

**Promising Results:
HIV Tracking by
Unique Identifier
In Illinois**

A Progress Report on
Illinois' HIV Identifier Trial

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The AIDS Foundation of Chicago (AFC) is Illinois' principal advocate for people living with and at risk for HIV disease. Established in 1985 to provide central leadership in the fight against the epidemic, AFC promotes sound HIV/AIDS public policy, funds HIV/AIDS care and prevention projects, and, through its Service Providers Council, helps to coordinate the delivery of essential HIV/AIDS services.

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Table of Contents

Page 5	<u>Executive Summary</u> : AFC's Progress Report on Illinois' HIV Identifier Trial
Page 9	<u>Purpose</u> : AFC Report Aims To Raise Awareness of Innovative System and Inform How State Officials Proceed with Evaluation Plans
Page 11	<u>Background</u> : How and Why Illinois Developed A Non-Name-Based HIV Reporting System
Page 15	<u>Progress</u> : Preliminary Findings Show Promise, Areas For Improvement
Page 17	<u>Findings</u> : Research Reveals System is Hindered By Problems Related to Implementation, Operation, and Trial Design
Page 24	<u>Recommendations</u> : IDPH Should Ensure A Fair and Impartial Review That Includes Evaluation of the System's Implementation, Operation, and Trial Design
Page 27	<u>Conclusion</u> : Illinois Can and Should Lead U.S. In Efforts to Develop Innovative, Non-Name-Based HIV Surveillance Methods
Page 29	<u>Additional Materials</u> :
	Glossary
	Current Status of HIV Infection Reporting
	Common Questions and Answers on Mandatory Name Reporting
	Unique Identifier Systems in the U.S.
	Illinois Department of Public Health Adult HIV/AIDS Confidential Case Report Form

Executive Summary:

**AIDS Foundation of Chicago Releases
Progress Report on Illinois' HIV Identifier Trial**

November 2000

The AIDS Foundation of Chicago (AFC) has prepared this report, *"Promising Results: HIV Tracking by Unique Identifier in Illinois,"* to examine the performance of Illinois' HIV surveillance system, which is designed to track HIV case reports by alphanumeric code rather than by name. The system is currently operating on a trial basis until July 2001, when the Illinois Department of Public Health (IDPH) will decide whether to maintain the system or switch to HIV tracking by name.

In the report, AFC shows that Illinois' unique identifier system is outperforming states with name-based reporting. Given the short period of time that the system has been in effect, these early results show tremendous promise that Illinois' system will achieve its intended goals of gathering HIV surveillance information and promoting HIV testing, while safe guarding the privacy of persons testing and receiving treatment for HIV infection. While aspects of the system can and must be improved through the steps recommended below, a preliminary assessment of the system's performance, released by IDPH in March 2000, does not fairly capture the system's achievements.

Background

Since the early 1980s, Illinois and all other states have monitored the spread of the HIV/AIDS epidemic by collecting information on individuals diagnosed with AIDS. Because powerful new therapies introduced in 1996 have reduced the incidence of AIDS across the country, AIDS case surveillance is becoming less reliable in describing the full magnitude of the HIV/AIDS crisis. Meanwhile, federal and state officials have called for the creation of HIV surveillance systems nationwide to better assess population-specific trends of the HIV/AIDS epidemic, particularly new infections.

In 1999, the Illinois Department of Public Health (IDPH) developed an innovative approach to HIV case surveillance that protects the privacy of HIV-positive individuals while facilitating data collection on Illinois HIV cases. The system requires medical and testing sites that diagnose or treat HIV disease to report characteristics of the HIV-positive individual to IDPH using a unique "patient code number (PCN)" in place of the individual's name. Several states and municipalities have modeled the use of "unique identifiers" as an effective way to collect individual case information and promote HIV testing while providing enhanced privacy for the report subjects. In addition to Illinois, six states and territories currently use unique identifiers for HIV surveillance: Connecticut, Massachusetts, Maryland, Puerto Rico, Rhode Island, and Vermont. Four other jurisdictions are moving toward developing such systems: California, the District of Columbia, Hawaii, and Kentucky. In addition, every state and territory reports AIDS case information to the federal Centers for Disease Control and Prevention (CDC) by unique identifier.

Currently, 34 states* are collecting HIV case information by name. The vast majority of these states (with the exception of Florida, New Jersey, and Texas) have a low incidence of HIV and a medium or small population. In 1998, IDPH proposed establishing a name-based HIV surveillance system in Illinois, but encountered broad opposition from AIDS community advocates, AIDS service providers, people living with HIV/AIDS, and even public health officials. Those opposed to the proposal, including the AIDS Foundation of Chicago, cited studies suggesting that name-based reporting can discourage individuals at high-risk from seeking HIV counseling and testing services. In addition, government-held lists of names of HIV-positive people increase the chance for unauthorized disclosures of information and/or the use of such information for non-public-health purposes. Following the recommendations of an IDPH-convened working group, state officials agreed to withdraw their original proposal and, instead, implement a non-name-based HIV surveillance system on a trial basis for 18 months. The state adopted regulations establishing strict performance criteria for the new surveillance system and provisions to change to a name-based reporting system in July 2001 if any of the performance measures are not fully met.

Progress

In March 2000, IDPH released preliminary information about the system's performance, casting doubts on the system's ability to meet pre-determined performance criteria. Evaluating only the first six months of operation, IDPH found that the system was deficient in two of four areas measured. IDPH's six-month report prompted AFC, and other AIDS advocates, to investigate the PCN system's progress, challenges, and ways the system's performance might be bolstered.

Through research, and interviews with local health department officials, reporting entities, and individuals close to the system's operation, AFC identified several procedural and operational problems that are affecting the system's performance. They include:

- **Performance criteria established by IDPH are inconsistent with standards recommended by the federal government, and are unrealistically high**
- **Epidemiological follow-up activities—which are required by state regulation—are not being conducted or reported uniformly, and in some instances, may not be occurring at all**
- **IDPH's evaluation plans are biased against non-name-reporting methods**
- **Reporting forms contain questions that are not required by state regulation, yet are being evaluated for completeness of reporting**
- **A lack of on-going provider education and technical assistance is impairing the system's performance**
- **Local health departments lack funding to adequately implement the system**

* Connecticut and Oregon require HIV name reporting only for pediatric HIV cases.

- **IDPH has not provided sufficient staff support and expertise to properly implement the surveillance trial**

Recommendations

AFC has several substantive recommendations for IDPH intended to correct operational problems, improve the system's performance, and evaluate the system in a fair and objective manner. AFC urges IDPH to:

- **Reconvene its advisory HIV Case Surveillance Working Group to receive community input in developing “next steps” and the evaluation**
- **Develop and implement procedures to ensure that local health departments systematically conduct epidemiological follow-up activities—as required by state regulation—for HIV case reports with missing information**
- **Revise how reporting of “other required information” is evaluated to conform with state requirements**
- **Adjust the system's performance criteria to reflect the performance measures for HIV surveillance recommended by the CDC**
- **Conduct an independent, impartial, process evaluation of the system's operation during a 12-month period beginning in July 2001**
- **Fund an independent contractor to give providers statewide education and technical assistance, so they can better comply with state reporting requirements and maintain accurate client PCN logs**
- **Together with medical and public health professionals, university-based evaluators, community representatives and people living with HIV, design and implement a rigorous outcome evaluation plan (to commence January 2003 and end by January 2004) to measure the ability of the system to track trends in the HIV epidemic**

Conclusion

Illinois has developed a model system for HIV surveillance that protects individuals' privacy and promotes voluntary HIV counseling and testing. Preliminary findings show that the system is potentially more reliable than systems that rely on name-based reports. IDPH should adopt new state regulations that help identify ways to strengthen the system's operations and conduct a rigorous and meaningful evaluation of the system's ability to track trends in the epidemic.

Purpose:

AFC Report Aims To Raise Awareness of Innovative System And Inform How State Officials Should Proceed With Evaluation Plans

The AIDS Foundation of Chicago has prepared this *Progress Report on Illinois' HIV Identifier Trial* to inform elected and appointed officials, public health professionals, health care and social service providers, people living with HIV/AIDS, and the general public, about the merits of Illinois' innovative HIV tracking and reporting system. Developed in partnership with medical and public health professionals, AIDS advocates, service providers, and HIV-positive people, the system is designed to track trends in the HIV epidemic while protecting the privacy of those who receive an HIV-positive test result. In this report, AFC explores how the system is operating, whether it is meeting public health goals, and whether it is performing within the standards established by the Illinois Department of Public Health (IDPH).

AFC decided to investigate how the system is performing after IDPH released a preliminary report earlier this year that described the system's inability, after six months of operation, to fully meet the performance criteria IDPH had established for the system. How the system performs during the first 18 months of operation is critically important to determine whether Illinois continues to use a non-name-based method for HIV case surveillance. State regulations created by IDPH require a change to name-based HIV reporting in July 2001 if any of several performance criteria, established by IDPH, are not fully met.

In sections that follow, AFC describes several internal and external factors affecting the system's ability to meet performance standards. In particular, AFC found that problems with the system's implementation, operation, and trial design are to blame for sluggish results in IDPH's preliminary review of the system. AFC documents that the system is performing better than other HIV surveillance systems in the country and shows that it is meeting important public health goals. AFC argues that IDPH-established evaluation criteria and timeframes are biased against non-name-based methods, inappropriate for measuring whether the system is accurately tracking characteristics of the HIV epidemic, and inconsistent with the HIV surveillance trials of other states. The report also describes efforts needed to improve the system's operation and what steps IDPH should take to fairly judge its performance. In addition, the report provides background information on mandatory name reporting, the creation of Illinois' HIV tracking system, and similar work in other states.

In preparing this report, AFC conducted a detailed data-analysis and literature review, and key informant interviews with local health department officials, service providers, and individuals close to the system's operation. Many thanks to members of AFC's Policy/Advocacy Committee, including representatives of the American Civil Liberties Union of Illinois, the Chicago Department of Public Health, Equip for Equality, Lambda Legal Defense and Education Fund, and Test Positive Aware Network, for providing invaluable assistance in preparing this report.

Background :

How and Why Illinois Developed a Non-Name-Based HIV Reporting System

HIV/AIDS stigma and discrimination.

A chronic, incurable, and potentially terminal infection, HIV continues to be connected to tremendous misunderstanding, stigma, and discrimination across the United States.¹ In addition to these persistent barriers, advancing HIV/AIDS care and prevention policies and programs requires sensitivity to the interests and needs of those at high risk for infection. HIV/AIDS has disproportionately affected historically disenfranchised communities, including people living in poverty, people of color, people who use controlled substances, and men who have sex with men. For many individuals from these groups, negative personal and collective experiences have eroded confidence in and fostered suspicion of, public policies and government entities.² For these reasons, effective HIV/AIDS public policy in the U.S. has been the product of government partnerships with affected communities, people living with HIV/AIDS, and their service providers and advocates. Examples of such policy-making models include the use of local planning for distribution of federal HIV/AIDS care and prevention funds, and federal and state sub-contracts with trusted, community-based service providers that deliver essential HIV/AIDS services.

The need for HIV surveillance.

There is broad support among medical, public health, and HIV/AIDS experts for the development of HIV surveillance systems to more accurately track the spread and growth of the HIV/AIDS epidemic.³ Since the 1980s, the nation has relied on AIDS case reports, by name in every state, to monitor the spread and demographics of the epidemic. Tracking cases of AIDS, which is the end-stage of HIV disease, was facilitated in many cases by the use of death records and retrospective case studies. Because of virtually non-existent HIV therapies, individuals frequently tested for HIV late in their disease progression. Thus, AIDS case information became the foundation for determining trends in the epidemic. While reliable, such information was dated, as AIDS would manifest approximately 10 years after infection. With the advent of powerful new classes of anti-HIV medications, however, tracking AIDS cases became less significant. New therapies have reduced the number of deaths that result from AIDS and have helped thousands of individuals delay an AIDS diagnosis. In 1999, the CDC called on all states to establish HIV surveillance systems by 2002 in an effort to garner national HIV case data. HIV reporting is currently in place in 42 states; virtually every remaining state is either developing or discussing plans to establish HIV surveillance.⁴

Mandatory name reporting.

There is compelling evidence that individuals at high risk for infection are less likely to undergo HIV testing for fear of discrimination, including the inability to obtain health insurance and employment^{5 6}. In a 1998 study of high-risk individuals, supported by the Centers for Disease Control and Prevention (CDC), researchers 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 compared to states without name reporting.⁷ The study found that

concern over name reporting was particularly pronounced among men who have sex with men. 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% of whom reported not testing in part because they knew their name would be reported. Men who have sex with men and injection drug users are the two groups at highest risk for HIV infection: nearly 84% of the 24,397 cumulative AIDS cases reported in Illinois list male-to-male sex and/or injection drug use as the likely mode of HIV transmission.⁸ Moreover, a 1996 study presented at the International Conference on AIDS found that 86% 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.⁹ Some 37% of the same group said they might not have sought treatment if a name-based reporting system had been in place. Government entities are beginning to acknowledge the need for sensitivity to the opinions of at-risk groups in designing programs to promote HIV testing and care. In a recent publication, the CDC acknowledges the need to address real or perceived barriers to HIV testing, including “fears concerning confidentiality ... including the impact of implementing HIV name reporting.”¹⁰

Medical record privacy.

Surveys show that the American public is increasingly concerned about protections for their private medical record information.¹¹ For people living with HIV/AIDS, these concerns have real-life implications. The unauthorized disclosure of a person’s HIV-positive status may result in employment, housing, and health care coverage discrimination as well as other legal and personal implications. Even when confidentiality is scrupulously maintained, fear of loss of confidentiality and the resulting isolation and discrimination can lead people away from HIV testing and care services. HIV name reporting puts HIV-positive individuals at an increased risk for breaches in confidentiality.[^] In addition, mandatory name reporting requires doctors to report a patient’s confidential medical information to government officials, without the patient’s consent, causing unnecessary strain on the doctor-patient relationship.

HIV tracking in Illinois.

With no input from affected communities, the Illinois Department of Public Health (IDPH) announced in early 1998 its intention to create nearly 100 HIV-positive name registries at local health departments across the state. Testing sites, health centers, laboratories, and physicians would be required to report HIV-positive people by name to the local health authority. Concerned that the new rule would deter people at high risk from seeking testing services, the AIDS Foundation of Chicago, hundreds of community-based organizations, and thousands of individuals across the state signed petitions, wrote letters, and provided public testimony against the proposal. Among those expressing concern with the proposal were several lawmakers, including State Senator Steven Rauschenberger (R-Elgin) and State Representatives Sara Feigenholtz (D-Chicago) and Larry McKeon (D-Chicago), who helped negotiate with IDPH an agreement to delay implementation of the proposed rule in order for the department to convene an advisory panel to explore alternative methods of conducting HIV case surveillance. The

[^] In 1996 alone, there were two reported incidents of confidentiality breaches regarding AIDS registries. A Florida public health official took his laptop, which included the names of 4,000 individuals living with AIDS, and shared the information with others, including an individual who sent two disks containing the 4,000 names to a local newspaper. In an unrelated incident, a Florida welfare clerk was able to access the state’s computer system, access confidential health records, and inform others of an individual’s HIV status.

advisory group, known as the HIV Surveillance Working Group, was nearly unanimous in recommending that Illinois implement a “unique identifier” HIV case tracking system on a trial basis, similar to systems in place in Maryland and Massachusetts. In September 1998, IDPH withdrew its original proposal and announced plans to implement the trial system now in place.

In order to establish the trial system, IDPH promulgated an administrative rule[†] creating the system and establishing a mechanism to measure the system’s performance after 18 months.¹² The Joint Committee on Administrative Rules (JCAR), a legislative oversight committee, approved the rule in October 1998. While the HIV Surveillance Working Group was instrumental in persuading IDPH to adopt a trial system, the working group had no input in designing the trial or establishing the performance criteria. The rule established HIV reporting by “patient code number (PCN),” which is derived by demographic information and/or elements of the individual’s name and/or identifying information. The rule required providers and laboratories to begin reporting HIV case information by PCN to the local health authority on July 1, 1999. The rule established that anonymous testing sites are not required to report PCNs. If the performance measures established in the rule are not met, name-based reporting is to commence on July 1, 2001.

Illinois’ Patient Code Number (PCN).

With input from an advisory committee, IDPH developed a PCN comprised of information from an individual’s last name, gender, and date of birth. Specifically, the PCN includes the first and third letters of the person’s last name, the number of characters in the last name, a letter signifying the person’s sex at birth, and an eight-digit numerical date of birth. For example, the PCN for Janet Doe, born on January 12, 1968, would be: DE3F01121968. In determining Illinois’ PCN, IDPH opted against using part of an individual’s Social Security number as part of the identifier (which is an element of other state’s PCNs) because many individuals do not have or do not know their Social Security number.

Established Performance Criteria.

According to promulgated administrative rules, an evaluation of the system’s performance during the first 18 months of data collection is to commence on January 1, 2001. If the performance criteria are not met, HIV case surveillance by name will commence on July 1, 2001. The performance criteria are as follows:

- PCNs are complete in at least 90% of reported cases
- No more than 5% of cases in the HIV database are duplicate reports
- Risk information (that is, the high risk behaviors that likely exposed an individual to HIV) is attained in at least 90% of reported cases, after epidemiological follow-up
- Other required information is complete in at least 85% of reported cases, after epidemiological follow-up
- At least 95% of providers have mechanisms in place to link at least 95% of PCNs they report to corresponding case reports if and when additional follow-up is needed

[†] Also referred to herein as “state regulation”

Progress:

Preliminary Findings Show Promise, Areas for Improvement

In a review of preliminary data at six months, IDPH reported that the system performed above established standards in two of the four areas evaluated.¹³ In addition, while IDPH's criterion for risk ascertainment was not met, CDC data show that Illinois' system outperformed states with name-based HIV surveillance. Below is a review of the findings:

Providers assigned complete patient code numbers in 99.1% of all reports.

Performance by this measure far surpassed the established standard of attaining complete patient code numbers in at least 90% of all reports.

Less than one percent of cases in the HIV database were found to be duplicates.

The established standard for this area--no more than 5% duplicate cases--was surpassed.

Risk information was obtained for 74% of reports.

While lower than the established standard (risk information obtained in at least 90% of reports), performance in this area was higher than the national average and on par with national AIDS surveillance. According to the CDC, the 34 states with name-based HIV reporting systems obtained risk information in only 59% of case reports in 1999.¹⁴ The national AIDS surveillance system, which is dependent on data from states and territories, obtained risk information in only 76% of case reports in 1999.¹⁵ With only six months of operation, Illinois' system demonstrated tremendous potential. In time, with continued provider support and assistance, the number of case reports with complete risk information is bound to increase.

These promising results come even though IDPH based its evaluation on an invalid data set. State regulation requires evaluation of the system's performance "after epidemiological follow-up." However, it appears that follow-up activities were not reflected in the six-month data set reported by IDPH. Consistent and uniform follow-up would have resulted in even greater numbers of providers reporting needed risk information.

Other required information was complete in 8% of reported cases.

This was the area of least compliance with established standards: the administrative rule requires complete information in at least 85% of reported cases, after epidemiological follow-up. Several factors contributed to the poor performance in this area including inadequate training for providers in meeting this requirement, inadequate or non-existent epidemiological follow-up as required by state regulation, and data-collection procedures biased against meeting the requirement. In particular, questions left unanswered for which the likely answer is "unknown" contributed to an artificially low compliance rate in this category. In addition, the report form contains several questions that are not

required by state regulation and are not essential for HIV surveillance, yet they counted against the system's performance when left unanswered. A detailed review of these and other factors affecting the system's performance are described in the section that follows.

Findings:

Research Reveals System Is Hindered by Problems Related to Implementation, Operation and Trial Design

IDPH's performance criteria are unrealistically high.

Available data suggest that Illinois has established performance criteria for its HIV surveillance system that cannot be met, regardless of the method used to track reported cases (PCNs or names). According to the CDC, risk information was reported for only 59% of HIV case reports in 1999 among the 34 states with name-based HIV surveillance systems. Measured by Illinois standards (requiring 90% of case reports to identify risk), these systems would be deemed ineffective. Over time, states typically intensify their follow-up activities and collect missing risk information for most case reports. This is why data on cumulative HIV case reports, within the 34 states, reflect a higher percentage (61%) of case reports with identified risk information. However, even this 61% remains far below the 90% standard established for risk information by IDPH.

It is instructive to compare the performance of HIV surveillance systems with the national AIDS case surveillance system, in place since the early 1980s and dependent on name-based case reports tracked by states and territories. In 1999, risk information was collected for 76% of AIDS case reports nationwide. (By comparison, Illinois' HIV identifier system collected risk information for 74% of case reports after only six months of operation.) Data on cumulative U.S. AIDS case reports, including the earliest AIDS cases, is more complete: 91% of case reports contain risk information. It is important to note that a full 59% of cumulative U.S. AIDS case reports are for people who have died. Complete information for many AIDS case reports was obtained from death certificates, medical records, and provider interviews. In many cases, obtaining complete information spanned several years. In addition, AIDS cases have generally involved more intensive interactions between the reporter of information (medical provider) and the patient than are usually obtained in contexts producing HIV case reports. With HIV surveillance, reporting often occurs after only two client encounters: pre- and post-test counseling.

Evaluation plans ignore importance of process evaluation.

The evaluation plan as codified in state regulation does not make an important distinction between process and outcome evaluation. Evaluating a new surveillance system after 6 to 18 months is most instructive in understanding the system's implementation and operation. Such an evaluation can illuminate what implementation activities were successful at meeting identified goals, which ones were not successful, and what implementation/operation gaps exist. This is called process evaluation. Process evaluation helps identify and address areas of a system's implementation and operation that may need retooling. Process evaluation seeks to answer: "Is the system operating as it is intended to operate? And, if not, why?" An important part of determining whether the PCN system is able to accurately track trends in the HIV epidemic is to determine, first, whether the system has been implemented and operated appropriately. A thorough process evaluation would identify activities needed to make the system more efficient and capable of meeting its goals.

Process evaluation typically precedes outcomes evaluation. An outcomes evaluation determines whether the intended goals are being achieved. Outcomes evaluation seeks to answer: “Is the system producing the results that it is suppose to produce? And if not, why?” A thorough outcomes evaluation is only meaningful after first conducting a process evaluation that identifies operational strengths and weaknesses and then implementing activities that improve the system’s operation. Without process evaluation, it is not possible to determine if the problems identified during the outcomes evaluation are inherent to the system’s design or a factor of poor implementation/operation. Yet IDPH would skip the essential process evaluation altogether.

Indeed, the PCN evaluation plan, as codified in state regulation, does not require any review of the system’s implementation and operation. Rather, evaluation requirements mandate that the system, which embodies the most significant change in HIV/AIDS surveillance in the state’s history, meet impossibly high performance standards in only 18 months of operation. The HIV surveillance system requires coordination and cooperation among more than 100 local and state public health entities and their personnel, hundreds of providers (testing sites, clinics, physicians, and laboratories), and thousands of individuals testing positive for HIV. Implementing such a complex system requires careful and constant attention. Evidence from other states indicates that 18 months is insufficient to fully implement such a system. This also appears to be true of states employing name-based surveillance.

A preliminary review of Maryland’s unique identifier (UI) HIV tracking system, launched in mid-1994, initially found sluggish compliance among laboratories in reporting UIs to the state health department¹⁶. In Maryland, providers generate UIs for all individuals seeking HIV testing. The UI accompanies the blood screen to the laboratory, which reports it back to the provider with the test result and also to the health department if the sample tests positive for HIV. Despite a difficult start-up, the system improved markedly and was found capable of tracking HIV case reports in a subsequent evaluation. In two studies, researchers compared data from the UI database with data from publicly funded HIV testing sites to determine whether individuals who had tested HIV-positive had been reported in the UI system. Such comparisons were necessary to determine whether the UI system was sufficiently accurate and reliable at describing the characteristics of those who have tested HIV-positive. The matching rate (i.e. the percentage of testing-site cases that were also recorded in the UI system) increased from 52% in the initial sample to 87.8%.¹⁷ Health department officials attributed the increase to targeted efforts to educate laboratories about reporting requirements, improvements in handling and entering reported data, and the use of an algorithm to help match UIs that were incomplete or had missing information. It is instructive for Illinois to note that the subsequent evaluation, which showed vast improvements over the initial study, evaluated case reports for a 12-month period, beginning 18 months *after* the system’s initial implementation. In addition, Maryland officials reported to the CDC that based on their experience, four to five years are needed for such a system to become fully operational.¹⁸

Massachusetts, which initiated a unique identifier system in January 1999, has determined that the system is operating successfully based on a review of data collected in the first 12 months of operation. In its review, Massachusetts officials found that unique identifiers were assigned correctly in 92% of case reports and with complete information in greater than 99% of reports. The system generated a low number of duplicate reports and a high rate of reported risk information (92% as of July 1, 2000). The review also determined that the system was well

accepted by providers and laboratories. Having completed this initial process evaluation, Massachusetts is now embarking on an outcomes evaluation. The state has retained the services of an independent contractor to measure completeness of the HIV database in comparison with other client databases (such as Medicaid, the AIDS Drug Assistance Program, and private insurers) to determine to what extent the UI system is capturing reports on those who have tested HIV-positive. The evaluation will help determine how reliable the system is at describing trends in the state's HIV epidemic, and will provide information on where outreach and education should be targeted to improve provider compliance. The evaluation began in August 2000 and will end in August 2001. State officials expect the system to be fully operational in 2002, a full three years after initial implementation.

Epidemiological follow-up activities--which are required by state regulation--are not being conducted or reported uniformly across the state, and in some instances, may not be occurring at all.

Illinois state regulation creating the PCN system requires state and local health officials to conduct epidemiological follow-up on HIV case reports with missing information. Additionally, regulations require that the system be evaluated utilizing a data set enhanced by epidemiological follow-up activities. Despite this clear directive, IDPH released preliminary information on the system's performance based on a data set for which little or no ascertainable follow-up activities had occurred. In addition, IDPH has provided little or no guidance to local health departments on their obligation to conduct epidemiological follow-up activities. Several health departments contacted by AFC said that IDPH had provided no direction as to whether they should conduct follow-up activities prior to sending case reports to Springfield or whether follow-up should occur after reports are submitted to IDPH. There appear to be no uniform standards for collecting missing information through follow-up and no established mechanisms to ensure that follow-up information is reflected in the data-set on which future evaluations of the system will be based. Local health department officials reported vastly different approaches and degrees of success in carrying out epidemiological follow-up activities. This has led AFC to question whether IDPH has adequately monitored the quality of follow-up activities. Indeed, AFC is unsure what, if anything, IDPH is doing to ensure that follow-up activities are occurring at all.

In some instances, IDPH appears to be collecting information in a way that precludes the system from reflecting information ascertained through follow-up. The Chicago Department of Public Health (CDPH), for example, was instructed to forward HIV case reports to IDPH "in the original form as they were received," and prior to follow-up, in order that they could be immediately entered into the state evaluation database. Although CDPH officials are conducting follow-up activities and reporting to IDPH all additional information they collect, they consider it unlikely that such information is being entered into the state evaluation database. Other health departments said that IDPH had not explained whether local health departments should follow-up on missing information nor told them how data collected by follow-up ought to be reported to IDPH. Such procedures give the impression that IDPH is preparing to evaluate the system's performance without the benefit of follow-up activities, which runs counter to state regulation as well as professional standards of epidemiology.

Follow-up activities on missing information are integral to any disease surveillance system. The Centers for Disease Control and Prevention (CDC) considers follow-up activities to be a core function of HIV/AIDS surveillance, and as such, has created guidelines for these processes.¹⁹

CDC guidelines recommend that the state or local health department, within six months of receiving a case report with missing risk information, investigate by: (1) contacting the appropriate health care provider (e.g. primary physician, social worker, infectious disease physician, nurse, etc.); (2) reviewing other medical records (e.g. hospital records, inpatient clinic records); (3) reviewing ancillary records (such as STD records and hepatitis B registries); and (4) considering contact with the person living with HIV or AIDS or a proxy for an interview (Under current state regulation, Illinois public health officials have access only to individual contact information for AIDS cases.) If the case report subject has died, CDC also recommends reviewing the death certificate, autopsy report, and re-contacting the physician, other health care providers, and/or family members.

Data handling procedures are skewing results.

IDPH's "Adult HIV/AIDS Confidential Case Report" form contains more than 45 required questions, including contact information for the facility filing the report, the subject's PCN, and the test subject's risk and demographic information. In numerous questions, including country of birth, whether service referrals were conducted, and whether the patient is receiving PCP prophylaxis, the provider may respond "yes," "no," or "unknown." Providers commonly leave questions blank if the answer is "unknown." Unfortunately, IDPH has decided to count entire reports as incomplete if even one question of the more than 45 is left unanswered, regardless of the importance of the question or the likelihood that a blank answer really meant "unknown." This administrative decision is the reason why only 8% of case reports from the first six months of operation were deemed to contain the "other required information," a figure far below the IDPH-established performance criteria of 85% completion for attaining "other required information" in case reports. IDPH should not evaluate completeness of "other required information," according to questions whose likely answers are "unknown." Moreover, the impact of inconsistent procedures to collect missing information is most apparent in this context, where follow-up with providers could confirm the intended answer of "unknown."

Reporting forms contain questions that are not required by state regulation and not essential for HIV surveillance.

At least six questions on Illinois' HIV/AIDS case report form are not required by state regulation and are not essential for HIV surveillance activities. Providers are asked to report: whether the patient has been referred for medical and substance abuse treatment services; whether the patient is receiving anti-retroviral therapies and PCP prophylaxis; the patient's last documented HIV-negative test result; and the patient's medical record number at the facility completing the form. While it is critical for providers to help clients link to important medical and social services, these practices do not constitute essential information about trends in Illinois' HIV epidemic, nor are they usually the responsibility of HIV/AIDS surveillance staff. The same critique applies to questions about anti-retroviral therapies and PCP prophylaxis. In fact, for individuals testing for the first time, such questions are irrelevant. Additionally, some institutions are unwilling to report a patient's medical record number in order to protect the individual's confidentiality, and while state regulations require providers to maintain a system that can identify the test subject of a PCN they generated, the administrative rule does not require reporting patient medical record numbers. A seventh question that seeks the last four digits of a person's Social Security number is useful for follow-up activities but is also not required by state regulation. State regulation requires reporting of Social Security numbers for AIDS case reports, but not for HIV case

reports, which invalidates using the question to determine whether “other required information” is complete. While answers to these questions could help improve public health services, incomplete answers to questions that are not essential for HIV surveillance and/or not required by state regulation should not be evaluated to determine whether “other required information” has been collected.

Additional and on-going provider technical assistance is needed.

Prior to the implementation of HIV surveillance, IDPH and the Chicago Department of Public Health (CDPH) jointly developed a training curriculum for providers about their new HIV reporting requirements. IDPH and CDPH held 12 full-day training sessions throughout the state, reaching over 400 providers in Chicago alone. While these efforts were essential in helping providers understand and comply with new reporting requirements, additional and ongoing sessions have not taken place throughout the year to help new providers or new/continuing staff comply with reporting requirements. In addition, IDPH did not alert providers or local health departments about “incomplete” report forms, despite preliminary evidence that most providers were not answering all report questions. Finally, IDPH has not provided reporting entities with sufficient guidance on creating and maintaining PCN client logs, which are also required. While this criterion has yet to be evaluated, it is likely that with little or no guidance on meeting this requirement many entities may have incomplete or inefficient log systems.

Local health departments lack funding necessary to adequately implement the system.

Conducting high quality HIV/AIDS surveillance requires significant staff and financial resources, especially in highly affected areas such as Chicago, which accounts for approximately 70% of Illinois AIDS cases. Implementation of the HIV surveillance system has put an enormous strain on the Office of HIV/AIDS Surveillance at the Chicago Department of Public Health (CDPH). Because physicians are required to make a report each time they newly diagnose or treat an individual for HIV infection, CDPH has experienced a 300% increase in combined HIV/AIDS case reports received and processed from July 1, 1999 to June 30, 2000. While the initial change in reporting requirements resulted in many providers reporting cases that had been first diagnosed months or even years earlier, CDPH anticipates that the volume of new case reports will continue to be high. Despite the increased volume of case reports, CDPH has not received any additional funding to expand its staff. Additional staff are needed to continue to conduct high quality epidemiological follow-up on HIV and AIDS case reports with missing information.

IDPH has not provided sufficient staff support and expertise to properly implement the surveillance trial.

IDPH’s AIDS Activity Section was without a staff epidemiologist during the first 10 months of the HIV identifier trial. The Section, in the Division of Infectious Diseases, is now without a permanent director (an interim director is managing the day-to-day operations). A key position within the HIV/AIDS surveillance unit, responsible for monitoring follow-up activities, was vacant during 10 months between 1999-2000. Key staff positions within the Division of Infectious Diseases, including the director and deputy director, are also vacant. These staff vacancies likely affected IDPH’s ability to implement and operate the HIV identifier trial.

Recommendations :

IDPH Should Ensure A Fair and Impartial Review That Includes Evaluation of System’s Implementation, Operation and Trial Design

AFC urges IDPH to take into consideration each of the following recommendations:

***Recommendation #1:* IDPH should reconvene its advisory HIV Case Surveillance Working Group in order to update the group on the trial system’s progress and to gather advice on evaluation plans and next steps.**

Justification: In June 1998, IDPH convened a working group of medical and public health professionals, community representatives, and people living with HIV to review HIV data collection systems and advise IDPH about its name-reporting proposal. At the end of its two-month process, the group suggested conducting an HIV identifier system on a trial basis, which IDPH accepted. Given its pivotal role in the creation of the system, the Working Group should be afforded an opportunity to learn about and comment on the system’s implementation and progress to date. Working group members, selected for their expertise and leadership on HIV issues, can provide the Department with valuable assistance in developing the evaluation and determining next steps.

***Recommendation #2:* IDPH should develop procedures to ensure that local health departments systematically conduct epidemiological follow-up activities for HIV case reports with missing information.**

Justification: Epidemiological follow-up to collect missing information is the hallmark of any high quality disease surveillance system. IDPH should develop procedures to ensure that local health entities systematically conduct follow-up activities, in accordance with CDC guidelines, for HIV case reports with missing information. Unanswered questions, such as date form completed, patient’s zip code, and other required information can be obtained easily by contacting the provider. IDPH may also contact providers in those instances where the local health authority has failed to do so. Evaluation plans must factor in sufficient time to collect missing information and must be based on a data set that includes information collected by follow-up.

***Recommendation #3:* IDPH should revise the way it measures whether “other required information” is being reported. Only those questions required by state regulation should be reviewed in determining whether “other required information” is being collected.**

IDPH should revise the way it determines whether “other required information” is complete. State regulation establishes required information for each case report; at least seven questions of the reporting form are not required. IDPH, however, has indicated that it is making a determination about “other required information” based on a review of answers to all questions on the reporting form. Questions not required by state regulation should not be reviewed for completeness of information. In addition, questions that are left blank where the option to

answer “unknown” exists should not be reviewed in determining completeness of “other required information.” In accordance with state regulation, an evaluation of the completeness of “other required information” must be conducted after epidemiological follow-up. IDPH should adjust its evaluation schedule to allow additional time for these activities. After a period for follow-up, IDPH can then, more appropriately determine whether “other required information” has been collected.

Recommendation #4: IDPH should adjust the system’s performance criteria in order to reflect the performance measures for HIV surveillance recommended by the CDC.

Justification: The CDC issued important guidelines for states on conducting HIV case surveillance in December 1999.²⁰ In the guidelines, the CDC calls on all states to establish HIV case surveillance by 2002 and pledges to provide states with assistance in establishing such systems, whether by name or unique identifier. The guidelines recommend minimum performance criteria for HIV surveillance systems, which Illinois should adopt in lieu of criteria established by administrative rule. CDC’s performance criteria are representative of the national standard by which Illinois and other states will be measured in the years to come. In comparing criteria from Illinois and the CDC, both require the rate of duplicate case reports to be less than 5%. Illinois, however, has established a higher criterion for risk ascertainment, 90% vs. CDC’s recommendation of 85%. Illinois has not established performance criteria in several important areas. CDC recommends that HIV case surveillance be complete in at least 85% of case reports (e.g. that at least 85% of those who test HIV-positive be counted in the system). In addition, CDC recommends that at least 66% of cases be reported within six months of diagnosis. It is important to note that CDC criteria is intended for both name and non-name-based HIV surveillance systems and that states that currently conduct name-based HIV surveillance are not in compliance with CDC criteria and will need to make improvements in the years to come.

Recommendation #5: IDPH should conduct an independent, impartial process evaluation of the system’s operation. The process evaluation should endeavor to identify ways in which the system’s operation—and compliance with reporting requirements—can be strengthened. IDPH should implement recommendations that emerge from the process evaluation.

Justification: Conducting an independent and impartial process evaluation is the only fair way of determining whether the system has been implemented and administered appropriately. Such an evaluation should investigate the system’s operation from multiple vantage points such as provider compliance; patient and community acceptance; local health department experience; data collection and management; and internal policies and procedures. The aim of the evaluation should be to identify activities (policy changes, staff/personnel needs, outreach/communication activities, training and technical assistance, etc.) necessary to improve the system’s efficiency and effectiveness. IDPH should also make a commitment to implement recommendations that emerge from the evaluation. Conducting a process evaluation and implementing recommended activities will allow for a meaningful outcome evaluation of the system’s ability to track trends in the HIV epidemic.

***Recommendation #6:* IDPH should fund an independent contractor to provide education about the system and technical assistance services to providers statewide on complying with state reporting requirements. In addition, IDPH should provide funding to design and evaluate procedures for providers on establishing and maintaining client PCN logs that comply with state regulation.**

Justification: Provider compliance can be improved with enhanced education, outreach, and training activities tailored to offer new providers and/or new personnel a solid understanding of their requirements under this regulation. Such activities should be offered statewide and on an ongoing basis, in recognition of the dynamic nature of the epidemic and the entities that offer HIV testing. In addition, both large and small providers will need guidance on developing and maintaining client PCN logs that facilitate matching a PCN with the source patient in instances where additional information is needed.

***Recommendation #7:* Together with medical and public health professionals, university-based evaluators, community representatives and people living with HIV, IDPH should design and implement an outcome evaluation plan designed to measure the ability of the current system to track trends in the HIV epidemic in Illinois. The evaluation should commence in January 2003, following completion of a rigorous process evaluation, and end no later than January 2004.**

Justification: IDPH should collect information about similar outcome evaluations in other states that compare HIV case report data against data from other relevant client registries to determine the “completeness” of the HIV case registry (i.e. the degree to which data from the surveillance system matches data on individuals who tested HIV-positive or receive HIV-related care services). A comparison of surveillance data against a representative sample of people who have tested HIV-positive will help determine to what extent the system is “complete.” Of course, no surveillance system will be able to describe characteristics of those who are living with HIV but do not know it. This is why maintaining policies that promote HIV testing, particularly among high-risk populations, is so important.

A diverse panel of AIDS experts, academics, community representatives and people living with HIV could help design an outcome evaluation of the system that would yield meaningful results. The evaluation of the system as currently codified in state regulation is only capable of describing how well (or how poorly) the system was implemented and operated during its first year and a half of operation. Such a review cannot quantify its potential to accurately reflect characteristics and trends of Illinois’ HIV epidemic.

Conclusion:

Illinois Can and Should Lead U.S. Efforts To Develop Innovative, Non-Name-Based HIV Surveillance Methods

Illinois has developed a model system for HIV surveillance that protects individuals' privacy and promotes voluntary HIV counseling and testing. Preliminary findings show that the system is potentially more reliable than systems that rely on name-based reports. IDPH should adopt new state regulations that facilitate the identification of ways to strengthen the system's operations and that allow a rigorous and meaningful evaluation of the system's ability to track trends in the epidemic.

¹ Centers for Disease Control and Prevention (CDC). 2000. Draft HIV Prevention Strategic Plan Through 2005: 25.

² National Public Radio/Kaiser Family Foundation/Kennedy School Poll. 2000. Attitudes Toward Government, Summary: 4.

³ Institute of Medicine. 2000. No Time to Lose, Getting More from HIV Prevention:10.

⁴ State policies on HIV reporting. 2000. *AIDS Policy & Law* 15: 5.

⁵ National HIV case reporting. 1998. *New England Journal of Medicine* 338:626-7.

⁶ Name-based reporting of HIV-positive test results as a deterrent to testing. 1999. *American Journal of Public Health* 89:1097-1100.

⁷ CDC. December 25, 1998. *Morbidity and Mortality Weekly Report (MMWR)* 47.

⁸ Illinois Department of Public Health. June 2000. Illinois AIDS/HIV Surveillance Report:6.

⁹ Peterson, Senak, Etzel, and Reed. 1996. "An Assessment of the Impact of Mandatory Names Reporting on HIV Testing and Treatment. International Conference on AIDS 11:2, 400: Abstract No. Th.D. 4958.

¹⁰ CDC. 2000. Draft HIV Prevention Strategic Plan Through 2005: 38.

¹¹ Electronic Privacy Information Center. 1993. Medical Privacy Public Opinion Polls.

¹² 77 Illinois Administrative Code § 693.10-693.140

¹³ Illinois Department of Public Health (IDPH). March 17, 2000. Press release.

¹⁴ CDC. 1999. *HIV/AIDS Surveillance Report*, 11,2:15.

¹⁵ CDC. 1999. *HIV/AIDS Surveillance Report*, 11,2:14.

¹⁶ CDC. 1998. Evaluation of HIV Case Surveillance Through use of Non-Name Unique Identifiers – Maryland and Texas, 1994-1996. *MMWR* 46:1254-71.

¹⁷ Solomon, L. et al. 1999. Evaluation of a Statewide Non-Name-Based HIV Surveillance System. *Journal of Acquired Immune Deficiency Syndromes* 22:272-279.

¹⁸ Solomon, L. 1998. Comments on "Draft Guidelines for HIV Case Surveillance, Including Monitoring HIV Infection and Acquired Immunodeficiency Syndrome." Maryland Department of Health and Mental Hygiene.

¹⁹ CDC. 1992. Investigation of HIV/AIDS Cases Reported with No Identified Risk.

²⁰ CDC. 1999. Guidelines for National Human Immunodeficiency Virus Case Surveillance, Including Monitoring for HIV and AIDS. *MMWR* 48, RR-13.

Glossary of Acronyms

- AFC — AIDS Foundation of Chicago
- AIDS — Acquired Immune Deficiency Syndrome
- CDC — Centers for Disease Control and Prevention
- CDPH — Chicago Department of Public Health
- HIV — Human Immunodeficiency Virus
- UI — Unique Identifier
- IDPH — Illinois Department of Public Health
- PCN — Patient Code Number
- STD — Sexually Transmitted Disease

Current Status of HIV Infection Reporting – September 2000

Name-Based Reporting

Alabama
Alaska
Arizona
Arkansas
Colorado
Florida
Idaho
Indiana
Iowa
Kansas
Louisiana
Michigan
Minnesota
Mississippi
Missouri
Nebraska
Nevada
New Jersey
New Mexico
North Carolina
North Dakota
Ohio
Oklahoma
South Carolina
South Dakota
Tennessee
Texas
Utah
Virgin Islands
Virginia
West Virginia
Wisconsin
Wyoming

Moving to Names

New York

Code-Based Reporting

Illinois
Connecticut
Maryland
Massachusetts
Vermont
Puerto Rico
Rhode Island

Moving to Code

California
District of Columbia
Hawaii
Kentucky

Pediatric Reporting²

Connecticut
Oregon

Other Reporting³

Georgia
New Hampshire

Hybrid Reporting¹

Maine
Washington

Moving to Hybrid

Delaware
Montana
Oregon

No Reporting

Pennsylvania

States in *italics* offer only confidential and not anonymous HIV testing. All other U.S. states and territories offer anonymous testing.

¹ HIV cases are initially reported by name. After public health follow-up and collection of epidemiological data, names are converted to codes.

² Requires name-based reports of HIV infection in children.

³ In these states, providers, hospitals, and labs send health departments individual-level HIV data using various anonymous methods (e.g. initials, a date of birth, or a test number). These states generally do not conduct follow-up activities on this information and have not evaluated their systems.

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.¹ 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.²

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.³

2) Is the fear that the names of HIV-positive individuals will not be kept confidential overstated?

No. It is important to point out that the vast majority of public health disease registries take confidentiality and security concerns very seriously. However, the stigma that still surrounds HIV and AIDS makes confidentiality issues in this situation extremely important. In 1996 alone, there were two reported incidents of confidentiality breaches regarding AIDS registries. A Florida public health official took his laptop, which included the names of individuals living with AIDS, and shared the information with others. This was discovered after a Florida newspaper received two disks containing 4,000 names of people living with AIDS, from an anonymous third party. In an unrelated incident, a Florida welfare clerk was able to access the state's computer system, access confidential health records, and inform others of an individual's HIV status.⁴ Confidentiality concerns surrounding name-based reporting are especially salient in smaller communities and counties.

3) Will a name-based reporting system facilitate the placement of HIV-positive individuals into appropriate care settings and aid in partner notification efforts?

No. The goal of a surveillance system is to provide basic epidemiological information on affected populations and the risk practices involved. A surveillance system in and of itself is not the most effective or appropriate vehicle for ensuring that individuals access the health care system. Public health programs use surveillance data to understand the disease and develop strategies to reach affected and at-risk populations. Guaranteeing access to care

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.⁵

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.⁶ 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.⁷ 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.

¹ 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.

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

³ 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.

⁴ *AIDS Policy and Law* May 16, 1997.

⁵ *Annals of Internal Medicine* November 16, 1999.

⁶ *AIDS Policy and Law* May 26, 2000.

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

Unique Identifier Systems Across the United States

	Implementation Date	Code Elements	Provider required to have system to match code to patient file*	Progress to date
California	Pending	Pending	Pending	Governor Davis agreed to establish a Unique Identifier system in 2000, and approved a FY01 state budget that includes a \$2.8 million allocated for this purpose. The health department is currently deliberating on the system's design and elements.

	Implementation Date	Code Elements	Provider required to have system to match code to patient file*	Progress to date
Connecticut	1/1/1999	<ul style="list-style-type: none"> • Age • Ethnicity • Gender • Zip code of current residence 	NO	Laboratories report HIV-positive test results, without names, to the state health department. State officials are reviewing how to facilitate better follow-up because laboratories frequently report cases with incomplete information.

	Implementation Date	Code Elements	Provider required to have system to match code to patient file*	Progress to date
District of Columbia	Pending	Pending	Pending	In late 1999, Mayor Anthony Williams directed the health department to establish a Unique Identifier system. The health department has convened an advisory committee to help develop the system. Implementation may begin as soon as 2001.

	Implementation Date	Code Elements	Provider required to have system to match code to patient file*	Progress to date
Hawaii	1/1/2001	<ul style="list-style-type: none"> • Date of birth • Elements of first and last name 	YES	Hawaii Department of Health is preparing to implement an Unnamed Test Code (UTC) system after an advisory group of physicians, people living with HIV, epidemiologists, civil rights attorneys, and laboratories recommended the non-name-based system as the best system to provide critical data, while safeguarding patient confidentiality.

	Implementation Date	Code Elements	Provider required to have system to match code to patient file*	Progress to date
Illinois	7/1/1999	<ul style="list-style-type: none"> • Date of birth • Elements of last name • Gender 	YES	Initial evaluation (after just six months) revealed code elements complete in 99% of reports.

	Implementation Date	Code Elements	Provider required to have system to match code to patient file*	Progress to date
Kentucky	Legislation passed 7/14/2000	<ul style="list-style-type: none"> • Date of birth • Elements of last name • Last four digits of Social Security number 	YES	The Kentucky legislature convened a task force before the 2000 session to consider methods for conducting HIV surveillance. The task force initially supported a name-based system, but the legislature, concerned about medical record privacy, passed a bill with bipartisan support to establish a Unique Identifier system.

	Implementation Date	Code Elements	Provider required to have system to match code to patient file*	Progress to date
Maryland	6/1/1994	<ul style="list-style-type: none"> • Date of birth • Gender • Last four digits of Social Security Number • Race/ethnicity 	YES	87.2% of reports had complete Unique Identifier (UI) numbers. 99.8% unduplicated rate when compared to existing AIDS registry. Last four digits of the Social Security number was the element most likely to be incomplete on reports.

	Implementation Date	Code Elements	Provider required to have system to match code to patient file*	Progress to date
Massachusetts	1/1/1999	<ul style="list-style-type: none"> • Elements of last name • Last four digits of Social Security Number • Zip code of current residence 	YES	Code has been complete in 99% of case report forms received. Social Security number is missing on 9% of forms (most incomplete element). State-funded comprehensive evaluation of the system is underway; results anticipated in early 2001.

	Implementation Date	Code Elements	Provider required to have system to match code to patient file*	Progress to date
Rhode Island	4/1/2000	<ul style="list-style-type: none"> • Age • Date of Birth • Gender • Social Security Number 	YES	Cases are reported retroactively to 1/1/00. Community Planning Council pushed for Unique Identifier system after strong opposition to name-based system from racial and ethnic minority groups. Evaluation process is under construction at this point.

	Implementation Date	Code Elements	Provider required to have system to match code to patient file*	Progress to date
Texas	3/1/1994	<ul style="list-style-type: none"> • Date of Birth • Ethnicity • Gender • Last four digits of Social Security Number 	NO	Texas switched from a Unique Identifier (UI) system to a name-based reporting system in 1998 after initial studies showed a low completeness rate (62%). Only 60% of UIs could be matched to a patient record in the same study; however, Texas did not require providers or labs to maintain registries linking UIs to patient records.

	Implementation Date	Code Elements	Provider required to have system to match code to patient file*	Progress to date
Vermont	2/1/2000	<ul style="list-style-type: none"> • Elements of first and last name • Last four digits of Social Security Number 	YES	Vermont has yet to embark on a process to evaluate the HIV surveillance system.

Information compiled by the Chicago Department of Public Health from interviews with health department officials in each jurisdiction.

*** Effective HIV surveillance systems include a mechanism for follow-up activities with the health care provider who first administered the HIV test. Most non-name-based systems require providers to maintain a log by which they can provide follow-up information when necessary.**

ILLINOIS DEPARTMENT OF PUBLIC HEALTH ADULT HIV/AIDS CONFIDENTIAL CASE REPORT

(Patients ≥13 years of age at time of diagnosis)

DATE FORM COMPLETED

Month Day Year

REPORT SOURCE

I. HEALTH DEPARTMENT USE ONLY

CITY _____ COUNTY _____ DATE RECEIVED BY LHP _____ SOURCE _____ STATE NO. _____

II. FOR HIV AND AIDS - MUST BE COMPLETED (ESSENTIAL INFORMATION)

FIRST LETTER OF LAST NAME <input type="text"/>	THIRD LETTER OF LAST NAME <input type="text"/>	NUMBER OF LETTERS IN LAST NAME (if >9, enter 9) <input type="text"/>	SEX M = Male F = Female <input type="checkbox"/> M <input type="checkbox"/> F	BIRTH DATE Month Day Year <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	DIAGNOSTIC STATUS AT REPORT (check one) <input type="checkbox"/> 1 HIV infection (not AIDS) <input type="checkbox"/> 2 AIDS
---	---	---	--	---	---

III. DEMOGRAPHIC INFORMATION

CURRENT STATUS Alive Dead Unknown <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 9	AGE AT DIAGNOSIS <input type="text"/> <input type="text"/>	DEATH DATE Month Day Year <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	STATE/TERRITORY OF DEATH _____	COUNTRY OF BIRTH <input type="checkbox"/> 1 U.S. <input type="checkbox"/> 7 U.S. Dependencies and Possessions (including Puerto Rico) (specify) _____ <input type="checkbox"/> 8 Other (specify) _____ <input type="checkbox"/> 9 Unknown
RACE/ETHNICITY <input type="checkbox"/> 1 White (not Hispanic) <input type="checkbox"/> 2 Black (not Hispanic) <input type="checkbox"/> 3 Hispanic <input type="checkbox"/> 4 Asian/Pacific Islander <input type="checkbox"/> 5 American Indian/Alaskan Native <input type="checkbox"/> 6 Not Specified		IF HISPANIC, PLEASE CHECK ONE <input type="checkbox"/> 3A Mexican <input type="checkbox"/> 3C Cuban <input type="checkbox"/> 3E South American <input type="checkbox"/> 3B Puerto Rican <input type="checkbox"/> 3D Central American <input type="checkbox"/> 3F Other		LAST FOUR DIGITS OF SOCIAL SECURITY NUMBER <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
Check if HIV infection is presumed to have been acquired outside United States and Territories <input type="checkbox"/> Specify Country _____				
RESIDENCE AT DIAGNOSIS City _____ County _____ State/Country _____ ZIP Code _____				

IV. FACILITY OF DIAGNOSIS

A. FACILITY OF FIRST POSITIVE HIV TEST

Facility Name _____

City _____ State/Country _____

FACILITY TYPE (check one)

01 Physician, HMO 32 Hospital, Outpatient
 29 Community Health Center 88 Other (specify) _____
 30 Correctional Facility
 31 Hospital, Inpatient 99 Unknown

B. FACILITY OF AIDS DIAGNOSIS

Facility Name _____

City _____ State/Country _____

FACILITY TYPE (check one)

01 Physician, HMO 32 Hospital, Outpatient
 29 Community Health Center 88 Other (specify) _____
 30 Correctional Facility
 31 Hospital, Inpatient 99 Unknown

V. PATIENT HISTORY (Respond to ALL categories)

AFTER 1977 AND PRECEDING THE FIRST POSITIVE HIV ANTIBODY TEST OR AIDS DIAGNOSIS, THIS PATIENT HAD

	Yes	No	Unk.
* Sex with male	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
* Sex with female	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
* Injected nonprescription drugs	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
* Received clotting factor for hemophilia/coagulation disorder Specify disorder <input type="checkbox"/> 1 Factor VIII (Hemophilia A) <input type="checkbox"/> 2 Factor IX (Hemophilia B) <input type="checkbox"/> 8 Other (specify) _____	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
* HETEROSEXUAL relations with any of the following	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
a. Intravenous/injection drug user	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
b. Bisexual male	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
c. Person with hemophilia/coagulation disorder	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
d. Transfusion recipient with documented HIV infection	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
e. Transplant recipient with documented HIV infection	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
f. Person with AIDS or documented HIV infection, risk not specified	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
* Received transfusion of blood/blood components (other than clotting factor) Month Year First <input type="text"/> <input type="text"/> Last <input type="text"/> <input type="text"/>	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
* Received transplant of tissue/organs or artificial insemination	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
* Worked in a health-care or clinical laboratory setting (specify occupation) _____	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9

VI. LABORATORY DATA

<p>1. HIV ANTIBODY TESTS AT DIAGNOSIS</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th rowspan="2">TEST</th> <th colspan="2">Pos</th> <th colspan="2">Neg</th> <th rowspan="2">Ind</th> <th rowspan="2">Done</th> <th colspan="2">TEST DATE</th> </tr> <tr> <th>1</th> <th>0</th> <th>1</th> <th>0</th> <th>Month</th> <th>Year</th> </tr> </thead> <tbody> <tr> <td>HIV-1 EIA</td> <td style="text-align: center;"><input type="checkbox"/> 1</td> <td style="text-align: center;"><input type="checkbox"/> 0</td> <td style="text-align: center;"><input type="checkbox"/> 1</td> <td style="text-align: center;"><input type="checkbox"/> 0</td> <td style="text-align: center;"><input type="checkbox"/> 8</td> <td style="text-align: center;"><input type="checkbox"/> 9</td> <td style="text-align: center;"><input type="text"/></td> <td style="text-align: center;"><input type="text"/></td> </tr> <tr> <td>* HIV-1 Western blot/IFA</td> <td style="text-align: center;"><input type="checkbox"/> 1</td> <td style="text-align: center;"><input type="checkbox"/> 0</td> <td style="text-align: center;"><input type="checkbox"/> 1</td> <td style="text-align: center;"><input type="checkbox"/> 0</td> <td style="text-align: center;"><input type="checkbox"/> 8</td> <td style="text-align: center;"><input type="checkbox"/> 9</td> <td style="text-align: center;"><input type="text"/></td> <td style="text-align: center;"><input type="text"/></td> </tr> <tr> <td>* Other HIV antibody test (specify) _____</td> <td style="text-align: center;"><input type="checkbox"/> 1</td> <td style="text-align: center;"><input type="checkbox"/> 0</td> <td style="text-align: center;"><input type="checkbox"/> 1</td> <td style="text-align: center;"><input type="checkbox"/> 0</td> <td style="text-align: center;"><input type="checkbox"/> 8</td> <td style="text-align: center;"><input type="checkbox"/> 9</td> <td style="text-align: center;"><input type="text"/></td> <td style="text-align: center;"><input type="text"/></td> </tr> <tr> <td>* HIV-2 antibody test</td> <td style="text-align: center;"><input type="checkbox"/> 1</td> <td style="text-align: center;"><input type="checkbox"/> 0</td> <td style="text-align: center;"><input type="checkbox"/> 1</td> <td style="text-align: center;"><input type="checkbox"/> 0</td> <td style="text-align: center;"><input type="checkbox"/> 8</td> <td style="text-align: center;"><input type="checkbox"/> 9</td> <td style="text-align: center;"><input type="text"/></td> <td style="text-align: center;"><input type="text"/></td> </tr> </tbody> </table> <p>2. POSITIVE HIV DETECTION TEST (record earliest test)</p> <p>* HIV PCR, DNA or RNA probe Specify viral load (RNA copies/ml) _____ Month Year <input type="text"/> <input type="text"/></p> <p>* Other (specify) _____ Month Year <input type="text"/> <input type="text"/></p>	TEST	Pos		Neg		Ind	Done	TEST DATE		1	0	1	0	Month	Year	HIV-1 EIA	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="text"/>	<input type="text"/>	* HIV-1 Western blot/IFA	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="text"/>	<input type="text"/>	* Other HIV antibody test (specify) _____	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="text"/>	<input type="text"/>	* HIV-2 antibody test	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="text"/>	<input type="text"/>	<p>* Date of last documented negative HIV test (specify type) _____ Month Year <input type="text"/> <input type="text"/></p> <p>* If HIV laboratory tests were not documented, is HIV diagnosis documented by a physician? <input type="checkbox"/> 1 <input type="checkbox"/> 0 <input type="checkbox"/> 9 Month Year <input type="text"/> <input type="text"/></p> <p>If yes, provide date of documentation by physician _____ Month Year <input type="text"/> <input type="text"/></p> <p>3. IMMUNOLOGIC LAB TESTS AT OR CLOSEST TO CURRENT DIAGNOSTIC STATUS</p> <p>* CD4 Count _____ cells/uL Percent <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Month Year <input type="text"/> <input type="text"/></p> <p>First <200 uL or <14% Month Year <input type="text"/> <input type="text"/></p> <p>* CD4 Count _____ cells/uL Percent <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Month Year <input type="text"/> <input type="text"/></p>
TEST		Pos		Neg				Ind	Done	TEST DATE																																										
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FOR AIDS CASES ONLY (ESSENTIAL INFORMATION FOR AIDS CASES)

Patient's Name _____ (Last, First, M.I.) Phone No. () _____ Social Security No. _____

Address _____ City _____ County _____ State _____ ZIP Code _____

- Patient Identifier Information is not transmitted to CDC -

VII. AIDS-DEFINING CONDITIONS

CLINICAL RECORD REVIEWED		Yes <input type="checkbox"/>	No <input type="checkbox"/>						
AIDS INDICATOR DISEASES	Initial Diagnosis		Initial Date		AIDS INDICATOR DISEASES	Initial Diagnosis		Initial Date	
	Def.	Pres.	Month	Year		Def.	Pres.	Month	Year
Candidiasis, bronchi, trachea or lungs	<input type="checkbox"/>	NA	<input type="checkbox"/>	<input type="checkbox"/>	Lymphoma, Burkitt's (or equivalent term)	<input type="checkbox"/>	NA	<input type="checkbox"/>	<input type="checkbox"/>
Candidiasis, esophageal	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Lymphoma, immunoblastic (or equivalent term)	<input type="checkbox"/>	NA	<input type="checkbox"/>	<input type="checkbox"/>
Carcinoma, invasive cervical	<input type="checkbox"/>	NA	<input type="checkbox"/>	<input type="checkbox"/>	Lymphoma, primary in brain	<input type="checkbox"/>	NA	<input type="checkbox"/>	<input type="checkbox"/>
Coccidioidomycosis, disseminated or extrapulmonary	<input type="checkbox"/>	NA	<input type="checkbox"/>	<input type="checkbox"/>	<i>Mycobacterium avium</i> complex or <i>M.kansasii</i> , disseminated or extrapulmonary	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cryptococcosis, extrapulmonary	<input type="checkbox"/>	NA	<input type="checkbox"/>	<input type="checkbox"/>	<i>M. tuberculosis</i> , pulmonary	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cryptosporidiosis, chronic intestinal (>1 month duration)	<input type="checkbox"/>	NA	<input type="checkbox"/>	<input type="checkbox"/>	<i>M. tuberculosis</i> , disseminated or extrapulmonary	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cytomegalovirus disease (other than in liver, spleen or nodes)	<input type="checkbox"/>	NA	<input type="checkbox"/>	<input type="checkbox"/>	<i>Mycobacterium</i> , of other species or unidentified species, disseminated or extrapulmonary	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cytomegalovirus retinitis (with loss of vision)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<i>Pneumocystis carinii</i> pneumonia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIV encephalopathy	<input type="checkbox"/>	NA	<input type="checkbox"/>	<input type="checkbox"/>	Pneumonia, recurrent, in 12-month period	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Herpes simplex: chronic ulcer(s) (> 1 month duration); or bronchitis, pneumonitis or esophagitis	<input type="checkbox"/>	NA	<input type="checkbox"/>	<input type="checkbox"/>	Progressive multifocal leukoencephalopathy	<input type="checkbox"/>	NA	<input type="checkbox"/>	<input type="checkbox"/>
Histoplasmosis, disseminated or extrapulmonary	<input type="checkbox"/>	NA	<input type="checkbox"/>	<input type="checkbox"/>	Salmonella septicemia, recurrent	<input type="checkbox"/>	NA	<input type="checkbox"/>	<input type="checkbox"/>
Isosporiasis, chronic intestinal (>1 month duration)	<input type="checkbox"/>	NA	<input type="checkbox"/>	<input type="checkbox"/>	Toxoplasmosis of brain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kaposi's sarcoma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Wasting syndrome due to HIV	<input type="checkbox"/>	NA	<input type="checkbox"/>	<input type="checkbox"/>

Def. = definitive diagnosis Pres. = presumptive diagnosis

VIII. TREATMENT/SERVICES REFERRALS

<p>Has this patient been informed of his/her HIV infection? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk.</p> <p>Patient's sex or needle sharing partners have been or will be notified and counseled by physician/provider? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk.</p> <p>If no, does the health department need to notify and counsel the patient's sex or needle sharing partners? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk. <i>(If yes, the provider will be contacted by health department for followup)</i></p>	<p>This patient received or is receiving:</p> <ul style="list-style-type: none"> • Anti-retroviral therapy <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk. • PCP prophylaxis <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk. <p>This patient is receiving or has been referred for:</p> <ul style="list-style-type: none"> • HIV-related medical services <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA <input type="checkbox"/> Unk. • Substance abuse treatment services <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA <input type="checkbox"/> Unk.
<p>FOR WOMEN</p> <ul style="list-style-type: none"> • This patient is receiving or has been referred for gynecological or obstetrical services <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk. • Is this patient currently pregnant? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk. • Has this patient delivered live-born infant(s)? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk. <p>If yes and delivery occurred after 1977, provide birth information for the most recent birth.</p>	<p>CHILD'S BIRTH DATE Month Day Year</p> <p>Hospital of Birth _____</p> <p>City _____ State _____</p>

IX. COMMENTS

Provider's Name _____ <small>(Last, First, M.I.)</small>	Phone No. () _____	Patient Medical Record No. _____
Hospital/Facility _____	Person Completing Form _____	Phone No. () _____

- Provider Identifier information is not transmitted to CDC -