

## **Common Questions and Answers on Mandatory Name Reporting**

### **1) Will a name-based reporting system deter some individuals from being tested for HIV for fear that their status will be reported to government agencies?**

Yes. Fear of discrimination still exists among individuals who may be at risk for HIV infection. There is compelling evidence that some high-risk groups will be less likely to undergo testing for fear of discrimination, including the inability to obtain health insurance and employment.<sup>1</sup> In a 1998 study of high-risk individuals—supported by the United States Centers for Disease Control and Prevention (CDC) and performed by researchers at the University of California at San Francisco (UCSF) and participating state health departments—it was found that more individuals cited "concern about having one's name reported to the government" as a factor for not seeking HIV testing, in states with name reporting policies as compared to states without name reporting.<sup>2</sup>

The study found that concern over name reporting was particularly pronounced among men who have sex with men (MSM). Thirty-five percent of these men said that concern over name reporting was a factor in keeping them from seeking testing. Findings were similar for injection drug users, 21 percent of whom reported not testing in part because they knew their name would be reported. A 1996 study, presented at the International Conference on AIDS, found that 86.1 percent of clients in Los Angeles HIV testing facilities reported that they would not seek testing if they thought their name would be reported to government agencies. 37.2 percent of the same group said they might not have sought treatment if a name-based reporting system had been in place.<sup>3</sup>

### **2) Is the fear that the names of HIV -**

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should occur at the point of contact with the patient, such as a testing site or physician's office. A recent study conducted by the University of California at San Francisco's Department of Epidemiology and Biostatistics found that states that rely on name-based systems do no better in placing HIV-positive individuals in to treatment and care settings than do states that do not track HIV cases using patient names.<sup>5</sup>

There is no evidence that name-based reporting systems aid in partner notification programs. In fact, these important prevention programs are most effective when names are not collected from those who test positive for HIV. Partner notification is most successful when providers are able to gain the trust of those who have tested HIV-positive. Both the Chicago Department of Public Health and the Illinois Department of Public Health administer effective partner notification programs within a non-name-based reporting system.

Finally, the partner notification process can only take place if individuals are willing to be tested for HIV. If name-based reporting systems will deter some individuals from getting tested, partner notification efforts are impossible to implement.

**4) Other diseases such as cancer, syphilis, and hepatitis are reported by name. Why not report HIV by name as well?**

Persistent stigma and discrimination sets HIV/AIDS apart from other diseases. People living with HIV and AIDS are more vulnerable to discrimination than people living with certain types of cancer. In addition, while other sexually transmitted diseases (STDs) may be curable, HIV and AIDS are not, at this time, curable diseases. The fact that discrimination exists—in areas such employment, health insurance and housing—makes it imperative that precautions be taken to safeguard the privacy of those living with HIV and AIDS.

**5) Other states seem to be moving away from non-name-based reporting systems in favor of name-based reporting. Isn't this evidence that non-name-based systems are not proving to be effective?**

No. To the contrary, more states have moved toward implementing non-name-based HIV reporting systems than name-based systems in the past two years. While five states have implemented name-based systems, eight states have adopted a unique identifier system or a hybrid reporting system.<sup>6</sup> Several high-incidence areas are among those implementing a non-name-based system, including California and the District of Columbia. Texas received substantial attention in 1998 after it switched from a non-name-based system to a system where patient names would be reported. However, the Texas system was lacking mechanisms to link the unique patient code numbers to the patient's medical records in the provider's office. Unlike all other states with non-name-based systems, such as Maryland, Massachusetts, and Illinois, Texas law did not require providers or laboratories to maintain a system where a code could be readily linked to a patient record. This missing element made it very difficult for the state to effectively track and monitor specific cases.

While recent trends have favored non-name-based systems, more states are tracking HIV cases by name. Currently, 32 states and the Virgin Islands have a name-based reporting system, 6 states and Puerto Rico are using unique identifiers, and 2 states have "hybrid systems" with elements of both name and code-number reporting. Among states now

developing HIV surveillance systems, 1 is moving toward name reporting, 4 (including the District of Columbia) are establishing non-name-based systems, and 3 are establishing hybrid systems. Three other states have yet to define what type of system they will develop.

**6) Hasn't initial evaluation of the current Illinois non-name-based reporting system proved that the system is not working?**

No. The Illinois Department of Public Health (IDPH) has established performance criteria for its evaluation of the current system, which is based on Patient Code Numbers (PCN) instead of patient names. The evaluation of the system is scheduled to begin on January 1, 2001 and conclude on July 1, 2001. If IDPH's performance criteria are not fully met, the state plans to move to a name-based reporting system.

Even in the initial phase of the PCN system, Illinois exceeded two of the five performance criteria. Despite this, IDPH officials, commenting on the system's performance during the first six months of operation (July 1, 1999 through December 31, 1999), said that the system would need to improve drastically or Illinois would change to name reporting. However, it appears that most, if not all, of the data used by IDPH in this initial assessment was gathered prior to follow-up activities being conducted. Therefore, the initial data relied on by IDPH likely did not take into account the impact of follow-up calls to providers that obtained information missing from the report. Such a preliminary assessment both conflicts with state regulation and is counter to the best practices of public health epidemiology. Consistent and uniform follow-up activities would greatly improve provider compliance with reporting requirements.

It is also difficult to conduct an effective evaluation of the system in the very short timeframe set by IDPH. By the time IDPH's evaluation is scheduled to begin, the system will have been in place for only 18 months. Studies have revealed that non-name-based reporting systems improve dramatically over time. In Maryland, for example, initial reports of the state's Unique Identifier (UI) system showed only average report completeness rates. However, a subsequent study, published in the *Journal of Acquired Immune Deficiency Syndromes*, examined completeness statistics for a 12-month period beginning 18 months after implementation. The result was a markedly improved completeness rate.<sup>7</sup> Since that time, Maryland's UI system has been deemed a success in its ability to capture necessary epidemiological data, while maintaining the confidentiality of those who test positive for HIV.

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<sup>1</sup> National HIV case reporting. *New England Journal of Medicine* 1998;338:626-7 and Name-based reporting of HIV-positive test results as a deterrent to testing. *American Journal of Public Health* 1999;89:1097-1100.

<sup>2</sup> *Morbidity and Mortality Weekly Report* Centers for Disease Control. December 25, 1998 [volume 47]

<sup>3</sup> Peterson, Senak, Etzel, and Reed. "An Assessment of the Impact of Mandatory Names Reporting on HIV Testing and Treatment." International Conference on AIDS 1996; 11:2,400: Abstract No. Th.D. 4958.

<sup>4</sup> *AIDS Policy and Law* May 16, 1997.

<sup>5</sup> *Annals of Internal Medicine* November 16, 1999.

<sup>6</sup> *AIDS Policy and Law* May 26, 2000.

<sup>7</sup> Evaluation of a Statewide Non-Name -Based HIV Surveillance System. *Journal of Acquired Immune Deficiency Syndromes*, 1999; 22:272-279.