

## Name-Based Surveillance and Public Health Interventions for Persons with HIV Infection

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Name-based surveillance of HIV infection is the law in 31 U.S. states but remains controversial. This policy can be advocated solely to support surveillance of the epidemic, but a frequent argument is that it also provides a public health benefit by allowing follow-up of HIV-infected persons. These persons can then receive timely medical care and can be assisted with notifying sex and needle-sharing partners.

Few comparative data are available to evaluate the outcomes of these interventions. In five states with name-based surveillance of HIV infection, the Multistate Evaluation of Surveillance for HIV Study Group surveyed a cross-sectional probability sample of persons with AIDS who tested positive for HIV before the date of their AIDS diagnosis. Health department follow-up of a reported HIV infection was not associated with more timely receipt of medical care after a positive HIV test result. Only 8.6% of persons who delayed medical care after their first positive HIV test result gave concern about being reported by name as a reason; no person gave it as the main reason. Persons who were tested anonymously and those who were tested confidentially did not differ in the mean number of sex and needle-sharing partners notified: Those tested anonymously reported personally notifying 3.85 sex and needle-sharing partners, and those tested confidentially reported notifying—personally and through the health department—3.80 partners. Many researchers and policymakers believe that name-based surveillance of HIV infection will have positive or negative effects on partner notification and access to health care. These results suggest that the potential for such effects has been exaggerated.

In the United States, each state has the authority to require disease reporting. Although all states mandate that persons with AIDS be reported by name to public health departments, reporting HIV-infected adults by name remains controversial. This policy has been adopted by 31 states but by only 5 of the 10 states with the highest incidence of reported AIDS cases. Effective new antiretroviral treatments for HIV infection have decreased the incidence of AIDS and increased interest in using an HIV reporting policy to monitor the epidemic. Effective treatments also provide a stronger rationale for early diagnosis and treatment of HIV infection. Name-based surveillance is now under consideration in the states that do not have it, but it remains a subject of debate.

The policy debate about name-based surveillance has focused on the potential for benefit or harm in three areas: epidemic monitoring, HIV testing behavior and timely medical care, and interventions by public health personnel who follow up on name reports of persons with newly identified infections (1–3). Name-based surveillance could be harmful if confidentiality is breached or if concern about confidentiality deters high-risk persons from being tested or, if they test positive for HIV, from seeking care. The potential benefits of name-based reporting include improved surveillance of the epidemic (which can, in turn, help allocate funding and target public health services) and use of public health interventions to assist newly infected persons after follow-up. Two types of public health interventions have been offered: 1) assistance with health education and access to treatment and 2) notification of at-risk sex and needle-sharing partners. Name-based surveillance can be conducted without these interventions, and some states provide them without name-based surveillance (for example, by offering partner notification at anonymous HIV test sites).

Although the theoretical benefits of health department intervention are easily described, studies of the results of intervention have usually lacked comparison data on the consequences of no intervention (4–10). Name-based surveillance linked

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with partner notification has long been a feature of sexually transmitted disease programs. Its effectiveness has been controversial in the control of bacterial sexually transmitted diseases, such as syphilis and gonorrhea (for which treatment prevents transmission), and is even more controversial in control of HIV infection (for which preventive treatment has not been available) (11, 12).

### **The Multistate Evaluation of Surveillance for HIV Project**

The Multistate Evaluation of Surveillance for HIV (MESH) project, which was funded by the Centers for Disease Control and Prevention (CDC) to evaluate HIV surveillance systems, was carried out as a collaboration among nine state health departments, the University of California, and the CDC. Two surveys, one of persons at high risk for HIV infection and one of persons who had recently received a diagnosis of AIDS, were carried out in 1995 and 1996 in these nine states, which had different laws for reporting HIV infection (13, 14). In addition, the policy of reporting HIV infection by using a system of non-name unique identifiers was evaluated in two of the states (15).

Potential avoidance or delay of HIV testing among high-risk persons has been the greatest concern surrounding name-based surveillance of HIV infection. In the MESH project survey of persons at risk for HIV infection, 2370 HIV-negative or untested persons were interviewed. This sample was made up of nearly equal numbers of men who had sex with men, persons who used injection drugs, and heterosexual persons attending sexually transmitted disease clinics. Most respondents delayed or avoided HIV testing out of fear of learning that they were infected or out of a belief that they were not at risk (14). Of the 25% of the sample who had never been tested for HIV, 19% cited fear of having their name reported as a reason and 2% gave it as the main reason. Among untested men who had sex with men, 28% gave fear of having their name reported as a reason for delaying testing; in states with name reporting, 35% gave it as a reason and 3% gave it as the main reason; and in states without name reporting, 11% gave it as a reason and 7% gave it as the main reason. The level of concern was lower than many opponents of name-based surveillance had expected, but it was also clear that confidentiality was a greater concern among men who had sex with men than among other high-risk populations.

The AIDS patient survey done by the MESH Study Group was designed to examine, in a population-based sample, the effect of type of HIV test and type of HIV surveillance on the timeliness of

testing and receipt of medical care and on notification of partners (13). A probability sample of recently reported patients with AIDS was drawn from eight states. Five of the states had name-reporting policies for HIV infection (Arizona, Colorado, Mississippi, Missouri, and North Carolina) and three of the states did not (Texas, Oregon, and New Mexico; New Mexico adopted name-based surveillance after the MESH Study was completed). Researchers conducting the survey sought to interview, in each state, all persons or a stratified probability sample of persons whose new diagnosis of AIDS was reported from May 1995 through December 1996, who were alive at the time of report, who were living in the state, who were at least 18 years of age, who received the AIDS diagnosis within 12 months of the report date, who spoke English or Spanish, and who were healthy enough to consent to and complete an interview. The date of the first AIDS diagnosis was extracted from the AIDS surveillance database and was combined with the interview data for analysis; no patient identifiers were sent to the University of California or to the CDC. Interviews were completed with 1913 persons (completion rate, 68.3%). Because almost all HIV-infected persons eventually progress to AIDS (16), this survey provided a population-based sample of the experience of HIV-infected persons that may avoid potential biases caused by use of venue-based samples.

Participants self-reported the month and year of their first positive HIV test result and their first receipt of HIV-related care. The number of sex and needle-sharing partners notified was the sum of the number of partners that participants notified personally and the number of partners that participants asked public health personnel to notify (however, it is not known whether public health personnel carried out this notification). A validity check of self-reported contact with the health department was done in Colorado, where state contact records were compared with self-reports for a random 10% of interviewed participants. Records agreed with self-reports in 25 of 28 cases (89.3%).

Type of HIV test was classified as anonymous or confidential on the basis of whether the participant reported giving a number or a name to receive the HIV test result. Participants who said that they gave a false name were excluded from analysis ( $n = 55$ ). Anonymous tests are usually associated with numbers, and confidential tests are usually associated with names. From a public health perspective, the key difference is that confidential HIV tests are recorded in a patient's medical record or chart but anonymous tests are not. State public health laws for such activities as surveillance or follow-up of persons affect the information contained in patient records. The effect of reporting policies on HIV

**Table. Time to First Receipt of HIV-Related Medical Care after a Positive HIV Test Result in a Probability Sample of Patients with AIDS (n = 388)\***

Variable	Receipt of First HIV-Related Medical Care			
	< 3 Months after First Positive Result	P Value	< 6 Months after First Positive Result	P Value
	%		%	
Contact with the health department after a name reporting of an HIV-positive test result				
Yes (n = 279)	67.0		70.2	
No (n = 94)	69.1	>0.2	76.0	>0.2
Symptoms at the time of the first HIV-positive test result				
Yes (n = 208)	75.0	0.001	83.2	<0.001
No (n = 172)	59.3		64.5	
Regular source of medical care at the time of first HIV-positive test result				
Yes (n = 171)	75.4	0.006	81.9	0.004
No (n = 207)	62.3		69.1	

\* The sample was taken from five states with name-based surveillance of HIV infection. All participants had a positive HIV test result that was confidential and was received >1 month before their AIDS diagnosis. Participants were reported HIV-positive by name and therefore could have been contacted by public health personnel.

testing behavior must be considered in conjunction with the effect of the availability of options for anonymous and confidential testing. In the AIDS patient survey, four of the five states that practiced name-based surveillance also offered an anonymous HIV testing option. Previous analysis of data from the MESH AIDS patient survey found that, among persons who had sought HIV testing, those who were tested anonymously were tested and received care earlier in the course of HIV disease than those who were tested confidentially (13). The availability of anonymous testing was an important option, particularly for men who had sex with men, who were more likely to have concerns about confidentiality.

### Delayed Medical Care after a Positive HIV Test Result

Most participants began medical care soon after receiving a positive HIV test result (47% began when they learned of their HIV infection, 66% began within 2 months, 76% began within 6 months, 83% began within 1 year, and 94% began within 3 years). The proportion seeking timely care in states with and without name-based surveillance of HIV infection differed only slightly (66% compared with 67% at 2 months and 81% compared with 86% at 1 year, respectively).

The experience of survey participants in the five states with name reporting was examined to evaluate public health interventions from February 1990 (after all five states had name-based surveillance laws in effect) through the survey period. During that period, 441 persons had a positive result on an HIV test before their AIDS diagnosis; 388 of these persons (88%) were tested confidentially and could have been contacted by public health personnel and assisted with information and access to medical

care. Of these 388 persons, 75% reported contact with the health department (range, 46% to 89% across the five states). Contact with the health department was not associated with receiving more timely care. The percentage of persons who received care within 3 months of the positive test result was 67% among those contacted and 69% among those not contacted (Table). The variables most strongly associated with seeking care early were having symptoms at the time of the HIV-positive test result or having a regular source of care (Table). Persons who were contacted by health departments were more likely to have a regular source of medical care than those who were not contacted, although this difference was not statistically significant. Even after adjustment for symptoms of HIV infection, a regular source of care, medical insurance, HIV transmission group, ethnicity, age, sex, education, income, and date of positive HIV test result, persons contacted by health departments were no more likely to have received care within 3 or 6 months of the first positive HIV test result (for receipt of care within 6 months, the odds ratio for contact with the health department was 0.95 [95% CI, 0.51 to 1.79];  $P > 0.2$ ).

To determine whether name-based surveillance had deterred persons from seeking care after a positive test result, we asked participants who had not sought care within 2 months of the positive test result (37.9% of those who were tested before developing AIDS) to give their reasons for delay. Most participants reported that feeling well or not wanting to think about HIV infection as their main reasons for delay; 8.6% said that fear of being reported to the health department was a reason (7.6% in states with name-based reporting and 11.2% in states without name-based reporting). No participant said that fear of being reported to the health

department was the main reason for delaying care. Persons who were tested anonymously in a state with name-based reporting would be most likely to delay medical care because obtaining care would result in being reported by name. Among persons who delayed care and were tested anonymously in a state with name-based reporting, 6 of 25 (24%) said that fear of being reported was a reason compared with 3 of 20 (15%) who were tested anonymously in a state without name-based reporting ( $P > 0.2$ ). The only reasons given that varied significantly by type of surveillance policy were uncertainty about where to go for care and inability to afford a physician visit, both of which were cited more often in states without name-based surveillance.

### Partner Notification

In the five states with name-based surveillance of HIV infection, the mean number of partners personally notified by the 53 persons who had an initial anonymous HIV test (3.85 partners) was almost identical to the number of partners personally notified plus the mean number of partners whose names were given to the health department by 387 persons who had an initial confidential test (3.80 partners). Adjustment for a regular source of care, medical insurance, HIV transmission group, ethnicity, age, sex, education, income, and date of positive HIV test result did not significantly change this result (estimated least-square mean, 3.7 and 4.1, respectively;  $P > 0.2$ ). Confidential testing did not seem to increase the number of partners notified.

### Policy Implications

Opponents of name-based surveillance of HIV infection have claimed that it deters persons from seeking HIV testing and medical care. Proponents who want to link surveillance with public health interventions claim that name-based surveillance with follow-up of new infections produces benefit. These claims have, for the most part, been made in the absence of data on outcomes (10). The AIDS patient survey done by the MESH Study Group found no evidence that health department follow-up of name-reported HIV infection resulted in more timely care for HIV infection or in more persons being notified of exposure to an HIV-infected partner. On the other hand, it also found no evidence that name-based surveillance of HIV infection was a substantial barrier to seeking health care promptly after a positive test result.

Several studies of partner notification for sexually transmitted diseases and HIV infection have found

conflicting evidence of benefit (11, 12, 17–20). Partner notification is ineffective when patients have large numbers of anonymous sexual encounters (17). However, our results are contrary to those reported in the only randomized, controlled trial of partner notification for HIV infection. In this trial, Landis and colleagues (19) noted a significant increase in the number of partners notified by health department referral compared with no assistance by health department referral. The discrepancy between their results and the results of the MESH Study could be caused by a limitation in the way that the survey measured the effect of notification. Self-notification of partners lacks the counseling and offer of HIV testing that accompany health department notification. Some benefit from these services may not have been captured when persons were asked only about the number of partners notified. However, the discrepancy may be an example of the potential difference between an efficacy trial and a measure of effectiveness of an intervention in a population-based sample. In the trial by Landis and colleagues (19), such a small proportion of the potential participants were randomly assigned—only 74 of the initial sample of 534 HIV-positive persons—that the measure of efficacy may lack generalizability and may poorly represent the actual effects of a partner notification policy at the population level.

Because most patients begin medical care soon after their positive test result or already have HIV-related symptoms when they first receive this test result, limited opportunity exists for an intervention to facilitate access to care. However, improved treatment for HIV infection has increased the focus on early testing and treatment of infected persons. If a much higher proportion of infected persons could be tested in the early stages of disease, more opportunity may become available for such interventions. Targeted follow-up of the persons who most need it may be a more effective strategy. The question is whether states with name-based surveillance of HIV infection could substantially improve initiation of care for persons with newly diagnosed HIV infection and whether the resources required for such an intervention would be best spent in that way.

Separating the issues about surveillance itself from the issues about the use of surveillance to deliver the interventions discussed here would help focus the debate. Name-based surveillance of HIV infection can detect duplicate reports to a registry. Some researchers suggest a compromise: a reporting method that uses non-name unique identifiers. However, the MESH Study Group's evaluation of numerical unique identifiers in Texas and Maryland found a high rate of incomplete case reporting (34% and 22% of cases, respectively, were missing the required portion of the Social Security number) (15).

In states with name-based surveillance, inferences about the HIV epidemic have been made from reports of HIV infection that were not possible from AIDS reporting alone (21). The relative contribution of name-based surveillance of HIV infection compared with that of other sources of data on the epidemic, such as targeted studies of incident infection and seroprevalence surveys, is less clear. A careful assessment of the contribution of different approaches to monitoring the epidemic would be a useful addition to the policy debate.

Using a reporting system to facilitate follow-up contact with newly identified HIV-infected persons assumes that follow-up by public health personnel is an effective use of funds. In a polarized debate, strong claims of benefit or harm from public health interventions should be examined with data on the relevant outcomes. Many researchers and policymakers believe that name-based surveillance of HIV infection will have positive or negative effects on partner notification and access to health care. Our findings suggest that the potential for such effects has been exaggerated.

### Appendix: Members of the Multistate Evaluation of Surveillance for HIV Study Group

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