Effect of HIV Reporting by Name on Use of HIV Testing in Publicly Funded Counseling and Testing Programs

Allyn K. Nakashima, MD; Rosemarie Horsley; Robert L. Frey, PhD; Patricia A. Sweeney, MPH; J. Todd Weber, MD; Patricia L. Fleming, PhD

Context.—Policies requiring confidential reporting by name to state health departments of persons infected with the human immunodeficiency virus (HIV) have potential to cause some of them to avoid HIV testing.

Objective.—To describe trends in use of HIV testing services at publicly funded HIV counseling and testing sites before and after the implementation of HIV reporting policies.

Design and Setting.—Analysis of service provision data from 6 state health departments (Louisiana, Michigan, Nebraska, Nevada, New Jersey, and Tennessee) 12 months before and 12 months after HIV reporting was introduced.

Main Outcome Measure.—Percent change in numbers of persons tested at publicly funded HIV counseling and testing sites after implementation of confidential HIV reporting by risk group.

Results.—No significant declines in the total number of HIV tests provided at counseling and testing sites in the months immediately after implementation of HIV reporting occurred in any state, other than those expected from trends present before HIV reporting. Increases occurred in Nebraska (15.8%), Nevada (48.4%), New Jersey (21.3%), and Tennessee (62.8%). Predicted decreases occurred in Louisiana (10.5%) and Michigan (2.0%). In all areas, testing of at-risk heterosexuals increased in the year after HIV reporting was implemented (Louisiana, 10.5%; Michigan, 225.1%; Nebraska, 5.7%; Nevada, 303.3%; New Jersey, 462.9%; Tennessee, 603.8%). Declines in testing occurred among men who have sex with men in Louisiana (4.3%) and Tennessee (4.1%) after HIV reporting; testing increased for this group in Michigan (5.3%), Nebraska (19.6%), Nevada (12.5%), and New Jersey (22.4%). Among injection drug users, testing declined in Louisiana (15%), Michigan (34.3%), and New Jersey (0.6%) and increased in Nebraska (1.7%), Nevada (18.9%), and Tennessee (16.6%).

Conclusions.—Confidential HIV reporting by name did not appear to affect use of HIV testing in publicly funded counseling and testing programs.

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POLICIES for the confidential reporting by name of persons with acquired immunodeficiency syndrome (AIDS) to health departments exist in all states.1 From the Division of HIV/AIDS Prevention, National Center for HIV, STD, and TB Prevention, Centers for Disease Control and Prevention, Atlanta, Ga. 


Reprints: Allyn K. Nakashima, MD, Centers for Disease Control and Prevention, 1600 Clifton Rd, MS E-47, Atlanta, GA 30333 (e-mail: a1n1@cdc.gov).

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One barrier to the adoption of HIV reporting has been the concern that such policies might cause some individuals to avoid testing or medical care.3,5,6 These concerns have been based on surveys7-12 of at-risk populations. Although the populations surveyed were at high risk for HIV (eg, men who have sex with men [MSM]), they were limited by small numbers and narrow geographic coverage. Most surveys asked people about their intent to test without verifying testing behaviors after the implementation of HIV reporting.

Large-scale, publicly funded HIV counseling and testing (CT) programs have been in place in all states since 1985.1

See also p 1416.
These programs were initially implemented to provide sites for HIV testing other than blood banks and to offer anonymous or confidential HIV CT services to anyone seeking a test. Approximately 2.5 million HIV tests are furnished by the CT programs each year."14,15 In areas where HIV reporting legislation was introduced after implementation of CT programs, the data collected by these programs provide a unique opportunity to observe the effect of HIV reporting policies on testing. In this study, we used CT data to compare the changes in use of HIV testing services before and after HIV reporting was implemented.

**METHODS**

The Centers for Disease Control and Prevention (CDC) has funded 65 project areas in state, city, or territorial health departments for HIV CT services since 1985.16-18 Since 1990, most project areas have sent to CDC data on individual tests performed. For each test performed, information was collected on month and year of test; sex, race or ethnicity, and HIV risk exposure group (MSM, injection drug use, sex with a person infected with HIV or at risk for HIV) of the person tested; type of testing site (stand-alone counseling and testing site, sexually transmitted disease clinic, drug treatment center, family planning clinic, community health center, prison or jail, other); test result; and type of test (anonymous vs confidential), added after 1992.

In 5 states, HIV reporting was implemented after CT data collection was in place. In Louisiana, HIV reporting was implemented in February 1993; in Nebraska, September 1995; in Nevada, February 1992; in New Jersey, October 1991; and in Tennessee, January 1992. In Michigan, HIV reporting was required by regulation beginning in 1988. However, the health department did not actively solicit HIV case reports from physicians and other providers, including clinicians, laboratories, and institutions (eg, hospitals, clinics), until April 1992. Therefore, for Michigan this date was taken as the date on which HIV name reporting was implemented. In these 6 states, the number of HIV tests, the number of positive HIV test results, and the distribution of these tests by sex, race or ethnicity, type of testing site, and risk exposure group were compared for the 12 months before and the 12 months after HIV reporting was introduced; data for the month when HIV name reporting was introduced were excluded. We excluded CT sites reporting fewer than 50 tests to the client record system during the 25-month period of evaluation. Because of policy changes, changes in funding, or other program issues, sites may be added or eliminated from a state’s CT program. To minimize the effect of changes in sites, we excluded sites that reported no tests for any month during the 25-month study period.

Data on type of test were available for Louisiana and Nebraska and the percentages of anonymous and confidential tests before and after HIV name reporting were assessed by sex, race or ethnicity, and risk exposure group for these states.

To account for the variations in autocorrelated data (ie, the underlying statistical distribution of repeated measures over time in the same sites), we used a Poisson log-linear model. For this model, the number of tests was the response variable used to compare the months before and the months after implementation of HIV reporting. Within the model, the generalized estimating equations method was incorporated to fit a correlated response model.16,19 The trends in the number of tests before and after HIV reporting were also compared by using the model. The 3 variables in the model comparing trends were time (before vs after HIV reporting), trend (linear trend over 12 months), and time by trend interaction (trend same or different before vs after HIV reporting).

The data used in the analysis were collected to monitor service provision, not for use in a research study; for example, no population sampling was performed. In addition, because of the large numbers of tests performed in most areas, small percentage changes may result in statistically significant differences that are not practically meaningful. Therefore, we present stratified tables as comparisons of numbers of tests and percentage changes without further statistical description.

HIV/AIDS surveillance coordinators and HIV CT program coordinators in each of the 6 study areas were telephoned to obtain qualitative information about the methods used to inform the general public and health care providers such as physicians and other clinicians, laboratories, and institutions about HIV reporting, local HIV CT program characteristics, and occurrences (eg, media events, changes in program funding) that may have influenced counseling and testing trends at the time HIV name reporting was implemented.

**Table 1.—Number of HIV Tests Performed in Publicly Funded HIV Counseling and Testing Sites the Year Before and After Implementation of HIV Reporting by State**

<table>
<thead>
<tr>
<th>State</th>
<th>Before HIV Reporting</th>
<th>After HIV Reporting</th>
<th>% Change</th>
<th>Value†</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Louisiana</td>
<td>43,995</td>
<td>39,359</td>
<td>−10.5</td>
<td>.30</td>
<td></td>
</tr>
<tr>
<td>Michigan</td>
<td>66,704</td>
<td>65,398</td>
<td>−2.0</td>
<td>.70</td>
<td></td>
</tr>
<tr>
<td>Nebraska</td>
<td>4,348</td>
<td>5,035</td>
<td>15.8</td>
<td>&lt;.001</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>Nevada</td>
<td>9,613</td>
<td>14,264</td>
<td>48.4</td>
<td>.001</td>
<td></td>
</tr>
<tr>
<td>New Jersey</td>
<td>6,144</td>
<td>7,432</td>
<td>21.3</td>
<td>&lt;.001</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Tennessee</td>
<td>20,684</td>
<td>33,675</td>
<td>62.8</td>
<td>.001</td>
<td></td>
</tr>
</tbody>
</table>

*Data exclude tests without site numbers, tests reported from sites with fewer than 50 total tests during the 12 months before and the 12 months after implementation of HIV reporting.*

†Data are based on results of Poisson regression modeling.

Number of human immunodeficiency virus (HIV) tests performed per month at publicly funded HIV counseling and testing sites before and after implementation of HIV reporting by state. Dates HIV-reporting-by-name policies were implemented were as follows: for Louisiana, February 1993; Michigan, April 1992; Nebraska, September 1995; New Jersey, October 1991; Tennessee, January 1992; and Nevada, February 1992.
RESULTS

During the 25-month period before and after the implementation of HIV reporting, the total number of HIV tests provided through the states in the study were as follows: Louisiana, 86,734 tests at 50 sites; Michigan, 138,802 tests at 53 sites; Nevada, 97,497 tests at 8 sites; Nebraska, 25,002 tests at 3 sites; New Jersey, 141,946 tests at 84 sites; and Tennessee, 56,721 tests at 29 sites. These tests represented 63% of HIV tests performed in publicly funded CT sites in Louisiana during this period, 95% in Michigan, 77% in Nevada, 88% in Nevada, 84% in New Jersey, and 79% in Tennessee.

When we compared the total number of tests performed in the year before and the year after HIV reporting, 4 states—Nevada, Nebraska, New Jersey, and Tennessee—had increases in the number of tests performed after implementation (16%, 48%, 21%, and 63%, respectively; Table 1). Louisiana and Michigan had declines of 11% and 2%, respectively, in the total number of tests; however, these declines were not statistically significant.

When linear trends were examined throughout the study period, there were no large or prolonged declines in the number of tests performed in any area in the months immediately after HIV reporting was implemented (Figure). A transient decline in the number of tests in Michigan in the months immediately after implementation of active surveillance for HIV cases had returned to baseline by the end of the 12-month period of study. A declining trend in the number of tests in Louisiana began the month immediately after HIV reporting was implemented (Table 2). Counseling and testing coordinators in New Jersey and Tennessee attributed the large increase in testing in these states to increased counseling and testing in their states following the implementation of HIV reporting.

Among whites, the number of HIV tests increased after HIV reporting was implemented in all states but Louisiana, which had a 10% decline. The trends for Hispanic persons were similar to those for whites: a 22% decline for Hispanic persons was seen in Louisiana after HIV reporting. Among blacks, the number of tests performed after HIV reporting declined in Louisiana (10%), Michigan (26%), and New Jersey (2%).

Among MSM, the risk group that represents the largest number of tests, there was a decline in anonymous testing and an increase in confidential testing. Among white MSMs, in Louisiana, the number of anonymous tests decreased after HIV reporting was implemented, 11% in the year after HIV reporting was implemented (Table 2). Counseling and testing coordinators in New Jersey and Tennessee attributed the large increase in testing in these states to increased counseling and testing in their states following the implementation of HIV reporting.

In Louisiana, both the number of anonymous tests and the proportion of total HIV tests that were anonymous decreased after HIV reporting was implemented. At the same time, the number and proportion of confidential tests increased (Table 3). Opposite trends were seen in Nebraska (Table 3). In Nebraska, the number of confidential tests increased after HIV reporting was implemented. At the same time, the number and proportion of anonymous tests decreased (Table 3). In Louisiana, declines were seen among blacks both in anonymous and confidential testing after HIV reporting began. The decline in anonymous testing was greater than the decline in confidential testing. Both types of tests increased among blacks in Nebraska.
Counselors informed CT clients about HIV reporting requirements through verbal counseling, informed consent forms, or information pamphlets (Table 4). The methods used to inform health care providers and the public about HIV reporting requirements and the availability of anonymous testing services differed among areas (Table 4).

**COMMENT**

Confidential reporting of HIV-infected persons by name to health departments has been controversial and many states have been unable to implement HIV reporting policies because of opposition in the community.1 One of the key concerns about HIV reporting is that it might deter people at risk from being tested or seeking care. In a recent position statement, the American Civil Liberties Union stated that “name reporting is a counterproductive public health measure that will cause individuals to avoid testing.”3 The evidence on which such statements are based consists mostly of surveys such as the one reported by Kegeles et al,4 in which 60% of 180 persons surveyed in 1987 and 1988 would not be tested if positive results had to be reported to health officials or if partner notification (“contact tracing”) were conducted. These surveys on the perceived and hypothetical barriers to testing have been reviewed by Burris,5 who detected a number of flaws (some of which we discuss later). He concluded that they do not provide an “account of determinants of the underlying social risk [to testing]... and so fail to provide a basis for properly identifying what people are afraid of through research.” The evidence showing an effect of HIV reporting on actual testing behavior is scantier. In 1988, Johnson et al22 showed that concern about HIV reporting was the main reason they were not tested22; most could not correctly identify their state’s reporting policy.24 An analysis of data from the 1988 AIDS Knowledge and Attitudes Survey of more than 20,000 people also found no relationship between HIV reporting requirements and previous or planned use of testing.26 Our results showing no large declines in the number of persons (overall or among high-risk groups) seeking testing at publicly funded CT sites after the implementation of HIV reporting policies complement and confirm these last 2 studies.

One reason for the differences in findings from these studies is the populations studied. The studies that focused on groups (eg, MSM8,11 or persons seeking anonymous testing12) that have a greater interest in confidentiality and discrimination issues were more apt to find significant concerns about HIV reporting. Most of the persons in the 1988 general population survey25 were low-risk persons who would be less concerned about HIV reporting. Among highly concerned groups, either there must be heterogeneity of opinion or...
perceived risks stated in hypothetical surveys do not actually result in avoidance of testing, as suggested by the lack of declines in testing among MSM in our study. We found declines in testing among blacks and injection drug users in Louisiana, Michigan, and New Jersey after HIV reporting began. In New Jersey, the declines were less than 2% and were within the range expected for routine year-to-year variation. In Louisiana, the declines were consistent with overall declines in testing that were present before HIV reporting was implemented, as evidenced by the lack of significant differences in trends before and after HIV reporting. The declines in Louisiana may have been related to changes in CT program policy that were occurring during the study period. For example, many CT sites in this state had to be excluded from the analysis because they had stopped offering testing due to the low number of HIV-positive persons identified. In addition, many CT sites repeatedly test low-risk clients; over time, these sites may counsel persons at lower risk to return for testing less often.

The declining trends for blacks and injection drug users in Michigan were difficult to interpret because we were not able to define a date of HIV reporting implementation. Legislation on HIV reporting was enacted in Michigan in 1988. However, because the health department had no infrastructure to support additional data collection, HIV case reports were not actively solicited from physicians, clinicians, laboratories, and institutions until April 1992. The active solicitation of case reports was focused mostly on public providers and was not accompanied by publicity. Most clients at CT sites were probably unaware of this change in policy. In addition, Magic Johnson’s announcement was especially felt in Michigan because he had once lived there. His announcement was made in November 1991; in our analysis, the data for the year before HIV reporting included the months immediately after the announcement. The decline in the number of tests after HIV reporting could have been an artifact caused by a return to baseline levels of testing after a transient increase following the announcement. To further substantiate this, we examined additional data from Michigan 1 year after the study period; the number of tests for blacks had increased 9% (from 21,792 to 23,726), and the number of tests for injection drug users had increased 15% (from 2,247 to 2,830). These levels were similar to levels in the year before the study period: 23,391 tests for blacks and 3,518 tests for injection drug users.

Another reason for differences in results may be the timing of the studies. Many of the early studies were conducted before the highly effective antiretroviral therapies became available. As therapies have improved, the advantages to the patient of early diagnosis and treatment can provide a powerful incentive to testing, and these advantages may outweigh concerns about HIV reporting. Since the early years of the epidemic, there has also been considerable experience with the security and confidentiality of AIDS case-reporting data and with issues of discrimination, which may have allayed the concerns of persons considering HIV testing. Case-reporting data for AIDS have been heavily relied on to allocate resources and services for infected patients. Populations who benefit from these services may understand the need for this information and be willing to provide it.

Anonymous testing was available in 4 of the states in our study. Reports have suggested that the introduction of anonymous testing increases testing in high-risk populations and the elimination of it decreases testing in these groups. In Nevada and Tennessee, where anonymous testing was not available, overall testing increased after HIV reporting; however, a small decline in testing occurred among MSM in Tennessee. If there had been no access to anonymous testing in the other states, more declines in testing after HIV reporting policies might have been seen. In the states where we could evaluate anonymous vs confidential testing, the percentage of tests that were anonymous decreased from 15% to 13% in Louisiana and increased from 43% to 50% in Nebraska before and after HIV reporting. From these results we conclude that there may be some persons who wish to test anonymously and concur with the recent recommendation of the Council of State and Territorial Epidemiologists that states considering HIV reporting policies should make anonymous testing available.

The HIV CT data system has a number of limitations because it is designed to measure delivery and use of testing services, not to support a rigorous analysis of testing patterns. The system measures the number of tests rather than the number of persons tested; thus, people may be tested multiple times and the results cannot be identified as coming from repeat tests. Each state CT program is unique and policy changes (eg, in funding, personnel, testing resources, advice given by counselors on when to return for retesting, site selection), media events, availability of other testing services in the community, and many other factors unrelated to HIV reporting may have affected the secular trends in testing. We tried, through our survey of CT coordinators and our site exclusion criteria, to account for some of the minor factors that coincided with the implementation of HIV reporting. Finally, these data are not representative of testing trends in the offices of private physicians or other settings where persons may be tested. Despite these limitations, the number and variety of publicly funded CT sites and the large numbers of persons who use those testing services make it unlikely that a large adverse effect of HIV reporting on testing would have been missed.

With the changing trends in clinical AIDS incidence (~6% between 1985 and 1990) and AIDS deaths (~25% between 1995 and 1996) brought about by improved therapies, information on HIV-infected non-AIDS cases obtained through HIV case reporting will be needed for monitoring, planning, and allocation of resources for prevention and clinical services. As states implement confidential HIV reporting policies, these data indicate that the impact of surveillance on those seeking HIV testing will be small and should not hinder HIV prevention efforts.

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References
Effect of HIV Reporting on HIV Testing—Nakashima et al

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