Active |      |
|---------------------------|---------|------|--------|------|
|                           | No.     | %    | No.    | %    |
| Specialty                 |         |      |        |      |
| Internal Medicine         | 29      | 51.8 | 10     | 36.0 |
| Infectious Disease        | 10      | 17.9 | 13     | 44.8 |
| Allergy and Immunology    | 9       | 16.1 | 1      | 3.4  |
| Other                     | 6       | 10.7 | 5      | 17.2 |
| Unknown                   | 2       | 3.6  | 0      | 0    |
| City of practice          |         |      |        |      |
| Portland                  | 39      | 69.6 | 24     | 82.8 |
| Not Portland              | 17      | 30.4 | 5      | 17.2 |
| Previous AIDS Report      |         |      |        |      |
| Yes                       | 42      | 75.0 | 26     | 89.7 |
| No                        | 13      | 23.2 | 3      | 10.3 |
| Unknown                   | 1       | 1.8  | 0      | 0    |

of passive AIDS surveillance in Oregon in 1986–87 was only 64 percent, similar to preliminary findings from South Carolina<sup>4</sup> and less than an earlier New York study.<sup>5</sup> Passive AIDS surveillance, even in relatively low incidence areas, is incomplete. Projections based on passive surveillance would underestimate future incidence proportionately and could result in poor public health planning and resource distribution decisions.

Because almost all cases during this time in Oregon were occurring in urban gay and bisexual men, we recognized at the outset that we would not be able to assess differences in reporting based on case risk factor.

Infection control practitioners, medical record review, and death certificate review were all useful in identifying cases unreported more than 90 days after diagnosis. Each of the multiple reporting components independently identified cases that would otherwise have gone unreported.

Physicians and hospitals with previous reporting history appear to be the reservoir for the largest number of unreported cases and are the best targets for enhanced surveillance activities. As the epidemic continues, the ability to maintain effective active surveillance will include using resources efficiently, combating "reporting fatigue," and assuring timely reporting as clinical practice shifts diagnosis to outpatient settings. As the AIDS epidemic progresses and physicians and hospitals gain more experience with this disease, active surveillance may become more rather than less important.

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