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-CDC [Centers for Disease Control]-Guidelines-Draft Press

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

AIDS Tests,310
CDC proposes guidelines for tracking HIV

WASHINGTON (AP) States must better track Americans infected with the AIDS virus by reporting HIV cases either with the patient's name or by using a code, according to new government guidelines being proposed Thursday.

The proposal puts in writing what some Centers for Disease Control and Prevention experts have long said: Reporting HIV cases by name just as full-blown AIDS cases have been reported since 1981 works best. But because of privacy concerns, states can pick their own method, the guidelines say.

Whatever states decide, they must also allow anonymous HIV testing because some people will only get an HIV test if it is totally anonymous, the guidelines say.

The government lists 11 states that do not offer anonymous testing: Alabama, Idaho, Iowa, Mississippi, Nevada, North Carolina, North Dakota, South Carolina, South Dakota, Tennessee and Wyoming.

The CDC already had told states they must start counting HIV cases instead of just full-blown AIDS cases so that health workers can get a better handle on the epidemic. But in formally telling states they can use their own methods for tracking HIV cases, the proposed guidelines ease some AIDS activists' concerns that reporting-by-name would be mandated.

The guidelines also set the first quality criteria to ensure states do HIV surveillance properly as well as also establishing privacy standards so that states properly protect their lists. They include such protections as eliminating paper records, using computer encryption techniques, limiting access to the lists and requiring penalties for violators.

The guidelines, published in Thursday's Federal Register, are open for public comment for 30 days.

Currently, 29 states track HIV by name. Three other states report children's names only.
APWR-12-09-98 1825EST

Received by NewsEDGE/LAN: 12/9/98 6:25 PM

U.S. Asks States to Report People Who Take HIV Tests

Jonathan Curiel, Chronicle Staff Writer
Thursday, December 10, 1998

URL: http://www.sfgate.com/cgi-bin/article.cgi?file=/chronicle/archive/1998/12/10/MN26252.DTL

In guidelines to be announced today, federal health officials are asking states to begin tracking individuals who have taken HIV tests as a way of monitoring the spread of the infection. The proposal, issued by the Centers for Disease Control and Prevention, would let states set up their own system of tracking people getting HIV tests -- but the CDC recommends a name-based system.

The alternative is using ``unique identifier'' codes that provide demographic information without identifying individuals by name.

The suggestion of a name-based system caused great concern last night among AIDS patient advocates in San Francisco.

``We're pleased that, at a minimum, the guidelines allow for flexibility and allow the states to decide what the best system is, but we're quite disappointed that there's an advisement that names be used,'' said Fred Dillon, state policy director with the San Francisco AIDS Foundation.

``We feel that the far better system is a non-name-based system that will give us the data we need without deterring individuals from HIV testing and treatment.''

The CDC guidelines mark the first time that federal officials have formally asked

states to consider name-based reporting. Currently, 29 states track rates of HIV infection by name. California uses names-reporting for full-blown AIDS cases but not for HIV testing, which is currently handled anonymously.

HIV is the virus that causes AIDS. Doctors and AIDS activists fear that name-based reporting would discourage people from being tested for HIV out of fear that their medical status might become publicly known.

``It (a name-based system) would be repressive and counterproductive,'' said San Francisco Supervisor Tom Ammiano.

``It's a terrible idea,'' said Larry Brinkin, who is coordinator of the Lesbian, Gay, Bisexual, Transgender and HIV Unit at the San Francisco Human Rights Commission. `It's very, very difficult in many, many cases to get people with HIV to come in for testing, to find out if they're infected, because of fears of discrimination. If you're going to attach names, then that effort will be severely curtailed.

``Right now, even with anonymous testing, it's difficult to get people to trust that nothing

will happen."

This year, Governor Pete Wilson vetoed a bill sponsored by Assemblywoman Carole Migden proposing to keep track of HIV infection by a system that uses codes, not names. Midgen's bill was widely supported by Dillon and others as a compromise between names- based reporting and no reporting at all. Governor-elect Gray Davis reportedly has said he would sign a similar bill if it were passed again by the California Legislature.

The CDC's guidelines have been discussed informally for the past year. CDC officials believe they can better track HIV if names are used. They believe a name- based system gives them a better idea, for example, of which ethnic communities are undergoing the most rapid spread of HIV and where health officials might better concentrate their work. CDC officials were unavailable for comment last night.

The CDC said that whatever systems are chosen, states must meet specific requirements established by the agency, including strict safeguards to ensure confidentiality.

States will have several years to implement their reporting systems; while the recommendations are not mandatory, CDC will provide federal funds to states designing systems that meet performance criteria established by the agency.

The CDC already had told states they must start reporting the number of HIV cases in addition to full-blown AIDS cases so health workers can get a better handle on the epidemic.

The guidelines, published in today's Federal Register, are open for public comment for 30 days.

Dillon and others say it would be politically unlikely that California would go to name-based reporting -- but the CDC's new guidelines are a warning, they say, that anything could happen.

``I wouldn't rule anything out," said Dillon. ``I believe there will be bills offered next year (that would require name-based reporting.)"

A San Francisco man who has tested positive for HIV, who did not want his name used, said, ``I personally feel that name reporting is not a good idea. If they were to report my name to a national data base, I would feel threatened. I'm not out to my entire family."

``However," he added, ``if they were to use some sort of code system as Carol Migden has proposed, I would support that."

Thursday, December 10, 1998

CDC to Ask States to Track HIV Cases, Not Just AIDS

■ Public health: Agency believes best method would be to confidentially identify those infected by name. But identifier codes could be employed.

By MARLENE CIMONS, JULIE MARQUIS, Times Staff Writers

WASHINGTON--Federal health officials will call upon states today to track HIV infection as an integral part of their AIDS reporting programs, urging that individuals be identified by name, as states now do with those who have full-blown AIDS.

But, while officials believe name-reporting to be the best way to conduct this surveillance, the Centers for Disease Control and Prevention will leave it to the states to decide on their own systems, including the use of so-called unique identifier codes.

The CDC said, however, that whatever system is chosen must meet specific requirements established by the agency, including strict safeguards to ensure confidentiality. The issue has been an extremely contentious one, especially in California.

Virtually everyone agrees that because infected people are generally staying healthy longer with the help of powerful new drugs, it is imperative to track HIV by infection as well as by AIDS cases to better understand the scope of the epidemic, where it is spreading and among what groups.

Such comprehensive information will better enable health officials to target areas eligible for federal AIDS funds for treatment, access to other services, and for education and prevention programs.

But AIDS activists and others worry that tracking those infected with HIV by name will result in people becoming reluctant to undergo testing because of privacy and discrimination concerns.

In its last session, the California Legislature passed a "unique identifier" bill, but it was vetoed by Gov. Pete Wilson, who agreed with critics that name reporting is more practical and facilitates partner notification. The issue is expected to be taken up again in January.

Several AIDS organizations in California welcomed the

flexibility in the CDC's new recommendations.

"Obviously, we wish [the recommendations] hadn't been biased toward names," said Fred Dillon of the San Francisco AIDS Foundation. "We are confident that we will be able to come up with a non-names-based system in California that will meet the expectations of the CDC."

But some proponents of name-based reporting were disappointed. "The CDC has relinquished its responsibility of protecting the public against a deadly disease," said Cary Savitch, a Ventura County physician who has organized a pro-names network.

The new guidelines are scheduled to be published in today's Federal Register and will be open for public comment for 30 days before final guidelines are issued.

States will have several years to actually implement their reporting systems; while the reporting recommendations are not mandatory, the CDC will provide federal funds to states based on their ability to meet the reporting criteria.

The recommendations give the states a choice of using either names or a "unique identifier" code that still provides demographic information, such as "gay, white male," without specifically identifying the individual.

A six-state study released earlier this fall suggested that tracking infection by names would not discourage a person's willingness to be tested.

The CDC also urged the continued availability of anonymous testing services and recommended that states provide such options among its AIDS programs. In those cases, the names could be reported when patients sought treatment.

While all states, including California, track full-blown AIDS cases by name, 32 states report infection by name, including three that report only pediatric infections by name.

In the United States, about 700,000 individuals are HIV-positive and know it, while an additional 300,000 are infected and unaware of it, according to AIDS Action.

Cimons reported from Washington and Marquis from Los Angeles.

Received Dec-10-98 08:41am from CCITT G3 → 5108358813 page 1

12/10/98 08:45:32 RightFAX->5108358813 RightFAX Page 001

NEWS RELEASE

1-page FAX to: Assignment Editor (HIV/AIDS)

FOR IMMEDIATE RELEASE

Media Contact: Jeff De Lucio-Brock (415) 487-3072
Pager (415) 280-0223

Draft Federal Guidelines Urge HIV Reporting, Allow State Flexibility

Guidelines Inappropriately Advise Names Reporting, Which May Deter HIV Testing and Treatment

San Francisco, CA, Thursday, December 10, 1998—The Centers for Disease Control and Prevention (CDC) today published draft guidelines calling on all states to require reporting cases of HIV infection to health officials. All states currently require AIDS cases reporting. Although the guidelines allow states to choose between using names or unique codes for HIV reporting, the CDC advises the use of names, an approach that many public health officials and HIV advocates contend will deter HIV testing and treatment.

"Fortunately, states will have the flexibility to decide what type of HIV reporting system works best for their communities and the CDC will provide financial and technical assistance for states designing either type of system," says S.F. AIDS Foundation Public Policy Director Regina Aragón, who is also a member of President Clinton's Advisory Council on HIV/AIDS. "The guidelines also include important provisions for states regarding the availability of anonymous HIV testing and the need for strict security and confidentiality for HIV-related data. However, the guidelines inappropriately advise states to adopt names reporting, an approach that would most certainly deter individuals from testing and treatment. This must be changed in the final guidance to ensure that the federal government and states are doing everything possible to encourage, not discourage, testing and treatment."

The CDC issued these guidelines in response to recent treatment advances that have slowed the progression from HIV to AIDS for many individuals, making improved tracking of HIV necessary for more effective targeting of prevention and care services. However, studies have found that names reporting would result in fewer individuals being tested, due to the stigma still associated with HIV and individuals' fears of HIV-related dis-crimination. For example, a 1997 study of gay and bisexual men seeking anonymous testing in San Francisco found that 68% would not be willing to get tested if their names were to be reported to the government.

"Our hope is that the State Legislature and Governor-Elect Gray Davis will enact legislation to implement HIV reporting in California using unique codes," says Fred Dillon, State Policy Director at the AIDS Foundation. "Enacting such legislation in 1999 would provide critical information on the epidemic without deterring people from testing and treatment." In 1998, the Legislature passed AB 1663, a bill authored by Assemblywoman Carole Migden that would have implemented such a system, but outgoing Governor Pete Wilson vetoed the bill.

The state of Maryland has successfully used a 'unique identifier' system since 1993. In addition, several other states, including Massachusetts, Illinois, and Hawaii are in the process of developing a coded approach to HIV reporting and several other states are actively considering such an option.

The Boston Globe boston.com

Nation | World

States urged to use names in HIV reports

Fears raised over confidentiality loss

By Louise D. Palmer, Globe Correspondent, 07/19/98

WASHINGTON - High-ranking officials of the Centers for Disease Control and Prevention, in what AIDS activists angrily call a "traveling road show," are crisscrossing the country lobbying state health officials to report the names of people who test positive for the AIDS virus.

AIDS advocates and state health officials say the CDC has made clear its preference for a national database to track the spread of the human immunodeficiency virus, or HIV, by using names rather than codes, though federal health officials say they have not yet reached a decision on the issue.

Publicly, AIDS advocates have likened names-reporting to a scarlet letter for people with the virus and say the practice would discourage testing and possibly contribute to the epidemic. CDC officials, however, have warned againstinflammatory statements and fearmongering over the issue.

For the past year, the Clinton administration has been pushed and pulled by these factions over whether to rely on names or codes to track HIV. But by the time the administration decides on one of the most important public health issues facing the nation, most states may already have set their policies, say AIDS advocates, state officials, and civil libertarians.

About 30 states require the reporting of names, while about a half-dozen, including Massachusetts, are developing code systems. The remaining states, including those with the highest concentration of AIDS cases, are undecided, and some states with existing policies are reconsidering them.

States must weigh the claims of epidemiologists, who insist names are the best way to capture the information necessary to monitor and prevent the spread of the virus, against people on the front lines of the AIDS fight who say codes can be used to meet these goals. Unlike using names, codes do not sacrifice privacy or scare people away from being tested for the virus, AIDS advocates say.

EDITORIALS
COLUMNS
CALENDAR
DISCUSSIONS
CLASSIFIEDS
EXTRAnet
ARCHIVES

Low-graphics version

While federal policy is in limbo, an implicit endorsement of names-reporting by the CDC - as well as the agency's refusal to pay for states to develop alternatives to name-based reporting - could tip the scales.

"Is the CDC backing the [administration] into a position it has never committed to?" asked Christopher Anders, legislative counsel at the American Civil Liberties Union.

"We have restrained our discussion to the technical aspects of how we gather quality data, the attributes of good surveillance activities, the uses of data, in the absence of a formal publication" of a policy, said Kevin M. De Cock, director of the CDC's HIV/AIDS prevention division.

Sandra Thurman, director of the White House Office of National AIDS Policy, said it is essential for federal and state agencies to proceed with caution, given that the administration has not decided on its policy.

"We're not just counting heads, we're trying to save lives, and we don't want to do anything to discourage testing," Thurman said. "This epidemic can't be looked at in a vacuum. It is unlike anything we've dealt with heretofore."

The push to expand HIV surveillance - tracking how and where the virus strikes - began in 1996. For the first time, the number of AIDS cases - and deaths - dropped, while the incidence of HIV increased, particularly among the poor, women, and blacks.

According to people who attended community forums across the nation, the CDC has made it clear that names-reporting is essential, though states should maintain the option of offering anonymous tests. The presentations have been described by state health officials and AIDS advocates as "proselytizing visits," sending the message that "states should do names or else."

"I hope we haven't given the impression of inflexibility," said De Cock. There may be alternatives to names-reporting, but he said the CDC has found scant evidence that special codes that contain personal information about an individual without revealing one's identity are effective.

"A tracking system must respond quickly to the disease, be accurate, and capture as many cases as possible, while eliminating duplicates so the same people aren't reported twice," he said. "Evidence at the present time suggests that these diverse functions would be more effective and easily conducted with a name-based system."

The CDC has always relied on names-reporting for diseases such as syphilis and tuberculosis. Reporting HIV this way would allow the CDC to link HIV cases with other databases if there were an outbreak of an HIV-related illness, and make it easier to go back to health care providers for crucial information, such as how the virus was contracted, according to De Cock.

Names-reporting also would be a cheaper and more effective system to implement because a blueprint for how to capture complete and accurate information already exists, he said.

CDC studies of the code-based tracking systems in Texas and Maryland found them to be flawed.

"At the end of the day, if we're going to do surveillance, we must ensure data of high quality," De Cock said. "If not, we must reconsider doing it at all."

Maryland, however, rejects that evaluation because the CDC study was completed before wrinkles in the system were ironed out, explained Liza Solomon, director of that state's AIDS administration.

Solomon said the state now boasts completed data on 89 percent of the HIV cases reported, which is on par with a name-based system and "has allowed us to see the trends in the epidemic."

Massachusetts is developing a system using "unique identifier" codes. After studying the systems of two states, advisory groups concluded that these codes were just as effective as names.

"Both states were able to profile changes going on in the epidemic," said Jean McGuire, director of the Massachusetts Department of Public Health's AIDS bureau. "It is quite possible to get the information needed to profile the disease without using names. ... The concern that names-based reporting would discourage testing was very significant."

Because of the stigma and discrimination associated with AIDS, there is deep concern among health care providers like McGuire that some people may delay or avoid being tested if they believe their name would end up on a government list.

"There's no question that if people see their names being collected for no apparent reason, their worst fears will be fueled," said Daniel Zingale, executive director of AIDS Action, representing a network of 2,400 AIDS service providers. "Some of the people we need to reach most urgently, people of color, the poor, immigrants, the disenfranchised, have little faith in government."

Opponents of names-testing say several studies illustrate this point. They also say they fear breaches of confidentiality.

The CDC has its own study showing that only a tiny minority of people would delay testing because they fear names-reporting. De Cock conceded that the issue is not resolved, but said the bottom line is clear: The government has a long track record protecting the confidentiality of sensitive information.

"I certainly understand concerns about confidentiality," said De Cock. "Terrible things could happen someplace, somewhere, but experience says this hasn't happened so far."

Some dismiss the issue entirely, saying fears are baseless.

"I think there is a risk in continuing to advise people that there is an extraordinary danger associated with testing for HIV," said Michael T. Isbell, a member of the President's Advisory Board on HIV/AIDS.

For Anna Forbes, a longtime AIDS care provider and policy analyst, the debate about confidentiality misses the point entirely.

"Now that we can do something medically about the AIDS virus, it seems very irresponsible to put anything at all in the way of being tested."

This story ran on page A01 of the Boston Globe on 07/19/98.

- -