FOIA Number: 2018-0758-F

FOIA MARKER

This is not a textual record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

Collection/Record Group: Clinton Presidential Records

Subgroup/Office of Origin: National AIDS Policy Office

Series/Staff Member: Todd Summers

Subseries:

OA/ID Number: 21089

FolderID:

Folder Title:
Issues - HIV Surveillance-Studies

Stack:	Row:	Section:	Shelf:	Position:
S	66	6	3	1

Elizabeth Summy <esummy @ os.dhhs.gov>
12/23/98 04:07:23 PM

Please respond to esummy@os.dhhs.gov

Record Type: Record

To: jennings_c @ a1.eop.gov, Todd A. Summers/OPD/EOP

cc: Devorah R. Adler/OPD/EOP
Subject: Q&A on the MMWR article on HIV

FYI - The article is on it's way. Happy Holidays!

Q: What bearing does today's MMWR article have on the guidance CDC has published on HIV surveillance? Is CDC attempting to use this study to support their recommendation that states use a names-based reporting system, and was it timed to come out during the 30-day comment period on that guidance?

A: This article is part of the research CDC and others have carried out which examines attitudes toward HIV testing, and barriers that prevent or delay early testing. It's important that we look at all data available, and those commenting on the guidance will be able to include their views on this article in their comments.

While CDC's December 10th guidance recommended names-based reporting as the system most likely to provide the best information on HIV infection for public health purposes, CDC understands that the privacy concerns expressed by many advocacy groups and individuals are real, and we take them very seriously. That is why the guidelines make it clear that CDC will work with each state to put in place a surveillance and reporting system that best meets the needs of that state -- whether it is name-based, or uses a code or "unique identifier." Nothing in today's article affects that position. Additionally, the guidance published December 10th stresses CDC's strong position that every state should provide anonymous testing, and today's MMWR article underlines the need for such testing.

Q: Some would say the data in this study suggest that names-based reporting can be a deterrent to testing among certain high-risk groups. How does that square with CDC's guidance, and the department's attempts to encourage HIV testing and new surveillance?

A: As we said when the guidance was released, the changing face of the epidemic makes it critical that we gather good information about HIV infection rates, so that we can best target resources to fight the disease. CDC will work closely with states to ensure that no matter what form of surveillance a state undertakes, the information gathered will be subject to the strictest confidentialty and privacy standards. We will also monitor the effects of changes in HIV surveillance in the states to see whether

there is any adverse effect on testing. CDC will work with public health professionals and advocates at the local, state and national level to make sure that every step is taken to ensure the security and confidentialty of surveillance data -- and to make sure the message goes out to communities at risk that their privacy will be protected.

FACSIMILE

DATE: 12/23

TO: Todd Summers

FAX#: 456-2438

FROM: Elizabeth Summy
Deputy Chief of Staff

Phone: 202/690-7431 Fax: 202/401-5783

COMMENTS:

7 **Pages [including this cover]**

HIV Testing Among Populations at Risk for HIV Infection — Nine States, November 1995–December 1996

Extending acquired immunodeficiency syndrome (AIDS) case surveillance systems to include confidential (name-based) reporting of human immunodeficiency virus (HIV) infections provides data representing recent HIV transmission patterns (*1*). These data may improve the ability of public health agencies to plan and evaluate HIV prevention and treatment services. Thirty-two states conduct name-based HIV infection case surveillance as an extension of AIDS case surveillance (*2*), and such surveillance is being considered in other states. Some community representatives and public health officials, however, are concerned that HIV infection surveillance may deter some at-risk persons from seeking HIV testing. This report describes the results of a survey conducted to assess deterrents to HIV testing in populations at risk for HIV infection during 1995 and 1996. The findings indicate that in these populations knowledge of state HIV reporting policies was low, and fear of a positive HIV test result and a lack of perceived risk for HIV infection were the most common deterrents to testing in all risk groups. However, untested men who have sex with men (MSM) who resided in states with name-based reporting cited concerns about reporting as a reason they had not tested more often than untested MSM in states without name-based reporting.

HIV Testing — Continued

The HIV Testing Survey (HITS) was a cross-sectional study conducted among persons at risk for HIV infection in nine states with different HIV reporting policies.* MSM were recruited from gay bars; injecting-drug users (IDUs), through street outreach; and sexually active heterosexuals, through sexually transmitted disease clinics. The study was designed to recruit approximately equal numbers of persons from each of these populations in all states. Using an anonymous structured questionnaire, trained interviewers from health departments and community-based organizations assessed participants' knowledge of state HIV reporting laws, self-reported HIV testing history, and reasons for delaying testing or not being tested.

During December 1995–November 1996, 2570 eligible participants were interviewed. Of these, 200 (7.8%) reported being HIV infected and were excluded from this analysis. Of the remaining 2370 HIV-negative or untested persons, 1810 (76%) had been tested for HIV at least once. The proportion of persons who had been tested for HIV differed by risk group: 582 (68%) of 851 heterosexuals, 596 (79%) of 750 MSM, and 632 (82%) of 769 IDUs had been tested. Testing rates were the same for men and women (76% of 1774 men and 592 women); similar for non-Hispanic blacks (76% of 934), non-Hispanic whites (76% of 873), and Hispanics (75% of 444); and differed significantly by age group (persons aged 18–24 years were less likely to have been tested [68%] than persons in older age groups [range: 76%–81%]).

Most of the respondents stated that they did not know whether persons with HIV infection were reported to the health department by name: 60% in name-based reporting states, 60% in unique identifier (UI)-based reporting states, and 66% in nonreporting states. Only a small proportion of respondents knew their state's HIV reporting policy: 19% in states with name-based reporting, 12% in states with UI-based reporting, and 11% in states with neither name-based or UI-based reporting.

Respondents were asked about the likelihood of being tested for HIV infection during the next 12 months according to several scenarios. Overall, 84% of respondents stated that they were likely to get tested during the next year if they could be tested anonymously and no results were reported to the health department. Respondents were then asked their likelihood of seeking testing during the next 12 months if no anonymous testing was available and various HIV case reporting scenarios existed: no HIV reporting, 72%; UI-based HIV reporting, 73%; and name-based HIV reporting, 61%.

Respondents were asked to indicate whether each of 17 factors had contributed to not being tested (556 respondents) or to delaying testing (1810 respondents) and which of these was the main factor (Table 1). The main factors for not being tested or delaying testing were fear of learning they were HIV-positive (25% and 23%, respectively); thinking they were unlikely to have been exposed to HIV (18% and 10%); thinking that they were HIV-negative (13% and 11%); not wanting to think about the possibility of being HIV-positive (8% and 9%); and thinking there was little they could do about being HIV-positive (6% and 4%). Among persons who had not been tested, a concern about having one's name reported to the government was cited as one of the factors for not testing for 19% and was the main factor for 2% (Table 1). Concern about

*Name-based HIV case surveillance was conducted in Arizona, Colorado, Mississippi, Missouri, and North Carolina (patient names are not reported to CDC); unique identifier (UI)-based HIV case surveillance was conducted in Maryland and Texas; neither name-based nor UI-based HIV case surveillance was conducted in New Mexico and Oregon during the study period. All states except Mississippi offered publicly funded anonymous HIV testing and counseling.

TABLE 1. Percentage of untested respondents reporting factors* for not testing for HIV, and percentage of tested respondents reporting factors* for delaying testing, by HIV risk factor — HIV Testing Survey,† December 1995–November 1996

Testing status/Factor	Men who have sex with men		Heterosexual		Injecting-drug user		Total§	
	A factor	Main factor	A factor	Main factor	A factor	Main factor	A factor	Main factor
Not testing¶	(n=151)		(n=269)		(n=136)		(n=556)	
Afraid to find out	59	27	41	21	51	30	48	25
Unlikely to have been exposed	52	17	48	25	25	7	44	18
Thought they were HIV negative	57	19	49	15	33	6	47	13
Didn't want to think about being positive	55	7	42	8	54	10	48	8
Could do little if HIV positive	45	9	19	3	40	7	31	6
Didn't have time	14	3	20	4	20	5	19	4
Unsure where to go	15	2	21	4	32	6	22	4
Worried name would be reported	28	4	13	1	18	1	19	2
Test costs too much	5	2	5	<1	17	3	8	2
People might think you have AIDS	27	1	10	<1	18	4	17	1
Delaying testing**	(n=596)		(n=582)		(n=632)		(n=1810)	
Afraid to find out	53	26	38	18	47	24	46	23
Thought they were HIV negative	41	10	45	13	36	9	41	11
Unlikely to have been exposed	29	9	34	14	25	6	29	10
Didn't want to think about being positive	49	8	42	8	49	10	47	9
Didn't have time	16	5	16	6	18	5	17	5
Could do little if HIV positive	22	2	18	3	31	6	24	4
Waiting for results would be hard	38	7	22	3	28	3	30	4
Afraid of needle used to draw blood	15	4	16	4	7	<1	12	3
Worried name would be reported	22	4	11	<1	18	3	17	2
Worried about who would learn results	25	3	15	1	19	1	20	2

*Data presented for the 10 most frequently cited factors of 17 listed in the survey.
†Survey was conducted in Arizona, Colorado, Maryland, Mississippi, Missouri, New Mexico, North Carolina, Oregon, and Texas.
§The totals are based on unweighted data from all participants included in this analysis; data do not represent the general population or a weighted average of populations at increased risk for HIV infection.
¶Main factors do not sum to 100% because 10 of 17 factors are presented and 62 (11%) of 556 untested respondents cited no factors for not testing.
**Main factors do not sum to 100% because 10 of 17 factors are presented and 374 (21%) of 1810 tested respondents cited no factors for delaying testing.

HIV Testing — Continued

reporting was the main factor for not testing for 4% of untested MSM, 1% of untested IDUs, 1% of untested heterosexuals, 3% of untested non-Hispanic whites, <1% of untested non-Hispanic blacks, and 3% of untested Hispanics. Among persons who had been tested, the proportions of these subgroups citing concern about reporting as the main factor for delaying testing were similar (≤4%).

Among the 556 untested persons, concern about name-based reporting was stratified by state HIV reporting policy (Table 2). A higher proportion of MSM in states with name-based reporting than in states without name-based reporting cited concern about having their name reported to the government as a factor for not testing (35% compared with 11%; p<0.01), but there was no difference in the frequency of concern about reporting as the main factor for not testing (3% compared with 7%, p=0.4).

Reported by: FM Hecht, MD, AB Bindman, MD, D Osmond, PhD, K Vranizan, MA, S Colman, PhD, D Keane, MPH, MA Chesney, PhD, Univ of California, San Francisco. AL Reingold, MD, Univ of California, Berkeley. Div of HIV/AIDS Prevention–Surveillance and Epidemiology, National Center for HIV, STD, and TB Prevention, CDC.

Editorial Note: The findings in this report indicate that, although the proportion of respondents that had been tested was high (76%), most reported at least some delay before getting tested. Fear of learning that one is infected with HIV and the belief that one is unlikely to have been exposed to HIV were cited most frequently as factors for delaying testing or not testing. Reducing fear and increasing knowledge about HIV risk present ongoing challenges to designing effective prevention programs.

TABLE 2. Frequency of concern about having one's name reported to the government as a factor for not testing for HIV infection, by state HIV reporting policy — HIV Testing Survey,* December 1995–November 1996

Characteristics	Named		Non-named†		p value§
	No.	(%)	No.	(%)	
Men who have sex with men	107		44		
A factor	38	(35)	5	(11)	<0.01
Main factor	3	(3)	3	(7)	0.4
Heterosexual	177		92		
A factor	22	(13)	14	(15)	0.5
Main factor	3	(2)	1	(1)	1
Injecting-drug user	66		70		
A factor	14	(21)	10	(14)	0.3
Main factor	2	(3)	0	(0)	0.2
Total¶	**350**		**206**		
A factor	**74**	**(21)**	**29**	**(14)**	**0.05**
Main factor	**8**	**(2)**	**4**	**(2)**	**1**

*Name-based HIV case surveillance was conducted in Arizona, Colorado, Mississippi, Missouri, and North Carolina (patient names are not reported to CDC); unique identifier (UI)-based HIV case surveillance was conducted in Maryland and Texas; neither name-based nor UI-based HIV case surveillance was conducted in New Mexico and Oregon during the study period.

†UI-based reporting was implemented during the year preceding the study in Maryland and Texas; 67% of tested respondents in these states had been tested at least once before this policy change. Because of the state reporting policy changes and to avoid small cell sizes in the analysis restricted to the minority of respondents who had never been tested, UI-based reporting and nonreporting states were combined in the non-named reporting category.

§Fisher's exact test.

¶The totals are based on unweighted data from all participants included in this analysis; data do not represent the general population or a weighted average of populations at increased risk for HIV infection.

HIV Testing — Continued

Although concern about having one's name reported to the government was a less commonly cited factor for not testing or delaying testing for HIV infection, the findings suggest that state HIV reporting policies may deter or delay some persons, particularly MSM, from being tested. The effect of HIV-infection reporting policies on actual testing may be limited because in this study most respondents did not know their state's HIV reporting policy and because the implementation of name-based HIV reporting policies also does not appear to have a significant effect on use of publicly funded counseling and testing programs (*3*). However, any potential deterrent effect on HIV testing among MSM or other at-risk populations (e.g., racial/ethnic minorities) is important. The findings in this report support the importance of addressing privacy concerns both in states that are considering implementing name-based HIV reporting and in states that already have adopted such policies. CDC and the Council of State and Territorial Epidemiologists are promoting development of model privacy statutes, which will strengthen current state confidentiality protections. In addition, CDC requires standardized security measures for all recipients of CDC HIV/AIDS surveillance funds and continues to provide technical assistance to all states to monitor the effect of changes in HIV testing and reporting policies on testing behaviors.

In this study, respondents reported they would be more likely to seek future testing if an anonymous HIV test option were available. Persons who recognize their risk, seek early HIV testing, and receive counseling can modify their behavior to reduce HIV transmission and seek medical care and other services that promote health and improve survival. Maintaining access to anonymous HIV testing is an important option for some persons at high risk for HIV infection (*4*), and CDC strongly recommends that all states provide publicly funded anonymous HIV testing and counseling.

The findings in this report are subject to at least four limitations. First, the study was not population-based; it was designed to enroll equal proportions of each of three groups recruited from specific venues and it may not represent all at-risk populations or their distribution in the general population. Second, findings from the nine states included in the survey may not be generalizable to all other states. Third, stated intentions by respondents in this survey may not reflect actual behaviors in obtaining testing for HIV infection. Finally, the beneficial effects of recently available therapies (*5,6*) or increased knowledge about state HIV reporting policies (*7*) may alter current test-seeking behavior.

HITS and related studies and analyses (*3,4,8–10*) were conducted to enhance the scientific basis for public health policy on HIV case surveillance. To monitor the effect of changes in HIV reporting policies on HIV testing behaviors, studies similar to HITS will be conducted in additional states. CDC will continue to provide technical assistance to state and local health departments so that they, in collaboration with public health organizations, health-care providers, and representatives of affected communities, can adopt effective HIV/AIDS surveillance practices that continue to protect confidentiality and permit an effective public health response to the epidemic.

References

1. CDC. Update: trends in AIDS incidence—United States, 1996. MMWR 1997;46:861–7.
2. CDC. HIV/AIDS surveillance report. Atlanta, Georgia: US Department of Health and Human Services, Public Health Service, CDC, 1997;(vol 9, no. 2).
3. Nakashima AK, Horsley R, Frey R, et al. Effect of HIV reporting by name on the use of HIV testing in publicly funded counseling and testing programs. JAMA 1998;280:1421–6.

HIV Testing — Continued

4. Bindman AB, Osmond D, Hecht FM, et al. A multistate evaluation of anonymous HIV testing and access to medical care. JAMA 1998;280:1416–20.
5. CDC. Report of the NIH panel to define principles of therapy of HIV infection. MMWR 1998; 47(no. RR-5).
6. CDC. Guidelines for the use of antiretroviral agents in HIV-infected adults and adolescents. MMWR 1998;47(no. RR-5).
7. US Department of Health and Human Services, CDC. Draft guidelines for HIV case surveillance, including monitoring HIV infection and acquired immunodeficiency syndrome (AIDS). Federal Register 1998;63:68289.
8. CDC. Diagnosis and reporting of HIV and AIDS in states with integrated HIV and AIDS surveillance—United States, January 1994–June 1997. MMWR 1998;47:309–14.
9. CDC. Evaluation of HIV case surveillance through the use of non-name unique identifiers—Maryland and Texas, 1994–1996. MMWR 1998;46:1254–8,1271.
10. Gostin LO, Lazzarini Z, Neslund VS, Osterholm MT. The public health information infrastructure: a national review of the law on health information privacy. JAMA 1996;275:1921–7.

CDC National Prevention Information Network

A Service of the National Center for HIV, STD, and TB Prevention

Operators of the CDC National AIDS Clearinghouse

P.O. Box 6003

Rockville, Maryland 20849-6003

Phone: (800) 458-5231 TTY: (800) 243-7012 Fax: (888) 282-7681 International: (301) 562-1050

CDC Broadcast Fax Cover Page

Date: DECEMBER 23, 1998

To: THE HONORABLE SANDRA THURMAN

Fax Number: 2024562438

Subject: *MMWR*

Pages: 9 (INCLUDING COVER)

Organization: WHITEHOUSE OFF OF NATL AIDS POLICY

Phone Number: 202 4562437

MAY CONTAIN TIME SENSITIVE INFORMATION

Please deliver to the intended recipient immediately! This fax may contain time sensitive information.

DEPARTMENT OF HEALTH & HUMAN SERVICES Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta, GA 30333

December 23, 1998

Dear Colleague:

I would like to call your attention to an article, "HIV Testing Among Populations at Risk for HIV in Nine States: Results from the HIV Testing Survey (HITS) - November 1995 - December 1996," published today in the Centers for Disease Control and Prevention's (CDC) *Morbidity and Mortality Weekly Report* (*MMWR*). This study analyzes the reasons why people at risk for HIV infection either do not get tested or delay testing for HIV.

Although most (76%) of the high-risk individuals in the nine-state study had been tested for HIV, there were several common factors for not getting tested or delaying testing. The reasons most frequently cited (accounting for 70% of the main reasons for not being tested and 57% of reasons for delaying testing) were fear of a positive test result (reported by 25% of those who had not been tested and 23% of those who had delayed testing), thinking that they were HIV negative (reported by 18% and 10% respectively), not wanting to think about the possibility of being HIV positive (8% and 9% respectively), and thinking there was little they could do about it if they were HIV positive (6% and 4% respectively). The data also indicated that HIV reporting policy did not serve as a major deterrent to HIV testing. However, most of the respondents did not know HIV reporting policies for their state (60% of respondents from states that conduct HIV reporting and 66% of respondents from states that don't.) While 19% of respondents who had never been tested for HIV listed concern about HIV reporting by name as a factor in not being tested, only 2% indicated HIV name reporting was the main deterrent. However, this concern was higher among men who have sex with men, with 4% listing it as the main factor for not being tested.

To help ensure that reporting policies do not deter even a small number of high-risk people from seeking testing and to address confidentiality concerns in states that implement HIV surveillance by name, CDC:

- strongly recommends that all states provide publicly funded anonymous HIV testing and counseling
- is encouraging the development of model privacy laws for adoption by states
- is requiring enhanced security measures for all recipients of CDC HIV/AIDS surveillance funds
- will assist states in monitoring the effect of changes in HIV testing and reporting policies on testing behaviors

CDC will also continue to provide technical assistance to health departments so that they, in collaboration with public health organizations, health care providers, and representatives of affected communities, can adopt the best HIV/AIDS surveillance practices. We hope this information is of assistance. As always, if you have any questions, feel free to call our Office of Communications at (404) 639-8890.

Sincerely,

Helene D. Gayle

Helene D. Gayle, M.D., M.P.H.
Director
National Center for HIV, STD, and TB Prevention

CDC
CENTERS FOR DISEASE CONTROL AND PREVENTION

December 25, 1998 / Vol. 47 / No. 50

MMWR™

MORBIDITY AND MORTALITY WEEKLY REPORT

HIV Testing Among Populations at Risk for HIV Infection — Nine States, November 1995–December 1996

Extending acquired immunodeficiency syndrome (AIDS) case surveillance systems to include confidential (name-based) reporting of human immunodeficiency virus (HIV) infections provides data representing recent HIV transmission patterns (*1*). These data may improve the ability of public health agencies to plan and evaluate HIV prevention and treatment services. Thirty-two states conduct name-based HIV infection case surveillance as an extension of AIDS case surveillance (*2*), and such surveillance is being considered in other states. Some community representatives and public health officials, however, are concerned that HIV infection surveillance may deter some at-risk persons from seeking HIV testing. This report describes the results of a survey conducted to assess deterrents to HIV testing in populations at risk for HIV infection during 1995 and 1996. The findings indicate that in these populations knowledge of state HIV reporting policies was low, and fear of a positive HIV test result and a lack of perceived risk for HIV infection were the most common deterrents to testing in all risk groups. However, untested men who have sex with men (MSM) who resided in states with name-based reporting cited concerns about reporting as a reason they had not tested more often than untested MSM in states without name-based reporting.

HIV Testing — Continued

The HIV Testing Survey (HITS) was a cross-sectional study conducted among persons at risk for HIV infection in nine states with different HIV reporting policies.* MSM were recruited from gay bars; injecting-drug users (IDUs), through street outreach; and sexually active heterosexuals, through sexually transmitted disease clinics. The study was designed to recruit approximately equal numbers of persons from each of these populations in all states. Using an anonymous structured questionnaire, trained interviewers from health departments and community-based organizations assessed participants' knowledge of state HIV reporting laws, self-reported HIV testing history, and reasons for delaying testing or not being tested.

During December 1995–November 1996, 2570 eligible participants were interviewed. Of these, 200 (7.8%) reported being HIV infected and were excluded from this analysis. Of the remaining 2370 HIV-negative or untested persons, 1810 (76%) had been tested for HIV at least once. The proportion of persons who had been tested for HIV differed by risk group: 582 (68%) of 851 heterosexuals, 596 (79%) of 750 MSM, and 632 (82%) of 769 IDUs had been tested. Testing rates were the same for men and women (76% of 1774 men and 592 women); similar for non-Hispanic blacks (76% of 934), non-Hispanic whites (76% of 873), and Hispanics (75% of 444); and differed significantly by age group (persons aged 18–24 years were less likely to have been tested [68%] than persons in older age groups [range: 76%–81%]).

Most of the respondents stated that they did not know whether persons with HIV infection were reported to the health department by name: 60% in name-based reporting states, 60% in unique identifier (UI)-based reporting states, and 66% in nonreporting states. Only a small proportion of respondents knew their state's HIV reporting policy: 19% in states with name-based reporting, 12% in states with UI-based reporting, and 11% in states with neither name-based or UI-based reporting.

Respondents were asked about the likelihood of being tested for HIV infection during the next 12 months according to several scenarios. Overall, 84% of respondents stated that they were likely to get tested during the next year if they could be tested anonymously and no results were reported to the health department. Respondents were then asked their likelihood of seeking testing during the next 12 months if no anonymous testing was available and various HIV case reporting scenarios existed: no HIV reporting, 72%; UI-based HIV reporting, 73%; and name-based HIV reporting, 61%.

Respondents were asked to indicate whether each of 17 factors had contributed to not being tested (556 respondents) or to delaying testing (1810 respondents) and which of these was the main factor (Table 1). The main factors for not being tested or delaying testing were fear of learning they were HIV-positive (25% and 23%, respectively); thinking they were unlikely to have been exposed to HIV (18% and 10%); thinking that they were HIV-negative (13% and 11%); not wanting to think about the possibility of being HIV-positive (8% and 9%); and thinking there was little they could do about being HIV-positive (6% and 4%). Among persons who had not been tested, a concern about having one's name reported to the government was cited as one of the factors for not testing for 19% and was the main factor for 2% (Table 1). Concern about

*Name-based HIV case surveillance was conducted in Arizona, Colorado, Mississippi, Missouri, and North Carolina (patient names are not reported to CDC); unique identifier (UI)-based HIV case surveillance was conducted in Maryland and Texas; neither name-based nor UI-based HIV case surveillance was conducted in New Mexico and Oregon during the study period. All states except Mississippi offered publicly funded anonymous HIV testing and counseling.

TABLE 1. Percentage of untested respondents reporting factors* for not testing for HIV, and percentage of tested respondents reporting factors* for delaying testing, by HIV risk factor — HIV Testing Survey,† December 1995–November 1996

Testing status/Factor	Men who have sex with men		Heterosexual		Injecting-drug user		Total§	
	A factor	Main factor	A factor	Main factor	A factor	Main factor	A factor	Main factor
Not testing¶	(n=151)		(n=269)		(n=136)		(n=556)	
Afraid to find out	59	27	41	21	51	30	48	25
Unlikely to have been exposed	52	17	48	25	25	7	44	18
Thought they were HIV negative	57	19	49	15	33	6	47	13
Didn't want to think about being positive	55	7	42	8	54	10	48	8
Could do little if HIV positive	45	9	19	3	40	7	31	6
Didn't have time	14	3	20	4	20	5	19	4
Unsure where to go	15	2	21	4	32	6	22	4
Worried name would be reported	28	4	13	1	18	1	19	2
Test costs too much	5	2	5	<1	17	3	8	2
People might think you have AIDS	27	1	10	<1	18	4	17	1
Delaying testing**	(n=596)		(n=582)		(n=632)		(n=1810)	
Afraid to find out	53	26	38	18	47	24	46	23
Thought they were HIV negative	41	10	45	13	36	9	41	11
Unlikely to have been exposed	29	9	34	14	25	6	29	10
Didn't want to think about being positive	49	8	42	8	49	10	47	9
Didn't have time	16	5	16	6	18	5	17	5
Could do little if HIV positive	22	2	18	3	31	6	24	4
Waiting for results would be hard	38	7	22	3	28	3	30	4
Afraid of needle used to draw blood	15	4	16	4	7	<1	12	3
Worried name would be reported	22	4	11	<1	18	3	17	2
Worried about who would learn results	25	3	15	1	19	1	20	2

*Data presented for the 10 most frequently cited factors of 17 listed in the survey.
†Survey was conducted in Arizona, Colorado, Maryland, Mississippi, Missouri, New Mexico, North Carolina, Oregon, and Texas.
§The totals are based on unweighted data from all participants included in this analysis; data do not represent the general population or a weighted average of populations at increased risk for HIV infection.
¶Main factors do not sum to 100% because 10 of 17 factors are presented and 62 (11%) of 556 untested respondents cited no factors for not testing.
**Main factors do not sum to 100% because 10 of 17 factors are presented and 374 (21%) of 1810 tested respondents cited no factors for delaying testing.

HIV Testing — Continued

reporting was the main factor for not testing for 4% of untested MSM, 1% of untested IDUs, 1% of untested heterosexuals, 3% of untested non-Hispanic whites, <1% of untested non-Hispanic blacks, and 3% of untested Hispanics. Among persons who had been tested, the proportions of these subgroups citing concern about reporting as the main factor for delaying testing were similar (≤4%).

Among the 556 untested persons, concern about name-based reporting was stratified by state HIV reporting policy (Table 2). A higher proportion of MSM in states with name-based reporting than in states without name-based reporting cited concern about having their name reported to the government as a factor for not testing (35% compared with 11%; p<0.01), but there was no difference in the frequency of concern about reporting as the main factor for not testing (3% compared with 7%, p=0.4).

Reported by: FM Hecht, MD, AB Bindman, MD, D Osmond, PhD, K Vranizan, MA, S Colman, PhD, D Keane, MPH, MA Chesney, PhD, Univ of California, San Francisco. AL Reingold, MD, Univ of California, Berkeley. Div of HIV/AIDS Prevention–Surveillance and Epidemiology, National Center for HIV, STD, and TB Prevention, CDC.

Editorial Note: The findings in this report indicate that, although the proportion of respondents that had been tested was high (76%), most reported at least some delay before getting tested. Fear of learning that one is infected with HIV and the belief that one is unlikely to have been exposed to HIV were cited most frequently as factors for delaying testing or not testing. Reducing fear and increasing knowledge about HIV risk present ongoing challenges to designing effective prevention programs.

TABLE 2. Frequency of concern about having one's name reported to the government as a factor for not testing for HIV infection, by state HIV reporting policy — HIV Testing Survey,* December 1995–November 1996

	Named		Non-named†		
Characteristics	**No.**	**(%)**	**No.**	**(%)**	**p value§**
Men who have sex with men	107		44		
A factor	38	(35)	5	(11)	<0.01
Main factor	3	(3)	3	(7)	0.4
Heterosexual	177		92		
A factor	22	(13)	14	(15)	0.5
Main factor	3	(2)	1	(1)	1
Injecting-drug user	66		70		
A factor	14	(21)	10	(14)	0.3
Main factor	2	(3)	0	(0)	0.2
Total¶	**350**		**206**		
A factor	**74**	**(21)**	**29**	**(14)**	**0.05**
Main factor	**8**	**(2)**	**4**	**(2)**	**1**

*Name-based HIV case surveillance was conducted in Arizona, Colorado, Mississippi, Missouri, and North Carolina (patient names are not reported to CDC); unique identifier (UI)-based HIV case surveillance was conducted in Maryland and Texas; neither name-based nor UI-based HIV case surveillance was conducted in New Mexico and Oregon during the study period.

†UI-based reporting was implemented during the year preceding the study in Maryland and Texas; 67% of tested respondents in these states had been tested at least once before this policy change. Because of the state reporting policy changes and to avoid small cell sizes in the analysis restricted to the minority of respondents who had never been tested, UI-based reporting and nonreporting states were combined in the non-named reporting category.

§Fisher's exact test.

¶The totals are based on unweighted data from all participants included in this analysis; data do not represent the general population or a weighted average of populations at increased risk for HIV infection.

HIV Testing — Continued

Although concern about having one's name reported to the government was a less commonly cited factor for not testing or delaying testing for HIV infection, the findings suggest that state HIV reporting policies may deter or delay some persons, particularly MSM, from being tested. The effect of HIV-infection reporting policies on actual testing may be limited because in this study most respondents did not know their state's HIV reporting policy and because the implementation of name-based HIV reporting policies also does not appear to have a significant effect on use of publicly funded counseling and testing programs (*3*). However, any potential deterrent effect on HIV testing among MSM or other at-risk populations (e.g., racial/ethnic minorities) is important. The findings in this report support the importance of addressing privacy concerns both in states that are considering implementing name-based HIV reporting and in states that already have adopted such policies. CDC and the Council of State and Territorial Epidemiologists are promoting development of model privacy statutes, which will strengthen current state confidentiality protections. In addition, CDC requires standardized security measures for all recipients of CDC HIV/AIDS surveillance funds and continues to provide technical assistance to all states to monitor the effect of changes in HIV testing and reporting policies on testing behaviors.

In this study, respondents reported they would be more likely to seek future testing if an anonymous HIV test option were available. Persons who recognize their risk, seek early HIV testing, and receive counseling can modify their behavior to reduce HIV transmission and seek medical care and other services that promote health and improve survival. Maintaining access to anonymous HIV testing is an important option for some persons at high risk for HIV infection (*4*), and CDC strongly recommends that all states provide publicly funded anonymous HIV testing and counseling.

The findings in this report are subject to at least four limitations. First, the study was not population-based; it was designed to enroll equal proportions of each of three groups recruited from specific venues and it may not represent all at-risk populations or their distribution in the general population. Second, findings from the nine states included in the survey may not be generalizable to all other states. Third, stated intentions by respondents in this survey may not reflect actual behaviors in obtaining testing for HIV infection. Finally, the beneficial effects of recently available therapies (*5,6*) or increased knowledge about state HIV reporting policies (*7*) may alter current test-seeking behavior.

HITS and related studies and analyses (*3,4,8–10*) were conducted to enhance the scientific basis for public health policy on HIV case surveillance. To monitor the effect of changes in HIV reporting policies on HIV testing behaviors, studies similar to HITS will be conducted in additional states. CDC will continue to provide technical assistance to state and local health departments so that they, in collaboration with public health organizations, health-care providers, and representatives of affected communities, can adopt effective HIV/AIDS surveillance practices that continue to protect confidentiality and permit an effective public health response to the epidemic.

References

1. CDC. Update: trends in AIDS incidence—United States, 1996. MMWR 1997;46:861–7.
2. CDC. HIV/AIDS surveillance report. Atlanta, Georgia: US Department of Health and Human Services, Public Health Service, CDC, 1997;(vol 9, no. 2).
3. Nakashima AK, Horsley R, Frey R, et al. Effect of HIV reporting by name on the use of HIV testing in publicly funded counseling and testing programs. JAMA 1998;280:1421–6.

HIV Testing — Continued

4. Bindman AB, Osmond D, Hecht FM, et al. A multistate evaluation of anonymous HIV testing and access to medical care. JAMA 1998;280:1416–20.
5. CDC. Report of the NIH panel to define principles of therapy of HIV infection. MMWR 1998; 47(no. RR-5).
6. CDC. Guidelines for the use of antiretroviral agents in HIV-infected adults and adolescents. MMWR 1998;47(no. RR-5).
7. US Department of Health and Human Services, CDC. Draft guidelines for HIV case surveillance, including monitoring HIV infection and acquired immunodeficiency syndrome (AIDS). Federal Register 1998;63:68289.
8. CDC. Diagnosis and reporting of HIV and AIDS in states with integrated HIV and AIDS surveillance—United States, January 1994–June 1997. MMWR 1998;47:309–14.
9. CDC. Evaluation of HIV case surveillance through the use of non-name unique identifiers—Maryland and Texas, 1994–1996. MMWR 1998;46:1254–8,1271.
10. Gostin LO, Lazzarini Z, Neslund VS, Osterholm MT. The public health information infrastructure: a national review of the law on health information privacy. JAMA 1996;275:1921–7.

DEPARTMENT OF HEALTH & HUMAN SERVICES Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta, GA 30333

December 23, 1998

Dear Colleague:

I would like to call your attention to an article, "HIV Testing Among Populations at Risk for HIV in Nine States: Results from the HIV Testing Survey (HITS) - November 1995 - December 1996," published today in the Centers for Disease Control and Prevention's (CDC) *Morbidity and Mortality Weekly Report* (*MMWR*). This study analyzes the reasons why people at risk for HIV infection either do not get tested or delay testing for HIV.

Although most (76%) of the high-risk individuals in the nine-state study had been tested for HIV, there were several common factors for not getting tested or delaying testing. The reasons most frequently cited (accounting for 70% of the main reasons for not being tested and 57% of reasons for delaying testing) were fear of a positive test result (reported by 25% of those who had not been tested and 23% of those who had delayed testing), thinking that they were HIV negative (reported by 18% and 10% respectively), not wanting to think about the possibility of being HIV positive (8% and 9% respectively), and thinking there was little they could do about it if they were HIV positive (6% and 4% respectively). The data also indicated that HIV reporting policy did not serve as a major deterrent to HIV testing. However, most of the respondents did not know HIV reporting policies for their state (60% of respondents from states that conduct HIV reporting and 66% of respondents from states that don't.) While 19% of respondents who had never been tested for HIV listed concern about HIV reporting by name as a factor in not being tested, only 2% indicated HIV name reporting was the main deterrent. However, this concern was higher among men who have sex with men, with 4% listing it as the main factor for not being tested.

To help ensure that reporting policies do not deter even a small number of high-risk people from seeking testing and to address confidentiality concerns in states that implement HIV surveillance by name, CDC:

- strongly recommends that all states provide publicly funded anonymous HIV testing and counseling
- is encouraging the development of model privacy laws for adoption by states
- is requiring enhanced security measures for all recipients of CDC HIV/AIDS surveillance funds
- will assist states in monitoring the effect of changes in HIV testing and reporting policies on testing behaviors

CDC will also continue to provide technical assistance to health departments so that they, in collaboration with public health organizations, health care providers, and representatives of affected communities, can adopt the best HIV/AIDS surveillance practices. We hope this information is of assistance. As always, if you have any questions, feel free to call our Office of Communications at (404) 639-8890.

Sincerely,

Helene D. Gayle

Helene D. Gayle, M.D., M.P.H.
Director
National Center for HIV, STD, and TB Prevention

CDC

December 25, 1998 / Vol. 47 / No. 50

MMWR™

MORBIDITY AND MORTALITY WEEKLY REPORT

HIV Testing Among Populations at Risk for HIV Infection — Nine States, November 1995–December 1996

Extending acquired immunodeficiency syndrome (AIDS) case surveillance systems to include confidential (name-based) reporting of human immunodeficiency virus (HIV) infections provides data representing recent HIV transmission patterns (*1*). These data may improve the ability of public health agencies to plan and evaluate HIV prevention and treatment services. Thirty-two states conduct name-based HIV infection case surveillance as an extension of AIDS case surveillance (*2*), and such surveillance is being considered in other states. Some community representatives and public health officials, however, are concerned that HIV infection surveillance may deter some at-risk persons from seeking HIV testing. This report describes the results of a survey conducted to assess deterrents to HIV testing in populations at risk for HIV infection during 1995 and 1996. The findings indicate that in these populations knowledge of state HIV reporting policies was low, and fear of a positive HIV test result and a lack of perceived risk for HIV infection were the most common deterrents to testing in all risk groups. However, untested men who have sex with men (MSM) who resided in states with name-based reporting cited concerns about reporting as a reason they had not tested more often than untested MSM in states without name-based reporting.

HIV Testing — Continued

The HIV Testing Survey (HITS) was a cross-sectional study conducted among persons at risk for HIV infection in nine states with different HIV reporting policies.* MSM were recruited from gay bars; injecting-drug users (IDUs), through street outreach; and sexually active heterosexuals, through sexually transmitted disease clinics. The study was designed to recruit approximately equal numbers of persons from each of these populations in all states. Using an anonymous structured questionnaire, trained interviewers from health departments and community-based organizations assessed participants' knowledge of state HIV reporting laws, self-reported HIV testing history, and reasons for delaying testing or not being tested.

During December 1995–November 1996, 2570 eligible participants were interviewed. Of these, 200 (7.8%) reported being HIV infected and were excluded from this analysis. Of the remaining 2370 HIV-negative or untested persons, 1810 (76%) had been tested for HIV at least once. The proportion of persons who had been tested for HIV differed by risk group: 582 (68%) of 851 heterosexuals, 596 (79%) of 750 MSM, and 632 (82%) of 769 IDUs had been tested. Testing rates were the same for men and women (76% of 1774 men and 592 women); similar for non-Hispanic blacks (76% of 934), non-Hispanic whites (76% of 873), and Hispanics (75% of 444); and differed significantly by age group (persons aged 18–24 years were less likely to have been tested [68%] than persons in older age groups [range: 76%–81%]).

Most of the respondents stated that they did not know whether persons with HIV infection were reported to the health department by name: 60% in name-based reporting states, 60% in unique identifier (UI)-based reporting states, and 66% in nonreporting states. Only a small proportion of respondents knew their state's HIV reporting policy: 19% in states with name-based reporting, 12% in states with UI-based reporting, and 11% in states with neither name-based or UI-based reporting.

Respondents were asked about the likelihood of being tested for HIV infection during the next 12 months according to several scenarios. Overall, 84% of respondents stated that they were likely to get tested during the next year if they could be tested anonymously and no results were reported to the health department. Respondents were then asked their likelihood of seeking testing during the next 12 months if no anonymous testing was available and various HIV case reporting scenarios existed: no HIV reporting, 72%; UI-based HIV reporting, 73%; and name-based HIV reporting, 61%.

Respondents were asked to indicate whether each of 17 factors had contributed to not being tested (556 respondents) or to delaying testing (1810 respondents) and which of these was the main factor (Table 1). The main factors for not being tested or delaying testing were fear of learning they were HIV-positive (25% and 23%, respectively); thinking they were unlikely to have been exposed to HIV (18% and 10%); thinking that they were HIV-negative (13% and 11%); not wanting to think about the possibility of being HIV-positive (8% and 9%); and thinking there was little they could do about being HIV-positive (6% and 4%). Among persons who had not been tested, a concern about having one's name reported to the government was cited as one of the factors for not testing for 19% and was the main factor for 2% (Table 1). Concern about

*Name-based HIV case surveillance was conducted in Arizona, Colorado, Mississippi, Missouri, and North Carolina (patient names are not reported to CDC); unique identifier (UI)-based HIV case surveillance was conducted in Maryland and Texas; neither name-based nor UI-based HIV case surveillance was conducted in New Mexico and Oregon during the study period. All states except Mississippi offered publicly funded anonymous HIV testing and counseling.

TABLE 1. Percentage of untested respondents reporting factors* for not testing for HIV, and percentage of tested respondents reporting factors* for delaying testing, by HIV risk factor — HIV Testing Survey,† December 1995–November 1996

Testing status/Factor	Men who have sex with men		Heterosexual		Injecting-drug user		Total§	
	A factor	Main factor	A factor	Main factor	A factor	Main factor	A factor	Main factor
Not testing¶	(n=151)		(n=269)		(n=136)		(n=556)	
Afraid to find out	59	27	41	21	51	30	48	25
Unlikely to have been exposed	52	17	48	25	25	7	44	18
Thought they were HIV negative	57	19	49	15	33	6	47	13
Didn't want to think about being positive	55	7	42	8	54	10	48	8
Could do little if HIV positive	45	9	19	3	40	7	31	6
Didn't have time	14	3	20	4	20	5	19	4
Unsure where to go	15	2	21	4	32	6	22	4
Worried name would be reported	28	4	13	1	18	1	19	2
Test costs too much	5	2	5	<1	17	3	8	2
People might think you have AIDS	27	1	10	<1	18	4	17	1
Delaying testing**	(n=596)		(n=582)		(n=632)		(n=1810)	
Afraid to find out	53	26	38	18	47	24	46	23
Thought they were HIV negative	41	10	45	13	36	9	41	11
Unlikely to have been exposed	29	9	34	14	25	6	29	10
Didn't want to think about being positive	49	8	42	8	49	10	47	9
Didn't have time	16	5	16	6	18	5	17	5
Could do little if HIV positive	22	2	18	3	31	6	24	4
Waiting for results would be hard	38	7	22	3	28	3	30	4
Afraid of needle used to draw blood	15	4	16	4	7	<1	12	3
Worried name would be reported	22	4	11	<1	18	3	17	2
Worried about who would learn results	25	3	15	1	19	1	20	2

*Data presented for the 10 most frequently cited factors of 17 listed in the survey.
†Survey was conducted in Arizona, Colorado, Maryland, Mississippi, Missouri, New Mexico, North Carolina, Oregon, and Texas.
§The totals are based on unweighted data from all participants included in this analysis; data do not represent the general population or a weighted average of populations at increased risk for HIV infection.
¶Main factors do not sum to 100% because 10 of 17 factors are presented and 62 (11%) of 556 untested respondents cited no factors for not testing.
**Main factors do not sum to 100% because 10 of 17 factors are presented and 374 (21%) of 1810 tested respondents cited no factors for delaying testing.

HIV Testing — Continued

reporting was the main factor for not testing for 4% of untested MSM, 1% of untested IDUs, 1% of untested heterosexuals, 3% of untested non-Hispanic whites, <1% of untested non-Hispanic blacks, and 3% of untested Hispanics. Among persons who had been tested, the proportions of these subgroups citing concern about reporting as the main factor for delaying testing were similar (≤4%).

Among the 556 untested persons, concern about name-based reporting was stratified by state HIV reporting policy (Table 2). A higher proportion of MSM in states with name-based reporting than in states without name-based reporting cited concern about having their name reported to the government as a factor for not testing (35% compared with 11%; p<0.01), but there was no difference in the frequency of concern about reporting as the main factor for not testing (3% compared with 7%, p=0.4).

Reported by: FM Hecht, MD, AB Bindman, MD, D Osmond, PhD, K Vranizan, MA, S Colman, PhD, D Keane, MPH, MA Chesney, PhD, Univ of California, San Francisco. AL Reingold, MD, Univ of California, Berkeley. Div of HIV/AIDS Prevention–Surveillance and Epidemiology, National Center for HIV, STD, and TB Prevention, CDC.

Editorial Note: The findings in this report indicate that, although the proportion of respondents that had been tested was high (76%), most reported at least some delay before getting tested. Fear of learning that one is infected with HIV and the belief that one is unlikely to have been exposed to HIV were cited most frequently as factors for delaying testing or not testing. Reducing fear and increasing knowledge about HIV risk present ongoing challenges to designing effective prevention programs.

TABLE 2. Frequency of concern about having one's name reported to the government as a factor for not testing for HIV infection, by state HIV reporting policy — HIV Testing Survey,* December 1995–November 1996

	Named		Non-named†		
Characteristics	No.	(%)	No.	(%)	p value§
Men who have sex with men	107		44		
A factor	38	(35)	5	(11)	<0.01
Main factor	3	(3)	3	(7)	0.4
Heterosexual	177		92		
A factor	22	(13)	14	(15)	0.5
Main factor	3	(2)	1	(1)	1
Injecting-drug user	66		70		
A factor	14	(21)	10	(14)	0.3
Main factor	2	(3)	0	(0)	0.2
Total¶	**350**		**206**		
A factor	**74**	**(21)**	**29**	**(14)**	**0.05**
Main factor	**8**	**(2)**	**4**	**(2)**	**1**

*Name-based HIV case surveillance was conducted in Arizona, Colorado, Mississippi, Missouri, and North Carolina (patient names are not reported to CDC); unique identifier (UI)-based HIV case surveillance was conducted in Maryland and Texas; neither name-based nor UI-based HIV case surveillance was conducted in New Mexico and Oregon during the study period.

†UI-based reporting was implemented during the year preceding the study in Maryland and Texas; 67% of tested respondents in these states had been tested at least once before this policy change. Because of the state reporting policy changes and to avoid small cell sizes in the analysis restricted to the minority of respondents who had never been tested, UI-based reporting and nonreporting states were combined in the non-named reporting category.

§Fisher's exact test.

¶The totals are based on unweighted data from all participants included in this analysis; data do not represent the general population or a weighted average of populations at increased risk for HIV infection.

HIV Testing — Continued

Although concern about having one's name reported to the government was a less commonly cited factor for not testing or delaying testing for HIV infection, the findings suggest that state HIV reporting policies may deter or delay some persons, particularly MSM, from being tested. The effect of HIV-infection reporting policies on actual testing may be limited because in this study most respondents did not know their state's HIV reporting policy and because the implementation of name-based HIV reporting policies also does not appear to have a significant effect on use of publicly funded counseling and testing programs (*3*). However, any potential deterrent effect on HIV testing among MSM or other at-risk populations (e.g., racial/ethnic minorities) is important. The findings in this report support the importance of addressing privacy concerns both in states that are considering implementing name-based HIV reporting and in states that already have adopted such policies. CDC and the Council of State and Territorial Epidemiologists are promoting development of model privacy statutes, which will strengthen current state confidentiality protections. In addition, CDC requires standardized security measures for all recipients of CDC HIV/AIDS surveillance funds and continues to provide technical assistance to all states to monitor the effect of changes in HIV testing and reporting policies on testing behaviors.

In this study, respondents reported they would be more likely to seek future testing if an anonymous HIV test option were available. Persons who recognize their risk, seek early HIV testing, and receive counseling can modify their behavior to reduce HIV transmission and seek medical care and other services that promote health and improve survival. Maintaining access to anonymous HIV testing is an important option for some persons at high risk for HIV infection (*4*), and CDC strongly recommends that all states provide publicly funded anonymous HIV testing and counseling.

The findings in this report are subject to at least four limitations. First, the study was not population-based; it was designed to enroll equal proportions of each of three groups recruited from specific venues and it may not represent all at-risk populations or their distribution in the general population. Second, findings from the nine states included in the survey may not be generalizable to all other states. Third, stated intentions by respondents in this survey may not reflect actual behaviors in obtaining testing for HIV infection. Finally, the beneficial effects of recently available therapies (*5,6*) or increased knowledge about state HIV reporting policies (*7*) may alter current test-seeking behavior.

HITS and related studies and analyses (*3,4,8–10*) were conducted to enhance the scientific basis for public health policy on HIV case surveillance. To monitor the effect of changes in HIV reporting policies on HIV testing behaviors, studies similar to HITS will be conducted in additional states. CDC will continue to provide technical assistance to state and local health departments so that they, in collaboration with public health organizations, health-care providers, and representatives of affected communities, can adopt effective HIV/AIDS surveillance practices that continue to protect confidentiality and permit an effective public health response to the epidemic.

References

1. CDC. Update: trends in AIDS incidence—United States, 1996. MMWR 1997;46:861–7.
2. CDC. HIV/AIDS surveillance report. Atlanta, Georgia: US Department of Health and Human Services, Public Health Service, CDC, 1997;(vol 9, no. 2).
3. Nakashima AK, Horsley R, Frey R, et al. Effect of HIV reporting by name on the use of HIV testing in publicly funded counseling and testing programs. JAMA 1998;280:1421–6.

HIV Testing — Continued

4. Bindman AB, Osmond D, Hecht FM, et al. A multistate evaluation of anonymous HIV testing and access to medical care. JAMA 1998;280:1416–20.
5. CDC. Report of the NIH panel to define principles of therapy of HIV infection. MMWR 1998; 47(no. RR-5).
6. CDC. Guidelines for the use of antiretroviral agents in HIV-infected adults and adolescents. MMWR 1998;47(no. RR-5).
7. US Department of Health and Human Services, CDC. Draft guidelines for HIV case surveillance, including monitoring HIV infection and acquired immunodeficiency syndrome (AIDS). Federal Register 1998;63:68289.
8. CDC. Diagnosis and reporting of HIV and AIDS in states with integrated HIV and AIDS surveillance—United States, January 1994–June 1997. MMWR 1998;47:309–14.
9. CDC. Evaluation of HIV case surveillance through the use of non-name unique identifiers—Maryland and Texas, 1994–1996. MMWR 1998;46:1254–8,1271.
10. Gostin LO, Lazzarini Z, Neslund VS, Osterholm MT. The public health information infrastructure: a national review of the law on health information privacy. JAMA 1996;275:1921–7.

CDC National Prevention Information Network

A Service of the National Center for HIV, STD, and TB Prevention

Operators of the CDC National AIDS Clearinghouse

P.O. Box 6003

Rockville, Maryland 20849-6003

Phone: (800) 458-5231 TTY: (800) 243-7012 Fax: (888) 282-7681 International: (301) 562-1050

CDC Broadcast Fax Cover Page

Date: DECEMBER 23, 1998

To: TODD SUMMERS

Fax Number: 2024562438

Subject: *MMWR*

Pages: 9 (INCLUDING COVER)

Organization: WHITEHOUSE OFFICE OF NATL AIDS POLICY

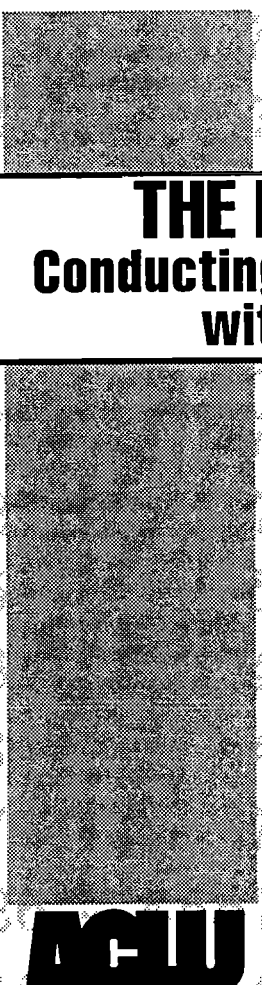
Phone Number: 202 4562437

MAY CONTAIN TIME SENSITIVE INFORMATION

Please deliver to the intended recipient immediately! This fax may contain time sensitive information.

THE MARYLAND LESSON

Conducting Effective HIV Surveillance with Unique Identifiers



ACLU

An American Civil Liberties Union Report

December 1997

AMERICAN CIVIL LIBERTIES UNION

125 Broad Street, 18th floor
New York, NY
(212) 549-2500

122 Maryland Avenue, NE
Washington, DC 20002
(202) 544-1681

Nadine Strossen
President

Ira Glasser
Executive Director

Kenneth B. Clark
Chair, National Advisory Council

This report has been prepared by the American Civil Liberties Union,
a nationwide, nonpartisan organization of 275,000 members
dedicated to preserving and defending the principles
set forth in the Bill of Rights

This paper can be accessed via the ACLU's website <http://www.aclu.org>
and our America Online site (keyword: ACLU).
Copies can also be obtained for $1.00 each through ACLU Publications
at 1-800-775-ACLU or P.O.B. 186, Wye Mills, Maryland, 21679

The Maryland Lesson

Conducting Effective HIV Surveillance with Unique Identifiers
December, 1997

Matthew Coles
Director, AIDS PRoject

Founded in 1986, the AIDS Project of the ACLU works
exclusively to protect the civil liberties of people with HIV and AIDS

Table of Contents

THE MARYLAND LESSON

CONDUCTING EFFECTIVE HIV SURVEILLANCE WITH UNIQUE IDENTIFIERS[1]

INTRODUCTION

Since June 1, 1994, the State of Maryland has utilized a Unique Identifier system to conduct HIV surveillance. As part of the ongoing public discussion about how to best expand HIV surveillance across the country to understand the changing epidemic, it is useful to evaluate Maryland's experience to determine whether Unique Identifiers form a viable surveillance option.

While some have suggested that it is not presently possible to implement a Unique Identifier system that works, Maryland's experience suggests that this is not true. In 1994 Maryland first began its HIV surveillance system using a non-names based Unique Identifier system. Since then the program has undergone constant evaluation and refinement. While more work remains to be done to perfect the program, at this time Maryland public health officials are satisfied that the program is running well and is adequately meeting Maryland's HIV surveillance needs. Maryland's increasingly successful experiment with Unique Identifiers suggests that effective HIV case reporting can occur without name reporting.

DESCRIPTION OF THE PROGRAM

Maryland's Unique Identifier system was implemented after attempts to institute HIV name reporting were defeated in the Maryland legislature in 1992 and 1994. The objectives of Maryland's UI system are: (1) to monitor HIV infection; and (2) to provide supplemental case identification for AIDS and HIV+ symptomatic cases. Under the UI program, a numerical code is assigned to each new case of HIV infection and to lab reports of CD4 counts of 200 or less.[2] The code consists of a 12-digit number including, from left to right, the last four digits of the individual's Social Security number, the individual's date of birth, race/ethnicity and gender.

Race and gender are coded by using the same coding scheme used in the CDC's HIV/AIDS Case Reporting Form. So, for example, an African-American male born on February 4, 1952 whose Social Security number is 678-01-1234 would have a UI of 123402045221.

---

[1] This report was authored by Michael Adams, staff counsel for the ACLU AIDS/HIV Project. The Maryland AIDS Administration verified all of the statistical data and analysis of that data contained in the report.

[2] CD4 cell counts are the most commonly used surrogate markers for assessing the state of the immune system. As the CD4 count declines, the risk of developing opportunistic infections increases. The normal range for CD4 counts is 500 to 1500 per cubic millimeter of blood. A CD4 count of 200 or less triggers an AIDS diagnosis.

Maryland's UI system proceeds through the following steps:

1) The provider orders the laboratory test and creates the Unique Identifier, which is sent with the laboratory requisition.

2) The lab sends the UI Report Form for positive HIV tests and CD4 counts of less than 200 to the State AIDS Administration office or to the local health department. (If the forms are sent to the local health department, they will be forwarded to the state AIDS Administration.)

3) The AIDS Administration matches each UI received against the State AIDS Registry (HARS), which has been coded with UI's using the same 12-digit numbering system.

4) The AIDS Administration generates a list of non-matches to the State AIDS Registry, thus creating a list of cases of HIV infection that are not yet reportable as AIDS or HIV+ symptomatic cases in Maryland.

5) Surveillance staff call physicians as necessary to obtain additional information on the patient, including the clinical status and risk categories. Patient names are not given to the surveillance staff.

6) If the patient is found to have an AIDS-defining illness or is HIV symptomatic (a reportable condition in Maryland), then the surveillance staff will obtain information, including the patient's name, which is used to create an AIDS case report.

In Maryland, it is the provider who is required to construct the UI and then transmit the number to the lab with the lab request form. The provider is required to maintain some means by which a surveillance officer can backtrack in the event that a UI number is incomplete and to provide additional clinical data and risk information. This is often referred to as the provider log, although providers use a variety of systems. Logs or other systems maintained by providers do not necessarily include the names of the individuals who test positive for HIV[3]. A log or other tracking mechanism might contain the UI and a corresponding medical record number or other non-name identifying information. The Johns Hopkins Medical Center, for example, maintains two separate databases, one containing the UI and the other additional patient information. The two

---

[3] Some concerns have been raised that Maryland's UI system may in fact provide greater possibility for breaches of confidentiality because of the provider logs. The possibility of confidentiality breaches is substantially decreased when providers do not include names in their logs or databases. In addition, a significant concern in HIV surveillance is testing deterrence as a result of testee concern about confidentiality breaches. In the realm of deterrence, the perception of the testee is as important as the actual possibility of breaches of confidentiality. The available data indicates that members of communities most affected by HIV are less trusting of government agencies than they are of their own doctors. See, *e.g.*, Woodrow Jones, "An Overview of Health Care Issues in Black America," *Black Health Care,* Jones and Rice, eds., 1987.

databases are merged for the purpose of obtaining information on clinical status and risk practices.

SUCCESS OF MARYLAND'S UI PROGRAM

Maryland recognizes that every system of HIV surveillance has its challenges. When Maryland's UI system was implemented in 1994, the challenge was to get complete UI numbers for as many lab reports of new cases of HIV infection as possible. An examination of Maryland's experience shows that the completeness of UI numbers has increased substantially over time, as providers have become more used to the UI system. While only 61% of UI's reported in the first six months of the program were complete, approximately 77% of UI's reported in the last six months of 1996 were complete. (See Table 1, "Completeness of UI Elements," below.) The major problem with UI code completeness lies in missing Social Security numbers. In the last evaluated five month period in 1996, Social Security numbers were missing from 15% of the reported UI numbers. (See Table 1, below.)

TABLE I

Completeness of UI Elements

Number of reports of HIV infection reported and percentage of reports that include data elements for unique identifiers (UIs), by reporting period — Maryland, July 1994 - December, 1996.

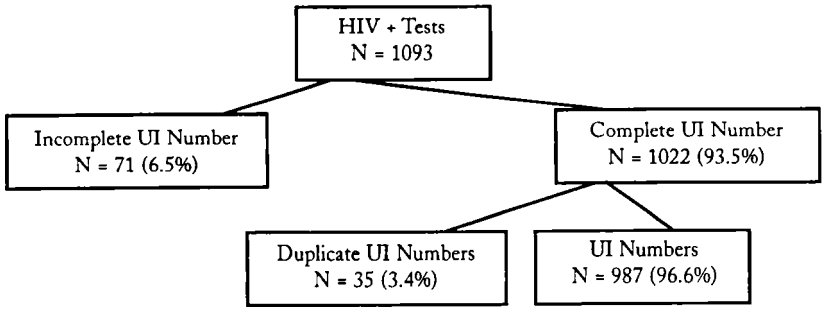
Cases/Data element	July– Dec. 1994	Jan-June 1995	July – Dec 1995	Jan– June 1996	July – Dec 1996	Overall
SSI Number	69.6%	73.1%	81.2%	83.5%	84.5%	78.4%
Date of Birth	95.2	96.3	98.7	99.3	98.8	97.6
Sex	96.8	97.2	98.7	99.2	99.4	98.3
Race/Ethnicity	85.8	88.5	91.6	94.0	89.9	89.8
Reports with complete UI	61.3	65.9	74.9	78.5	76.5	71.4
Total # cases Reported	2,338	1,691	1,866	1,881	2,295	9,971

The Maryland AIDS Administration has reason to believe they can improve on the 77% completion rate. In a pilot program, training on UI reporting was provided to staff at all Confidential Testing Sites in the State. After the training was completed, the completeness of UI numbers in reports from Confidential Testing Sites increased to 96.6%. (See Table 2, "Completeness Of UI Number From Confidential Testing Sites," next page.) While it may be unrealistic to assume that such a high rate of completeness can be achieved in all reported UI numbers, officials at the Maryland AIDS Administration are confident that with further work the completeness rate in the State's UI program will exceed 80%.

The success of a UI program is measured not just by the completeness of UI numbers reported, but also by the ability to match the UI's of persons listed in the UI Registry with the UI's of persons listed in the State's AIDS Registry and consequently to be able to distinguish new cases of HIV infection from previously reported AIDS cases. For example, in a perfect system, all persons who were tested for HIV in 1996 and were included in the AIDS Registry because of an AIDS diagnosis would also be included in the UI Registry. This would be a match rate of 100%. An analysis of Maryland's program indicates a system that is not perfect but is functioning reasonably well. After removing specimens sent from

TABLE 2

Completeness of UI Number From Confidential Testing Sites



one lab that was cited for non-reporting, the match rate was 76.5%. (See Table 3, "Completeness Of Reporting UI Status For Persons in CTS, Excluding Results From Cited Lab," next page.) CDC data from Alabama and Arizona, both of which use HIV name reporting, suggests that the match rate in those states is 79-90%.[4]

Is the success rate of Maryland's UI system good enough? That depends on what level of statistical precision is considered good enough to conduct adequate HIV surveillance. The Maryland AIDS Administration reports that its UI system fulfills all of the functions that can reasonably be expected of an HIV surveillance system. The UI program gives Maryland the data it needs to track HIV infection in the State and to guide decisions about AIDS funding and prevention efforts. Officials at the Maryland AIDS Administration are pleased that the Unique Identifier system has enjoyed considerable community support and is thought to create an environment in which individuals are more willing to be tested and learn their HIV status.

Maryland's confidence in this regard is bolstered by a comparison of the demographic characteristics of new cases reported in the State's AIDS registry and cases reported in the UI registry. The UI registry indicates an increasing number of HIV infections in Maryland among women (up to 34.5% in UI registry from

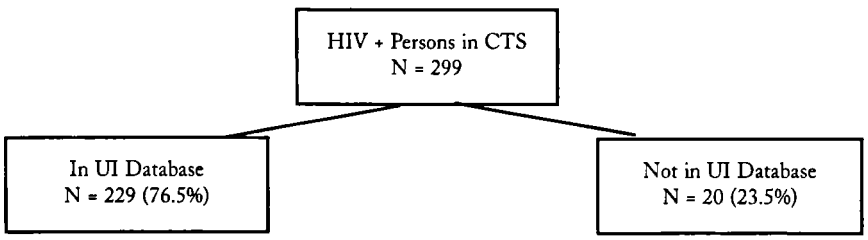
[4] Alabama and Arizona are low seroprevalence states, reporting 4,266 AIDS cases and 5,036 AIDS cases, respectively. Maryland, by contrast, is a high seroprevalence state and reports 15,298 AIDS cases. (CDC HIV/AIDS Surveillance Report, Vol. 8, 1997). The lighter caseloads of Alabama and Arizona may help to explain why they have been able to obtain slightly higher match rates than Maryland.

25.3% in AIDS registry) and people aged 13 to 29 (up to 19.4% in UI registry from 14.1% in AIDS registry). These trends are consistent with our current understanding of trends in HIV infection, and thus suggest that Maryland's UI system is effectively and accurately tracking the spread of HIV in that State.

Maryland public health officials readily acknowledge that there are some things that the State's UI system cannot do. For example, in the absence of good provider logs or their equivalent it will be difficult to obtain detailed information on clinical status and risk categories. Maryland has embarked on an education campaign to train clinicians in the importance of maintaining logs and is contemplating adding information on risk categories to the Unique Identifier in order to improve the information available to state health officials.

TABLE 3

Completeness of Reporting UI Status for Persons in CTS Excluding Results From Cited Lab



1 Reports entered as of 10/2/96
2 HIV + persons tested at confidential CTS sites during the period 7/1/95 through 6/30/96

CONCLUSION

An examination of Maryland's experience indicates that Unique Identifiers, while not problem-free, can provide a sound basis for HIV surveillance. Maryland is now effectively using UI's to fulfill the basic functions of HIV surveillance: to monitor HIV infection trends and to identify cases of HIV and AIDS. It is worth noting that Maryland has achieved a level of success using Unique Identifiers despite the fact that the federal Centers for Disease Control has failed to provide any funding to support the program[5]. Requests by Maryland to use funds from its surveillance cooperative agreement to support this program have been repeatedly denied by the Centers for Disease Control. Maryland is committed to continuing and improving its UI program, despite this continued lack of federal funding.

That Maryland's UI system does not accomplish all public health goals related to HIV should not be surprising, because every disease surveillance system is limited in what it can accomplish. Disease surveillance systems are not health

[5] By contrast, the CDC has provided funding to states to set up HIV names-based reporting systems.

care delivery systems. Nor are they means of conducting in-depth epidemiological investigations of individual cases of infection.[6] Thus, suggesting that a UI system does not work because, for example, it does not link individuals into health care, makes no more sense than suggesting that prevention education does not work because it does not increase AIDS funding.

In light of Maryland's increasingly successful experiment with Unique Identifiers, UI's must be considered as a viable alternative to names-based reporting as we expand HIV surveillance in response to the changing nature of the epidemic.

---

[6] This does not mean that we should ignore the possibilities for epidemiologic investigation that UI systems offer. For example, Maryland has participated with the federal Centers for Disease Control in surveillance of sub-types of HIV. In fact, it was through Maryland's UI system that the first case of sub-type G HIV was reported. P.S. Sullivan, Do., An.N., Robbins, K., *et. al.* "Surveillance for Variant Strains of HIV: Subtype G and Group O HIV-1," Letter, *JAMA*, 278:292 (1997).

CONVERSATION WITH DR. LIZA SOLOMON, DIRECTOR, MARYLAND AIDS ADMINISTRATION

ACLU: What should we look at to determine whether an HIV surveillance system like Unique Identifiers or names-based reporting is working?

L.S.: In order to assess whether a disease surveillance system is working, one must first clarify what are reasonable expectations for the system and what information is needed to accomplish the important public health goals of surveillance. If one looks to a surveillance system to give basic epidemiological information on populations that are affected and the risk practices involved, then some slight over or under-counting will not have a significant impact on the data. For example, it may only be important for epidemiological purposes to know that young heterosexual women are increasingly becoming infected with HIV. Knowing that there are 200 HIV positive women as compared to 220 will not impact service or prevention planning.

ACLU: What level of statistical precision is necessary in order to accomplish the public health goals we have for HIV surveillance?

L.S.: This question again relates to the goal of the surveillance activities. In order to plan services, prevention activities, and target programs, it is important to have a good, although not exact, idea of the number of individuals involved. Public health programs are usually targeted at populations and affected communities. Knowing each person's identity is not necessary to accomplish these goals.

ACLU: Would a surveillance system that included names be more helpful in insuring that individuals who need medical treatment have access to health care?

L.S.: Surveillance systems are not the most effective vehicle for insuring that individuals receive health care. Referring individuals into care and insuring that they have access to care is a critical public health objective. Disease registries, such as cancer registries or AIDS registries, have rarely been the means to identify individuals for referrals into care. Estimates from the Centers for Disease Control suggest that there is a significant lapse in time before an individual with AIDS is reported to the state registry. CDC estimates that 50% of people with AIDS are reported within 3 months of diagnosis while 20% are not reported to AIDS registries for more than one year. (CDC HIV/AIDS Surveillance Report, Vol. 8, 1997). Similar delays can be expected in any HIV case reporting system. Guaranteeing care and insuring that there are needed linkages to care should occur at the point of contact with the patient – at the testing site or clinician's office.

ACLU: Has Maryland been able to use its UI system to get accurate data for purposes of funding?

L.S.: Maryland has used data from its UI system to help inform decisions concerning allocation of resources and to provide information used in funding jurisdictions.

ACLU: Do you believe that it is possible to monitor recent trends in HIV infection in Maryland using Unique Identifiers?

L.S.: UI information is helpful in providing a picture of early infection and can provide information on new groups that may be affected by HIV. In a comparison of demographic information obtained from the UI registry and the AIDS registry in Maryland, we have seen that individuals with HIV are younger and more likely to be female than individuals in the AIDS registry. Using the UI and AIDS registries we have found that there is little difference by race among those with HIV and AIDS in Maryland.

ACLU: Has Maryland had difficulty providing services for people with HIV and AIDS because the state does not have a names-based surveillance system?

L.S.: Maryland has a comprehensive system of service delivery to insure that individuals needing services have access to them. In addition, Maryland has an AIDS Drug Assistance Program (ADAP) which provides medications to individuals with HIV and AIDS who have medical needs but inadequate resources to obtain medications. Maryland's ADAP provides unlimited access to all protease inhibitors and antivirals for individuals in the program. There are no waiting lists and no clinical restrictions other than a diagnosis of HIV.

ACLU: Would name reporting allow for more effective partner notification?

L.S.: Partner notification is an important component of Maryland's HIV prevention program. The contact point for insuring that partner notification is implemented is at the time that a person learns his/her HIV status. As part of Maryland's counseling procedure, when individuals receive HIV positive test results counselors inform them about the importance of partner notification and assist individuals in notifying. This process exists regardless of the surveillance system or the venue of the test, including anonymous test sites.

ACLU: Do we need name reporting in order to track down those individuals who are tested for HIV and do not return for their test results?

L.S.: It is critically important that individuals, both HIV positive and negative, learn their test results. In confidential HIV testing facilities, the patient name is known to the health care provider who orders the test. Follow-up with that patient can take place even though the State does not have a State-sponsored names-based registry of HIV. In anonymous testing facilities, the patient's name is not known to the provider. However, research shows that individuals who are tested anonymously are more

likely to retrieve their test results than individuals who provide their name at the time of testing.

ACLU: Doesn't Maryland's requirement that providers maintain a log of those who are tested mean that the possibilities for confidentiality breaches are even greater?

L.S.: In Maryland, providers are required to maintain some means for surveillance staff to backtrack to obtain additional information. Providers don't necessarily keep logs. Some keep computer databases. And logs and computer databases don't need to include names. They can instead include medical record numbers or other non-name identifying information. Also, we're worried about the perception of the person being tested and whether they will be deterred from testing. In our experience, individuals most at risk for HIV trust their doctors more than they trust government agencies. They are thus less likely to be deterred from being tested by provider logs or their equivalent.

ACLU: Why do you think Texas has a negative evaluation of its UI program, given the success of Maryland's program?

L.S.: Although Texas and Maryland have both used the same 12 digit UI number, the two states have differences in their programs. In Texas, both physicians and labs have the responsibility to report. This may have created some difficulty with the volume of reports. Also, Texas' system does not require that physicians keep a log or equivalent. Thus when questions arose there was no way to return to the physicians and get additional data. Ultimately, any new surveillance system requires considerable work with the physician community to insure that it is well-implemented. It appears that additional education efforts with labs and physicians would be helpful.

ACLU: Has Maryland received any money from the CDC to develop or implement its UI program? Has the state requested funds?

L.S.: Maryland has not received funds from the Centers for Disease Control to implement its HIV surveillance system. Maryland requested funds to support this program in our 1995, 1996 and 1997 surveillance cooperative agreement. All requests were denied. Maryland and Texas did receive funds from the CDC to evaluate the UI program.

ACLU: Do you think UI systems are more expensive than names-based surveillance systems?

L.S.: Maryland has implemented its UI system without additional funds. However, any expanded surveillance system, names-based or UI-based, does require additional resources. Although we have implemented our system without additional funds, we estimate that it would cost the State of Maryland $100,000 to more fully implement the UI surveillance system and have it reach the level of accuracy that is realized by our AIDS surveillance system.

ACLU: Does Maryland plan any improvements in its UI program?

L.S.: We are considering two revisions to our UI system that we believe will give us additional data and reduce errors. First, we are considering having the provider ascribe risk category and include this as part of the UI number. This would allow us to have complete risk categories for all individuals in our UI data base without needing to call the physician. In addition, we are considering changing the layout of our number. Currently the race/ethnicity categories (a 1 to 5 classification) is right next to the gender category (1,2 category). We believe this has caused transcription errors which may be reduced by changing to an alphanumeric code. We are also expanding our education and training for clinicians to help them comply with the law.

ACLU: Why has Maryland resisted conducting HIV surveillance through name reporting?

L.S.: Maryland adopted HIV surveillance by Unique Identifier after full discussion and debate within our General Assembly and our community. Bills promoting names reporting were introduced and defeated in the 1992 and 1994 General Assembly sessions. After a full discussion of these issues, legislation was passed which authorized the creation of the Unique Identifier system. This legislation has enjoyed considerable support from the HIV community. The AIDS Administration is committed to working in partnership with affected communities in all our programs.

ACLU: Does Maryland intend to continue using UI's, or to switch to names-based reporting?

L.S.: Maryland is continuing to refine and improve upon our HIV surveillance system. We have no plans to change to a names-based system.


ACLU
AMERICAN CIVIL LIBERTIES UNION

CDC UPDATE

CENTERS FOR DISEASE CONTROL AND PREVENTION

NCHSTP

Embargoed for Release:
4 p.m. EST, October 27, 1998

Contact: NCHSTP Office of Communications
(404) 639-8895

MEDIA CLARIFICATION
JAMA Articles on HIV Testing and Reporting

The *Journal of the American Medical Association* will publish a CDC article entitled, *"Effect of HIV Reporting by Name on Use of HIV Testing in Publicly Funded Counseling and Testing Programs"* in their October 28 issue. CDC would like to correct an inaccuracy in the JAMA press release on this article and clarify our strong support for anonymous HIV testing.

The *JAMA* press release begins with the premise that the CDC study contradicts the findings of another article by Andrew Bindman, M.D., from the University of California, San Francisco (UCSF). In fact, while the studies addressed different issues, both articles support the need for access to anonymous HIV testing.

The UCSF study, by Bindman and colleagues, evaluated whether anonymous HIV testing was associated with earlier HIV testing and HIV-related medical care than confidential HIV testing among people diagnosed with AIDS. The study found that HIV-infected individuals who used anonymous testing services got tested and entered care earlier than those who used confidential services. Many people tested in confidential settings did not seek testing prior to becoming ill. The findings underscore the critical need to educate individuals at-risk about the need to learn their HIV status, and if infected, to seek early care.

The CDC study, by Allyn Nakashima, M.D. and colleagues, looked at the impact of the implementation of HIV reporting in six states on test-seeking behavior. The data indicate that HIV reporting by name did not significantly affect the level of HIV testing in publicly funded anonymous and confidential test sites.

As an increasing number of states have either implemented, or begun considering implementation of, HIV surveillance, there has been some concern that HIV reporting might deter people from seeking care. This study should help allay these concerns, as these data show no significant declines in testing following the implementation of HIV reporting. The article concludes that as additional states implement confidential HIV reporting policies, the impact of surveillance on those seeking HIV testing will likely be small and should not hinder HIV prevention efforts. CDC will conduct ongoing evaluations to monitor the impact of policy changes on testing behaviors.

To help ensure that reporting policies do not deter even a small number of people from seeking testing, CDC recommends that states make anonymous testing available. Previous CDC studies indicate that the lack of anonymous testing options may serve as a deterrent to testing in some high-risk populations. Maintaining anonymous test sites is important for prevention efforts and may help ensure that more individuals learn their status and receive the maximum benefit from HIV treatment.

Anonymous testing is currently available in all but eleven states. CDC has strongly recommended that these states reevaluate their policies on this issue. Unless prohibited by state law, CDC requires that states offer anonymous HIV testing as a condition of funding.

###

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta, GA 30333

October 27, 1998

Dear Colleague:

Today's issue of the *Journal of the American Medical Association (JAMA)* contains an article by a Centers for Disease Control and Prevention (CDC) author and is entitled "Effect of HIV Reporting by Name on Use of HIV Testing in Publicly Funded Counseling and Testing Programs." Data from this study describes trends in HIV testing in publicly funded counseling and testing sites before and after implementation of name-based HIV reporting in six states (Louisiana, Michigan, Nebraska, Nevada, New Jersey, Tennessee).

Overall, there were no significant decreases in the number of HIV tests provided at the counseling and testing sites in the months immediately after HIV reporting was implemented in any state, other than those expected from trends present before HIV reporting. The article concludes that as additional states implement confidential HIV reporting policies, the impact of these policies on those seeking HIV testing will likely be small and should not hinder HIV prevention efforts. (The full text of this article can be found on the *JAMA* Web site at http://www.ama-assn.org/special/hiv/library/readroom/jama98/joc80227.htm.)

There is another article in this issue of *JAMA* entitled "A Multistate Evaluation of Anonymous HIV Testing and Access to Medical Care." This article, by Andrew Bindman, M.D., from the University of California, San Francisco (UCSF), is about a study that clearly demonstrates that individuals tested anonymously sought HIV testing and medical care earlier in the course of HIV disease than did persons tested confidentially.

The researchers used data collected as a part of a cooperative project between the University of California, Berkeley; CDC; and eight state health departments (Arizona, Colorado, Mississippi, Missouri, New Mexico, North Carolina, Oregon, and Texas). This project, called the AIDS Patient Survey (APS), found that anonymous testers spent over a year more (an average of 387 days) in medical care prior to an AIDS diagnosis than did confidential testers. The findings underscore the critical need to educate individuals at risk about the need to learn their HIV status and, if infected, to seek early care. (The full text of this article can be found on the *JAMA* Web site at http://www.ama-assn.org/special/hiv/library/readroom/jama98/joc80107.htm.)

Unfortunately, the original *JAMA* press release about these two articles began with the premise that their findings contradict each other. In fact, the studies simply address different issues. Attached are both studies.

CDC believes that both anonymous testing and comprehensive HIV reporting are vitally important to HIV prevention efforts. Anonymous testing is currently available in all but eleven states. CDC has strongly recommended that states not offering anonymous HIV testing reevaluate their policies on this issue. Unless prohibited by state law, CDC requires that states

offer anonymous HIV testing as a condition of funding. We strongly believe, and have seen demonstrated in states that have both anonymous testing and HIV reporting, that these critical elements of prevention can coexist and provide information that greatly enhances HIV prevention and treatment efforts.

Should you have any questions or need additional information, please call our Office of Communications at (404) 639-8063.

Sincerely,

Helene D. Gayle

Helene D. Gayle, M.D., M.P.H.
Director
National Center for HIV, STD, and TB Prevention
Centers for Disease Control and Prevention

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 (0.5%) 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.

JAMA. 1998;280:1421-1426

From the Division of HIV/AIDS Prevention, National Center for HIV, STD, and TB Prevention, Centers for Disease Control and Prevention, Atlanta, Ga.

Presented in part at the 125th Annual Meeting of the American Public Health Association, Indianapolis, Ind, November 9-13, 1997.

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).

POLICIES for the confidential reporting by name of persons with acquired immunodeficiency syndrome (AIDS) to health departments exist in all states.[1] The ability to monitor trends in the epidemic due to the human immunodeficiency virus (HIV) has been based on these AIDS case reports. In contrast, confidential reporting by name of HIV-infected adults and adolescents (aged ≥13 years) who do not meet the criteria for AIDS (HIV reporting)[1] has been implemented less completely; by January 1998, only 28 states required physicians and other health care providers, including clinicians, laboratories, and institutions (eg, hospitals, clinics), to report these cases.[2] Until recently, AIDS case reporting met most of the information needs of monitoring and characterizing the HIV epidemic. Because of changes in the epidemic, most notably those related to new therapies, AIDS case reports no longer provide adequate information, and HIV reporting will become increasingly important.[3,4]

See also p 1416.

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.[5,6] These concerns have been based on surveys[7-12] 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.[13]

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, [illegible] departments for HIV CT services since 1985.[13-16] 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 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.[16-18] 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).

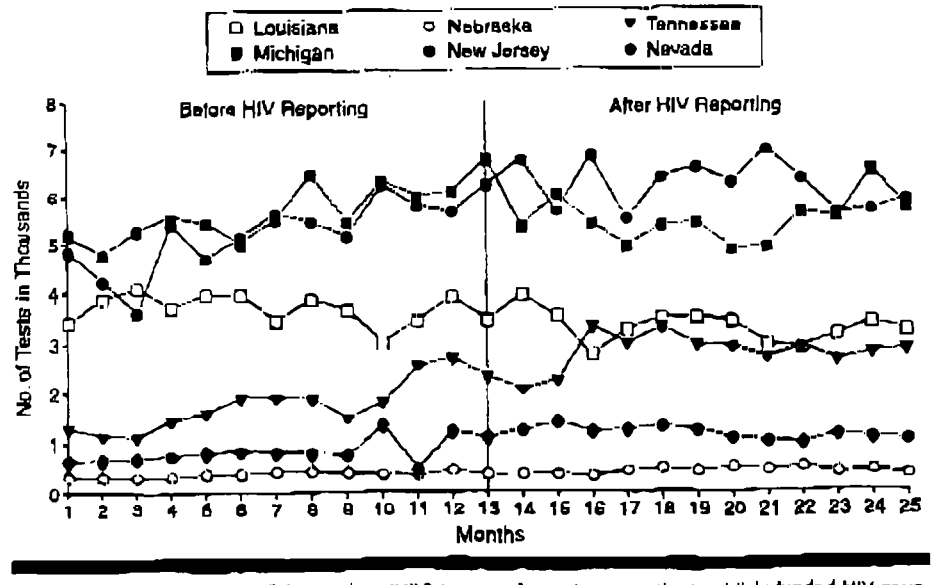
The data used in the analysis were collected to monitor service provision, not for use in a research study; for example, no population sampling was performed. In addition, because of the large numbers of tests performed in most areas, small percentage changes may result in statistically significant differences 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*

	No. of HIV Tests Performed			
	Before Reporting	After Reporting	% Change	P Value†
Louisiana	45 866	39 069	−10.5	.30
Michigan	66 704	65 398	−2.0	.70
Nebraska	4348	5035	15.8	<.001
Nevada	9613	14 264	48.4	<.001
New Jersey	61 440	74 324	21.3	<.001
Tennessee	20 684	33 675	62.8	<.001

*Data exclude tests without site numbers, tests reported from sites with fewer than 50 total tests during the 25-month study period, and sites reporting no tests during any single month. HIV indicates human immunodeficiency virus.
†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.

	Men Who Have Sex With Men			Injection Drug Users					
	Before Reporting	After Reporting	% Change	Before Reporting	After Reporting	% Change	Before Reporting	After Reporting	% Change
Louisiana	1332	1274	−4.3	1938	1562	−15.0	9967	11 009	10.5
Michigan	3966	4113	5.3	3419	2247	−34.3	5756	18 844‡§	225.1
Nebraska	460	574	19.8	238	242	1.7	888	939	5.7
Nevada	744	837	12.5	852	1013	18.9	897	3618	303.3
New Jersey	3242	3968	22.4	7051	7011	−0.6	2284	12 956	467.9§
Tennessee	2734	2622	−4.1	1508	1758	16.6	814	5729	603.6§

*HIV indicates human immunodeficiency virus.
†Includes persons with sexually transmitted diseases, persons who exchanged money or drugs for sex, and persons whose sex partners were at risk for HIV.
‡Large increase in this group was due in part to improved classification of persons initially classified without risk.
§Large increase in this group coincided with Earvin "Magic" Johnson's announcement of HIV infection.

RESULTS

During the 25-month period before and after the implementation of HIV reporting, the total numbers of HIV tests provided through the states in the study were as follows: Louisiana, 86 794 tests at 50 sites; Michigan, 138 802 tests at 53 sites; Nebraska, 9749 tests at 8 sites; Nevada, 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 Nebraska, 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—Nebraska, Nevada, New Jersey, and Tennessee—had increases in the number of tests performed after implementation (16%, 48%, 21%, and 68%, 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 before HIV reporting was implemented and continued afterward; the Poisson model showed no statistically significant difference in these trends (eg, the slope of a regression line drawn through number of tests per month before HIV reporting and the slope after HIV reporting were the same). A statistically significant difference in the before-and-after trends was found in Nevada, New Jersey, and Tennessee. In these 3 states, the level of testing was higher after HIV reporting.

Table 3.—Number of Anonymous and Confidential HIV Tests in the Year Before and After HIV Reporting for Selected Groups in Louisiana and Nebraska*

	No. of Anonymous HIV Tests			No. of Confidential HIV Tests		
	Before Reporting	After Reporting	% Change	Before Reporting	After Reporting	% Change
Louisiana						
All tests	8851	4987	−23.9	30 895	29 459	−4.6
White MSM	448	348	−22.3	160	174	8.8
African American	2156	1614	−24.7	24 675	22 911	−6.8
Injection drug user	967	268	−27.0	1253	1 148	−8.5
Nebraska						
All tests	1888	2535	34.3	2385	2444	2.5
White MSM	271	385	42.1	160	174	−17.0
African American	106	152	43.8	225	269	19.6
Injection drug user	106	118	11.3	124	121	−2.4

*Data exclude tests for which type of test was unknown or missing (<15% of total tests for Louisiana and <2% for Nebraska). HIV indicates human immunodeficiency virus; MSM, men who have sex with men.

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 reports have suggested would be the most likely to avoid testing if HIV reporting was implemented, the number of tests increased in 4 states in the year after HIV reporting was implemented (Table 2). Louisiana and Tennessee experienced decreases in testing of less than 5% for this group. Among injection drug users, declines in testing occurred in Louisiana and Michigan (Table 2). Among at-risk heterosexuals, which included persons with sexually transmitted diseases, persons who had exchanged money or drugs for sex, and those whose sex partners were at risk for HIV, increases in testing were seen in all areas after HIV reporting was implemented (Table 2). Counseling and testing coordinators in New Jersey and Tennessee attributed the large increases for this group partly to Earvin "Magic" Johnson's announcement of his infection in November 1991,[17] which nearly coincided with the implementation of HIV reporting policies in these states.

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, at the time HIV reporting was introduced, counselors were instructed to encourage clients to select anonymous testing. Among white MSMs, in Louisiana, there was a decline in anonymous testing and an increase in confidential testing. In Nebraska, the reverse was true. 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. Among injection drug users, confidential testing decreased in Louisiana and Nebraska after HIV reporting whereas anonymous testing increased in Nebraska and decreased in Louisiana.

Surveillance Coordinators and HIV CT Program Coordinators*

	Louisiana	Michigan	Nebraska	New Jersey	Nevada	Tennessee
Media coverage and strategies informing the public about HIV reporting						
Newspaper articles	X		X	X		X
Press conference				X		X
Evening television news			X			X
Radio news						X
Public and educational television				X		
Public hearings		X	X		X	X
Strategies used to introduce HIV reporting to service providers						
Pamphlets and information sheets	X		X	X		
Public health, epidemiology, or medical society newsletters and bulletins	X	X		X	X	X
Letter campaigns (eg, to physicians, laboratories, clinics)	X	X	X	X		X
Presentations at professional meetings	X	X		X	X	
Training courses	X			X		
Is anonymous testing available?	Yes	Yes	Yes	Yes	No	No
Are health department personnel required to notify partners?	No	No	No	No	No	No
How were publicly funded HIV CT sites notified about HIV reporting?						
Letters to all sites	X	X	X	X		
Training courses	X	X	X	X		X
Involvement in meetings or site visits to discuss HIV reporting		X			X	
How do HIV counselors inform patients about HIV reporting requirements?						
Part of informed consent form	X	X		X	X	
Part of routine counseling	X	X		X		X
Information sheets or pamphlets			X			
Other circumstances coinciding with HIV reporting that influenced CT trends						
Earvin "Magic" Johnson's announcement		X		X		X
Anonymous testing actively encouraged			X			
Expansion of CT programs				X	X	
Outreach efforts to high-risk populations					X	
Efforts to eliminate testing of low-risk populations	X					

*HIV indicates human immunodeficiency virus; AIDS, acquired immunodeficiency syndrome; and CT, counseling and testing.

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.[3] 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."[20] The evidence on which such statements are based consists mostly of surveys such as the one reported by Kegeles et al,[10] 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,[21] 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 al[22] showed that the rate of monthly attendance by MSM at an alternative HIV test site decreased 51% in the first 24 months after the reporting of HIV-positive persons by name became mandatory in South Carolina. In contrast with these reports, a multistate survey of high-risk populations conducted in 1996 found that only 2% of people who had not been tested said that concern about HIV reporting was the main reason they were not tested[23]; 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.[25] 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, MSM[8,11] or persons seeking anonymous testing[16]) 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 survey[25] were low-risk persons who would be less concerned about HIV reporting. Among highly concerned groups, either there must be heterogeneity of opinion or the

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[19] 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 16% (from 2847 to 2693). These levels were similar to the levels in the year before the study period: 23 391 tests for blacks and 3168 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 those 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.[28]

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[7,27,28] and the elimination of it decreases testing in these groups.[29-31] 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[32] 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 of CT coordinators and our site exclusion criteria, to account for some of the main 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 1995 and 1996) and AIDS deaths (−23% between 1995 and 1996) brought about by improved therapies,[4] 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.[3] 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.

The authors thank the following people for providing information about their HIV counseling and testing and HIV surveillance programs: Jeffrey Hanson, MPH, Maria Ludwick, and Sue Troxler, Louisiana Department of Health and Hospitals, New Orleans; Garry Goza, MS (Lansing), Kris Judd (Lansing), Eve Moketoff, MPH (Detroit), and Lissa Randall (Lansing), Michigan Department of Community Health; Tina Brubaker, MPH, and Steve Jackson, Nebraska Department of Health and Human Services, Lincoln; Bill Hill and Rick Raich, Nevada Department of Human Resources, Carson City; Samuel Costa, MA, and Helene Cross, MA, New Jersey Department of Health and Senior Services, Trenton; Chris Freeman and Herb Stone, MSSW, Tennessee Department of Health, Nashville.

References

1. Centers for Disease Control and Prevention. 1993 Revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults. *MMWR Morb Mortal Wkly Rep.* 1992;41(No. RR-17):1-19.
2. Centers for Disease Control and Prevention. *HIV/AIDS Surveillance Report.* Atlanta, Ga: Centers for Disease Control and Prevention; 1997;9:2. Report 9.
3. Gostin LO, Ward JW, Baker AC. National HIV case reporting for the United States—a defining moment in the history of the epidemic. *N Engl J Med.* 1997;337:1162-1167.
4. Centers for Disease Control and Prevention. Update: trends in AIDS incidence—United States, 1996. *MMWR Morb Mortal Wkly Rep.* 1997;46:861-867.
5. Forbes A. Naming names—mandatory name-based HIV reporting: impact and alternatives. *AIDS Policy Law.* May 1996:1-4.
6. *Should HIV Test Results Be Reportable? A Discussion of the Key Policy Questions.* Washington, DC: AIDS Action Foundation; 1993.
7. Fahrs LJ, Fleming D, Foster LR, et al. Trial of anonymous versus confidential human immunodeficiency virus testing. *Lancet.* 1988;2:379-382.
8. Kegeles SM, Coates TJ, Lo B, Catania JA. Mandatory reporting of HIV testing would deter men from being tested. *JAMA.* 1988;261:1275-1276.

9. Fordyce JE, Sambula S, Stoneburner R. Mandatory reporting of human immunodeficiency virus testing would deter blacks and Hispanics from being tested. *JAMA*. 1989;262:3441.
10. Kegeles SM, Catania JA, Coates TJ, Pollack LM, Lo B. Many people who seek anonymous HIV-antibody testing would avoid it under other circumstances. *AIDS*. 1990;4:585-587.
11. Myers T, Orr KW, Locker D, Jackson EA. Factors affecting gay and bisexual men's decisions and intentions to seek HIV testing. *Am J Public Health*. 1993;83:701-704.
12. Peterson DR, Senak MS, Etzel M, Reed GM. An assessment of the impact of mandatory name reporting on HIV testing and treatment. Abstract presented at: XI International Conference on AIDS; July 11, 1996; Vancouver, British Columbia.
13. Centers for Disease Control and Prevention. *HIV Counseling, Testing, and Referral Standards and Guidelines*. Atlanta, Ga: Centers for Disease Control and Prevention; 1994.
14. Centers for Disease Control and Prevention. *HIV Counseling and Testing in Publicly Funded Sites: 1996 Annual Report*. Atlanta, Ga: Centers for Disease Control and Prevention; 1998.
15. Weber JT, Frey RL, Horsley R, Guinn ML. Publicly funded HIV counseling and testing in the United States, 1992-1995. *AIDS Educ Prev*. 1997;9 (suppl B):79-91.
16. SAS Institute Inc. *SAS/STAT Software: Changes and Enhancements for Release 6.12*. Cary, NC: SAS Institute Inc; 1996:26-41.
17. Diggle PJ, Liang KY, Zeger SL. *Analysis of Longitudinal Data*. Oxford, England: Clarendon Press; 1994.
18. Thall PF, Vail SC. Some covariance models for longitudinal count data with overdispersion. *Biometrics*. 1990;46:657-671.
19. Centers for Disease Control and Prevention. Sexual risk behaviors of STD clinic patients before and after Earvin "Magic" Johnson's HIV-infection announcement—Maryland, 1991-1992. *MMWR Morb Mortal Wkly Rep*. 1993;42:45-48.
20. American Civil Liberties Union. *HIV Surveillance and Name Reporting: A Public Health Case for Protecting Civil Liberties*. Washington, DC: American Civil Liberties Union; 1997.
21. Burris S. Driving the epidemic underground? a new look at law and the social risk of HIV testing. *AIDS Public Policy J*. 1997;12:66-78.
22. Johnson WD, Francisco SS, Jackson KL. The impact of mandatory reporting of HIV seropositive persons in South Carolina. Abstract presented at: IV International Conference on AIDS; June 14, 1988; Stockholm, Sweden.
23. Lehman JS, Hecht FM, Fleming PL, et al. HIV testing behavior among at-risk populations: why do persons seek, defer, or avoid getting tested in the United States? Abstract presented at: XII International Conference on AIDS; July 2, 1998; Geneva, Switzerland.
24. Hecht FM, Colman S, Lehman JS, et al. Named reporting of HIV: attitudes and knowledge of those at risk [abstract]. *J Gen Intern Med*. 1997;12(suppl 1):108.
25. Phillips KA. The relationship of 1988 state HIV testing policies to previous and planned voluntary use of HIV testing. *J Acquir Immune Defic Syndr*. 1994;7:403-409.
26. Francis DP, Singleton JA. Reporting of HIV-1 infection through provision of essential services. *J Acquir Immune Defic Syndr*. 1998;6:285-286.
27. Hirano D, Gellert GA, Fleming K, Boyd D, Englender SJ, Hawks H. Anonymous HIV testing: the impact of availability on demand in Arizona. *Am J Public Health*. 1994;84:2008-2010.
28. Hoxworth T, Hoffman R, Cohn D, Davidson A. Anonymous HIV testing: does it attract clients who would not seek confidential testing? *AIDS Public Policy J*. 1994;9:182-189.
29. Hertz-Picciotto I, Lee LW, Hoyo C. HIV test-seeking before and after the restriction of anonymous testing in North Carolina. *Am J Public Health*. 1996;86:1446-1450.
30. Irwin KL, Valdiserri RO, Holmberg SD. The acceptability of voluntary HIV antibody testing in the United States: a decade of lessons learned. *AIDS*. 1996;10:1707-1717.
31. Kassler WJ, Meriwether RA, Klimko TE, Peterman TA, Zaidi A. Eliminating access to anonymous HIV antibody testing in North Carolina: effects on HIV testing and partner notification. *J Acquir Immune Defic Syndr Hum Retrovirol*. 1997;14:281-289.
32. Council of State and Territorial Epidemiologists. Position statement: national HIV surveillance: addition to the National Public Health Surveillance System. Presented at: Annual Meeting of Council of State and Territorial Epidemiologists; June 16, 1997; Saratoga Springs, NY.

Multistate Evaluation of Anonymous HIV Testing and Access to Medical Care

Andrew B. Bindman, MD; Dennis Osmond, PhD; Frederick M. Hecht, MD; J. Stan Lehman, MPH; Karen Vranizan, MA; Dennis Keane, MPH; Arthur Reingold, MD; and the Multistate Evaluation of Surveillance of HIV (MESH) Study Group

Context.—Infection with the human immunodeficiency virus (HIV) is the only infectious disease for which anonymous testing is publicly funded, an exception that has been controversial.

Objective.—To assess whether anonymous HIV testing was associated with earlier HIV testing and HIV-related medical care than confidential HIV testing.

Design.—Retrospective cohort.

Setting.—Arizona, Colorado, Missouri, New Mexico, North Carolina, Oregon, and Texas.

Participants.—Probability sample of 835 new acquired immunodeficiency syndrome (AIDS) cases reported to the state health department's HIV/AIDS Reporting System from May 1995 through December 1996. All had responded to the AIDS Patient Survey; 643 had been tested confidentially for HIV, and 192 had been tested anonymously.

Main Outcome Measures.—First $CD4^+$ cell count; number of days from HIV-positive test result to first HIV-related medical care, from first HIV-related medical care to AIDS, and from first HIV-positive test result to AIDS.

Results.—Persons tested anonymously sought testing and medical care earlier in the course of HIV disease than did persons tested confidentially. Mean first $CD4^+$ cell count was 0.427×10^9/L in persons tested anonymously vs 0.267×10^9/L in persons tested confidentially. Persons tested anonymously experienced an average of 918 days in HIV-related medical care before an AIDS diagnosis vs 531 days for persons tested confidentially. The mean time from learning they were HIV positive to the diagnosis of AIDS was 1246 days for persons tested anonymously vs 718 days for persons tested confidentially. After adjustment for the subject's age, sex, race/ethnicity, education, income, insurance status, HIV exposure group, whether the respondent had a regular source of care or symptoms at the time of the HIV test, and state residence, anonymous testing remained significantly associated with earlier entry into medical care ($P<.001$).

Conclusion.—Anonymous testing contributes to early HIV testing and medical care.

JAMA. 1998;280:1416-1420

BOTH CONFIDENTIAL and anonymous antibody testing for the human immunodeficiency virus (HIV) have been available at public testing sites in the United States since 1985. In confidential testing, a person's name is linked to the specimen, and the test result is recorded in a medical chart with a name. Early in the epidemic, the stigma associated with testing positive for HIV focused attention on the potential for breaches in the confidentiality of an HIV test result. Concerned that anxiety about the potential loss of confidentiality would deter some at-risk persons from voluntarily seeking testing for HIV, many state and local public health departments made this test available on an anonymous as well as a confidential basis. In anonymous testing, a unique identifier (typically a number) rather than a patient's name is used to link the specimen and the result to the patient. Anonymous test results are not recorded in a medical chart that has a patient's name. The availability of an anonymous HIV testing option has differed over time across states and localities. Currently, 40 states have publicly funded anonymous testing sites for HIV, and all 50 states have publicly funded confidential HIV testing sites.

See also p 1421.

Human immunodeficiency virus is the only infectious disease for which anonymous testing is publicly funded, an exception that has been controversial. Proponents of anonymous testing believe that it encourages persons who would not otherwise seek testing to learn their HIV infection status by eliminating the concern about potential loss of confidentiality. Persons tested anonymously who learn that they are HIV positive may be motivated by their test result to seek medical care earlier in the course of the disease than they might had only confidential testing been available. Some studies have suggested that anonymous testing increases the number of people who are willing to be voluntarily tested for HIV. In North Carolina, counties that offered anonymous testing experienced greater growth in testing than did counties that continued to offer only confidential testing.[1] Similarly, with the introduction of anonymous testing in Arizona and Oregon,[2,3] more people obtained testing than when only confidential testing was available. However, the findings have not been consistent; the Colorado State Health Department did not detect a meaningful increase in HIV testing with the introduction of anonymous HIV testing.[4]

Because people who test HIV positive anonymously cannot be individually identified, reporting systems that rely on the results of anonymous testing are prone to measurement error. It can be difficult to detect repeat tests, and the potential exists for duplicate reporting. Anonymous testing may undermine partner notification.[5] Furthermore, anonymous testing eliminates the opportunity to recontact persons who do not return for their test results or to assist HIV-infected persons in obtaining medical care.

From the Primary Care Research Center (Drs Bindman and Osmond, Ms Vranizan, and Mr Keane) and AIDS Division (Dr Hecht), San Francisco General Hospital, and Departments of Medicine (Drs Bindman and Hecht, Ms Vranizan, and Mr Keane) and Epidemiology and Biostatistics (Drs Bindman and Osmond), University of California, San Francisco; Division of HIV/AIDS Prevention, Surveillance and Epidemiology, Centers for Disease Control and Prevention, Atlanta, Ga (Mr Lehman); and Department of Epidemiology, University of California, Berkeley (Dr Reingold).

A complete list of the members of the MESH Study Group appears at the end of this article.

Corresponding author: Andrew B. Bindman, MD, San Francisco General Hospital, Bldg 90/Ward 95, 1001 Potrero Ave, San Francisco, CA 94110 (e-mail: bindman@itsa.ucsf.edu).

Because studies have been small, have been performed in only 1 state, or did little to control for differences in the characteristics of persons who used anonymous vs confidential testing, it has been difficult to draw clear conclusions about the value of anonymous HIV testing. We used data collected as a part of a cooperative project between the University of California, Berkeley, the Centers for Disease Control and Prevention (CDC), Atlanta, Ga, and several state health departments to evaluate anonymous HIV testing. We assessed the association of the type of HIV test (anonymous or confidential) with when in the course of the disease persons with acquired immunodeficiency syndrome (AIDS) (1) learned of their HIV infection and (2) sought HIV-related medical care.

METHODS

The AIDS Patient Survey was conducted in Arizona, Colorado, Mississippi, Missouri, New Mexico, North Carolina, Oregon, and Texas. Because nearly all HIV-infected persons are thought to progress to AIDS eventually and because AIDS surveillance is estimated to be 80% to 96% complete,[6] reported AIDS cases provide a population-based sample of the experience of HIV-infected persons that can potentially avoid biases that may be present in venue-based samples.

In each state we sought to interview, after obtaining consent, all persons who were described as having newly diagnosed AIDS in a 1-year period or a probability sample of new cases, depending on the projected incidence of new AIDS diagnoses in the state. The sampling frame was persons newly diagnosed as having AIDS reported to the state health department through the HIV/AIDS Reporting System (HARS) from May 1995 through December 1996, who were alive at time of report, who were at least 18 years old, and whose AIDS diagnosis had been made within 12 months of the date of their report to the health department.

An expected number of persons with newly diagnosed AIDS was estimated from the number reported from the previous year who met the sampling frame criteria. In states with an expected incidence of fewer than 500 cases, all new cases were sampled (Arizona, Mississippi, and New Mexico). In the remaining states, a probability sample was stratified by 4 HIV mode-of-exposure groups based on reported behavioral information in HARS: (1) men who have sex with men (MSM), including those with a reported history of injection drug use; (2) heterosexual injection drug users; (3) cases reported with no identified risk; and (4) all other modes of exposure (heterosexual contact, transfusion, hemophilia). To get adequate numbers in each stratum for analysis, we calculated sampling fractions with the goal of sampling equal numbers from each stratum. Colorado, Missouri, and Oregon sampled MSM and took all cases in the other 3 strata; North Carolina sampled 3 strata and took all in the other stratum; and Texas sampled all 4 strata. Uniform random numbers were generated for each new case in the 4 strata, and a new case with a random number equal to or less than the sampling fraction was selected for the study.

Sampled cases were considered eligible for the study if they were living in the state, English or Spanish speaking, and healthy enough to consent to and complete an interview. To avoid biasing our response rate upward by delaying the performance of the interview, patients who had died before the time of first contact were counted in the denominator of eligibles if contact had not been made within 6 months of report. Public health surveillance personnel in each state developed procedures for contacting and interviewing potential subjects.

All procedures were monitored by the University of California and CDC to ensure uniform methods across the states. Surveillance personnel completed an outcome report form for each sampled case, which indicated the consent process and the final outcome. Subjects were interviewed in either Spanish or English. The instrument was translated into Spanish and then back-translated to English before a final Spanish version was produced. Interviewers and supervisors from the state health departments were trained in joint training sessions in conducting a standard interview. States used between 1 and 4 interviewers to administer the survey and all study sites were visited at least once by University of California and CDC investigators to assess the consistency of their technique. All completed interviews and outcome report forms were stripped of personal identifiers, copied, and mailed to the University of California for data entry and conversion into electronic Statistical Analysis System (SAS Institute Inc, Cary, NC) files for analysis.

We compared the characteristics of respondents who were tested anonymously with those who were tested confidentially and examined whether the type of HIV test was associated with when in the course of the disease a subject sought HIV testing and HIV-related medical care. Date of AIDS diagnosis was extracted from the state HARS databases and combined with the interview data for analysis. Type of HIV testing was classified as anonymous or confidential depending on whether the subject reported giving a number (anonymous) or a name (confidential) to get the HIV test result. Subjects who in response to an explicit question said that they gave a false name were excluded from the analysis. To assess the validity of our method for classifying the type of HIV test, we compared the subject's report of having given a number or a name to obtain their test result with the type of testing site. Assuming that testing in a physician's office, hospital, jail or prison, or blood bank should have been reported as testing by name (confidential testing), we found that 96.4% of subjects tested in those settings reported they had received their results by name. Of those who reported that they had received their test result by number (anonymous testing), only 6.4% reported testing in one of those settings.

We limited our analysis to respondents who first tested HIV positive in the state from which they were sampled, lived in states that offered both anonymous and confidential testing (Mississippi excluded), and voluntarily sought HIV testing as opposed to being required to obtain a test because of regulations associated with prisons, drug treatment programs, the military, insurance plans, or blood banks. Thus, subjects were considered volunteers for testing if they, in response to a checklist of questions, reported that their reason for testing was (1) they felt sick and wanted to find out whether they had HIV, (2) they thought they might have HIV even if they did not feel sick, (3) someone told them that they should get tested, or (4) someone from the health department told them that they had had contact with an infected sex or needle-sharing partner.

In comparing the characteristics of persons tested anonymously vs persons tested confidentially, we tested differences in the proportions by using the χ^2 statistic. We examined the association of anonymous and confidential testing with several intervals: time from HIV-positive test result to AIDS, and this interval's 2 subcomponents: (1) time of HIV-positive test result to first HIV-related medical care and (2) time from first HIV-related medical care to AIDS. We used the date of AIDS diagnosis to anchor comparisons of the HIV-positive test result date and the HIV-related medical care date. Date of first HIV-positive test result and date of first medical care for HIV infection were self-reported as a month and a year. Time intervals used in analysis were constructed from these dates and the date of AIDS diagnosis as reported to HARS. We compared the mean time intervals among HIV testing, HIV-related medical care, and AIDS diagnosis for persons tested anonymously and persons tested confidentially. Time intervals that included an AIDS diagnosis were also stratified by whether the diagnosis was based on an opportunistic infection or a $CD4^+$ cell count of less than 0.20×10^9/L (200/μL).

Table 1.—Characteristics of Persons Voluntarily Tested for Human Immunodeficiency Virus (HIV)

Characteristics	Anonymous (n = 192)	Confidential (n = 643)	P Value
Age, mean, y	36	38	<.001
Male, %	86	84	.33
Race/ethnicity, %			
African American	11	29	.001
Hispanic	17	14	
Other	6	3	
White	65	54	
HIV exposure group, %			
Men who have sex with men	78	58	.001
Injection drug user	6	13	
Blood product	1	4	
Health worker	1	3	
Heterosexual	4	11	
Unknown	8	12	
Education, mean, y	13.1	12.7	.03
Monthly income, mean, $	1390	1450	.41
Insurance, %			
Private/other	48	49	.08
Medicaid	4	9	
None	47	42	
Regular source of care before HIV-positive test result, %	23	51	.001
Symptoms at time of HIV-positive test result, %	50	70	.001

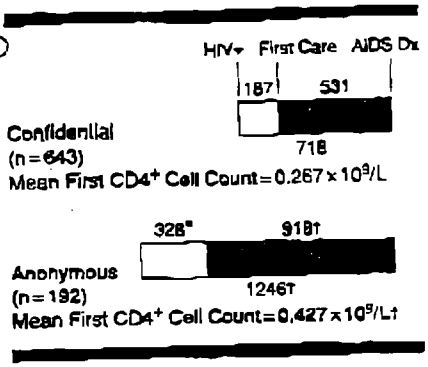


Figure 1.—Mean time in days to first human immunodeficiency virus (HIV)–related care and acquired immunodeficiency syndrome (AIDS) diagnosis by anonymous and confidential testing. Asterisk indicates $P<.01$ for confidential vs anonymous testing; dagger, $P<.001$ for confidential vs anonymous testing; HIV+, date of knowledge of HIV-positive status; first care, date of first HIV-related medical care; and AIDS Dx, date of AIDS diagnosis.

We compared subjects on the basis of whether they had symptoms of weight loss without dieting, fevers, heavy night sweats, diarrhea, oral thrush, frequent vaginal yeast infections, memory problems, shingles, pneumonia, Kaposi sarcoma, lymphoma, meningitis, or tuberculosis at the time they learned they had HIV. Subjects who said yes to any of these conditions were considered symptomatic at the time of the first HIV-positive test result. To estimate HIV disease severity at the time of first HIV-related medical care, we compared the mean self-reported first $CD4^+$ cell counts of persons tested anonymously and persons tested confidentially. To estimate the quality of HIV-related medical care for persons tested anonymously and persons tested confidentially, subjects were asked to report whether their HIV-related medical care had ever included tuberculin skin testing, taking zidovudine for at least 1 day, and taking trimethoprim-sulfamethoxazole (Septra, Bactrim, Cotrim) or aerosolized pentamidine as a measure of *Pneumocystis carinii* pneumonia (PCP) prophylaxis.

To isolate the independent contribution of the type of testing on the time intervals and the first $CD4^+$ cell count, we performed multivariate linear regression analyses that controlled for differences in the characteristics of persons tested anonymously vs confidentially. Marginal differences across states were controlled for using a state of residence indicator in the multivariate analyses. Means from multivariate analyses are the estimated least squares means from linear models. Because the distributions of time intervals and $CD4^+$ cell counts were skewed by some higher values, we repeated our multivariate analyses by using log transformations of the time intervals and $CD4^+$ cell counts. These analyses did not appreciably alter the significance of the results pertaining to anonymous vs confidential testing; therefore, for the purposes of providing measures of effect that are easily interpreted, we have chosen to display the results based on the nontransformed mean time intervals and $CD4^+$ cell counts.

The study was approved by institutional review boards at the University of California, the individual states that required review, and review boards at local institutions as required within some states.

RESULTS

In the 8 participating states, 3821 AIDS cases were sampled from May 1996 through December 1996; of those, 2801 met eligibility criteria. Overall, 1913 (68.3%) of 2801 eligible AIDS cases were interviewed in the AIDS Patient Survey. We excluded 1078 respondents from the analysis because they initially tested HIV positive in a different state from the one in which they were sampled (368), they were from a state that did not have anonymous testing (262), their reason for testing was not voluntary (247), they provided a false name at a confidential testing site (55), or they did not have complete data for all the variables used in the analysis (151). Of the remaining 835 subjects, 192 (23%) reported that their first positive test result had been from an anonymous test (Table 1). Persons tested anonymously tended to be younger, white, slightly more educated than persons tested confidentially, and more likely at risk for HIV because they were MSM. Persons tested confidentially were significantly more likely to have had a regular source of care before their first HIV-positive test result and to have had HIV-related symptoms at the time they received the test; however, half of the persons tested anonymously were also symptomatic.

Persons tested anonymously presented earlier in the course of HIV disease for testing and care than did persons tested confidentially. The mean time from learning they were HIV positive to the diagnosis of AIDS was almost a year and a half longer (529 days) for those tested anonymously than for those tested confidentially (Figure 1). The mean time was 1246 days for persons tested anonymously and 718 days for persons tested confidentially. Most of this difference was in the length of time in HIV-related medical care. Persons tested anonymously received an average of 387 more days in HIV-related medical care before an AIDS diagnosis than did persons tested confidentially. Comparisons of the median times from knowledge of being HIV positive to AIDS were even greater between persons tested anonymously and persons tested confidentially. The median time was 929 days among persons tested anonymously and 90 days among persons tested confidentially. An additional indicator that persons tested anonymously came earlier for testing and medical care than did persons tested confidentially was the significantly higher first $CD4^+$ cell count (0.427×10^9/L vs 0.267×10^9/L) despite the longer unadjusted interval between the HIV-positive test result and medical care.

To isolate the independent contribution of the type of HIV test on the timing of testing and medical care, we adjusted our results to account for differences in the characteristics of persons who sought each type of test. In the multivariate analysis, several characteristics were associated with the length of time between a person's learning of a positive HIV test re-

Table 2.—Multivariate Predictors of Number of Days Between Knowledge of Being Human Immunodeficiency Virus (HIV) Positive and Acquired Immunodeficiency Syndrome

Characteristics	No. of Days (95% CI)	P Value*
Age, y	1 (−7 to 9)	.78
Male	−183 (−409 to 44)	.11
Race/ethnicity		
African American	−49 (−234 to 137)	.61
Hispanic	−123 (−332 to 87)	.25
Other	65 (−286 to 416)	.72
White	Referent (. . .)†	. . .
HIV exposure group		
Men who have sex with men	405 (198 to 613)	<.001
Injection drug user	349 (108 to 591)	.005
Other	Referent (. . .)	. . .
Education, y	28 (−4 to 61)	.08
Monthly income, $	−53 (−130 to 23)	.17
Insurance		
Private/other	112 (−52 to 275)	.18
Medicaid	44 (−222 to 311)	.74
None	Referent (. . .)	. . .
Regular source of care before HIV-positive test result	−21 (−173 to 130)	.78
Symptoms at time of HIV-positive test result	−819 (−963 to −675)	<.001
Anonymous test	272 (101 to 443)	.002

*R^2 = 0.24 (including an indicator for respondent's state residence).
†Ellipses indicate data not applicable.

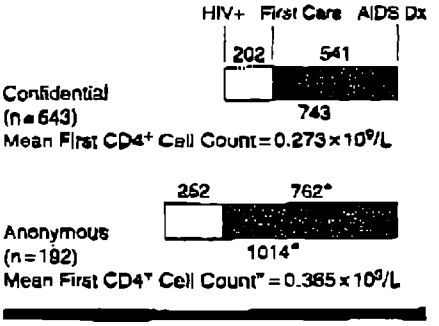


Figure 2.—Adjusted mean time in days to first human immunodeficiency virus (HIV)–related care and acquired immunodeficiency syndrome (AIDS) diagnosis by anonymous and confidential testing. Values are least squares means from a linear regression model and are adjusted for age, sex, race/ethnicity, education, income, insurance status, HIV risk group, regular source of care at the time of testing, symptoms at time of HIV-positive test result, and state residence. Asterisk indicates P<.001 for confidential vs anonymous testing: HIV+, date of knowledge of HIV-positive status; first care, date of first HIV-related medical care; and AIDS Dx, date of AIDS diagnosis date.

sult and receiving an AIDS diagnosis. Among HIV exposure groups, MSM and injection drug users had a significantly longer period of knowing they were HIV positive before their AIDS diagnosis (Table 2). The strongest predictor of the length of time between knowledge of HIV positivity and AIDS was having symptoms at the time of the HIV-positive test result. Having symptoms at the time of the HIV-positive test result decreased the length of time between knowledge of being HIV positive and AIDS by 819 days.

After adjustment for the subject's age, sex, race/ethnicity, education, income, insurance status, HIV exposure group, if the respondent had a regular source of care or symptoms at the time of the HIV-positive test result, and the state of residence, anonymous testing remained significantly associated with earlier medical care (Figure 2). Although the difference in the number of days between the positive test result and first medical care was no longer significant between the 2 groups, the length of time in medical care before AIDS was almost 8 months longer (221 days) for persons tested anonymously compared with persons tested confidentially. The mean adjusted first $CD4^+$ cell count was also 0.092×10^9/L higher for persons tested anonymously than for persons tested confidentially.

Persons tested confidentially were more likely than those tested anonymously (35% vs 16%) to have an AIDS diagnosis based on an opportunistic infection rather than on a $CD4^+$ cell count of less than 0.20×10^9/L. Accounting for this difference in how AIDS was diagnosed in the 2 testing groups further expands the adjusted difference in the duration of HIV-related medical care before AIDS diagnosis from 221 to 230 days.

Comparisons of tuberculin skin testing and the use of zidovudine and PCP prophylaxis suggest that care was similar for the 2 testing groups. Ninety-one percent of persons tested anonymously vs 89% of persons tested confidentially reported that they had received tuberculin skin testing during the course of their HIV-related medical care. Ninety-eight percent of persons tested anonymously vs 95% of persons tested confidentially were offered zidovudine, and 73% in each testing group had been given PCP prophylaxis. None of these testing or treatment differences were significant between the 2 groups.

COMMENT

In this multistate study, we found that anonymous testing was sought by approximately a quarter of HIV-positive persons who had been tested voluntarily before an AIDS diagnosis. Anonymous testing for HIV infection was associated with earlier testing and medical care. As a result of this earlier testing and care, persons tested anonymously received the potential benefits of a significantly longer period of HIV-related medical care compared with persons tested confidentially.

Although the determination of the type of HIV test, $CD4^+$ cell counts, and the intervals between HIV testing, medical care, and AIDS are in large part dependent on self-report, we suspect that the importance of this information for our respondents makes it reasonably likely that their reporting was accurate. Cunningham et al[7] found that self-reported $CD4^+$ cell counts were accurate when compared with values recorded in the medical record. To the extent that persons are misclassified by type of testing, this would tend to make the 2 testing groups look more similar. Acknowledging that there is also likely to be some error in the self-reported first $CD4^+$ cell count and dates of HIV testing and HIV-related care, we do not have any reasons to suspect that this reporting is biased by the type of HIV test a person received.

Anonymous testing was not available in all the study states in the early years of HIV testing. However, since all the respondents were diagnosed as having AIDS within the same year, there is a bias toward a positive association between confidential testing and the longest intervals between knowledge of being HIV positive and AIDS. When we limited our sample to more recent years in which both anonymous and confidential testing were available, we find a proportionally even greater difference between persons tested anonymously and persons tested confidentially in the length of time between knowledge of being HIV positive and AIDS diagnosis (data not shown).

A question can be raised whether the benefit we observed for anonymous testing is attributable to the availability of this type of testing or to characteristics of persons tested anonymously that make them seek earlier testing and care. For example, among HIV exposure groups, MSM are more likely to seek anonymous testing. From a policy perspective the question is whether the same persons who seek early HIV testing at anonymous sites would do so at confidential sites if anonymous testing sites were eliminated.[8] We cannot rule out the possibility that these same persons would have sought early testing and care even if anonymous test-

ing were not available. However, we designed our analysis to isolate the independent contribution of type of HIV testing to our outcome measures. To avoid a potentially biased comparison of persons who voluntarily sought testing at either anonymous or confidential testing sites with those who were required to be tested in confidential settings, we limited our analysis to those whose reasons for testing suggested that the action was voluntary. To avoid a bias toward confidential testing among sicker persons who sought medical care, we included symptoms at the time of HIV testing in our adjusted analysis. Of the persons tested anonymously, 50% reported that they were symptomatic, suggesting that even sick persons were making testing choices. We also controlled for a wide variety of other characteristics that differentiated persons tested anonymously and those tested confidentially and still found that anonymous testing was independently associated with a substantially higher first $CD4^+$ cell count and a longer period of HIV-related medical care before AIDS.

We explored the possibility that the longer duration of HIV-related medical care for persons tested anonymously could be due to explanations aside from their seeking medical care earlier. For example, if persons tested anonymously were diagnosed as having AIDS more often than persons tested confidentially on the basis of an opportunistic infection as opposed to a $CD4^+$ cell count below 0.20×10^9/L, this would create a bias toward lengthening the duration of HIV-related medical care before an AIDS diagnosis for persons tested anonymously. In general, opportunistic infections occur later in the HIV disease course than detection of a $CD4^+$ cell count below 0.20×10^9/L. However, since more persons testing confidentially than anonymously were diagnosed as having AIDS on the basis of an opportunistic infection, adjusting for this bias merely increases the duration of HIV-related medical care among persons tested anonymously compared with confidentially. A second explanation for the longer duration of HIV-related medical care for persons tested anonymously is that they were receiving better-quality medical care than were persons tested confidentially. However, comparisons between persons tested anonymously and confidentially in their receipt of several effective prevention and treatment services revealed no significant differences.

Some of the individual characteristics associated with earlier HIV testing and HIV-related medical care were expected, but others were not. For example, we had anticipated that persons who were symptomatic would seek care more quickly than persons who were asymptomatic. We found that after controlling for whether persons had HIV-related symptoms at the time they received a positive HIV test result eliminated the significant difference between persons tested anonymously and persons tested confidentially in the length of their delay between learning they were HIV positive and getting HIV-related medical care. However, we were surprised that neither health insurance nor having a regular source of care—2 traditional measures of access—was associated with early HIV testing or HIV-related medical care. This finding suggests that either physicians are not sufficiently identifying their high-risk patients and encouraging them to be tested early or that patients who have insurance or a regular source of care are reluctant to pursue HIV testing at any greater rate than is found among all at-risk individuals.

We found, as other reports have suggested, that black and Hispanic persons tended to have fewer days of knowing that they were HIV positive before AIDS and fewer HIV-related medical care days than whites[6]; however, the comparisons with whites were not significant in the adjusted analyses.

With the development of improved therapies for HIV-infected persons, the rationale for anonymous testing may be waning.[10] In our companion study of persons at high risk for HIV, we found that in the 1990s the annual rate of choosing anonymous rather than confidential testing was 44% to 58% (mean, 48%) (A.B.B., D.O., F.M.H., et al, unpublished data, December 1995-November 1996). This suggests that, at least through 1996, anonymous testing has remained a consistently important testing option for a significant proportion of at-risk persons. It is also possible that more at-risk persons will be interested in anonymous testing now that the Council of State and Territorial Epidemiologists has revised its statement on HIV reporting to favor name reporting[11] and a growing number of states and Congress are actively considering the implementation of HIV name-reporting policies.[12] To the extent that name-reporting surveillance systems create a barrier to HIV testing for some persons, anonymous testing might serve as a "safety valve" for those who fear that confidential surveillance systems cannot adequately protect their privacy.

Observational studies may never be able to fully tease apart the contribution that anonymous testing makes to the timing of HIV testing and to HIV-related medical care. In reality, there is a complex interplay among the characteristics of persons at-risk for HIV, changes over time in the perceived benefit of knowing one's serostatus, the availability of anonymous testing, the implementation of name-reporting policies, the opportunity to circumvent surveillance strategies by using a false name at confidential testing sites, and the availability of anonymous home HIV testing kits. We were able to adjust for many, but not all, of these factors. Nonetheless, we believe that our study provides the strongest evidence to date that anonymous testing contributes at a population level to early HIV testing and medical care. Thus, to achieve the public health goal of providing early access to HIV testing and HIV-related medical care, public health departments should maintain and in some instances enhance the broad availability of anonymous testing options.

Support for this project was provided by the CDC (DHHS 282-92-0048).

The MESH Study Group comprises John Ward, MD, MPH, and Patricia Fleming, PhD, CDC, Atlanta, Ga; Denise K. Boyd, MS, MPH, and Vjollca Berisha, MD, MPH, Arizona Public Health Department, Phoenix; Kenneth Gershman, MD, MPH, and Melanie Mattson, Colorado Public Health Department, Denver; John Newman and Craig Thompson, Mississippi Public Health Department, Jackson; Robert Hamm, MD, MPH, Kristin Wendt, MPH, and Linda Bell, Missouri Public Health Department, Jefferson City; Michael Samual, DrPH, and Mark Stenger, MS, New Mexico Public Health Department, Santa Fe; Steven Modesitt, RN, MPH, Roger Wirt, PhD, and David Fleming, MD, Oregon Public Health Department, Portland; and Ann S. Robbins, PhD, Sharon A. King, MA, and Douglas Ramaker, Texas Public Health Department, Austin. The participants from the North Carolina Public Health Department requested that their names not be included.

References

1. Hertz-Picciotto I, Lee L, Hoyo C. HIV test-seeking before and after the restriction of anonymous testing in North Carolina. *Am J Public Health*. 1996; 86:1446-1450.
2. Hirano D, Cellart G, Fleming K, Boyd D, Englender S, Hawks H. Anonymous HIV testing: the impact of availability on demand in Arizona. *Am J Public Health*. 1994;84:2008-2010.
3. Fehrs L, Foster L, Fox V, et al. Trial of anonymous versus confidential human immunodeficiency virus testing. *Lancet*. 1988;332:379-382.
4. Hoxworth T, Huffman R, Cohn D, Davidson A. Anonymous HIV testing. *AIDS Public Policy J*. 1994;9:182-189.
5. Kassler W, Meriwether R, Klimko T, Peterman T, Zaidi A. Eliminating access to anonymous HIV antibody testing in North Carolina. *J Acquir Immune Defic Syndr Hum Retrovirol*. 1997;14:281-289.
6. Rosenbaum S, Serrano R, Magar M, Stern C. Civil rights in a changing health care system. *Health Aff (Millwood)*. 1997;16:90-105.
7. Cunningham W, Rana H, Shapiro M, Hays R. Reliability and validity of self-report $CD4^+$ counts in persons hospitalized with HIV disease. *J Clin Epidemiol*. 1997;50:829-835.
8. Kegeles S, Catania J, Coates T, Pollack L, Lo B. Many people who seek anonymous HIV-antibody testing would avoid it under other circumstances. *AIDS*. 1990;4:585-588.
9. Wortley P, Chu S, Diaz T, et al. HIV testing patterns. *AIDS*. 1995;9:467-492.
10. Steinbrook R. Battling HIV on many fronts. *N Engl J Med*. 1997;337:779-781.
11. Council of State and Territorial Epidemiologists. *National HIV Surveillance: Addition to the National Public Health Surveillance System*. Atlanta, Ga: Council of State and Territorial Epidemiologists; 1997. Position Statement ID-4.
12. Richardson L. Progress on AIDS brings movement for less secrecy, more reporting urged. *New York Times*. August 21, 1997; section 1:1.

http://aspe.os.dhhs.gov/ncvhs/appO.h

ANALYSIS OF UNIQUE PATIENT IDENTIFIER OPTIONS

FINAL REPORT

November 24, 1997

Prepared for THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

by Soloman I. Appavu

ISSUES - HIV Surveillance

Download zipped copy of report (WordPerfect 6.1/WIN format).

Table of Contents

V. Compliance with Unique Patient Identifier Components Requirements
VI Compliance with Basic Functions Criteria
VII. Strengths and Weaknesses
VIII. Potential Barriers & Challenges to Overcoming the Barriers
IX. Solutions to the Barriers:

3. Unique Patient Identifier based on Bank Card Method

I. Description of the Option
II. Author/Proponent and Documentation
III. Compliance with ASTM Conceptual Characteristics
e) Design Characteristics
IV. Compliance with Operational Characteristics and Readiness
V. Compliance with Unique Patient Identifier Components Requirements
VI. Compliance with Basic Functions Criteria
VII. Strengths and Weaknesses
VIII. Potential Barriers & Challenges to Overcoming the Barriers
IX. Solutions to the Barriers:

4. Cryptography-based Patient Identifier

I. Description of the Option
II. Author/Proponent and Documentation
Compliance with ASTM Conceptual Characteristics
IV Compliance with Operational Characteristics
V. Compliance with Unique Patient Identifier Components Requirements
VI. Compliance with Basic Functions Criteria
VII. Strengths and Weaknesses
VIII. Potential Barriers & Challenges to Overcoming the Barriers
IX. Solutions to the Barriers:

5. Unique Patient Identifier based on Personal Immutable Properties

I. Description of the Option
II. Author/Proponent and Documentation
III. Compliance with ASTM Conceptual Characteristics
IV. Compliance with Operational Characteristics and Readiness
V. Compliance with Unique Patient Identifier Components Requirements
VI Compliance with Basic Functions Criteria
VII. Strengths and Weaknesses
VIII. Potential Barriers & Challenges to Overcoming the Barriers
IX. Solutions to the Barriers:

6. Unique Patient Identifier based on Biometrics

I. Description of the Option
II. Author/Proponent and Documentation
III. Compliance with ASTM Conceptual Characteristics
IV. Compliance with Operational Characteristics and Readiness
V. Compliance with Unique Patient Identifier Components Requirements
VI. Compliance with Basic Functions Criteria
VII. Strengths and Weaknesses
VIII. Potential Barriers & Challenges to Overcoming the Barriers

IX. Solutions to the Barriers:

7. Lifetime Human Service & Treatment Record (LHSTR) Number based on Birth Certificate

I. Description of the Identifier
II. Author/Proponent and Documentation
III. Compliance with ASTM Conceptual Characteristics
IV. Compliance with Operational Characteristics and Readiness
V. Compliance with Unique Patient Identifier Components Requirements
VI. Compliance with Basic Functions Criteria
VII. Strengths and Weaknesses
VIII. Potential Barriers & Challenges to Overcoming the Barriers
IX. Solutions to the Barriers:

8. Existing Medical Record Number (MRN) based identification

I. Description of the Option
II. Author/Proponent and Documentation
III. Compliance with ASTM Conceptual Characteristics
IV. Compliance with Unique Patient Identifier's Operational Characteristics
V. Compliance with Unique Patient Identifier Components Requirements
VI. Compliance with Basic Functions Criteria
VII. Strengths and Weaknesses
VIII. Potential Barriers & Challenges to Overcoming the Barriers
IX. Solutions to the Barriers:

9. Identification based on Medical Record Number and Provider Prefix

I. Description of the Option
II. Author/Proponent and Documentation
III. Compliance with ASTM Conceptual Characteristics
IV. Compliance with Unique Patient Identifier's Operational Characteristics and Readiness
V. Compliance with Unique Patient Identifier's Components Requirements
VI. Compliance with Basic Functions Criteria
VII. Strengths and Weaknesses
VIII. Potential Barriers & Challenges to Overcoming the Barriers
IX. Solutions to the Barriers:

10. CORBAMed Patient Identification Service (PIDS)

I. Description of the Option
II. Author/Proponent and Documentation
III. Compliance with ASTM Conceptual Characteristics
IV. Compliance with Unique Patient Identifier's Operational Characteristics
V. Compliance with Unique Patient Identifier Components Requirements
VI. Compliance with Unique Patient Identifier's Basic Functions Criteria
VII. Strengths and Weaknesses
VIII. Potential Barriers & Challenges to Overcoming the Barriers
IX. Solutions to the Barriers:

11. HL7 Master Patient Index Mediator

I. Description of the Option
II. Author/Proponent and Documentation
III. Compliance with ASTM Conceptual Characteristics
IV. Compliance with Operational Characteristics and Readiness
V. Compliance with Unique Patient Identifier Components Requirements
VI. Compliance with Basic Functions Criteria
VII. Strengths and Weaknesses
VIII. Potential Barriers & Challenges to Overcoming the Barriers
IX. Solutions to the Barriers:

12. FHOP's Core Data Element-Based Patient Identification

I. Description of the Options
II. Author/Proponent and Documentation
III. Compliance with ASTM Conceptual Characteristics
IV. Compliance with Operational Characteristics and Readiness
V. Compliance with Unique Patient Identifier Components Requirements
VI. Compliance with Basic Functions Criteria
VII. Strength and Weaknessess
VIII. Potential Barriers & Challenges to Overcoming the Barriers
IX. Solutions to the Barriers

13. Directory Service

I. Description of the Option
II. Author/Proponent and Documentation
III. Compliance with ASTM Conceptual Characteristics
IV. Compliance with Operational Characteristics and Readiness
V. Compliance with Unique Patient Identifier Components Requirements
VI. Compliance with Basic Functions Criteria
VII. Strengths and Weaknesses
VIII. Potential Barriers & Challenges to Overcoming the Barriers
IX. Solutions to the Barriers:

Part Eight: Central Trusted Authority Options

Part Nine: Result of the Analysis

1) General Findings
2) Compliance with Unique Patient Identifier Requirements
3) Compliance Summary
4)Compliance Matrix for ASTM Conceptual Characteristics
5) Compliance Matrix for Operational, Components and Basic Functions Requirements

Part Ten: Available Courses of Action

An Ideal Unique Patient Identifier
Available Courses of Action
The Need for Leadership

Part Eleven: References & Acknowledgments

FAX

Date: *May 28, 1998*

To: *Robert Greenwald*
Christine Lubinski
Mike Shriver
Seth Kilbourn
Todd Summers
Debra Von Zinkerngel

From: *Ray Hobbs/Regina Aragón*
San Francisco AIDS Foundation
P.O. Box 426182
San Francisco, CA 94142

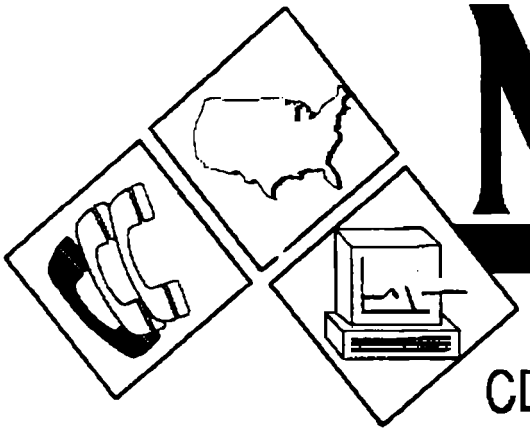
Phone: *415-487-3083*
Fax: *415-487-3089*

Total Pages: *7*

Remarks: [X] *Urgent* [ ] *For your review* [ ] *Reply ASAP* [ ] *Please Comment*

Please direct transmission to the appropriate person listed above.

ISSUES- HIV Surveillance



NAC FAX

from the
CDC National AIDS Clearinghouse

To: Attn: Director, Office of National AIDS Policy
From: Centers for Disease Control and Prevention

January 8, 1998 5:12 PM

Total number of pages (including cover): 12

The CDC National AIDS Clearinghouse (CDC NAC) is a national reference, referral, and distribution service for HIV/AIDS-related information. The Clearinghouse's services are designed to facilitate the sharing of information and resources among people working in HIV prevention, treatment, and support services.

P.O. Box 6003
Rockville, MD 20849-6003
E-mail: aidsinfo@cdcnac.org
URL: http://www.cdcnac.org

Voice: 1-800-458-5231
TTY: 1-800-243-7012
Fax: 1-301-519-6616

◆ *24-Hour Fax-on-Demand Service* ◆

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333

January 8, 1998

Dear Colleague:

The accuracy and completeness of AIDS surveillance data has proven to be invaluable in effectively targeting HIV prevention and treatment programs over the course of the epidemic. As you may know, we have now entered a time of transition for AIDS surveillance. As with most things in life, success in one area often creates challenges in another area. Such is the case here. As we recently reported in the September 19 issue of *Morbidity and Mortality Weekly Report (MMWR)*, our success in treating HIV infection has made AIDS surveillance data less reflective of recent trends in the epidemic. Therefore, in order to ensure that programs continue to have reliable data on which to base critical decisions and resource allocations, CDC has been taking steps to expand the current surveillance system to include more widespread HIV surveillance.

While there is general agreement that an expansion of the surveillance system is necessary, there remains a debate about how to best conduct HIV surveillance. At the heart is the debate about whether or not HIV surveillance should be conducted using names or unique identifiers (UIs).

Any decision about the best approach to HIV surveillance must balance multiple issues, including security and confidentiality, feasibility, and quality of data. AIDS surveillance has always been name based and since 31 state health departments already conduct name-based HIV surveillance, we feel there is adequate experience with which to evaluate name-based approaches.

Approaches using UIs (social security numbers) in Texas and Maryland have recently been evaluated. The results of this evaluation are summarized in the attached *MMWR* article, which will be released today. This evaluation revealed several problems, including a high number of reports with incomplete codes, low rates of reporting--even in settings where UI codes were complete, difficulty in conducting follow-up on specific cases, and the absence of behavioral risk data in this system. The *MMWR* article is being published in order to ensure that the state health departments which do not currently conduct HIV surveillance have access to current information as they consider the best ways to expand AIDS surveillance to include HIV reporting.

CDC is in the process of developing detailed guidance and technical assistance that will be provided to state health departments in the first few months of this year about the "best practices" related to the security and quality of HIV/AIDS surveillance. Because surveillance data are so critical to prevention and treatment efforts, CDC must recommend approaches based on their performance. Any potential HIV surveillance system will need to meet very specific performance criteria for effectiveness and security. The upcoming guidance, which will be released in a special *MMWR Recommendations and Reports*, will specify these criteria. The final guidance will be published after a process that allows for public comment.

Some people have told us they think that CDC is moving too fast to change AIDS surveillance practices. We believe that accurate and complete information with which to inform decisions about directing scarce HIV prevention and treatment resources is vital and, therefore, changes in the AIDS surveillance system need to be accomplished with a sense of urgency. At the same time, we are cognizant of ongoing concerns and respect the passion and commitment of those who have expressed concerns. In fact, we agree with the ideals that have been articulated--especially with the importance of protecting confidentiality and preventing discrimination.

CDC remains committed to resolving these important issues and will do everything possible to ensure that the public health benefits from changes in AIDS surveillance practice are maximized while minimizing the potential for risks. We look forward to hearing your comments after the draft guidance is developed and released, which should be within the next few months. In the meantime, we have provided additional information in the attached fact sheet. If you have any questions, please feel free to call our Technical Information Communication Branch at (404) 639-2072.

Sincerely,

Helene D. Gayle

Helene D. Gayle, M.D., M.P.H.
Director
National Center for HIV, STD, and TB Prevention

Kevin DeCock, M.D., F.R.C.P.
Director
Division of HIV/AIDS Prevention -
Surveillance and Epidemiology
National Center for HIV, STD, and TB Prevention

CDC UPDATE NCHSTP

January 1998
EMBARGOED: 4 p.m. ET

The Role of HIV Surveillance as U.S. Enters New Era in the Epidemic

Over the course of the HIV epidemic, AIDS surveillance, which has been the primary means to track the epidemic in the United States, has become increasingly important. These surveillance data are critical to help target and deliver prevention and treatment programs, ensuring that scarce resources for HIV prevention and treatment are appropriately directed. As the ability to treat HIV infection has advanced, the progression from HIV infection to AIDS is slowing and the number of people living with HIV (HIV prevalence) is increasing. Consequently, the reporting of AIDS cases alone is becoming less indicative of recent trends in the epidemic. CDC, therefore, proposes to implement national HIV infection case surveillance in order to continue to effectively track the epidemic as it evolves.

The development of a national HIV surveillance system is a public health priority. Unless surveillance systems are revised, health authorities at the local, state, and federal level will not have reliable information about HIV prevalence, the number of new cases diagnosed each year, recent or anticipated trends in HIV infection and behaviors that increase the risk of HIV transmission, or the impact on specific subpopulations.

Status of AIDS and HIV Reporting in the U.S.

States have conducted name-based AIDS reporting since 1981. As of January 1998, 31 states have implemented name-based HIV surveillance as an extension of their existing name-based AIDS surveillance programs; 3 of these states have HIV reporting for children only. Two additional states use coded non-name-based (unique identifier) HIV case surveillance. The 28 states with name-based reporting for adults report approximately 33 percent of the total U.S. AIDS cases. Of the 10 states with the highest rates of AIDS, only New Jersey, Florida, and Louisiana have name-based HIV case surveillance.[1] Currently, many States are having public discussions regarding the expansion of their surveillance activities to include name-based HIV surveillance.

Most state health departments use name-based surveillance methods because this approach provides a feasible, accurate, and efficient way to monitor the epidemic. Since health care providers are not reimbursed for public health surveillance activities, their ability and willingness to report depends in large part on the ease of reporting. Moreover, these systems are protected by state laws and regulations that have proven to be effective in maintaining the confidentiality of name reporting.

---

[1] States that have confidential, name-based HIV infection reporting are Alabama, Arizona, Arkansas, Colorado, Florida, Idaho, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, and Wyoming. Connecticut, Texas, and Oregon have confidential, name-based HIV infection reporting for pediatric cases only. Maryland and Texas also have unique identifier HIV infection reporting for non-pediatric cases.

Currently, medical and other health record systems in the United States primarily rely on names to differentiate records. Local public health authorities routinely use patient names to: (1) identify and eliminate duplicate reports of the same individual; (2) obtain additional epidemiologic information from health care providers; and (3) link to other name-based public health data systems (e.g., to tuberculosis) to obtain additional epidemiologic information, to evaluate the surveillance system, and, in some states, to conduct partner notification, TB or STD case management, or provide other services.

Efforts to Evaluate and Address Concerns About Name-Based HIV Reporting

While there is widespread support for expanded HIV surveillance, many people who support name-based AIDS reporting still have concerns regarding name-based reporting of HIV infection. Concerns about name-based HIV reporting have focused largely on potential breaches of confidentiality that may be associated with a name-based system and the potential adverse outcomes of such breaches. Many have also feared that name-based HIV surveillance may deter people from seeking HIV testing. Additionally, there is concern that name-based HIV surveillance may mean the elimination of anonymous testing.

CDC has worked extensively with community and public health representatives over the past several years to evaluate and address these concerns and to explore the possibility of using alternative systems for HIV surveillance. As part of this process, CDC has conducted several scientific assessments and has consulted with a diverse group of individuals and organizations from the scientific, public health, and AIDS community. Based on these assessments and consultations, CDC will issue draft guidance in early 1998 to assist states in refining and expanding their current surveillance systems.

Concerns about possible alternatives to name-reporting, the impact of reporting on test-seeking behavior, anonymous testing, and confidentiality will be addressed in detail in this guidance. CDC has taken numerous steps over the past three years to address these concerns, including:

Evaluation of alternative to names

In response to concerns about a name-based system, CDC has conducted a three-year evaluation of non-named, unique identifier (UI)-based surveillance systems in Maryland and Texas. The evaluation, published in the January 9, 1997, *Morbidity and Mortality Weekly Reports*, revealed several problems with these UI systems, including a high number of reports with incomplete codes (approximately 30-40%), low rates of completeness in reporting (approximately 25-50% complete), difficulty in conducting follow-up on specific cases, and the absence of behavioral risk data in this system. Additionally, a UI-based system may not reduce the potential risk for a breach of confidentiality when providers are required to maintain surveillance logs. This approach increases the number of surveillance lists that could be disclosed in a breach of confidentiality. Moreover, security and confidentiality laws that stringently protect surveillance records maintained by health departments may not extend to lists or records kept by physicians, laboratories, or other providers in all states.

Evaluation of impact on test-seeking behavior

CDC has also evaluated the impact of HIV surveillance on test-seeking behavior in a nine-state study. Preliminary findings indicate that HIV reporting does not serve as a major deterrent to HIV test seeking among at-risk individuals.

Support for anonymous testing

CDC continues to strongly support anonymous HIV testing. Unless prohibited by law, CDC requires that states receiving prevention funds make anonymous testing available in order to make testing as accessible as possible. Maintaining anonymous test sites is important for prevention efforts and will not seriously inhibit our ability to track the epidemic. Most people are diagnosed with HIV infection in confidential care settings. Moreover, the time between HIV diagnosis and the point at which individuals enter the care system has become increasingly shorter, given new treatment advances. Maintaining an anonymous testing option may help ensure that more individuals learn their status, and if infected, seek early treatment and care. Of the 31 states that currently conduct HIV case surveillance, 21 states provide anonymous HIV testing services and 10 do not. Anonymous HIV testing is available in all other states.

Strengthening systems to protect confidentiality

To date, states have maintained an exemplary record in protecting the confidentiality of HIV/AIDS data. Since 1981 there has been one reported breach of confidentiality of a state AIDS reporting system, and there have been no known breaches following the adoption of name-based HIV surveillance. Over the past few years, CDC has been working to evaluate additional measures at the state level that could improve confidentiality even further. To assess the strength of local confidentiality laws that protect HIV surveillance data, CDC requested that the Georgetown/Johns Hopkins Program on Law and Public Health review local laws and regulations. This review found that the strictest and most comprehensive protections of health data apply to government-held information generally and to HIV-related data specifically.

CDC has also recently reviewed state surveillance programs and is working to develop enhanced standards to be used in developing local confidentiality plans. Local programs will be required to meet the performance standards established by CDC and must be able to ensure confidentiality as a condition of funding. CDC has also initiated efforts to develop model confidentiality standards to further enhance and standardize local confidentiality laws. Security measures will be outlined in greater detail by CDC in the upcoming program guidance.

CDC Recommendations for HIV Surveillance: Upcoming Guidance Document

CDC program guidance for expanded HIV/AIDS surveillance will be published for public comment in the first few months of 1998. The guidance will outline best practices and performance criteria to ensure both the quality and confidentiality of surveillance systems as states expand and refine their surveillance systems. These data must be able to provide a reliable basis for directing scarce prevention and treatment dollars. To solicit comments and concerns from the public health and AIDS community, the guidelines will be available in draft form for public comment prior to the publication of the final document.

###

Evaluation of HIV Case Surveillance Through the Use of Non-Name Unique Identifiers — Maryland and Texas, 1994–1996

Notifiable disease reporting laws or regulations in states and territories require reporting of acquired immunodeficiency syndrome (AIDS) cases, including patient and physician names, to state or local health authorities. As of January 1, 1998, a total of 31 states were conducting name-based human immunodeficiency virus (HIV) case surveillance by using the same methods as surveillance for AIDS. However, because of concerns about name-based HIV surveillance, Maryland and Texas implemented HIV surveillance using non-name unique identifiers (UI)*. This report summarizes a 3-year collaboration by CDC and these states to evaluate UI surveillance for HIV infec-

*Reporting in Maryland is exempted for nonstate residents; persons who are tested at anonymous test sites; are blood, semen, or tissue donors; and participants of certain research projects. No exemptions to reporting exist in Texas.

HIV Case Surveillance — Continued

tion; the findings indicate some limitations to the use of a Social Security number-based UI for HIV surveillance.

In both Maryland and Texas, UI surveillance for HIV was implemented in early 1994, and both used the same 12-digit numeric UI code (comprising the last four digits of the patient's Social Security number [SSN], six-digit [month/day/year] date of birth [DOB], one-digit code for race/ethnicity, and one-digit code for sex). HIV-infection reports included residence data, diagnosing facility, and date of test, but did not include mode of HIV exposure. In both states, UI HIV surveillance databases were maintained separately from name-based AIDS surveillance databases.

Evaluation criteria included the proportion of reports with full UI codes, timeliness and completeness of HIV reporting, and potential for matching the UI-based case reports to alternate databases. In Texas, selected HIV reports also were evaluated for ability to follow back UI reports to patient records; in Maryland, provider compliance with maintaining patient surveillance logs was assessed. During July 1994–December 1996, Maryland reported 6412 AIDS cases and received 9971 HIV-infection reports, and Texas reported 12,041 AIDS cases and received approximately 23,000 HIV-infection reports.

Maryland

In 1993, the Maryland legislature mandated UI reporting of both positive HIV tests and patients with CD4+ T-lymphocyte counts of <200 cells/μL (CD4+)[†]. Health-care providers requesting HIV or CD4+ tests are required to construct the UI code for each patient, include the code on the laboratory slip, and record it in a surveillance log that matches the UI to patient identifiers (e.g., medical record number, patient name, or other patient code) for purposes of case investigation and follow up. Laboratories licensed by Maryland are required to submit the UI-based reports to the state health department through the local health departments.

Of 9971 HIV-infection reports entered during July 1994–December 1996, all UI elements were present for 7119 (71%) (Table 1). Element-specific presence ranged from 78% (SSN) to 98% (DOB and sex). The proportion of reports with full UI increased during July 1994–June 1996, and declined slightly during July–December 1996. The median time from date of HIV test to receipt of report by the state health department was 20 days (range: 1–847 days). During October–November 1997, all 72 providers in nine counties of eastern Maryland (the counties reported 3% of AIDS cases in Maryland in 1996) for whom laboratories had submitted HIV-infection reports were contacted to determine the proportion of providers who maintain the required surveillance log linking UI to patient identifiers; 32 (44%) of these providers maintained logs.

Completeness of HIV-infection reporting was estimated by comparison to cases of AIDS reported in the AIDS surveillance registry. Of AIDS cases with dates of HIV diagnosis from July 1995 through June 1996, data elements to construct UI were available for 633 (85%) cases. Of these, 319 (50%) matched to HIV-infection reports with full UI in the UI database (Table 2).

Data from the Maryland HIV counseling and testing (C&T) system (excluding sites offering only anonymous HIV tests) were used to evaluate the proportion of records

[†]HIV-infected persons with a CD4+ T-lymphocyte count of <200 cells/μL meet the 1993 expanded AIDS surveillance case definition and are reportable by name for AIDS surveillance.

HIV Case Surveillance — Continued

TABLE 1. Number of reports of HIV infection and percentage of reports that included data elements for unique identifiers (UIs), by reporting period — Maryland (MD) and Texas (TX), July 1994–December 1996

Reports/Data element	State	July–Dec. 1994	Jan.–June 1995	July–Dec. 1995	Jan.–June 1996	July–Dec. 1996	Overall
Total no. reports	MD	2,238	1,691	1,866	1,881	2,295	**9,971**
	TX*	3,932	3,399	3,597	2,852	2,339	**16,119**
Data element†							
Social Security number	MD	69.6	73.1	81.2	83.5	84.5	**78.4**
	TX	56.7	68.6	65.0	69.5	75.2	**66.0**
Date of birth	MD	95.2	96.3	98.7	99.3	98.8	**97.6**
	TX	88.4	89.8	93.1	96.8	97.6	**92.6**
Sex	MD	96.8	97.2	98.7	99.2	99.4	**98.3**
	TX	91.5	97.5	98.4	99.1	97.9	**96.6**
Race/Ethnicity	MD	85.8	88.5	91.6	94.0	89.9	**89.8**
	TX	80.8	91.6	94.4	97.1	95.4	**91.1**
% Reports with full UI	MD	61.3	65.9	74.9	78.5	76.5	**71.4**
	TX	51.8	61.9	61.6	66.5	71.3	**61.6**

*Excludes approximately 7000 records that had three or more missing UI data elements.
†Proportion of all reports containing specific UI data elements.

with full UI and completeness of HIV-infection reporting. In early 1995, counselors were instructed to obtain UI code information from clients and record the UI on the HIV C&T record. During 1995–1996, a total of 1093 records with a positive HIV test were entered into the C&T database; of these, all UI elements were present for 94%. HIV C&T reports for persons who had HIV diagnosed from July 1995 through June 1996 were matched to the UI database. Of the 528 reports, 276 (52%) matched.

Texas

In 1994, the Texas Board of Health amended regulations to require named reporting of HIV-infected children aged <13 years and UI reporting of HIV-infected adolescents and adults. Both health-care providers ordering an HIV test and laboratories performing the test report confirmed HIV infections to the Texas Department of Health (TDH) through the local health departments. Neither providers nor laboratories are required to maintain registries linking UI to patient identifiers.

Approximately 23,000 HIV-infection reports were received at TDH during the evaluation period. Since 1995, TDH excluded approximately 7000 paper HIV reports with three or more missing UI data elements. Of 16,119 HIV-infection reports entered into the UI database, all UI elements were present for 9923 (62%) (Table 1). Element-specific presence ranged from 66% (SSN) to 97% (sex). Overall, 60% of reports were submitted in periodic batches, which had a longer time from date of HIV test to receipt by TDH (median: 173 days; range: 26–974 days) than the 40% of reports submitted individually (median: 59 days; range: 2–906 days).

Completeness of HIV-infection reporting was estimated by comparison to AIDS surveillance data using the same methodology as in Maryland. Data elements to construct UI were available for 1762 (79%) of AIDS cases with dates of HIV diagnosis in the

HIV Case Surveillance — Continued

TABLE 2. Percentage completeness of HIV-infection reporting, availability of unique identifier (UI) data elements in alternate databases, and sources of report — Maryland and Texas, July 1994–December 1996

Characteristic	Maryland (n=9,971)	Texas (n=16,119)
Completeness of reporting		
HIV*	50.4	26.0
CD4+ T-lymphocyte count*	44.4	NA†
HIV§	52.3	NA
Availability of UI data elements in alternate databases		
Birth¶	No	No
Death	Yes	Yes
Sexually transmitted disease	No	No
Tuberculosis	No	No
Drug assistance**	Yes	Yes
Medical assistance††	Yes	No
Hospital discharge	No	No
Source of HIV report		
Public	30%§§	77%§§
Private	70%¶¶	23%***

*AIDS cases reported through July 1997 compared with the UI database.
†Not available.
§HIV cases diagnosed from July 1995 through June 1996 in HIV counseling and testing sites compared with the UI database.
¶Used for pediatric AIDS surveillance only.
**Federal- and state-funded medication program.
††Federal- and state-funded medical-assistance program.
§§Includes local health departments and state laboratory.
¶¶Includes community-based organizations and private clinics and laboratories.
***Includes community-based organizations, hospitals, private physicians, clinics, and laboratories.

specified period (Table 2). Of these, 454 (26%) matched to HIV-infection reports with full UI in the UI database.

To evaluate the feasibility of epidemiologic follow up, TDH sampled 765 HIV-infection reports submitted during January 1995–June 1996, in six areas of the state, reflective of variation in geography, demography, HIV morbidity, and reporting sources. Of these, 456 (60%) could be matched to a client record using any combination of UI (including records without full UI), health-care provider name, date of test, residential information, and other locally available information. Matched records that were missing the SSN data element (n=208) were reviewed to determine whether these data could be located. SSN could not be located for 120 (58%) of these records.

Reported by: L Solomon, DrPH, L Eldred, DrPH, J Markowitz, PhD, P Ryan, MS, G Benjamin, MD, Maryland Dept of Health and Mental Hygiene. AS Robbins, PhD, DW Hamaker, SA King, MA, SK Melville, MD, MC Thomas, MS, DM Simpson, MD, State Epidemiologist, Texas Dept of Health. Div of HIV/AIDS Prevention–Surveillance and Epidemiology, National Center for HIV, STD, and TB Prevention, CDC.

HIV Case Surveillance — Continued

Editorial Note: HIV and AIDS surveillance data are needed to provide reliable population-based data to guide public health programs. During 1995–1996, the first declines in the incidence of AIDS-opportunistic infections and AIDS deaths were reported in the United States (6% and 23%, respectively), in part, as a result of increasingly effective HIV therapy (*1*). On the basis of revised HIV treatment guidelines (*2*), the impact of treatment advances on AIDS trends is expected to continue and will reduce the usefulness of AIDS data alone to monitor HIV-infection trends and morbidity. CDC and other public health and advocacy organizations have recognized the need for national HIV case surveillance while continuing to discuss the relative merits of HIV surveillance methods based on numeric codes compared to the name-based approach employed for AIDS surveillance (*1,3*).

CDC uses established criteria to evaluate performance of public health surveillance systems to provide accurate data to target prevention and care programs (*4*). States conduct active surveillance using existing name-based clinical and public health records to decrease the reporting burden on providers, eliminate duplicate reports, and facilitate epidemiologic follow-up. These methods enable AIDS surveillance to attain high performance standards as reflected by completeness of reporting (>85%) (*5*) and documentation of risk exposures (≥93% of cases) (*6*). Evaluation of name-based HIV surveillance has shown 74%–97% completeness of reporting (*7*; CDC, unpublished data, 1997), and documentation of risk exposures (≥76% of cases) (*6*). Secure and confidential surveillance practices are required as a condition for receipt of federal resources for HIV and AIDS surveillance. At the state level, the most comprehensive protections of medical data apply to government-held data, and most specifically to HIV-related data (*8*). Names are removed before encoded and encrypted AIDS or HIV surveillance data are transmitted to CDC.

The evaluations in Maryland and Texas indicated that the use of UIs limits the performance of an HIV surveillance system and complicates efforts to collect risk-behavior information. Both systems demonstrated timely reporting. Although data from both states indicated increases in reporting of the SSN data element during the evaluation period, overall 22% of reports in Maryland and 34% in Texas were missing the SSN element, which contributed to a high rate of incomplete case reporting. The follow-back investigation in Texas suggests that SSNs are not readily available in client or medical records but, in the controlled environment of the Maryland HIV C&T system, counselors were able to collect SSNs for most clients. The completeness of reporting also may be affected by the ability of providers and laboratories to use UIs as part of routine HIV-testing practices. For example, one large laboratory providing HIV-testing services in Maryland did not report HIV infections during the evaluation period. The difficulty in collecting HIV data when persons are tested out of state also may affect completeness of reporting and the ability to eliminate duplicate reports. Maryland is continuing to evaluate its UI surveillance system, and Texas is exploring alternative HIV surveillance systems with input from community groups.

Effective HIV surveillance systems must include HIV risk information; however, this information often is not available at the time of the initial UI case report, and follow-up with health-care providers is necessary. To supply follow-up information, health-care providers must use lists or other mechanisms to link the UI to patient identifiers. The UI approach complicates efforts to collect this information and increases the number of lists of HIV-infected persons that could be disclosed in a breach of confidentiality.

(Continued on page 1271)

HIV Case Surveillance — Continued

CDC has recommended that all states and territories conduct HIV case surveillance as an extension of their AIDS surveillance systems (*1*). In addition, CDC is developing technical guidance to enhance security practices, standardize confidentiality laws and regulations, and promote uniform standards for HIV case surveillance systems. These guidelines will assist states and territories in implementing HIV case surveillance using data-collection and data-storage methods that provide high quality HIV surveillance data while assuring the confidentiality of surveillance information.

References

1. CDC. Update: trends in AIDS incidence, 1996. MMWR 1997;46:861–7.
2. Carpenter CC, Fischl MA, Hammer SM, et al. Antiretroviral therapy for HIV infection in 1997: updated recommendations of the International AIDS Society-USA panel. JAMA 1997;277:1962–9.
3. Council of State and Territorial Epidemiologists. CSTE: position statement ID-4. National HIV surveillance: addition to the National Public Health Surveillance System. Atlanta, Georgia: Council of State and Territorial Epidemiologists, 1997.
4. Klaucke DN. Evaluating public health surveillance. In: Teutsch SM, Churchill RE, eds. Principals and practices of public health surveillance. New York, New York: Oxford University Press, 1994:158–74.
5. Rosenblum L, Buehler JW, Morgan ME, et al. The completeness of AIDS case reporting, 1988: a multisite collaborative surveillance project. Am J Public Health 1992;82:1495–9.
6. CDC. HIV/AIDS surveillance report. Atlanta, Georgia: US Department of Health and Human Services, Public Health Service, 1997. (Vol 8, no. 1).
7. Meyer PA, Jones JL, Garrison CZ. Completeness of reporting of diagnosed HIV-infected hospital inpatients. J AIDS 1994;7:1067–73.
8. Gostin LO, Lazzarini Z, Neslund VS, Osterholm MT. The public health information infrastructure: a national review of the law on health information privacy. JAMA 1996;275:1921–7.

Contributors to the Production of the *MMWR* (Weekly)

Weekly Notifiable Disease Morbidity Data and 122 Cities Mortality Data

Denise Koo, M.D., M.P.H.

State Support Team

Robert Fagan
Karl A. Brendel
Siobhan Gilchrist, M.P.H.
Harry Holden
Gerald Jones
Felicia Perry
Carol A. Worsham

CDC Operations Team

Carol M. Knowles
Deborah A. Adams
Willie J. Anderson
Christine R. Burgess
Patsy A. Hall
Myra A. Montalbano
Angela Trosclair, M.S.

Desktop Publishing and Graphics Support

Morie M. Higgins
Peter M. Jenkins

CDC

CENTERS FOR DISEASE CONTROL
AND PREVENTION

National Center for HIV, STD, & TB Prevention

Office of the Director
FAX TRANSMITTAL COVER SHEET

From the desk of
Melissa Shepherd
Associate Director for Communications

Date: 1/8/97

Tel. no.: 404/639-8890
Fax no.: 404/639-8910

Current Mailing Address Below:

11 Corporate Square, Room 1212
Mailstop E-06
Atlanta, Georgia 30329

Pages 9 *(including cover)*

Name: Todd Summers
Tel. No.: (202) 632-1090
Fax No.: (202) 632-1096

Comments: As discussed. - MMWR article, Qs and As for the media, and summary paragraph (that went to the media this AM). Please call if you have any questions or need anything else.

Thanks

Melissa Shepherd

Evaluation of HIV Case Surveillance Through the Use of Non-Named Unique Identifiers--Maryland and Texas, 1994--1996

CDC Evaluation of Unique Identifier-Based HIV Surveillance Systems Finds that Current UI Systems Provide Limited Data and May Not Reduce Confidentiality Concerns

This article reports findings from a three year evaluation of HIV surveillance systems which utilize unique identifiers (UI) as the basis for HIV case reporting. Currently, 31 states conduct name-based HIV surveillance as an extension of their AIDS surveillance systems (3 for pediatric HIV infection only). Because of concerns about name-based reporting, CDC has worked with Maryland and Texas since 1994 to evaluate HIV surveillance systems which use a UI, based primarily on social security number, to report HIV cases. The evaluation revealed several problems with these UI systems, including a high number of reports with incomplete codes (approximately 30-40%), low rates of completeness in reporting (approximately 25-50% complete), difficulty in conducting follow-up on specific cases, and the absence of behavioral risk data in this system. Additionally, a UI-based system may not reduce the potential risk for a breach of confidentiality when providers are required to maintain lists to link the UI with patients because this approach increases the number of lists that could be disclosed in a breach of confidentiality.

Qs and As for use with the Media
Anticipated in response to *MMWR* on evaluation of Non-Named Unique Identifier Systems

Q1 What did this evaluation of UI-based HIV surveillance find?

A1 The evaluation revealed that social security number based UI systems do not provide reliable data for directing prevention and treatment and may not reduce confidentiality concerns. Specifically, the SSN based UI systems are limited in performance as follows:
* Completeness of reporting for the UI system (26 to 52 percent) was far less than for name-based HIV surveillance systems (79 to 90 percent).
* Many members of the affected communities may not have SSNs.
* Health departments could not reliably eliminate duplicate case reports from the UI systems.
* The UI-based systems in these states did not request HIV risk information on the initial case reports. Although risk information may be available on follow-up with providers, these UI-based systems greatly increase the complexity of follow-up necessary to complete basic risk information.
* The UI-based systems precluded the integration of HIV surveillance data with other relevant name-based public health information systems (e.g. tuberculosis).
* UI-based systems may not diminish the risk of breaches in confidentiality when providers are required to maintain logs to match UIs with patients, because this approach increases the number of lists of HIV infected people that could be disclosed in a breach of confidentiality.

Q2 Why is HIV surveillance needed?

A2 There is an urgent public health need to implement HIV surveillance. In comparison to AIDS surveillance alone, HIV surveillance provides population-based data not affected by treatment advances. In addition, HIV surveillance provides more timely information than AIDS surveillance about the changing demographics of the epidemic. HIV surveillance can also offer a more complete assessment of the burden of pediatric HIV infection and effectiveness of prevention interventions to reduce perinatal HIV transmission.

Q3 Will CDC be recommending name-based HIV surveillance?

A3 CDC has not finalized its policy on HIV surveillance. CDC recommendations will be published in draft form in a guidance document that will be released in the next few months. Because surveillance data are so critical to prevention and treatment services, (these data translate into prevention, services, and care for people with HIV/AIDS at national, state, and local levels) CDC must recommend approaches based on their performance. Any potential HIV surveillance system will need to meet very specific performance criteria for effectiveness and security. The upcoming guidance will specify these criteria.

CONFIRMATION REPORT - MEMORY SEND

Time : JAN-08-98 16:45
Fax number: 4046398910
Name : NCSEHSTP/COMMUNICATION OFFICE

Job	:	340
Date	:	JAN-08 16:42
To	:	912026321096
Doc. pages	:	06
Start time	:	JAN-08 16:42
End time	:	JAN-08 16:45
Pages sent	:	06
Job:340		*** SEND SUCCESSFUL ***

CDC
CENTERS FOR DISEASE CONTROL AND PREVENTION

National Center for HIV, STD, & TB Prevention

Office of the Director
FAX TRANSMITTAL COVER SHEET

From the desk of
Melissa Shepherd
Associate Director for Communications

Date: 1/8/97

Tel. no.: 404/639-8890
Fax no.: 404/639-8910

Current Mailing Address Below:
11 Corporate Square, Room 1312
Mailstop E-06
Atlanta, Georgia 30329

Pages 9 *(including cover)*

Name: Todd Summers
Tel. No.: (202) 632-1090
Fax No.: (202) 632-1091

Comments: As discussed - MMWR article, Qs and As for the media, and summary paragraph (what went to the media this AM). Please call if you have any questions or need anything else.

Melissa Shepherd

Evaluation of HIV Case Surveillance Through the Use of Non-Name Unique Identifiers — Maryland and Texas, 1994–1996

Notifiable disease reporting laws or regulations in states and territories require reporting of acquired immunodeficiency syndrome (AIDS) cases, including patient and physician names, to state or local health authorities. As of January 1, 1998, a total of 31 states were conducting name-based human immunodeficiency virus (HIV) case surveillance by using the same methods as surveillance for AIDS. However, because of concerns about name-based HIV surveillance, Maryland and Texas implemented HIV surveillance using non-name unique identifiers (UI)*. This report summarizes a 3-year collaboration by CDC and these states to evaluate UI surveillance for HIV infec-

*Reporting in Maryland is exempted for nonstate residents; persons who are tested at anonymous test sites; are blood, semen, or tissue donors; and participants of certain research projects. No exemptions to reporting exist in Texas.

HIV Case Surveillance — Continued

tion; the findings indicate some limitations to the use of a Social Security number-based UI for HIV surveillance.

In both Maryland and Texas, UI surveillance for HIV was implemented in early 1994, and both used the same 12-digit numeric UI code (comprising the last four digits of the patient's Social Security number [SSN], six-digit [month/day/year] date of birth [DOB], one-digit code for race/ethnicity, and one-digit code for sex). HIV-infection reports included residence data, diagnosing facility, and date of test, but did not include mode of HIV exposure. In both states, UI HIV surveillance databases were maintained separately from name-based AIDS surveillance databases.

Evaluation criteria included the proportion of reports with full UI codes, timeliness and completeness of HIV reporting, and potential for matching the UI-based case reports to alternate databases. In Texas, selected HIV reports also were evaluated for ability to follow back UI reports to patient records; in Maryland, provider compliance with maintaining patient surveillance logs was assessed. During July 1994–December 1996, Maryland reported 6412 AIDS cases and received 9971 HIV-infection reports, and Texas reported 12,041 AIDS cases and received approximately 23,000 HIV-infection reports.

Maryland

In 1993, the Maryland legislature mandated UI reporting of both positive HIV tests and patients with CD4+ T-lymphocyte counts of <200 cells/µL (CD4+)†. Health-care providers requesting HIV or CD4+ tests are required to construct the UI code for each patient, include the code on the laboratory slip, and record it in a surveillance log that matches the UI to patient identifiers (e.g., medical record number, patient name, or other patient code) for purposes of case investigation and follow up. Laboratories licensed by Maryland are required to submit the UI-based reports to the state health department through the local health departments.

Of 9971 HIV-infection reports entered during July 1994–December 1996, all UI elements were present for 7119 (71%) (Table 1). Element-specific presence ranged from 78% (SSN) to 98% (DOB and sex). The proportion of reports with full UI increased during July 1994–June 1996, and declined slightly during July–December 1996. The median time from date of HIV test to receipt of report by the state health department was 20 days (range: 1–847 days). During October–November 1997, all 72 providers in nine counties of eastern Maryland (the counties reported 3% of AIDS cases in Maryland in 1996) for whom laboratories had submitted HIV-infection reports were contacted to determine the proportion of providers who maintain the required surveillance log linking UI to patient identifiers; 32 (44%) of these providers maintained logs.

Completeness of HIV-infection reporting was estimated by comparison to cases of AIDS reported in the AIDS surveillance registry. Of AIDS cases with dates of HIV diagnosis from July 1995 through June 1996, data elements to construct UI were available for 633 (85%) cases. Of these, 319 (50%) matched to HIV-infection reports with full UI in the UI database (Table 2).

Data from the Maryland HIV counseling and testing (C&T) system (excluding sites offering only anonymous HIV tests) were used to evaluate the proportion of records

†HIV-infected persons with a CD4+ T-lymphocyte count of <200 cells/µL meet the 1993 expanded AIDS surveillance case definition and are reportable by name for AIDS surveillance.

HIV Case Surveillance — Continued

TABLE 1. Number of reports of HIV infection and percentage of reports that included data elements for unique identifiers (UIs), by reporting period — Maryland (MD) and Texas (TX), July 1994–December 1996

Reports/Data element	State	July–Dec. 1994	Jan.–June 1995	July–Dec. 1995	Jan.–June 1996	July–Dec. 1996	Overall
Total no. reports	MD	2,238	1,691	1,866	1,881	2,295	9,971
	TX*	3,932	3,399	3,597	2,852	2,339	16,119
Data element†							
Social Security number	MD	69.6	73.1	81.2	83.5	84.5	78.4
	TX	56.7	68.6	65.0	69.5	75.2	66.0
Date of birth	MD	95.2	96.3	98.7	99.3	98.8	97.6
	TX	88.4	89.8	93.1	96.8	97.6	92.6
Sex	MD	96.8	97.2	98.7	99.2	99.4	98.3
	TX	91.5	97.5	98.4	99.1	97.9	96.6
Race/Ethnicity	MD	85.8	88.5	91.6	94.0	89.9	89.8
	TX	80.8	91.6	94.4	97.1	95.4	91.1
% Reports with full UI	MD	61.3	65.9	74.9	78.5	76.5	71.4
	TX	51.8	61.9	61.6	66.5	71.3	61.6

*Excludes approximately 7000 records that had three or more missing UI data elements.
†Proportion of all reports containing specific UI data elements.

with full UI and completeness of HIV-infection reporting. In early 1995, counselors were instructed to obtain UI code information from clients and record the UI on the HIV C&T record. During 1995–1996, a total of 1093 records with a positive HIV test were entered into the C&T database; of these, all UI elements were present for 94%. HIV C&T reports for persons who had HIV diagnosed from July 1995 through June 1996 were matched to the UI database. Of the 528 reports, 276 (52%) matched.

Texas

In 1994, the Texas Board of Health amended regulations to require named reporting of HIV-infected children aged <13 years and UI reporting of HIV-infected adolescents and adults. Both health-care providers ordering an HIV test and laboratories performing the test report confirmed HIV infections to the Texas Department of Health (TDH) through the local health departments. Neither providers nor laboratories are required to maintain registries linking UI to patient identifiers.

Approximately 23,000 HIV-infection reports were received at TDH during the evaluation period. Since 1995, TDH excluded approximately 7000 paper HIV reports with three or more missing UI data elements. Of 16,119 HIV-infection reports entered into the UI database, all UI elements were present for 9923 (62%) (Table 1). Element-specific presence ranged from 66% (SSN) to 97% (sex). Overall, 60% of reports were submitted in periodic batches, which had a longer time from date of HIV test to receipt by TDH (median: 173 days; range: 26–974 days) than the 40% of reports submitted individually (median: 59 days; range: 2–906 days).

Completeness of HIV-infection reporting was estimated by comparison to AIDS surveillance data using the same methodology as in Maryland. Data elements to construct UI were available for 1762 (79%) of AIDS cases with dates of HIV diagnosis in the

HIV Case Surveillance — Continued

TABLE 2. Percentage completeness of HIV-infection reporting, availability of unique identifier (UI) data elements in alternate databases, and sources of report — Maryland and Texas, July 1994–December 1996

Characteristic	Maryland (n=9,971)	Texas (n=16,119)
Completeness of reporting		
HIV*	50.4	26.0
CD4+ T-lymphocyte count*	44.4	NA†
HIV§	52.3	NA
Availability of UI data elements in alternate databases		
Birth¶	No	No
Death	Yes	Yes
Sexually transmitted disease	No	No
Tuberculosis	No	No
Drug assistance**	Yes	Yes
Medical assistance††	Yes	No
Hospital discharge	No	No
Source of HIV report		
Public	30%§§	77%§§
Private	70%¶¶	23%***

*AIDS cases reported through July 1997 compared with the UI database.
†Not available.
§HIV cases diagnosed from July 1995 through June 1996 in HIV counseling and testing sites compared with the UI database.
¶Used for pediatric AIDS surveillance only.
**Federal- and state-funded medication program.
††Federal- and state-funded medical-assistance program.
§§Includes local health departments and state laboratory.
¶¶Includes community-based organizations and private clinics and laboratories.
***Includes community-based organizations, hospitals, private physicians, clinics, and laboratories.

specified period (Table 2). Of these, 454 (26%) matched to HIV-infection reports with full UI in the UI database.

To evaluate the feasibility of epidemiologic follow up, TDH sampled 765 HIV-infection reports submitted during January 1995–June 1996, in six areas of the state, reflective of variation in geography, demography, HIV morbidity, and reporting sources. Of these, 456 (60%) could be matched to a client record using any combination of UI (including records without full UI), health-care provider name, date of test, residential information, and other locally available information. Matched records that were missing the SSN data element (n=208) were reviewed to determine whether these data could be located. SSN could not be located for 120 (58%) of these records.

Reported by: L Solomon, DrPH, L Eldred, DrPH, J Markowitz, PhD, P Ryan, MS, G Benjamin, MD, Maryland Dept of Health and Mental Hygiene. AS Robbins, PhD, DW Hamaker, SA King, MA, SK Melville, MD, MC Thomas, MS, DM Simpson, MD, State Epidemiologist, Texas Dept of Health. Div of HIV/AIDS Prevention–Surveillance and Epidemiology, National Center for HIV, STD, and TB Prevention, CDC.

HIV Case Surveillance — Continued

Editorial Note: HIV and AIDS surveillance data are needed to provide reliable population-based data to guide public health programs. During 1995–1996, the first declines in the incidence of AIDS-opportunistic infections and AIDS deaths were reported in the United States (6% and 23%, respectively), in part, as a result of increasingly effective HIV therapy (*1*). On the basis of revised HIV treatment guidelines (*2*), the impact of treatment advances on AIDS trends is expected to continue and will reduce the usefulness of AIDS data alone to monitor HIV-infection trends and morbidity. CDC and other public health and advocacy organizations have recognized the need for national HIV case surveillance while continuing to discuss the relative merits of HIV surveillance methods based on numeric codes compared to the name-based approach employed for AIDS surveillance (*1,3*).

CDC uses established criteria to evaluate performance of public health surveillance systems to provide accurate data to target prevention and care programs (*4*). States conduct active surveillance using existing name-based clinical and public health records to decrease the reporting burden on providers, eliminate duplicate reports, and facilitate epidemiologic follow-up. These methods enable AIDS surveillance to attain high performance standards as reflected by completeness of reporting (>85%) (*5*) and documentation of risk exposures (≥93% of cases) (*6*). Evaluation of name-based HIV surveillance has shown 74%–97% completeness of reporting (*7*; CDC, unpublished data, 1997), and documentation of risk exposures (≥76% of cases) (*6*). Secure and confidential surveillance practices are required as a condition for receipt of federal resources for HIV and AIDS surveillance. At the state level, the most comprehensive protections of medical data apply to government-held data, and most specifically to HIV-related data (*8*). Names are removed before encoded and encrypted AIDS or HIV surveillance data are transmitted to CDC.

The evaluations in Maryland and Texas indicated that the use of UIs limits the performance of an HIV surveillance system and complicates efforts to collect risk-behavior information. Both systems demonstrated timely reporting. Although data from both states indicated increases in reporting of the SSN data element during the evaluation period, overall 22% of reports in Maryland and 34% in Texas were missing the SSN element, which contributed to a high rate of incomplete case reporting. The follow-back investigation in Texas suggests that SSNs are not readily available in client or medical records but, in the controlled environment of the Maryland HIV C&T system, counselors were able to collect SSNs for most clients. The completeness of reporting also may be affected by the ability of providers and laboratories to use UIs as part of routine HIV-testing practices. For example, one large laboratory providing HIV-testing services in Maryland did not report HIV infections during the evaluation period. The difficulty in collecting HIV data when persons are tested out of state also may affect completeness of reporting and the ability to eliminate duplicate reports. Maryland is continuing to evaluate its UI surveillance system, and Texas is exploring alternative HIV surveillance systems with input from community groups.

Effective HIV surveillance systems must include HIV risk information; however, this information often is not available at the time of the initial UI case report, and follow-up with health-care providers is necessary. To supply follow-up information, health-care providers must use lists or other mechanisms to link the UI to patient identifiers. The UI approach complicates efforts to collect this information and increases the number of lists of HIV-infected persons that could be disclosed in a breach of confidentiality.

(Continued on page 1271)

HIV Case Surveillance — Continued

CDC has recommended that all states and territories conduct HIV case surveillance as an extension of their AIDS surveillance systems (*1*). In addition, CDC is developing technical guidance to enhance security practices, standardize confidentiality laws and regulations, and promote uniform standards for HIV case surveillance systems. These guidelines will assist states and territories in implementing HIV case surveillance using data-collection and data-storage methods that provide high quality HIV surveillance data while assuring the confidentiality of surveillance information.

References

1. CDC. Update: trends in AIDS incidence, 1996. MMWR 1997;46:861–7.
2. Carpenter CC, Fischl MA, Hammer SM, et al. Antiretroviral therapy for HIV infection in 1997: updated recommendations of the International AIDS Society–USA panel. JAMA 1997;277:1962–9.
3. Council of State and Territorial Epidemiologists. CSTE: position statement ID-4. National HIV surveillance: addition to the National Public Health Surveillance System. Atlanta, Georgia: Council of State and Territorial Epidemiologists, 1997.
4. Klaucke DN. Evaluating public health surveillance. In: Teutsch SM, Churchill RE, eds. Principals and practices of public health surveillance. New York, New York: Oxford University Press, 1994:158–74.
5. Rosenblum L, Buehler JW, Morgan ME, et al. The completeness of AIDS case reporting, 1988: a multisite collaborative surveillance project. Am J Public Health 1992;82:1495–9.
6. CDC. HIV/AIDS surveillance report. Atlanta, Georgia: US Department of Health and Human Services, Public Health Service, 1997. (Vol 8, no. 1).
7. Meyer PA, Jones JL, Garrison CZ. Completeness of reporting of diagnosed HIV-infected hospital inpatients. J AIDS 1994;7:1067–73.
8. Gostin LO, Lazzarini Z, Neslund VS, Osterholm MT. The public health information infrastructure: a national review of the law on health information privacy. JAMA 1996;275:1921–7.

Contributors to the Production of the *MMWR* (Weekly)

Weekly Notifiable Disease Morbidity Data and 122 Cities Mortality Data

Denise Koo, M.D., M.P.H.

State Support Team
Robert Fagan
Karl A. Brendel
Siobhan Gilchrist, M.P.H.
Harry Holden
Gerald Jones
Felicia Perry
Carol A. Worsham

CDC Operations Team
Carol M. Knowles
Deborah A. Adams
Willie J. Anderson
Christine R. Burgess
Patsy A. Hall
Myra A. Montalbano
Angela Trosclair, M.S.

Desktop Publishing and Graphics Support
Morie M. Higgins
Peter M. Jenkins

A Multi-State Evaluation of Anonymous HIV Testing and Access to Medical Care

Andrew B. Bindman MD

Dennis Osmond PhD

Frederick M. Hecht MD

Stan Lehman MPH

Karen Vranizan MA

Dennis Keane MPH

Arthur Reingold MD

and the MESH Study Group

1. Primary Care Research Center, San Francisco General Hospital

2. Division of General Internal Medicine, San Francisco General Hospital

3. Department of Medicine, University of California San Francisco

4. Department of Epidemiology and Biostatistics, University of California San Francisco

5. AIDS Division, San Francisco General Hospital

6. Division of HIV/AIDS Prevention, Surveillance and Epidemiology, Centers for Disease Control and Prevention

7. Department of Epidemiology, University of California Berkeley

Word Count - 4,173

Corresponding Author - Dr. Andrew B. Bindman

San Francisco General Hospital, Bldg. 90/Ward 95, 1001 Potrero Ave., San Francisco, CA 94110

Phone: 415 206-6095/Fax: 415 206-5586

Email: bindman@itsa.ucsf.edu

Abstract

Context: HIV is the only infectious disease for which there is publicly funded anonymous testing, and this exception has been controversial.

Objective: We assessed whether anonymous HIV testing was associated with earlier HIV testing and HIV-related medical care than confidential HIV testing.

Design: Retrospective cohort

Setting: Arizona, Colorado, Missouri, New Mexico, North Carolina, Oregon, and Texas

Participants: Probability sample of all new AIDS cases reported to the state health department HIV/AIDS reporting system (HARS) between May 1995 and December 1996.

Main Outcome Measures: Days from HIV positive test to first receipt of HIV-related medical care, from first HIV-related medical care to AIDS, and from first HIV positive test to AIDS.

Results: Anonymous testers presented for testing and medical care earlier in their HIV disease course than did confidential testers. Anonymous testers experienced an average of 387 more days in HIV-related medical care prior to an AIDS diagnosis than did confidential testers. The mean time from learning they were HIV positive to the diagnosis of AIDS was 529 days greater among anonymous testers than confidential testers. After adjusting for the subject's age, sex, race/ethnicity, education income, insurance status, HIV exposure group, and whether the respondent had a regular source of care or symptoms at the time of the HIV positive test, anonymous testing remained significantly associated with earlier entry into medical care. The mean adjusted first CD4 count was 102 cells/μl greater in anonymous compared to confidential testers.

Conclusion: Anonymous testing contributes to enhancing early access to HIV testing and medical care. Public health departments should maintain and in some cases enhance broad availability of anonymous testing options.

CDC Technical Guidelines for HIV and AIDS Surveillance

- Background
- Case Definition
- Surveillance practices
  - Methods
  - Security/Confidentiality
- Relationship to other programs
- Commentary

CDC Technical Guidelines for HIV and AIDS Surveillance

- Surveillance Practices
  - Methods-**Recommended**
  - Collect standard concise set of data
  - Identify/investigate cases of epidemiologic importance
  - Laboratory initiated reporting

CDC Technical Guidelines for HIV and AIDS Surveillance

Surveillance Practices (cont'd)

- Performance criteria
  - Completeness
  - Timeliness
  - Duplication
  - HIV risk information
  - Required to be met for funding

CDC Technical Guidelines for HIV and AIDS Surveillance

- **Methods - (cont'd)**
  - Case Identifier - CDC recommends that state and local surveillance programs use the same name-based approaches for HIV reporting as currently used for AIDS surveillance
- **Rationale**
  - Approach most likely to meet performance criteria
  - Facilitates epidemiologic follow-up
  - CDC has not identified another basis for case reporting that functions at a level comparable to the name-based approach

CDC Technical Guidelines for HIV and AIDS Surveillance

- **Surveillance Practices**
  - Security **requirements**
  - Data collection/storage
    - Encrypted data transfers
    - Isolate name-based registries from other data
    - Data protections
      - Computer password
      - Physical security
    - Destroy unnecessary registries
    - Recommendation - A single encrypted electronic registry

CDC Technical Guidelines for HIV and AIDS Surveillance

Security Requirements

- Data access/release
  - Restrict to a few trained staff
  - Designate an official to control access
  - Use audit system to monitor access
  - Prohibit access by non-surveillance personnel
  - Submit proposed research uses to IRB
  - Strict data release policies

CDC Technical Guidelines for HIV and AIDS Surveillance

- **Security**
  - Data Retention Policies - Recommendation
    - Remove name-based identifiers from records of little/no public health value (ex. Deceased)
    - Identify through other means if feasible

CDC Technical Guidelines for HIV and AIDS Surveillance

Surveillance Practices

- Confidentiality laws and regulations
  - Recommended review/revision of laws
  - Protection from subpoena/court order
  - Penalties for disclosure
  - Other

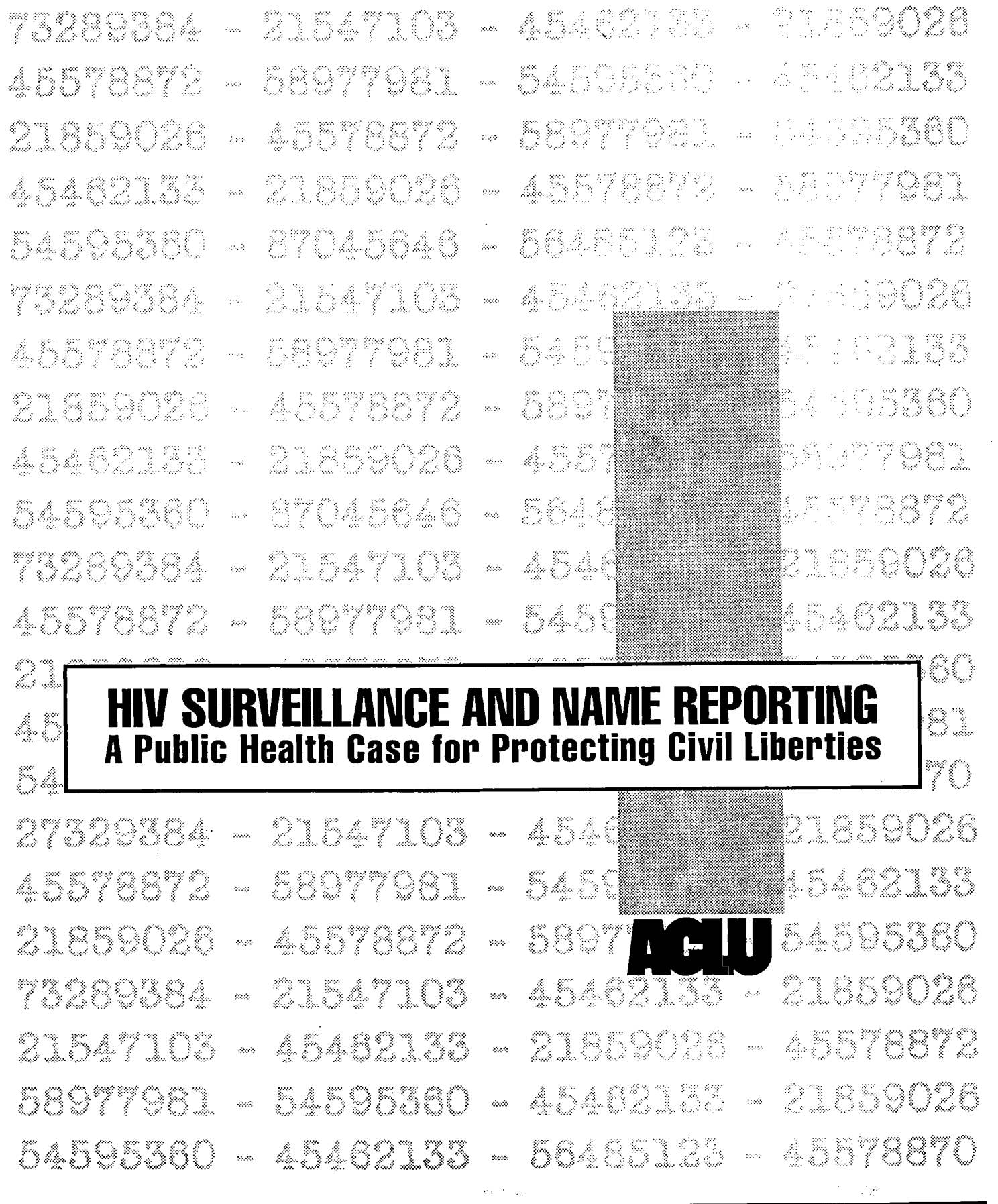
– CDC-ASTHO-NCSL - development of confidentiality law - available late 1998

CDC Technical Guidelines for HIV and AIDS Surveillance

- Relationship to HIV Prevention and Care Programs
  - Anonymous HIV testing
    - CDC requirement (unless prohibited by state law)
    - Recommend that states with laws prohibiting anonymous testing reconsider this practice
  - HIV testing
    - Voluntary
    - Informed consent
  - Linkage of surveillance to programs
    - Primary purpose of surveillance is for epidemiologic monitoring

CDC Technical Guidelines for HIV and AIDS Surveillance

- **Linkage to other programs**
  - Decisions to linkage surveillance and other programs
    - Local HD - CPG collaborative decision
    - Well defined public health objectives
    - Similar confidentiality protections
    - Ongoing process to evaluate risks and benefits



An American Civil Liberties Union Report

October 1997

AMERICAN CIVIL LIBERTIES UNION

National Office
125 Broad Street -- 18th Floor
New York, NY 10004
(212) 549-2500

Washington National Office
122 Maryland Avenue, NE
Washington, D.C. 20005
(202) 544-1681

Nadine Strossen
President

Ira Glasser
Executive Director

Kenneth B. Clark
Chair, National Advisory Council

This report has been prepared by the American Civil Liberties Union, a nationwide, nonpartisan organization of 275,000 members dedicated to preserving and defending the principles set forth in the Bill of Rights

This paper can be accessed via the ACLU's website <url: www.aclu.org>
Copies may also be obtained for $1.00 each through ACLU Publications at 1-800-775-ACLU or P.O.B. 186, Wye Mills, Maryland, 21679

HIV SURVEILLANCE AND NAME REPORTING:
A Public Health Case for Protecting Civil Liberties

October 1997

Matthew Coles
Director, AIDS Project

Founded in 1986, the AIDS Project of the ACLU works exclusively to protect the civil liberties of people with HIV and AIDS.

Table of Contents

HIV SURVEILLANCE AND NAME REPORTING:
A Public Health Case for Protecting Civil Liberties

EXECUTIVE SUMMARY

Recently, there have been renewed calls for HIV surveillance, and specifically for reporting the names of all those who test positive for HIV to public health authorities. Proponents of HIV surveillance and name reporting frequently suggest that there is a conflict between the privacy rights of individuals who have or may have HIV and the public health needs of the country, and that individual civil liberties must take a back seat in order to effectively battle the spread of HIV and AIDS.

In the public debate concerning society's response to the AIDS epidemic the American Civil Liberties Union has consistently advocated policies that protect the public health while respecting civil liberties and individual privacy. The ACLU recognizes that given the rapid speed with which HIV treatment, the social response to HIV and the disease itself change, every important social and legal policy about HIV must be under constant re-examination. There are no permanent answers. The ACLU also believes that policy must be based on cool examination of the best evidence we have, and not on ideology or visions of the world as we would like it to be. The ACLU is issuing this position paper now because the available evidence shows that, **when it comes to reporting the names of people with HIV, there is no conflict between public health and civil liberties**. Instead, the available evidence strongly suggests that public health measures that respect the privacy of individuals testing for HIV are more effective means of fighting the spread of HIV than intrusive measures like name reporting. Specifically, as discussed in more detail in this position paper, the evidence indicates that reporting the names of those who test positive for HIV will set back public health efforts. For this reason, the ACLU opposes name reporting.

Renewed calls for HIV surveillance are at least partly the result of new developments in the AIDS epidemic, primarily the emergence of promising new medical treatments. Proponents of name reporting argue that in the face of medical and other developments, it no longer makes sense to systematically track only AIDS cases, which represent the late stages of HIV disease; they argue that we must start to track HIV systematically from the point of infection.

A number of propositions are generally advanced in support of HIV

surveillance and name reporting*: 1) there is a need to monitor the spread of HIV and collect more accurate epidemiological data; 2) it would help better target prevention and public health efforts; 3) it would permit individuals with HIV to proactively link to appropriate health care services; 4) it would permit a more efficient allocation of AIDS funding; and 5) concerns about discrimination against people with HIV and AIDS are much reduced as a result of supposedly strong legal protections of confidentiality and against discrimination. Even though there are various methods for HIV surveillance that preserve the privacy of individuals with HIV, surveillance proponents generally argue that reporting the names of individuals who test positive for HIV is necessary for effective HIV surveillance.

The case for HIV surveillance may well be stronger at this juncture of the AIDS epidemic. However, while the reasons cited above may justify increased tracking of cases of HIV infection, they do not support name reporting for several reasons. First, while the goal of increased tracking of HIV infection is to bring those with HIV into the public health system and to obtain more accurate epidemiological data, name reporting will likely have the opposite effect. This is because the available evidence strongly suggests that eliminating anonymous HIV testing will discourage individuals from being tested, thus preventing their entrance into the public health system and hampering HIV tracking.

Second, name reporting is not essential to effectively monitor the epidemic, target prevention, link individuals with HIV to health care, and allocate AIDS funding. Existing HIV tracking mechanisms, including sentinel studies and incidence and prevalence surveys, help to accomplish these goals. And the use of unique identifiers (alphanumerical codes) provides an alternative means of reporting individual cases of HIV without using names.

Third, legal protections for people with HIV appear to be weaker than advocates of name reporting think they are. There are troubling examples of breaches of privacy in spite of the confidentiality protections that accompany name reporting in the states where it presently exists. And recent legal developments indicate that some courts do not believe that the Americans

---

* Proposals for HIV surveillance by name reporting can be divided generally into two groups. This paper uses the term "name reporting" to refer to both of them together. The first subgroup involves proposals in which reporting the names of all individuals who test positive for HIV would be required. This system, which would effectively eliminate anonymous HIV testing, is referred to in this paper as "mandatory name reporting." Some have suggested an HIV surveillance system in which name reporting is encouraged, but anonymous testing sites are maintained for those individuals who refuse to be tested by name. This system is referred to in this paper as "hybrid reporting."

with Disabilities Act provides broad-based protection to people with HIV who are not seriously ill. It is, in short, not accurate to say that the fears of discrimination that appear to drive people away from testing are groundless.

Finally, given that we presently are unable or unwilling to provide access to anti-retroviral therapy and other forms of health care to individuals with HIV who are already seeking treatment, it is hard to see how imposition of names-based reporting is going to result in better health care for those individuals with HIV who are not yet in the health care system.

Therefore, the ACLU opposes name reporting as a means of tracking HIV unless and until: (1) it has been demonstrated that there is a strong need for additional HIV surveillance; (2) there is no alternative means to accomplish this surveillance; (3) we can honestly assure those who will be tested that protection from discrimination is real; and (4) serious efforts to deliver care to those who will be identified will be made. These conditions have not been satisfied.

I. INTRODUCTION

AIDS first emerged in the early 1980's as a health crisis among gay men, who began experiencing an onset of severe and unexplained health problems that quickly turned fatal. At the time there was no medical understanding of the emerging epidemic, and there was widespread societal fear about possible contagion. AIDS became a marker for gay men, and since many in the population held strong biases against gay people, a social stigma attached to AIDS that set the syndrome apart from other contagious diseases. Gay men with AIDS were fired from their jobs, lost their health insurance and their homes, were turned away by health care providers, and were ostracized by their families, either because of their mysterious health condition, their sexual orientation, or both.

Surveillance of AIDS cases, including reporting the names of persons diagnosed with AIDS to public health authorities, began almost immediately and with little fanfare. There were several reasons for this. First, name reporting was a public health response which had been used with some other sexually transmitted diseases. Second, individuals who were diagnosed with AIDS were already in the late stages of what we now know to be HIV disease, and were for the most part already participating in the health care system. Thus in a real sense they had already been "identified" as persons with AIDS. And finally, although an AIDS diagnosis and public dissemination of that information often triggered a hostile societal response, the harsh reality was that persons diagnosed with AIDS usually died quickly, and the struggle for survival overwhelmed any attempt at leading a "normal life."

HIV was not discovered until 1983, and testing for HIV antibodies became available only in the mid 1980's. At that time, surveillance of cases of HIV infection, as opposed to AIDS diagnosis, was opposed by advocacy groups and public health authorities. There was widespread recognition that gay men, people of color and IV drug users, the sub-populations found to be at highest risk for HIV infection as the epidemic developed, would flee from the public health system if they believed that their names were being reported to government agencies. In the absence of any effective cure or medical treatment for HIV infection, the arguments in favor of HIV surveillance were weak.

II. BACKGROUND TO CURRENT DEBATE

In recent years a number of factors have shifted the focus of epidemiological surveillance to the "front end" of the AIDS epidemic, HIV infection. New medical treatments in the form of combination therapy offer greater hope for healthier and longer lives for people with HIV. Research suggests that combination therapy is most effective if begun soon after infection, making it important that therapy be offered to people before they become severely ill. Moreover some research suggests that combination therapy, by drastically reducing the amount of virus an individual carries, lessens infectiousness.[1]

For the first time in a decade the number of deaths attributable to AIDS is decreasing. AIDS deaths declined 19 percent in the first nine months of 1996 compared to the same period in 1995.[2] Public health officials, while encouraged by this development, worry that individuals continue to become infected. As medical treatments prolong the lives of people with HIV and significantly delay the amount of time from infection to AIDS diagnosis, surveillance of AIDS cases tells us less and less about how HIV infection is developing and spreading.

In addition, as the AIDS epidemic nears the completion of its second decade, the early societal panic about AIDS has diminished. Legal protections for people with AIDS have improved, thanks largely to the passage of the Americans With Disabilities Act (ADA). Many cities have passed legislation specifically designed to prevent discrimination on the basis of HIV. Prominent celebrities have announced that they are HIV positive, and courageous AIDS activists have won broad admiration in many quarters of society. These developments have somewhat lessened fears that the inevitable result of infection with HIV was complete social isolation.

Against this background, calls for enhanced HIV surveillance, name reporting, and an end to so-called "AIDS exceptionalism" have begun to emerge.[3] Even though there are numerous means of conducting HIV

---

[1] R. Royce et al., *Sexual Transmission of HIV: Current Concepts*, 336 New Eng. J. of Med. 1072 (1997).

[2] L.K. Altman, *AIDS deaths drop 19% in U.S., continuing a heartening trend,* New York Times, July 15, 1997, at A1.

[3] The term "AIDS exceptionalism" has been coined by some advocates of HIV surveillance and name reporting to refer to the fact that traditional intrusive public health measures, such as mandatory name reporting, have not been systematically applied to HIV infection. The

surveillance while maintaining the anonymity of persons with HIV, including the use of unique identifiers, sentinel studies, and incidence and prevalence studies, some have championed name reporting as a "traditional" response to infectious diseases which should be used with AIDS.

Twenty seven states have already implemented name reporting HIV surveillance.[4] But these states represent only 24 percent of the AIDS cases that have been reported to the CDC.[5] "High incidence" states have thus far refused to adopt name reporting in the face of strong opposition from community groups and public health officials.

Proposals for name reporting take numerous forms. The unifying element is reporting the names of individuals who test positive for HIV to a government agency. Most often proposals for name reporting require individuals being tested for HIV (or an equivalent test, such as viral load or CD4) to provide their name, contact, and demographic information when they seek an HIV test. If the individual tests positive for HIV antibodies, then her/his name is reported to public health officials. Name reporting schemes generally have provisions designed to protect the confidentiality of the individual with HIV.

III. NAME REPORTING IS BAD PUBLIC POLICY

A. Name Reporting Is Bad Policy If it Discourages People From Being Tested For HIV, And The Available Evidence Shows That it Does

The available evidence strongly suggests that name reporting is a counterproductive public health measure that will cause individuals to avoid HIV testing. Numerous studies indicate that individuals avoid HIV testing that is not anonymous because they do not have faith that test results will remain confidential and because they fear the stigma and discrimination that is often associated with HIV and AIDS. One study found that over 60% of individuals tested anonymously would not have tested if their names were

---

term is an unfortunate misnomer, since the public health response to all infectious diseases has not been uniform and since there is no indication that a "one-size-fits-all" approach to all public health problems is effective.

[4] See Appendix II.

[5] Centers for Disease Control and Prevention, HIV/AIDS Surveillance Report, 1997, Vol. 9, No. 1.

reported to public health officials.[6] By contrast, anonymous testing encourages individuals to seek testing in the belief that they will be able to control the dissemination of information about their HIV status. People are more likely to be voluntarily tested for HIV if the testing is anonymous.[7]

Anonymous testing also reduces the period of time that individuals delay testing. Research indicates that the availability of anonymous testing reduces the average delay between deciding to get tested and actually going for the test by more than one half, from a mean of 12 months to a mean of 5 months.[8] Testing associated with name reporting (confidential testing) deters people from discovering their HIV status.

Of course, HIV testing is of little use if the person tested does not return for his or her results. The available data indicates that individuals who test at locations with name reporting are much less likely to return for their results than individuals who are anonymously tested. An analysis of HIV testing in North Carolina found that 30.3% of testees undergoing confidential testing did not return, while only 8.2% of anonymous testers did not retrieve their results.[9] In Colorado, a testing survey showed that 95% of anonymous testers retrieved their results, but only 85% of confidential testees returned.[10]

The deterrent effect of name reporting is most pronounced in the very populations with the greatest need for preventive intervention: gay and bisexual men, people of color, intravenous drug users, and sex workers. Research indicates that gay men are more likely to be aware of name reporting requirements and, as a result, to avoid testing altogether.[11] One study found that half of the men who were tested anonymously would not have been tested at all if only confidential testing were offered.[12] In South

---

[6] Susan M. Kegeles et al., Many People Who Seek Anonymous HIV-Antibody Testing Would Avoid it Under Other Circumstances, 4 AIDS 585, 586 (1990).

[7] Kathleen Irwin, et al., *The Acceptability of Voluntary HIV Antibody Testing In the United States: A Decade of Lessons Learned,* AIDS, vol. 10, no. 14, 1707, 1711 (1996); Geoffrey Reed, et al., *The Impact of Mandatory Name Reporting on HIV Testing and Treatment,* Poster Presentation for the XI International Conference on AIDS (July 1996); Douglas Hirano et al., *Anonymous HIV Testing: The Impact of Availability on Demand in Arizona,* 84 AM. J. PUB. HEALTH 2008, 2010 (1994).

[8] Laura Fehrs et al., *Trial of Anonymous Versus Confidential Human Immunodeficiency Virus Testing,* 2 LANCET 391 (1988).

[9] Irva Hertz Picciotto et al., *HIV Test-Seeking Before and After the Restriction of Anonymous Testing in North Carolina,* 86 AM. J. PUB. HEALTH 1446, 1448 (1996).

[10] Richard E. Hoffman et al., Colorado Department of Health Division of Disease Control and Environmental Epidemiology, HIV Anonymous Test Site Evaluations 7 (1992).

[11] HIRANO, *supra* note 5, at 2009; KEGELES, *supra* note 4.

[12] Susan M Kegeles et al., *Mandatory Reporting of HIV Testing Would Deter Men from Being Tested,* 261 JAMA 1275 (1989).

Carolina, after anonymous testing was eliminated the number of men who have sex with men who were tested for HIV dropped by 51%.[13] The converse is also true: once anonymous testing is offered, more gay and bisexual men will be tested. Oregon, for example, reported a 125% increase in the demand for HIV testing once the option of anonymous testing was provided.[14] Fear of discrimination and stigmatization is so strong among gay and bisexual men, they will travel to other states if necessary to preserve their anonymity. One South Carolina AIDS service agency reported that 40% of the people it serves were tested out of state.[15] If gay and bisexual men do test confidentially, as opposed to anonymously, they often will wait longer to do so.[16] Given the high seroprevalence rate among gay and bisexual men, delays are counterproductive to the public health goal of HIV prevention.[17]

Name reporting is also likely to deter HIV testing by African-Americans and Latinos.[18] The rate of HIV infection is increasing rapidly among people of color.[19] Given this country's history of race discrimination in the guise of public health initiatives, minority communities often distrust coercive public health programs. Mandatory names reporting would only exacerbate this distrust. Researchers from the New York City Department of Health found that 22% of African-American and Hispanic participants would not be tested for HIV if their names were reported to public health officials.[20] One clinician commented that mandatory name reporting "will be the final blow" alienating minority women from clinicians and the health care system, causing them to go "underground fast." [21]

Other groups are also deterred from HIV testing by name reporting. Intravenous drug users and sex workers, many of whose primary contact with

---

[13] WD Johnson et al., The Impact of Mandatory Reporting on HIV Seropositive Persons in South Carolina (1988) (Presented at the Fourth International Conference on AIDS, Stockholm, Sweden).

[14] FEHRS et al., *supra* note 6.

[15] JOHNSON, *supra* note 14.

[16] HIRANO, *supra* note 5, at 2009.

[17] *Id.* at 2010.

[18] While people of color are discussed separately from gay and bisexual men in this position paper because of the high rates of HIV infection in many communities of color, it is worth noting that the two groups are not mutually exclusive - i.e. many and gay and bisexual men of color are infected with HIV.

[19] See, e.g., Allan P. Frank, et al., *Anonymous HIV Testing Using Home Collection and Telemedicine Counseling: A Multicenter Evaluation*, 157 ARCHIVES INTERNAL MED. 309 (1997).

[20] E. Fordyce et al., *Mandatory Reporting of Human Immunodeficiency Virus Testing Would Deter Blacks and Hispanics from Being Tested*, 262 JAMA 349 (1989).

[21] Letter from B. Joyce Simpson, RN, MPH, to Robert M. Greenstein, Director of Division of Human Genetics, University of Connecticut Health Center (November 30, 1992)(on file with the ACLU AIDS/HIV Project).

government has been through the criminal justice system, are more likely to test anonymously. One study found a 56% increase in HIV testing among female sex workers and a 17% increase among intravenous drug users when anonymous testing was an option.[22] Women, in general, are often wary of mandatory names reporting schemes. One study found that mandatory names reporting led to a 31% decline in the number of women agreeing to an HIV test as they sought Ob/Gyn care.[23]

Some proponents of HIV surveillance have proposed maintaining anonymous testing, but imposing the mandatory name reporting requirement on medical providers, as a means of avoiding testing deterrence. This is not an acceptable solution, since it simply shifts the deterrence problem away from testing and instead deters people from entering treatment. In a recent survey of individuals testing for HIV in Los Angeles County, 22.6% of survey participants said they would delay treatment until they were actually sick if their doctor were required to report their name to public health authorities.[24]

It has been suggested by some that name reporting should be adopted but that anonymous testing should be preserved for those who do not want to be reported. It is far from clear that this type of hybrid reporting would accomplish any of the goals advanced for increased surveillance. Moreover, to make that system work and not deter people from testing, people must understand their options. Individuals would have to be advised that they have the option of anonymous testing, and anonymous testing sites would have to provide the same array of services provided by sites that record the name of the testee for reporting purposes (confidential testing sites). Medical providers could not be required to report the names of patients who are HIV positive against the patients' will, since that would deter treatment as opposed to testing. The history of minority communities and public health suggests that a system like this would not truly reassure those who need to be tested. If proponents of name reporting believe this option, faithfully implemented, would advance the goals of increased surveillance, it ought to be tried on a trial basis and the effect on both reporting and deterrence assessed before it is widely used.

In sum, the available evidence indicates that rather than helping to control the spread of HIV and AIDS and encouraging earlier medical intervention,

---

[22] FEHRS et al, *supra* note 6.

[23] B. Lo et al., AIDS Screening: Who is Willing to be Tested (1988)(Presented at the Fourth International Conference on AIDS, Stockholm, Sweden).

[24] Geoffrey Reed, et al., *The Impact of Mandatory Name Reporting on HIV Testing and Treatment*, Poster Presentation for the XI International Conference on AIDS (July 1996).

name reporting is likely to lead to decreased testing by those who most need it. That means that far from advancing the goals proponents offer for increased surveillance -- more accurate information and earlier medical intervention -- name reporting is likely to defeat them.

B. Testee Fear of HIV Name Reporting Cannot Be Dismissed as Irrational

Many individuals apparently fear taking an HIV test that is not anonymous, as the evidence discussed in the last section shows. It is worth stressing that the perception of the testee is what matters most. If that perception is going to prevent an individual from testing, it does not matter whether the perception is based on misinformation, reality, or some combination of the two. The sad truth, however, is that these fears cannot be dismissed as irrational.

At the heart of the fear is concern about discrimination on the basis of HIV status, and this concern is real. Laws cannot prevent family and friends from abandoning a loved one because she has HIV or because he is gay. And recent legal developments indicate that persons with HIV still have reason to worry about even those types of discrimination that the law is designed to address. Although it had once been assumed that the Americans with Disabilities Act (ADA) provided broad legal protections from discrimination against anyone with HIV, according to some federal courts this is not the case. A federal appeals court has ruled that the ADA does not protect people with HIV who have not yet developed serious health problems, even if they have suffered from discrimination.[25] Another federal appeals court has held that the ADA does not protect many people with either HIV or AIDS from discrimination in insurance.[26] Thus, the anti-discrimination protections supposedly provided by the ADA may be becoming illusory for people with HIV.

It is unlikely that the fears of individuals at high risk for HIV can be overcome by promises that name reporting will be accompanied by privacy protections. Minority communities are often distrustful of public health authorities and coercive public health programs.[27] Existing privacy protections have not prevented breaches of confidentiality from occurring. In one example, thieves stole a computer containing the names of 60 persons

---

[25] *Runnebaum v. Nationsbank of Maryland*, __F.3d__, 1997 WL 465301 (4th Cir. Aug. 15, 1997) (*en banc*).

[26] *Parker v. Metropolitan Life Insurance Company* __F.3d__, (6th Cir. Aug. 1, 1997) (*en banc*).

[27] See, e.g., Woodrow Jones, An Overview Of Health Care Issues In Black America, in *Black Health Care,*, Jones & Rice, eds., 1987.

with AIDS from a public health office in Sacramento, California.[28] As this incident demonstrated, computerization and modern security devices do not provide complete security. Moreover, the complexity of modern computer systems and data banks will inevitably lead to mistakes that are at once common and difficult to correct.[29] These general problems take on special significance in the context of HIV surveillance, given the sensitivity of HIV-related information.

Despite the frequent claim that this has never happened, confidentiality is breached. Agencies cannot control how authorized personnel use the data to which they have access, creating a risk of both inadvertent and intentional confidentiality breaches.[30] Personnel with access to names include federal, state and local public health administrators, HIV-related social service and medical professionals, field service staff, and, due to recent efforts to integrate tuberculosis and HIV surveillance, non-HIV public health officials. Carelessness and simple human error can have serious consequences. In Florida, a computer disk containing the names of 4000 people with AIDS was discovered in the parking lot of a bar. Apparently it belonged to an AIDS surveillance case worker who misplaced it.[31] In New York, a log containing the names of 500 people who were tested for HIV "vanished" from a clinic.[32] Almost a week later, authorities still did not know if the log was stolen, thrown out, misplaced or destroyed. The Federal Bureau of Investigation has admittedly used improperly obtained HIV information, and local law enforcement agencies have disclosed HIV status to neighbors, prison inmates, and broadcast the names of people with HIV over police radios.[33]

Moreover, present assurances of confidentiality cannot prevent later evisceration of privacy guarantees. Once public health officials have compiled a list of individuals who are HIV-positive, there is no way to safeguard the list from overzealous public health efforts and misguided

---

[28] Richard C. Paddock, *Thieves Steal Computer Containing Confidential List of 60 AIDS Victims*, L.A. Times, July 9, 1987, at 3.

[29] Bob Davis, *Abusive Computers: As Government Keeps More Tabs on People False Accusations Rise*, Wall St. J., August 20, 1987, at 1.

[30] Robert Trigaux, *Leak sparks security fears*, St. Petersburg Times, September 20, 1996, at 1A. *See also* Lawrence O. Gostin, *Health Information Privacy*, 80 Cornell L. Rev 451, 493 (1995)("It is the proliferation of...legitimate users of information that pose the greatest risk to informational privacy").

[31] Sue Landry, *AIDS list is out*, St. Petersburg Times, September 20, 1996, at 1A.

[32] *Log, Said to List AIDS Test-Takers, Is Lost*, N.Y. Times, April 23, 1987, at A21.

[33] *Doe v. Attorney General of the United States* 941 F. 2d 780 (9th Cir. 1991); *Doe v. Borough of Barrington* 729 F.Supp. 376 (D.N.J. 1990); *Woods v. White* 689 F.Supp. 874 (W.D.Wis. 1988); details on Union City, California's practice of broadcasting the names of people with HIV on radios used by police, fire, and emergency medical workers are on file with the ACLU AIDS Project.

political mischief in the future. Just as a legislature may enact confidentiality provisions, so too may it later create exceptions or revoke protections en toto. This almost occurred in 1991 when the state of Illinois passed a law that directed the Department of Health to identify all HIV-positive health care workers by comparing the state's confidential lists of persons with HIV against the records of health care licenses. Any patient of a health care worker who engaged in invasive medical procedures (surgery) while HIV-positive was to be contacted. This government-sponsored violation of privacy was approved despite widespread recognition that the policy would do little to advance the public health. Although never funded due to intense opposition, this experience demonstrates the inherently precarious nature of a seemingly ironclad confidentiality guarantee.

Finally, it is too early to know if the emergence of promising new medical treatments (should the promise hold) will increase the impetus to be tested, and the extent to which they will ameliorate or eliminate the well-documented deterrent effect that occurs when anonymous testing is eliminated. It is, therefore, simply not responsible to glibly assume that the existence of these therapies removes the public health problems created by the elimination of anonymous testing. Moreover, it is reasonable to assume that, in any event, combination therapy will increase the attractiveness of testing only for those individuals who believe they can get access to the treatment if they test positive for HIV. Combination therapy is not made available to all those who presently need it, as has been painfully demonstrated by the recent experiences of ADAP programs in Mississippi and other states that have been forced to cut people with HIV off medication due to a lack of funds. Low income people who do not have the means to pay for medication could reasonably conclude that, even if they test positive for HIV, they will not be able to access appropriate medical care.[34]

In sum, the fears that drive people away from HIV testing with name reporting are not groundless. To eliminate them, we need more than education; we need solid anti-discrimination protection and real availability of treatment for the poor and the uninsured. Name reporting is not appropriate until we make real progress toward those two goals.

---

[34] Sheryl Gay Stolberg, *AIDS Drugs Elude the Grasp of Many of the Poor*, New York Times, October 14, 1997, at A22.

IV. UNIQUE IDENTIFIERS: A BETTER ALTERNATIVE TO NAME-BASED REPORTING

The desire for more comprehensive HIV surveillance can be accommodated without name reporting. HIV surveillance is already being conducted through sentinel studies and prevalence and incidence studies, and those efforts can be expanded. In addition, systematic HIV surveillance can be implemented through the use of a system of unique identifiers.

Unique identifiers are numeric and alpha-numeric codes that are used to identify a particular individual. We use these every day in the form of social security numbers, driver's license numbers, and account numbers, among others. In the context of HIV testing, the concept is to create a code that identifies only one person and to associate the HIV test result with that unique identifier, rather than with the name of the individual. The code may be reported to public health authorities, providing accurate epidemiological data regarding HIV infection rates along with various demographic indicators. But because the code cannot be traced back to the person tested, the anonymity of the testee is preserved.

With computerized encryption and modern technology, unique identifiers may offer a viable alternative to name reporting. There are sound reasons to pursue this option if expanded HIV surveillance is desired. First, by preserving the anonymity of the testee, a unique identifier system encourages individuals to be tested and enlists the support of community organizations that are opposed to name reporting. Second, it is at least possible that unique identifier systems may ultimately provide <u>better</u> epidemiological data than name reporting confidential testing.[35] In a unique identifier system, an individual will most likely use the same code for each test (e.g. birth date and the last four digits of social security number). With one unique identifier composed of intimate information (so the individual remembers it), a repeat tester can be identified as such and not double counted. The accuracy of names-based reporting, by contrast, depends upon whether the testee uses his or her real name, and the available evidence suggests that many people who are required to give their name when taking an HIV test use a pseudonym to hide their identity.[36] While distrust causes testees to use pseudonyms in confidential testing, in anonymous testing there is no incentive to create more than one unique identifier.

---

[35] FORBES, *supra* note 3, at 4.

[36] T. Hoxworth et al., *Anonymous HIV Testing: Does It Attract Clients Who Would Not Seek Confidential Testing?* 9 AIDS PUB. POL*Y J. 182 (1994).

Two states, Maryland and Texas, presently use unique identifier systems to track HIV cases. The experiences of both states should be analyzed to determine the benefits and drawbacks of unique identifiers, and to identify what work must be done to make them effective tools for HIV surveillance.

It appears that developing effective unique identifier systems will require the investment of significant time and resources. But given the evidence that name reporting will discourage testing, particularly among those who most need it for themselves and for accurate surveillance, it remains the most sensible option today.

V. CONCLUSION

There may come a time when HIV is so unremarkable a part of our social landscape, and care for it so routinely available to those who need it, that no one will reasonably fear being identified as a person with HIV. But we are nowhere close to that time yet. On the contrary, the best evidence we have suggests that those who most need HIV testing are afraid of name reporting because they fear discrimination. Moreover, we know those fears are not groundless.

We cannot honestly allay these fears unless we truly provide people with HIV the protection from discrimination we have been promising them. We cannot honestly use the availability of new treatment to get people to overcome their fears of discrimination unless we are ready to make treatment available. Since we have done neither, we cannot honestly tell people they should overcome their fears of testing. Under these circumstances, name reporting is not appropriate.

American Civil Liberties Union
AIDS Project
October 1997

Matthew Coles
Director

Michael Adams
Jennifer Middleton
Staff Attorneys[37]

[37] Matthew Robison, a law student, provided significant assistance in the research and writing of this report.

APPENDIX I:
Responses to Common Arguments For Name Reporting

Argument: *If we already have name reporting for people with AIDS, there is no reason why we shouldn't have name reporting for people with HIV.*

Response: There is a fundamental difference between the two. A person diagnosed with AIDS is by definition already within the health care system. He or she has received an AIDS diagnosis because of demonstrable health conditions. There is no risk that name reporting will deter this person from entering the health care system and receiving counseling. By contrast, a person who has not yet been tested for HIV is not yet in the health care system. If the goal is to get him or her to test for HIV and enter the system if infected, it makes no sense to adopt an HIV surveillance policy that is going to discourage testing.

Argument: *Name reporting provides more accurate epidemiological data by eliminating individuals who are double counted. In the present system, there is no way to determine whether an individual has been tested before, creating the potential for double counting, either by the same jurisdiction over time or by different jurisdictions (if the individual moves, for example).*

Response: First, name reporting deters many people, disproportionately those most at risk for HIV, from getting tested. Many people who have HIV therefore will not be counted at all. This overwhelms any advantage of eliminating double counting.

Second, name reporting does not eliminate double counting if patients provide false information, a practice which is not uncommon. At confidential test sites in Colorado, 27% of test seekers admitted providing false information.[38] If an individual provides a false name, there is no way to determine if this individual has been tested before or not.

Third, name reporting is not necessary to eliminate the risk of double counting. A properly designed system of unique identifiers could suffice while protecting the privacy of the individual.

---

[38] HOXFORTH et al., *supra* note 30.

Argument: *Name reporting would enable more complete and comprehensive demographic data because of the opportunity to follow up with a patient. Public health officials or social workers could pursue follow up interviews with individuals who test positive for HIV and fill in any information gaps discovered after the person leaves the testing site. This demographic data would permit the CDC and other organizations to identify the needs of specific subpopulations affected by the epidemic and narrowly tailor prevention efforts.*

Response: First, name reporting is not needed to gather more comprehensive demographic data. With pre- and post- test counseling sessions accompanying each HIV test, social workers and public health officials have two opportunities to gather this information. Well-designed questionnaires and guided personal interviews can gather all the information necessary for targeting specific prevention programs, making follow-up interviews unnecessary.

Second, name reporting will distort epidemiological assessments of subpopulation needs because it deters individuals from getting tested. Studies indicate that its deterrent effect on HIV testing is more pronounced among gay men and racial and ethnic minority groups, whom the epidemic has hit hardest. The number of HIV-positive individuals in the gay community and in communities of color would be undercounted.

Third, name reporting does not prevent individuals from lying by giving false names and contact information, making a follow up interview impossible. Providing false information is common and is even encouraged by some counselors in jurisdictions that do not provide anonymous HIV testing.[39]

Finally, anonymous testing encourages individuals to return for their HIV test results, reducing the need for intrusive, resource-intensive follow-up by public health officials. Studies indicate that persons who test anonymously are more likely to return for their results, as compared to individuals who are tested confidentially.[40] While fear of a positive test result may deter individuals from both cohorts from receiving their HIV test results, it appears that anonymous testing provides individuals with a higher degree of confidence that their privacy will be protected.

---

[39] HOXWORTH, *supra* note 30.

[40] HERTZ PICCIOTTO et al., *supra* note 7, at 1448; HOFFMAN, *supra* note 8.

Argument: *Name reporting would benefit individuals who test positive for HIV by connecting them with counseling and other services, and shortening the amount of time that passes before they receive medical attention. Given promising new medical treatments, intervention may significantly increase both the length and quality of an individual's life.*

Response: First, each supposed benefit of name reporting--provision of counseling services, medical referrals and treatment, long term medical follow-up--can also be accomplished with anonymous testing. For example, well-designed pre- and post- test counseling can provide information and referrals for further counseling and medical treatment.

Second, name reporting is not treatment, nor does it automatically lead to treatment. Presently, there is no system to ensure that people with HIV receive potentially life-saving treatments. The barriers to proper health care--poverty and lack of funding--will not in any way be addressed by adopting name reporting.[41] Unless name reporting schemes are accompanied by specific linkages between testing and treatment, including policy guidelines and (most importantly) funding, then such connections will not be made. Moreover, there is no reason to believe that name reporting will be more effective than properly structured anonymous testing in ensuring access to treatment.

Argument: *Mandatory names reporting would enable other traditional strategies of protecting the public health, including partner notification and contact tracing to be more effective. With the names of all HIV positive individuals, social workers or public health officials could conduct numerous follow-up interviews to notify spouses or partners (partner notification).*

Response: First, name reporting is not necessary for successful partner notification or contact tracing. During post-test counseling sessions, counselors can and do review and provide materials on partner notification and contact tracing. The information includes the importance of notifying one's partner and/or other individuals potentially exposed in the past, ways to notify a partner (and others with whom the individual has engaged in high risk activity) of their potential exposure, who to contact for

---

[41] One study found that 72% of HIV-infected patients with less than 200 CD4 T cells attending STD clinics in Baltimore, MD either had no insurance or relied on public assistance for health care. C.M. Hutchinson et al., *CD$ Lymphocyte Concentration in Patients with Newly Identified HIV Infection Attending STD Clinics*, 266 JAMA 235.

more information. Knowing the name of the testee is not necessary for partner notification and contact tracing. As long as sufficient information is given to notify past partners, the name of the individual providing the information is irrelevant.

Moreover, the demonstrated deterrent effect of name reporting means that it will do serious harm to the effort to counsel people with HIV about how to protect themselves and those with whom they have been intimate, and to efforts to warn contacts. Neither counseling nor partner notification is possible if people decide not to test.

Argument: *Name reporting would enable intervention even when people do not pick up their test results. Public health officials could track down those individuals who tested positive and connect them with medical and social services, along with public health intervention strategies like partner notification and contact tracing. Thus, name reporting enables public health officials to intervene where otherwise they could not.*

Response: Again, the demonstrated deterrent effect of name reporting defeats the purpose. People cannot be contacted at all if they do not come in for testing in the first place.

Moreover, anonymous testing poses less of a problem with unclaimed test results anyway. Studies indicate that individuals who participate in anonymous testing are more likely to return to receive their results than those who provide their names. Finally, name reporting schemes will allow public health officials to track down individuals who do not return for their test results only if the individuals provided accurate identifying information.

Tracking down those who do not want to learn their test results consumes precious resources. Given that anonymous testing removes the need for much of it (because more people pick up their results), and given that name reporting discourages people who need to be tested from doing so at all, the benefits are not worth the costs.

Argument: *People with HIV/AIDS do not need to be as concerned as they used to be about discrimination and social stigma because there are now full legal protections against discrimination thanks to the Americans with Disabilities Act (ADA) and comparable state legislation.*

Response: The ACLU worked hard for passage of the ADA and believes it was a tremendous step forward in protecting the rights of the disabled, including those with HIV and AIDS. The ACLU also believes that the ADA covers HIV and AIDS discrimination in employment, housing, public accommodations and public transportation. However, recent court decisions are whittling away at the legal protections that the ADA provides for people with HIV, with some courts saying the ADA does not protect people who are HIV-positive but asymptomatic,[42] and other courts saying the ADA does not prohibit discrimination by insurers.[43] While the ACLU believes that these court decisions are wrong, the decisions nonetheless indicate that there are important holes in the legal protections for people with HIV and AIDS.

Equally important, people with HIV and AIDS face many forms of bias and mistreatment that cannot be addressed by a civil rights bill like the ADA, most notably social stigma and ostracism by family and friends. For example, one recent study of Baltimore health-care providers found that 45% of those providers had at least one female patient who expressed fear of physical violence resulting from disclosure of her HIV status to her partner.[44] The fears of individuals with HIV are thus based on the realities of their lives, and not necessarily on lack of knowledge about legal protections.

---

[42] see, e.g., *Runnebaum v. Nationsbank of Maryland*, __F.3d__, 1997 WL 465301 (4th Cir. Aug. 15, 1997) (*en banc*)

[43] see, e.g., *Parker v. Metropolitan Life Insurance Co.*, __F.3d__, (6th Cir. Aug. 1, 1997) (*en banc*)

[44] K. Rothenberg, et al., *The Risk of Domestic Violence and Women with HIV Infection: Implications for Partner Notification, Public Policy, and the Law*, Am. J. of Public Health, vol. 85, no. 11, 1569, 1570 (1995).

APPENDIX II:
State-by-State List of HIV Name Reporting Systems

+ Twenty seven (27) states currently use names-based reporting systems to track all cases of HIV:

Alabama	*Minnesota*	*Oklahoma*
Arizona	*Mississippi*	*South Carolina*
Arkansas	*Missouri*	*South Dakota*
Colorado	*Nebraska*	*Tennessee*
Florida	*Nevada*	*Utah*
Idaho	*New Jersey*	*Virginia*
Indiana	*North Carolina*	*West Virginia*
Louisiana	*North Dakota*	*Wisconsin*
Michigan	*Ohio*	*Wyoming*

+ Three (3) states require name reporting only for certain types of HIV cases:

California *(reporting of HIV infection of individuals convicted of certain sex crimes for the purpose of sentence enhancement in the event of future arrests)*

Illinois *(requires reporting of HIV-infected school-age children in keeping with a state statute requiring notification of school principals)*

Oregon *(requires reporting by name of HIV infection of blood/plasma donors, sexual offenders, children under age 6, persons under 21 with special education needs, persons who request public sector assistance with partner notification, and individuals with tuberculosis)*

+ Two (2) states conduct HIV surveillance through unique identifier systems: *Maryland, Texas*

+ The twenty seven (27) states that have instituted HIV surveillance through names-based reporting account for twenty four (24) percent of reported AIDS cases. (*Centers for Disease Control and Prevention, HIV/AIDS Surveillance Report, 1997, Vol. 9, No. 1.*)

APPENDIX III:
Studies on Anonymous and Confidential HIV Testing

Irva Hertz-Picciotto et al., *HIV Test-Seeking Before and After the Restriction of Anonymous Testing in North Carolina*, 86 AM. J. PUB. HEALTH 1446 (1996)

- In September 1991, North Carolina restricted anonymous testing to 18 of its 100 counties until January 1, 1993, when a court ordered that anonymous testing be resumed in every county. Researchers with the Dept. of Epidemiology of the University of North Carolina at Chapel Hill's School of Public Health studied state-wide HIV test patterns from May 1991 to December 1992 and concluded: "[O]ur data are consistent with a detrimental effect of elimination of anonymous testing." Specifically, the study found that HIV testing increased more rapidly in counties that maintained anonymous testing, compared to counties that did not. Hertz-Picciotto at 1449.

- "Circumstantial evidence from this study supports a detrimental effect of elimination of anonymous testing. A higher proportion of individuals declined a test after pretest counseling at sites offering only confidential testing, even though an HIV test was the recorded reason for their visit, and a lower proportion of persons who were tested confidentially received their results." Hertz-Picciotto at 1448. Rates of decline in confidential-only counties were three times higher than counties that offered both confidential and anonymous testing.

Geoffrey Reed, et al., *The Impact of Mandatory Name Reporting on HIV Testing and Treatment*, Poster Presentation for the XI International Conference on AIDS (July 1996)

- Survey of 546 individuals at both confidential and anonymous test sites in Los Angeles found that 70.6% of survey participants stated they would not seek testing if they knew that the names of individuals with positive test results would be reported to a county health agency.

- 22.6% of survey participants stated that if medical providers were required to report the names of patients who are HIV positive, they would not seek treatment until they got sick.

Douglas Hirano et al., *Anonymous HIV Testing: The Impact of Availability on Demand in Arizona*, 84 AM. J. PUB. HEALTH 2008 (1994).

- "Among men who have sex with men, availability of an anonymous test option fostered a selective increase in test demand that was sustained during the entire 20-month study period. The increase appeared to have been attributable largely to the policy change: 22% of such men tested claimed to have delayed testing until an anonymous option was available. . . [the study suggests] a direct effect of testing policy change on increased test demand among these men." Hirano at 2009.

- "Among those men who have sex with men, the significantly higher rate of HIV infection observed for those who awaited availability of an anonymous test option is of particular concern. The previous named reporting policy and fear of discrimination could well have discouraged such men at elevated risk for HIV infection from seeking testing." Hirano at 2010.

Rose Weitz, *Anonymity in Testing for HIV Antibodies: Desired Option,* 81 AM. J. PUB. HEALTH 1212 (1991)

- A study in Arizona by a researcher from the Dept. of Sociology at Arizona State University compared the rates of HIV testing before and after the availability of anonymous HIV testing. During the first three months after anonymous testing became available once again after a two year moratorium, "requests for testing from gay and bisexual men increased 40.3% in Arizona, compared with 18.6% in New Mexico, where laws have always guaranteed anonymous testing." Weitz at 1213.

- "The most common reasons given for not getting tested (mentioned by 50% of untested persons) was not wanting states to learn if they tested positive. In addition, 36% mentioned fear of discrimination if others learned they had been tested." Weitz at 1213.

Susan M. Kegeles et al., *Many People Who Seek Anonymous HIV-Antibody Testing Would Avoid It Under Other Circumstances,* 4 AIDS 585 (1990).

- Researchers from the Center for AIDS Prevention Studies and the Division of General Internal Medicine at the School of Medicine at the University of California, San Francisco, conducted a three year study at the second largest HIV testing site in the country and concluded that "people are less willing to seek testing when it is offered without complete assurances of anonymity." Kegeles at 587.

- "40% of the respondents stated that they would have avoided testing if

it had not been conducted anonymously. Over 60% stated that they would not have taken the HIV-antibody test if positive results had to be reported to health officials or if contact tracing were conducted. Even with anti-discrimination legislation enacted, nearly half the respondents would have avoided testing if the results had to be reported." Kegeles at 586.

Susan M. Kegeles et al., *Mandatory Reporting of HIV Testing Would Deter Men From Being Tested*, 261 JAMA 1275 (1989).

+ Using a longitudinal sample of 574 gay men, researchers from the University of California School of Medicine, San Francisco, found that "mandatory [name] reporting would reduce the number of homosexual men willing to be tested [for HIV]." Kegeles at 1276. While 93% of the subjects were willing to have an HIV test if the results would not be reported to health officials, only 31.3% would be willing to have an HIV test if the results were reported to health officials.

E. Fordyce et al., *Mandatory Reporting of Human Immunodeficiency Virus Testing Would Deter Blacks and Hispanics from Being Tested*, 262 JAMA 349 (1989).

+ "These data suggest that fear of disclosure of human immunodeficiency virus test results is not limited to men who have sex with men, and that mandatory reporting would deter a sizable proportion of sexually transmitted disease clinics' clients from learning their human immunodeficiency virus status and seeking health care when appropriate... [T]his deterrent effect among minorities is disquieting given the differential impact the acquired immunodeficiency syndrome epidemic has had in New York City, where 60% of 18,116 adult patients, 85% of 2249 women patients, and 90% of 402 pediatric patients reported as of January 25, 1989 have been black or Hispanic."

Laura Fehrs et al., *Trial of Anonymous Versus Confidential Human Immunodeficiency Virus Testing*, 2 LANCET 391 (1988).

+ Researchers studied the impact of Oregon's policy change permitting anonymous testing. All testing had previously required names, i.e. confidential testing. As measured by reports of those tested, the option of anonymous testing increased the overall demand for HIV testing by 50%, 125% among gay/bisexual men, 56% among female sex workers, 17% among intravenous drug users, and 32% for all others. Twice as many seropositive persons were identified as a result of the anonymous testing option.

W.D. Johnson et al., The Impact of Mandatory Reporting on HIV Seropositive Persons in South Carolina (1988) (presented at the Fourth International Conference on AIDS, Stockholm, Sweden).

- In South Carolina, following the implementation of MNR in February 1986, the rate of monthly attendance at test sites by men who have sex with men decreased by 51%, with a 43% decline in identifying HIV-positive individuals. The authors concluded: "The current policy of mandatory reporting of HIV-positive persons is associated with a decrease in attendance for testing and counseling by individuals most at risk for exposure to HIV."