

# **AIDS Foundation**

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## **OF CHICAGO**

### **Name-Based Reporting in Illinois Frequently Asked Questions**

*On October 19, 2005, Dr. Eric Whitaker, director of the Illinois Department of Public Health, announced that Illinois will begin tracking cases of HIV by name rather than alphanumeric code beginning next year in response to mounting federal pressure to bring its HIV surveillance system in line with those operating in most other states. Despite its longstanding advocacy for non-name-based reporting, the AIDS Foundation of Chicago (AFC) supports IDPH's decision in order to preserve the integrity of HIV care, prevention, and housing systems across the state. This set of "Frequently Asked Questions" is meant to help educate concerned Illinoisans about HIV surveillance and name-based reporting.*

**Q: When will name-based HIV reporting begin in Illinois?**

**A:** According to the announcement made by the Illinois Department of Public Health (IDPH), cases of HIV will be reported by name beginning in January 2006.

**Q: Why is Illinois switching to name-based reporting?**

**A:** Every year, Illinois receives more than \$50 million to provide HIV/AIDS services from the federal Ryan White CARE Act. Starting in 2006, the federal government will begin to distribute CARE Act funding based in part on HIV data reported to the Centers for Disease Control and Prevention (CDC). The CDC has said it will only accept data from states that report HIV cases by name. To ensure that we do not lose that essential funding, Illinois must develop a high-quality and secure name-based HIV reporting system. IDPH officials, along with AFC, are working to ensure that the new reporting system does not compromise individual confidentiality or undermine efforts to promote acceptance of testing.

**Q: Who will be affected by this change?**

**A:** People who test positive for HIV and those who receive HIV-related healthcare services will be reported by name to IDPH. In metropolitan areas, like Chicago, the name will also be reported to the local health department.

**Q: How will the names be used?**

**A:** Case reports will continue to be strictly confidential and used solely for public health monitoring purposes, such as identifying patterns and emerging trends in the HIV epidemic. Only medical personnel involved in providing testing and healthcare services and public health professionals will have access to HIV case reports.

**Q: Aren't AIDS cases already reported by name?**

**A:** Yes, cases that meet the medical definition of AIDS (i.e., advanced HIV disease) have been reported by name to IDPH since the early 1980s. Under this new rule, HIV cases will also be reported by name. Every state and territory in the U.S. collects AIDS case reports by name.

**Q: Will name-based case records be sent to CDC?**

A: No. Name-based HIV and AIDS case records are converted into an alphanumeric code before being sent to the CDC.

**Q: Are other diseases and conditions tracked by name?**

A: Yes. There are actually more than 60 diseases, ranging from syphilis to mumps, that doctors and hospitals already report by name to the public health department. This change just adds HIV to that list.

**Q: Will anonymous testing continue to be available?**

A: Yes. Anonymous HIV testing will remain available across Illinois at public health clinics.

**Q: Are anonymous test results reported by name?**

A: No. People who seek anonymous HIV testing are assigned a code, which they use to receive their test results. Because testing is anonymous, positive results are not reported to HIV surveillance. However, upon seeking HIV-related healthcare, medical providers are required to generate HIV case reports for all patients with an HIV or AIDS diagnosis. This report will include the patient's name.

**Q: There have been recent, well-publicized breaches of confidentiality with the HIV/AIDS surveillance system in the state of Florida. Has anything like these ever occurred in Illinois?**

A: No, there have been no known breaches of confidential HIV/AIDS databases in Illinois. State law protects people living with HIV/AIDS against unauthorized disclosures of their HIV-positive status. Anyone suspected of disclosing an individual's HIV-positive status without that individual's consent can be charged with a criminal felony. State law also protects HIV/AIDS surveillance records from subpoena in a court of law.

**Q: What safeguards are in place to ensure that HIV/AIDS confidentiality is not breached ?**

A: HIV/AIDS records are stored in a secure facility and can be accessed only by specially trained epidemiological staff solely for the purposes of public health monitoring. Unauthorized disclosures are punishable under the Illinois AIDS Confidentiality Act. In addition, IDPH is convening a special task force to review surveillance procedures and strengthen confidentiality protections.

**Q: Why is HIV/AIDS surveillance important?**

A: Disease surveillance is an integral part of a comprehensive public health response to an outbreak of disease. Complete and accurate data on cases of HIV/AIDS can help identify populations and geographic areas more acutely affected, and inform where best to target scarce prevention and care resources. Surveillance can also help measure whether responses to the epidemic are sufficient and effective.

**Q: What is the difference between HIV surveillance and AIDS surveillance?**

A: HIV surveillance collects data on the number of people who receive an HIV-positive diagnosis and their characteristics (i.e., gender, age, race/ethnicity, likely mode of transmission) for a given location and period of time. AIDS surveillance collects data on

people with advanced HIV disease who receive a diagnosis of AIDS. Because of the natural history of the disease, cases of AIDS occur on average ten years after HIV infection. Powerful antiretroviral therapy has also prevented an AIDS diagnosis for many HIV-positive people receiving treatment. This means that HIV surveillance data provides a more timely and accurate picture of the epidemic and is a better indicator of emerging trends in HIV transmission than AIDS surveillance data alone.

**Q: What is AFC's position on HIV name reporting?**

A: AFC supports a comprehensive response to HIV/AIDS, including ready access to HIV prevention, education, voluntary counseling and testing, and care services; the collection of complete and accurate HIV/AIDS surveillance data; strong HIV/AIDS confidentiality protections and penalties for unauthorized disclosures; community input in service planning and program development; and public policies designed to reduce stigma and discrimination and respond to the needs of people living with and at risk for HIV. AFC has long championed non-name-based reporting systems to promote greater acceptance of voluntary HIV counseling, testing, and care services, and guard against inappropriate uses of HIV surveillance data and/or unauthorized disclosures. AFC continues to believe in the public health merits of non-name-based reporting. Unfortunately, maintaining non-name-based HIV reporting in Illinois would significantly diminish federal resources available for HIV prevention and care services. As a result, Illinois must develop a sophisticated and professionally managed name-based HIV reporting system that does not compromise individual confidentiality or undermine efforts to promote acceptance of testing.

**Q: What are the repercussions for Illinois and other states that previously reported HIV cases by code and must now switch to a name-based system?**

A: Without congressional interventions, code-to-name jurisdictions could likely lose CARE Act funding beginning next year (Fiscal Year 2007) until their name-based HIV surveillance systems are sufficiently mature. This is because the federal government will begin to distribute CARE Act funding based in part on HIV surveillance data reported to the CDC. The CDC has refused to accept code-based HIV data, which means that none of Illinois' 13,000 reported HIV cases have been counted by the CDC. However, state decisions to implement non-name-based surveillance are consistent with the most recent CDC Guidelines for National Human Immunodeficiency Virus Case Surveillance (1999, MMWR 48, RR-13), which does state CDC's preference for name-based reporting but allows states to make their own determinations. The Institute of Medicine's 2003 report *Measuring What Matters* urges CDC to work with the 13 code-based jurisdictions, and to accept their data. States like Illinois should not be penalized for following CDC guidance, which permits the establishment of non-name-based reporting.

Congress can remedy the situation through CARE Act reauthorization legislation. Congress should include provisions to allow code-to-name states to phase in their programs, without funding penalties, or retain current hold-harmless provisions until HIV surveillance is sufficiently mature and complete across the country to use for funding distributions.