

Policy



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HIV Testing and Reporting

*By Ronald Bayer, PhD
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Columbia University
New York, NY
(Posted March 1996)*

Overview

From the outset, the test developed to detect antibody to HIV mired in controversy.

Uncertainty about the significance of the test's findings and about its quality and accuracy provided the technical substrate of disputes that inevitably took on a political and ethical character, since issues of privacy, communal health, social and economic discrimination, coercion, and liberty were always involved.

The availability of the test, first used on a broad scale in blood banking, quickly raised a host of key questions. For example, how would the test be used outside of the testing context? Would groups at increased risk for AIDS be encouraged to take the test? How forceful would such encouragement be? How would those who agreed to be tested be counseled about the test's significance for themselves and others? Would and could the results be kept confidential? Would voluntary testing be a prelude to compulsory screening? What would be the consequence of testing for the right to work? To go to school? To obtain insurance? To bear children? To remain free?

Each of these questions would force a confrontation over the fundamental matter of the relationship between the defense of privacy and the protection of the public health, over the roles of voluntarism and coercion in the social response to the threat of AIDS.

The issue of medical confidentiality is so important in the HIV testing and reporting context because it has been widely recognized as a central element in the effective response to AIDS. Not only does the principle rest upon ethical norms of autonomy and respect for privacy, but it has been viewed as crucial to encouraging those most at risk to come forward for HIV testing and for clinical attention.

But as important as the principle of confidentiality is, it has its limits. When competing social concerns are of sufficient magnitude, physicians and ethicists have acknowledged that exceptions may be made. The definition of when the concerns reach the standard of sufficient magnitude, however, has always been a matter of grave dispute.

Early in the century, for example, private practitioners found themselves in conflict with public officials who believed that the public health required that the names of those with tuberculosis and venereal disease be reported to confidential registries for purposes of epidemiological surveillance, contact investigation and

clinical follow-up.

These debates resurfaced in the context of the AIDS epidemic. Interestingly, in the epidemic's early years, when state health departments moved to require the reporting of the names of those with AIDS, there was little protest because of a near universal recognition that an understanding of the new disease required complete surveillance data.

Where there as been protracted bitter controversy and ethical dispute has been over the question of whether the logic of AIDS reporting requires that the names of those with asymptomatic HIV be reported as well. The debate has been largely framed by the question of whether such reporting would have the counterproductive consequence of discouraging HIV testing or whether it would enhance the public health goals of surveillance and contact tracing.

During the past decade, the debate over HIV testing has evolved, driven by changing social concerns and fears about casual transmission, conceptions of the role of the test in fostering behavioral change, and advances in therapeutics that have altered the justification for identification of those with asymptomatic infection.(1)

In the first years after the HIV test was developed, ethical analyses tended to underscore the need to protect the privacy interests of those who were tested while encouraging voluntary testing. (2) The major exception to the principle of voluntariness that was embedded in the prevailing ethical framework was blinded or anonymous testing for purposes of epidemiological surveillance. (4)

Debate also emerged over the role of testing in both health and life insurance. (5) Proponents of testing would argue that it merely represented an extension of sound underwriting principles; opponents would characterize such screening as the basis for invidious discrimination.

Conflict also has occurred over the question of screening travelers, immigrants, and refugees. (6) Proponents of such screening have depicted it as a rational approach to preventing the "transmission" of new infections across borders; those who have resisted such efforts have claimed that in the case of travelers, HIV screening would present a logistical nightmare with profound human rights implications. In the case of immigrants and refugees, opponents of screening have emphasized the importance of treating HIV no differently than other chronic conditions.

The most heated controversy has centered on the question of newborn testing and testing during pregnancy. In these cases, the debate has centered on the question of whether the child's interest in identification for purposes of therapeutic intervention or for purposes of prophylaxis against infection can override the claims of maternal privacy. (7,8) This debate, like others, underscores in an important way the central ethical concern about privacy and voluntarism in the decade-long controversy over HIV testing.

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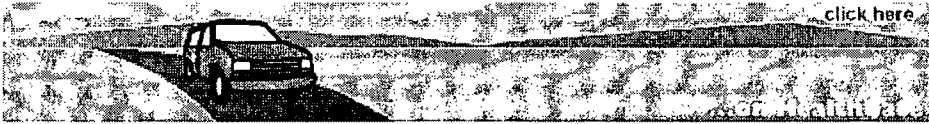
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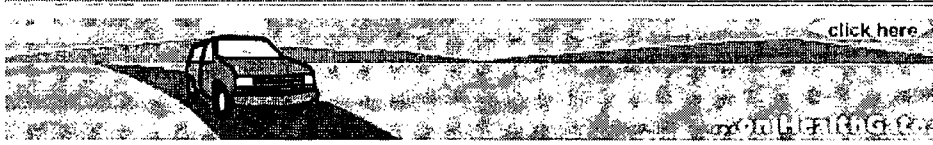


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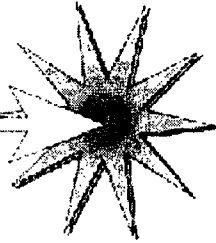
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GLMA Public Policy

Caution in Implamenting HIV Surveillance System

Resolution: 110-97

Approved: October 25, 1997

WHEREAS, treatment of HIV/AIDS has vastly improved in the past several years, which has resulted in declines in AIDS diagnosis and death; and

WHEREAS, the Centers for Disease Control and Prevention (CDC) AIDS Surveillance system, especially for reporting trends in infection, is no longer adequate; and

WHEREAS, the CDC is preparing to advise states that HIV case reporting must be implemented and that named HIV surveillance is reasonable; and

WHEREAS, research shows reluctance by some to be tested for the antibodies to HIV if the names those who test positive are to be reported to the state; and

WHEREAS, discrimination and bias against those who are HIV infected still occurs, and once privacy is breached it can not be restored; and

WHEREAS, named HIV reporting would result in greater risk of exposure to breaches in privacy for HIV infected individuals who could remain on a "list" years longer than those currently being reported with an AIDS diagnosis; and

WHEREAS, state assurances to protect the confidentiality of individuals in a named HIV reporting system cannot be guaranteed (and in the past has not been) as policy and procedures regarding maintenance of such a list could change over time; and

WHEREAS, individuals who participate in high-risk behaviors should be encouraged to get tested and get into treatment if HIV-infected, not frightened away from testing and treatment because of fear of the loss of confidentiality; and

WHEREAS, a named HIV case report surveillance system will still not adequately represent the epidemic as it will provide information only on those choosing to be tested, therefore be it

RESOLVED: That the Gay and Lesbian Medical Association strongly opposes named HIV reporting as it is detrimental to testing and treatment efforts, would be contrary to public health surveillance and prevention, and is not needed for tracking the epidemic; and be it further

RESOLVED: That GLMA encourages the CDC to further study and improve unique identifier systems and other solutions, such as encryption, for the complete protection of confidential medical data before it continues any more efforts to promote a surveillance system involving named reporting of HIV; and be it further

RESOLVED: That GLMA supports improved HIV surveillance so that the epidemic can be more accurately tracked and resources devoted to prevention and services can be most effectively targeted; and be it further

RESOLVED: That GLMA encourages the CDC to expand the use of anonymous population-based seroprevalence studies to more accurately track the epidemic; and be it further

RESOLVED: That GLMA believes that anonymous testing is an essential component of the public health response to the HIV epidemic and must be fully funded and enhanced in every state, and be it

further

RESOLVED: That GLMA strenuously rejects any plan to link surveillance with any other public health effort of disease control, such as partner notification.

For further information contact:

Peter Sawires, Public Policy Associate: psawires@glma.org

Importance of Accurate HIV surveillance Systems

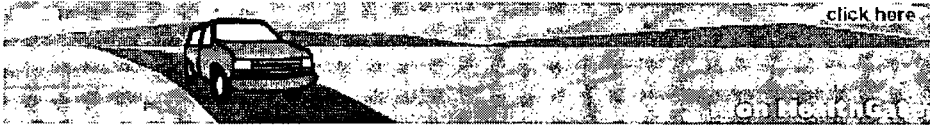
HIV affects _____ AIDS kills _____
It is important to have an accurate understanding of extent & scope of epidemic in order to allocate limited resources, _____.

The Advocate Community^{ies} Favors Non-Name Based Surveillance Systems.

The ^{AIDS} advocate community has come out strongly in favor of non-name based surveillance systems. (Name groups) ① There is concern that mandatory name reporting → discourage treatment & testing. ② Records for longer period of time. The use of ~~Privacy Protection Codes~~ or ~~other~~ non names based → better data, privacy protections.

Privacy^{Non-Names} Based Systems Provide Greater Privacy Protections

Privacy concerns are huge - once breached, can't be undone.



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Title

CDC says names, not numbers, do better job in tracking HIV. Centers for Disease Control and Prevention.

Author

Anonymous

Address

Source

AIDS Policy Law, 1998 Jan 23, 13:1, 6-7

Abstract

The Centers for Disease Control and Prevention (CDC) released the results of a three-year evaluation of the unique identifier systems used in Maryland and Texas to track HIV cases. The report indicates that the unique identifier systems fall short of the more widely-used name reporting systems. Currently all States track AIDS cases by name and 30 States also list HIV cases by name; only Maryland and Texas use the numerical alternative. CDC's report indicates the main problem lies in getting health care providers to include the Social Security number in reports to health departments. More than one-fifth of the unique identifiers were missing the Social Security number, severely limiting the success of the surveillance system. The CDC added that findings from surveys of public attitude toward name-based surveillance indicate that the use of names is not a major deterrent to HIV testing for high-risk individuals. The American Civil Liberties Union reported that the unique identifier system was a viable alternative in Maryland, noting that the coded data were 76 percent complete during the second half of 1996, a rate that surpasses some States with higher rates of HIV.

Language of Publication

English

Unique Identifier

98703272; AIDS/98703272



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MeSH Heading (Major)

Disease Notification|*MT; HIV Infections|*EP; Population Surveillance|*MT

MeSH Heading

Adult; Centers for Disease Control and Prevention (U.S.); Confidentiality; Contact Tracing|MT; Human; Maryland; Names; Registries; United States|EP

Publication Type

NEWSLETTER ARTICLE

ISSN

0887-1493

National Library of Medicine: IGM Full Record Screen



TITLE: The University of Minnesota Youth and AIDS Projects' Adolescent Early Intervention Program: a model to link HIV-seropositive youth with care.

AUTHOR: Remafedi G

AUTHOR AFFILIATION: Department of Pediatrics, University of Minnesota, Minneapolis, USA.

SOURCE: J Adolesc Health. 1998 Aug;23(2 Suppl):115-21.

SECONDARY SOURCE ID: MED/98376077

ABSTRACT: The survival of human immunodeficiency virus (HIV)-positive adolescents may be abbreviated by delays in health care delivery. Methods of linking youth with services have not been well studied. With support from the Special Projects of National Significance Program, the Youth and Acquired Immunodeficiency Syndrome (AIDS) Projects' (YAP) Adolescent Early Intervention Program offers early intervention health care services to all affected youth in Minnesota, a state with mandatory reporting of HIV/AIDS cases. The conceptual framework is a novel application of traditional public health disease surveillance strategies to link HIV-positive adolescents with health care services. The target population is composed of all 13-22-year-old HIV-positive persons reported to the Minnesota Department of Health (MDH). MDH staff locate and contact HIV-positive youth, conduct structured interviews regarding health status and needs, and facilitate enrollment at YAP. Sixteen male and 20 female participants (mean age 21 years; 56% people of color; 32% gay or bisexual) reported serious health risks, including inconsistent condom use (83%), poverty (78%), high school dropout (56%), unemployment (50%), illegal conduct (50%), medical debt (42%), unstable living situations (33%), running away (33%), substance abuse (33%) and attempted suicide (28%). More than one third reported each of six HIV-related symptoms. Seventy-five percent of participants sought advocacy/case coordination; 56%, clinical trials of experimental therapies; and 50%, vocational training and access to entitlement/eligibility programs. Linking HIV-positive youth to care is a valuable extension of the work of disease intervention specialists in states with similar reporting systems.

MAIN MESH HEADINGS: Acquired Immunodeficiency Syndrome/*PREVENTION & CONTROL
Adolescent Health Services/*ORGANIZATION & ADMIN
*Models, Organizational

ADDITIONAL MESH HEADINGS:

National Health Programs/*ORGANIZATION & ADMIN
Acquired Immunodeficiency Syndrome/THERAPY
Adolescence
Adult
Case Management/STANDARDS
Female
Health Education/METHODS
Human
HIV Infections/PREVENTION & CONTROL
HIV Infections/THERAPY
Intervention Studies
Male
Minnesota
Program Evaluation
Risk Factors
Support, U.S. Gov't, P.H.S.

PUBLICATION TYPES:

JOURNAL ARTICLE

LANGUAGE:

Eng



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TITLE: Protection of HIV/AIDS surveillance data in the United States.

AUTHOR: Metler R; Gostin LO; Posid JM; Gnesda DS; Sullivan PS; Riedford DG; Lazzarini Z

AUTHOR AFFILIATION: CDC, Atlanta, GA, USA.

SOURCE: Int Conf AIDS. 1998;12:973 (abstract no. 44185).

SECONDARY SOURCE ID: ICA12/98406917

ABSTRACT:

BACKGROUND: Protection of HIV/AIDS information and surveillance data, to prevent disclosure and discrimination, is a human rights concern and essential to the conduct of surveillance. The Centers for Disease Control and Prevention (CDC) assessed current security practices at surveillance units (SU) and reviewed state and federal confidentiality laws to see if protections were adequate. **METHODS:** A 124-question survey of security practices was administered at 33 of 61 SUs. A survey of state epidemiologists and legal database search were used to assess state laws. To assess federal protections, a review of federal statutes, regulations, constitutional law, case law, legal journals, agency recommendations, and legislative committee reports was undertaken. **RESULTS:** Of 33 SUs surveyed, all had disciplinary policies for improper disclosure of data, 89% closed off the work area containing surveillance data with identifiers to outsiders, and 82% prohibited cleaning crews from entering surveillance units unescorted. All states had legal protection for HIV/AIDS data, but their content varied widely. For example, exceptions to confidentiality laws allowed disclosures to: health providers (83%), needle-sharing or sex partners (71%), subpoena or court order (56%), blood banks (42%), correctional institutions (27%), school officials (23%), and insurance companies (15%). At the federal level, protection consists of removal of names before encrypted HIV/AIDS data are transmitted to CDC and of a collection of statutory and constitutional safeguards. **CONCLUSIONS:** In summary, protection must be assured at all 3 levels: SU, state, and federal. While all SUs have security policies, CDC is further strengthening protections by using survey findings to implement minimum security standards. To address state law variability, CDC is developing model state legislation on public health information privacy, with emphasis on HIV data. Federal legislation providing uniform protection of individual health information, including HIV data, is being considered.

MAIN MESH HEADINGS: *Acquired Immunodeficiency Syndrome
Confidentiality/*LEGISLATION & JURISPRUD
*HIV Infections

***HIV Infections**
***Population Surveillance**

**ADDITIONAL MESH
HEADINGS:**

Human
Privacy
United States

PUBLICATION TYPES:

ABSTRACT

LANGUAGE:

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TITLE: Assessment of the impact of a major HIV/AIDS confidentiality breach, Florida.

AUTHOR: Liberti T; Conti LA; Lieb S; Dulin S; Maddox L; Crockett LK

AUTHOR AFFILIATION: Florida Department of Health, Tallahassee 32399-0700, USA.

SOURCE: Int Conf AIDS. 1998;12:928 (abstract no. 43421).

SECONDARY SOURCE ID: ICA12/98405049

ABSTRACT: **BACKGROUND:** In September 1996, a computer diskette containing the names and demographic information of numerous HIV-positive patients was anonymously mailed to a local health department and 2 major newspapers serving the 5-county Tampa Bay area of Florida. The newspapers publicized the receipt of the unauthorized information, but did not further disclose the identities of the patients. Investigations of the incident were launched by the Florida Department of Health (DOH) and the Florida Department of Law Enforcement. **METHODS:** Law enforcement officials gathered evidence about the incident. The DOH conducted a study to assess the impact of the breach on the AIDS surveillance system and HIV counseling and testing programs. **RESULTS:** A DOH employee and a non-employee were implicated in the confidentiality breach. The volume of AIDS case reports declined temporarily in the county where the employee worked due to his being placed on administrative leave and the time consumed by the criminal and internal DOH investigations. There was no evidence to suggest that local provider confidence in the AIDS reporting system was adversely affected by the breach. When active AIDS surveillance resumed in early 1997, case reporting in the area returned to normal levels, and missed cases were collected retrospectively. Elsewhere in the state, no effect on case reporting was evident. Statewide, as well as in the 5-county Tampa Bay area, overall HIV counseling and testing patterns for October-December 1996 were similar to those for the same period in 1995. In the county where the employee worked, a slight decline in HIV testing was observed in the immediate post-breach period, which was followed by a return to the pre-breach level. Implementation of legislatively mandated HIV infection reporting--initially scheduled for January 1997--was postponed by 6 months. **CONCLUSIONS:** The breach had minimal impact on the AIDS surveillance system and HIV counseling and testing programs statewide. The employee resigned, and he and the non-employee were convicted of criminal charges. No class action or individual lawsuit was filed by patients. Following the breach, DOH

security and confidentiality measures were enhanced statewide, and such measures became a model for other states' HIV/AIDS surveillance systems. HIV infection reporting was successfully implemented in July 1997.

MAIN MESH HEADINGS: Acquired Immunodeficiency Syndrome/*DIAGNOSIS
*Confidentiality
*Confidentiality/LEGISLATION & JURISPRUD
HIV Infections/*DIAGNOSIS
*Truth Disclosure

ADDITIONAL MESH HEADINGS: Acquired Immunodeficiency Syndrome/EPIDEMIOLOGY
Counseling
Crime
Disease Notification/LEGISLATION & JURISPRUD
Florida
Human
HIV Infections/EPIDEMIOLOGY
Population Surveillance

PUBLICATION TYPES: ABSTRACT

LANGUAGE: Eng



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TITLE: Facing reality [letter]
AUTHOR: Gault MH
SOURCE: CMAJ. 1998 Sep 8;159(5):443, 445.
SECONDARY SOURCE ID: MED/98429715
MAIN MESH HEADINGS: HIV Infections/*PREVENTION & CONTROL
 *Medical Missions, Official
 *Occupational Health
 *Voluntary Workers
ADDITIONAL MESH HEADINGS: Female
 Human
 HIV Infections/EPIDEMIOLOGY
 HIV Infections/TRANSMISSION
 Lesotho/EPIDEMIOLOGY
 Male
 Population Surveillance
 World Health Organization
PUBLICATION TYPES: LETTER
 JOURNAL ARTICLE
LANGUAGE: Eng



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October 27, 1998

Study: Anonymous HIV Testing Is Key

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Filed at 7:54 p.m. EST**By The Associated Press**

CHICAGO (AP) -- Anonymous screening for the AIDS virus leads to people getting tested and treated much earlier, a study found.

But where name-linked testing is required -- as it is now in 11 states -- public clinics have seen no significant decline in the number of people tested, another study found.

In confidential testing, the person's name is linked to test results in a medical chart and kept on file at health departments to prevent cases from being tracked more than once. The names are stripped before results are sent to the Centers for Disease Control and Prevention. In anonymous testing, only a number is recorded with the test result, never a name.

Federal authorities favor the availability of both. They say name reporting is the only way to track the epidemic, but anonymous testing may help curb it by getting people into treatment earlier.

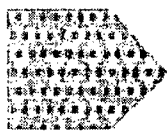
"The history of this disease has been a little different than ... other diseases, because we haven't had a therapy until recently that was highly effective," said Dr. Allyn K. Nakashima, lead author of one study and a CDC medical epidemiologist.

Public reluctance to give names to public health officials for testing has eased, since a person's anonymity disappears when he or she becomes a patient, she said.

The CDC studied about 459,000 tests at health departments in six states before and after they implemented reporting of names of people who tested positive for HIV, the virus that causes AIDS.

Name reporting did not appear to diminish the use of testing in the states studied -- Louisiana, Michigan, Nebraska, Nevada, New Jersey and Tennessee -- the CDC said in Wednesday's Journal of the American Medical Association.

Name reporting has been required since 1981 in all states for full-blown AIDS and has been routine even longer in all states for other diseases ranging from

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October 27, 1998

States That Track HIV Cases by Name

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Filed at 7:53 p.m. EST**By The Associated Press**

These 11 states require reporting by name of anyone who tests positive for HIV to local health departments for confidential case tracking. All other states offer anonymity as an option in HIV testing.

Alabama

Idaho

Iowa

Mississippi

Nevada

North Carolina

North Dakota

South Carolina

South Dakota

Tennessee

Wyoming

GMHC News Release

FOR IMMEDIATE RELEASE

March 26, 1998

Contact: Stephen Soba: (212) 367-1214/Pager: (917) 556-6797
Greg Lugliani, (212) 367-1210/Pager: (917) 556-6356

GMHC Welcomes State HIV Workgroup's Call for Monitoring and Firm Rejection of Mandatory Partner Notification and Names Reporting

A Unique Identifier System is Clearly Recommended

Ronald Johnson, Managing Director for Public Policy, Communications and Community Relations at Gay Men's Health Crisis, released the following statement:

GMHC welcomes the New York State AIDS Advisory Council HIV Surveillance Workgroup's long-awaited report on tracking the epidemic. The report clearly states the compelling need for collecting HIV data as the best weapon to stop the future spread of HIV. New York urgently needs a new system to monitor the AIDS epidemic, and GMHC hopes this report will provide the needed impetus to legislation that makes this system a reality.

In light of an ill-considered bill currently in Albany sponsored by Assemblywoman Nettie Mayersohn (D-Queens) and Senator Guy Velella (R-Bronx), perhaps the report's most significant recommendation is its unequivocal rejection of coercive, mandatory government-run partner notification programs. The report instead recognizes the importance of partner notification remaining voluntary and within the context of clinical care.

The report also wisely comes out for the continuation of anonymous testing in New York State and the safeguarding of confidentiality for those who test positive. Given the real fears many HIV-positive people have of being named and reported to the government, we are truly heartened that the HIV Surveillance Workgroup overwhelmingly rejected a names-based system. Gay Men's Health Crisis is opposed to any names-based HIV surveillance system.

Shockingly, workgroup members from the New York City Department of Health caved to political pressure and changed their votes to support criminal penalties for HIV-positive people who do not disclose their status to sexual or needle-sharing partners, even if they are engaging in safer sex. Despite the City's flip-flop, this measure was defeated. Lawmakers who seek a quick fix to the worst public health crisis the state has ever faced and who would contemplate punishments for people with HIV should heed the report's overarching message that simple solutions in the fight against AIDS don't save lives. Policies that promote, not discourage, HIV testing are the only way to go.

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GMHC News Release

FOR IMMEDIATE RELEASE

January 13, 1998

Contact: Stephen Soba, (212) 367-1214

Gay Men's Health Crisis Calls for Monitoring of HIV Infections

Demands New York State Develop System that Collects and Uses Data to Expand Treatment and Prevent New Infections, While Protecting Privacy

Gay Men's Health Crisis called today for a new system for tracking HIV infection in New York State. Until now, GMHC had opposed plans to report HIV infections. But with changes in the epidemic, the agency now believes that the old hospital-based AIDS reporting system is obsolete. A new monitoring system is critical to help prevent new infections, especially among young people, as well as to expand health care for those already infected with HIV. The numbers of AIDS cases and deaths have been available for years, but the huge number of those infected with HIV — and of new infections each year — remains a mystery.

"Shifts in HIV infections and new early treatment options demand new approaches," said Ronald S. Johnson, GMHC's Managing Director for Public Policy, Communications and Community Relations. "Counting only those who are hospitalized reveals yesterday's epidemic, not today's. We are committed to fighting for a new system of tracking HIV infections with strong privacy protections that will help those most at risk: the poor, women, youth, especially gay youth, and young adults."

New York's current monitoring system, designed in 1983, tracks the epidemic by counting people who become hospitalized with, or die from, AIDS-related illnesses. The system misses the shift of HIV care from hospitals to outpatient clinics and doctors' offices. It also misses the large numbers of people who have learned they are HIV positive but have remained healthy.

GMHC is calling for a monitoring system with strong and enforceable privacy protections to prevent discrimination against people who are HIV positive. Personal information gathered by the state public health department needs to be protected as stringently as the current AIDS monitoring system has guarded privacy for nearly two decades. Public health data in New York State are among the most highly protected form of medical information. GMHC believes that the real threat to privacy is the unregulated free market for private medical records among insurers, drug companies, industry and employers.

GMHC also favors the preservation of free, publicly-funded anonymous testing. Anonymous testing is an important vehicle for some people to receive counseling and testing, enter medical care, and prevent further transmission. Anonymous testing is an important adjunct to any HIV monitoring system, because lack of this option leads some people to delay testing, donate blood as a means to be tested anonymously, and give false information at confidential testing sites.

"Our call for a new monitoring system should not become a vehicle for enacting punitive, ineffective or unrelated HIV policies," said Mr. Johnson. "Some propose linking a new monitoring system to the issue of partner notification. We are opposed to mandatory,

government-run partner notification. We are convinced that counseling about voluntary disclosure and protecting sexual partners must continue to be performed by doctors, nurses, social workers and community-based organizations. The real challenge for New York State public health officials and elected leaders is to use the data collected from a new HIV monitoring system to increase care for the infected and to prevent new infections from occurring."

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GMHC News Release

FOR IMMEDIATE RELEASE

March 26, 1998

Contact: Stephen Soba, (212) 367-1214

GMHC Strongly Opposes Coercive Partner Notification Bill

Bill Would Deter HIV Testing, Endanger People with HIV and Their Partners

The following statement was released by Ronald S. Johnson, Managing Director for Public Policy, Communications and Community Relations at Gay Men's Health Crisis: Gay Men's Health Crisis firmly rejects legislation mandating government- directed contact tracing, a misguided, ineffective and perilous approach to a complex question. Mandatory partner notification is not the answer. It would accomplish nothing, except to heighten the threat of domestic violence and lead people at risk for HIV to avoid early testing and medical treatment, driving the infected and their partners into a state of increased ignorance and even greater danger.

The Mayersohn/Veella bill (A.6629/S.4422) demands that physicians report the names of HIV-positive persons to local health departments, which would in turn notify spouses and/or known sexual partners. In an election year, politicians may conveniently forget that existing state law already authorizes partner notification, regardless of the consent of people with HIV, whenever physicians believe there is risk of infection to an unsuspecting partner. Communities most vulnerable to infection -- gay men, intravenous drug users, adolescents, women of color -- will not be tested if they believe government is collecting names of HIV positive people and hunting down their partners. Rather than compelling people to resist getting tested, as this bill will do, New York should commit itself to aggressively promoting HIV testing. That's the best way of stemming the spread of HIV.

If this bill passes, spouses and partners, particularly women, will fall prey to domestic violence, which is far more likely to occur as a result of government-driven HIV disclosure. To argue that HIV is the same as other STDs is deceptive; unlike syphilis and gonorrhea, HIV is an incurable life-long infection. Furthermore, the Mayersohn/Veella bill would create an outrageously costly bureaucratic structure — the cost could be as high as \$5,600 for every single contact — wasting precious funds that could be spent more effectively to promote testing and prevention.

We share the legitimate concerns reflected in the Mayersohn/Veella bill. However, stopping the spread of HIV will require more than a simplistic response. Partner notification will only succeed when an individual and a health care provider work together to identify and notify a partner.

[Press Room](#) | [Facts & Statistics](#) | [A History of GMHC & AIDS](#) | [GMHC at a Glance](#) |





NEWS & INFORMATION

What's new? Find out about the latest theories, discoveries, and treatments for HIV and AIDS.

In the News

12th World AIDS Conference or try this mirror site, or this one

Two of AIM's finest were in Geneva, Switzerland for the conference on AIDS. Dr. David Ostrow offered a poster on Hepatis and HIV risk among drug-using men who have sex with men, and the impact of new combination HIV therapies on knowledge, attitudes, and behaviors among Chicago gay men. Dr. David McKirnan offered a poster on HIV sexual risk among subgroups of drug and alcohol-involved men who have sex with men. For abstracts of the posters, and links to more information about the conference, see our Geneva Update, and view the press release.

CBC calls for declaration of Public Health Emergency

The Congressional Black Caucus called upon Donna Shalala, Secretary of Health and Human Services to declare AIDS/HIV a public health emergency. Key to the plan developed by the CBC is the integration of substance abuse treatment with HIV prevention and care, as well as prevention and treatment of HIV in prison populations. Representatives also stated a strategy must be developed to combat anti-gay bias.

On the record

Want to know how your representative voted on the ban against needle exchange programs? Check out the discussion and the vote from the Congressional Record. (If you want more info, check the Library of Congress search engine, search for needle exchange.)

Drinks, Drugs and HIV

As the weather warms up and some of us begin to drag ourselves out of winter hibernation and onto the party circuit, it's a good time to review the impact of drugs and drinking on people with HIV. We start this month's discussion with an informative brochure from Gay Men's Health Crisis.

Name Reporting in Illinois

The Illinois Department of Public Health opened up the discussion of its proposed rule change to require mandatory reporting of names of HIV positive people. The results of the discussion are unclear: some sources say there is now a work group to study other options, while IDPH is still stating the proposal is going on as scheduled, meaning the proposal will continue to be refined over the next few months. Many health organizations and AIDS treatment advocates are opposing names reporting. While tracking HIV is a crucial part of treatment and research, experts say there are other ways to ensure effective tracking without names. We will keep you posted as details of the proposed rule change become available.

Viagra and PIs

Reports indicate Viagra may interact with drugs commonly used to fight HIV, including some protease inhibitors and antibiotics. There also may be possible adverse, or even fatal, effects of combining amyl nitrate (poppers) with Viagra. Check out the Gay and Lesbian Medical Association press release and JAMA's article for more information.

HIV as Disability? UPDATE: The U.S. Supreme Court has decided HIV is considered a disability protected under the Americans with Disabilities Act. As we reported last month, *Bragdon v. Abbot*, centered on the refusal of a dentist to fill the cavity of a patient with HIV unless she agreed to have the procedure done in a hospital. For information on the case, see [Chicago Sun-Times](#) or [The Washington Post](#).

PEP Talk In the launch of our Feedback column, the discussion of Post-Exposure Prevention continues. Tell us what you think. We'll include your comments in next month's Feedback.

Undetectable Viral Load Studies indicate undetectable viral load in the blood doesn't mean the virus is gone. It still hides in semen and in the brain.

Barebacking Well into the second decade of the AIDS crisis, it seems more people are engaging in barebacking (sex without a condom). Sometimes it's intentional, either as a part of a philosophy of risk taking, or as acceptable risk between HIV-positive partners. If you are into barebacking, we'd like to talk with you. We are currently conducting interviews with men in the Chicago area who are having sex with other men, who feel there is no longer a need to be quite so careful, maybe because of the availability of new treatments, or maybe just because...

The interviews take about an hour and a half, and a small stipend is offered. To get more information or sign up for an interview, please give us a call at 773.525.0246, and tell 'em you saw it on the web.

Let's talk about Sex... Can you talk to your doctor about your sexuality? Check out this [Washington Post](#) article for information on how a doctor can talk about sex more comfortably with his or her patients, including suggestions by our own [Dr. David Ostrow](#).

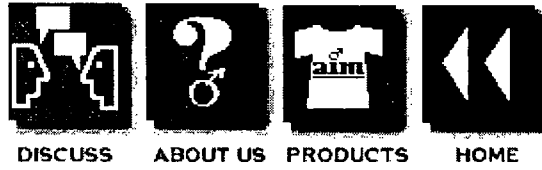
Celebrate Summer with the AIM Boys Ah, summer. Parades, lakefront gatherings, late night strolls down Halsted. Through it all, AIM is out and about at area venues. For a complete schedule of when and where you can meet us to talk, check out this month's calendar.

Want more? With HIV as with the rest of life, act locally, think globally. [Click here for a list of resources in Chicago](#), and links to publications, information and organizations all over the planet.

From the TAKEAIM Library [Behavioural and psychosocial implications of the new protease inhibitors](#) by David Ostrow, M.D., Ph.D. A discussion of the implications of the new treatment options and viral load measurements.

[Wake Up! Turn Off the auto-pilot Now](#) by Stephen Gendin. A reality check in the wake of media hype about the successes of new treatments. Reprinted from the December issue of Community Prescription

Service Info Pack.



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IMPROVING HIV SURVEILLANCE SYSTEMS

This proposal would

The President has proposed a demonstration project providing States with funds to develop HIV surveillance systems that utilize privacy protection codes rather than names based reporting. These States would be required to apply their disease surveillance strategies in ways that link infected individuals with critical health care and social support services. As a condition of receiving funds, States would also be required to evaluate their new surveillance systems.

BACKGROUND

Importance of Accurate HIV Surveillance Systems

In 1995, AIDS became the leading cause of death for all Americans aged 25-44. Over half a million American men, women and children have been diagnosed with AIDS, and more than 300,000 have already died from this disease. AIDS strikes hardest against younger people, robbing the country of valuable energy, talent and promise for the future. It is vitally important to have an accurate national surveillance system in order to allocate limited resources, target and evaluate prevention efforts, and project the future of the epidemic.

~~Current Surveillance Systems Are No Longer Adequate~~

Presently, all people diagnosed with AIDS are reported by name to State and local health departments. State officials then delete identifying information from the reports and forward them to the Centers for Disease Control (CDC) for compilation of national data on the AIDS epidemic. At the beginning of the epidemic, this was a reliable way to determine the extent of infection nationwide, because people with HIV routinely developed AIDS within a very short time period. However, because of the success of new HIV drug therapies, people are living longer with asymptomatic HIV disease. Therefore, the current method of tracking the AIDS epidemic is no longer reliable, because it is based solely on the end stages of disease progression. Health care organizations, AIDS advocates, and Federal, State, and local public health officials are all in agreement that generating better data on the scope of the HIV epidemic is essential.

States Work Independently to Track Levels of HIV Infection

State and local public health officials are currently working together to develop accurate HIV surveillance systems. Thirty-one States have chosen to implement name-based HIV surveillance systems that build off their current surveillance systems. Because of privacy concerns, three States (Maryland, Massachusetts, and Texas) have chosen to implement non-name based systems, where HIV infected individuals would be reported to public health officials by a unique code that cannot be traced rather than by name. Although there is a high level of interest in developing non-name based surveillance systems, there is a significant cost associated with the development of these systems because there is no existing public health infrastructure to support them.

The Advocate Community Favors Non-Name Based Surveillance Systems

Advocates have come out strongly in favor of non-name based HIV surveillance systems. There is considerable concern that mandatory name based reporting will discourage people from getting tested and seeking treatment. In addition, because people are living longer with asymptomatic

HIV disease, public health officials would have the names of people with HIV on record for an extended period of time, increasing the possibility of confidentiality breaches. Advocates believe that non-name based surveillance systems will reduce the fear of stigma and the loss of confidentiality while enabling the collection of better data on HIV infection.

Initial Evaluation of Non-Name Based Reporting Systems is Inconclusive
Information from CDC studies here.

X
November

Movement Towards a National HIV Surveillance System

The CDC has developed draft regulations that would require States to implement HIV surveillance systems by April of 1999. As presently drafted, these regulations emphasize the importance of State flexibility when developing a reporting system. They do not require any particular method of surveillance and establish performance measures for both names based and non-names based systems.

POLICY DESCRIPTION

The President has proposed a three part demonstration project to explore the issues surrounding non-name based HIV surveillance.

1. Developing New Surveillance Systems

States will be provided funding to develop and implement HIV surveillance systems that use encryption and other non-name based methodologies to track the level of HIV infection in their State. These systems will utilize "privacy protection codes" rather than the names of individuals when forwarding data to the State Department of Health, ensuring that only patients and health care providers have identifying information on the HIV status of individuals.

2. Linking Infected Individuals with Critical Health Care and Social Support Services

States must enhance their current efforts to link infected individuals with critical health care and social support services. Special outreach efforts to educate individuals about the new privacy safeguards and the importance of early diagnosis and treatment should be undertaken. In addition, strategies to improve referral to primary care sources should be implemented for those infected individuals being tested at publicly funded sites.

3. Evaluating the New Surveillance Systems

States would be required to perform a technical evaluation of their new surveillance systems that focused on rates of record duplication and lost or missing data. They would also be required to evaluate the success of the outreach, education, and patient referral strategies in promoting HIV testing and early entry of infected individuals into primary care.

BUDGET EFFECTS

Unknown.

ADVANTAGES

① privacy agenda

② advocate support.

IMPROVING HIV SURVEILLANCE SYSTEMS

Summary: (No italics.)

This proposal would fund a demonstration project providing States with funds to develop HIV surveillance systems that utilize privacy protection codes rather than name-based reporting. These States would be required to apply their disease surveillance strategies in ways that link infected individuals with critical health care and social support services. As a condition of receiving funds, States would also be required to evaluate their new surveillance systems.

do I need this?
yes - it's good

BACKGROUND

Bullets

Bold, No + underlined

- 6 - **Importance of Accurate HIV Surveillance Systems.** In 1995, AIDS became the leading cause of death for all Americans aged 25-44. Over half a million American men, women and children have been diagnosed with AIDS, and more than 300,000 have already died from this disease. It is vitally important to have an accurate national surveillance system in order to allocate limited resources, target and evaluate prevention efforts, and project the future of the epidemic.

Surveillance Systems Are Outdated. Presently, all people diagnosed with AIDS are reported by name to State and local health departments. State officials then delete identifying information from the reports and forward them to the Centers for Disease Control (CDC) for compilation of national data on the AIDS epidemic. At the beginning of the epidemic, this was a reliable way to determine the extent of infection nationwide, because people with HIV routinely developed AIDS within a very short time period. However, because of the success of new drug therapies, people are living longer with asymptomatic HIV disease. Therefore, because the current method of tracking the AIDS epidemic is based solely on the end stages of disease progression, it is no longer reliable. Health care organizations, AIDS advocates, and Federal, State, and local public health officials are all in agreement that generating better data on the scope of the HIV epidemic is essential.

Present State Surveillance Systems Raise Privacy Concerns. State and local public health officials are currently working together to develop accurate HIV surveillance systems. Thirty-one States have chosen to implement name-based HIV surveillance systems. Although this issue is still being debated, there is concern in both the public health and advocacy communities that name-based surveillance systems would discourage infected individuals from seeking testing and treatment because of the fear of confidentiality breaches. In addition, because people are living longer with asymptomatic HIV disease, public health officials would have the names of people with HIV on record for an extended period of time, increasing the possibility of confidentiality breaches. Although there is a high level of interest in developing non-name based surveillance systems that include essential privacy protections, the significant cost associated with the development of these systems is discouraging for many States.

Movement Towards a National HIV Surveillance System. The CDC has developed draft regulations that would require States to implement HIV surveillance systems by April of 1999. As presently drafted, these regulations emphasize the importance of State flexibility when developing a reporting system. They do not require any particular method of surveillance and ^{to be released in} but establish performance measures for both names based and non-names based systems.

POLICY DESCRIPTION

~~The President has proposed a three part~~ demonstration project to explore the issues surrounding non-name based HIV surveillance.

This proposal would establish a

[Questions - Competitive? How many states? 1-year? who Administers?]

1. Developing New Surveillance Systems?

States ~~will~~ ^{would} be provided funding to develop and implement HIV surveillance systems that use encryption and other non-name based methodologies to track the level of HIV infection in their State. These systems ~~will~~ ^{would} utilize "privacy protection codes" rather than the names of individuals when forwarding data to the State Department of Health, ensuring that only patients and health care providers have identifying information on the HIV status of individuals. Recent evaluations of existing non-name based surveillance systems indicate that States have higher rates of missing data and may have difficulty conducting adequate follow-up with infected individuals in order to collect HIV risk information. States would need to adequately address these issues in their grant proposals.

2. Linking Infected Individuals with Critical Health Care and Social Support Services

States ~~must~~ ^{will} enhance their current efforts to link infected individuals with critical health care and social support services. Special outreach efforts to educate individuals about the new privacy safeguards and the importance of early diagnosis and treatment ~~should~~ ^{will} be undertaken. In addition, strategies to improve referral to primary care sources ~~should~~ ^{will} be implemented for those infected individuals being tested at publicly funded sites.

As a condition of receiving federal funds,

3. Evaluating the New Surveillance Systems

States would be required to perform a technical evaluation of their new surveillance systems that focused on rates of record duplication and lost or missing data. They would also be required to evaluate the success of the outreach, education, and patient referral strategies in promoting HIV testing and early entry of infected individuals into primary care.

POLICY RATIONALE

Funding a demonstration project that would assist States in the development and implementation of non-name based HIV surveillance systems would be advantageous for the following reasons:

Non-name Based Surveillance Systems Provide Greater Privacy Protections

AIDS advocates have come out strongly in favor of non-name based HIV surveillance systems. ~~There is considerable concern that mandatory name-based reporting will discourage people from getting tested and seeking treatment.~~ Advocates believe that non-name based surveillance systems will reduce the fear of stigma and the loss of confidentiality while enabling the collection of better data on HIV infection.

Shantanu said earlier

Non-name Based Surveillance Systems Protect the Hispanic Community

The AIDS epidemic disproportionately affects the Hispanic population. In 1997, the incidence of AIDS among Hispanics was 37.7 per 100,000 individuals, almost 4 times the incidence rate for whites. There is a widespread fear among the Hispanic population that mandatory names

Butler

reporting for HIV infection will eventually lead to deportation of infected individuals. This provides a strong disincentive to request testing or receive care. The implementation of non-name based surveillance systems will help assure the Hispanic community that their infection status will not be used by State or Federal immigration agencies to discriminate against them when they apply for citizenship or naturalization.

Provides a Test Case for National Unique Medical Identifiers

There was a great deal of concern when the Administration proposed to implement a national system of unique medical identifiers. We have since stated that we would not move to implement such a system until we have passed privacy protection legislation. However, implementing a non-names based surveillance system to monitor the level of HIV infection differs significantly from the original Federal proposal. This system would be developed at State option for a limited subset of individuals who would otherwise be identified by name to State public health agencies. It is important to note, however, that if States are able to design non-name based surveillance systems that are able to meet current public health needs and adequately protect the privacy of HIV infected individuals, they may provide a roadmap towards designing a portable medical record that uses unique medical identifiers.

BUDGET EFFECTS

Unknown.