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Bureau of HIV and STD Prevention

Public Health

Recommendations on HIV Infection Reporting

January, 1998

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Introduction

During the past three years, the nature of the HIV epidemic has drastically changed in the United States. New therapies that, for many people, appear to successfully retard disease progression and improve health status, have been widely prescribed. These drugs do not appear to work for everyone, and in some the benefits are not permanent, but new drugs which show great promise are quickly being developed. These and other environmental changes have prompted the Bureau of HIV and STD Prevention of the Texas Department of Health (TDH) to conduct a thorough analysis of the effectiveness and efficiency of our current HIV disease reporting and follow-up systems, including how well they will be able to meet the new challenges posed by HIV and other sexually transmitted diseases (STDs) in the near future.

As a result of this analysis, we have concluded that our current HIV reporting system will not serve either our communities or individual citizens well over the next few years. The need is critical to make changes now to improve our ability to monitor the epidemic and to link clients with needed care, treatment and prevention services. Without these changes, our public's health will suffer. Additionally, Texas will be in an increasingly poor position to compete for ever-scarcer resources.

This paper details the need for HIV infection reporting, the reasons AIDS case reporting alone is not adequate, an assessment of Texas' current Unique Identifier (UI) HIV reporting system, and our recommendation for adopting a name based HIV reporting system in Texas.

Background: National HIV/AIDS Case Reporting

The Historic Focus on AIDS Reporting Rather than HIV Infection Reporting: Why?

Historically, surveillance for HIV disease has been tied to the onset of late-stage infection markers (AIDS). In 1982, the Centers for Disease Control and Prevention (CDC) published the first definition of AIDS to provide for surveillance of the syndrome identified a year earlier. That definition focused on conditions epidemiologically linked to related cases and did not include the full spectrum of HIV manifestations. In the absence of a reliable, inexpensive test for what was then only recognized as AIDS, this definition was the best tool for incidence monitoring. A national reporting system was put in place and all states adopted this surveillance case definition.

Changes to the original AIDS surveillance case definition have reflected increased knowledge of HIV-related illnesses. As experts gained a greater understanding of the underlying mechanisms of disease development, the AIDS case definition and focus of disease surveillance shifted from tracking diagnoses of opportunistic infections (1982 case definition) to using laboratory evidence of severe immunosuppression (CD4+ below 200 microliters per decaliter of blood) as a marker

of the beginning of AIDS (1993 case definition).

Along with the evolution of the AIDS case definition came a broader understanding of the role that HIV played in the development of AIDS. Experts understood that the public health concern relating to this epidemic was in fact infection with HIV. This broader understanding, coupled with the widespread availability of a serum antibody test to screen for HIV in 1985, led many states to initiate reporting of HIV infection in addition to AIDS case reporting.

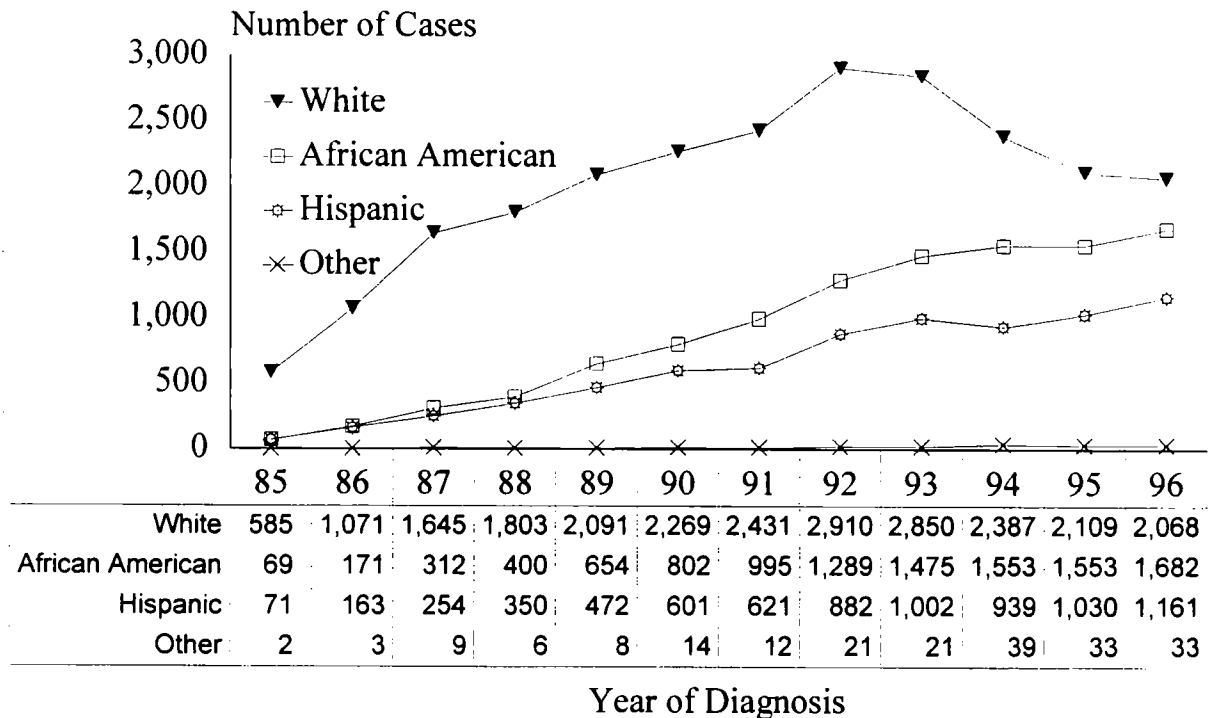
Why AIDS Case Reporting Is Not Enough: Effects of New Treatments

From a public health and epidemiologic perspective, the advantages of tracking and profiling HIV are significant, as HIV infection marks the beginning of the disease process rather than the end. In contrast, AIDS surveillance is triggered by events marking late-stage progression of disease. Due to the effect of new HIV treatments, those states and territories which rely on AIDS case surveillance information to target HIV prevention efforts will have a distorted picture of HIV-infected populations.

Using AIDS case reporting information to target prevention and service resources has been criticized because of the lag between infection and the development of the conditions used to diagnose AIDS. This lag was longest for people diagnosed under the case definition based on development of opportunistic infections (OIs), for at that time, OIs did not appear until eight to ten years after infection with HIV. The case definition shift in 1993 meant people were counted as AIDS cases earlier in the development of disease, and this change was expected to make AIDS slightly more reflective of the front end of the HIV epidemic. However, for reasons outlined in this paper, this shift in AIDS definition is still not detecting persons early enough in the disease process.

New triple combination therapies and protease inhibitors have become available which delay for an unknown amount of time the drop in T-cell counts which currently defines AIDS. As can be seen in Figure 1 below, the number of white adult and adolescent AIDS cases declined after 1992. The rise of similar African American cases also slowed, as did cases for Hispanics and for people of other racial or ethnic groups. Some of the change may be attributed to prevention efforts. However, it is also possible that in recent years fewer people have reached the point of having low enough T-cell counts to be diagnosed as AIDS cases, thus contributing to the decline of AIDS among whites and its slowing among African Americans. As the effect of the new therapies on HIV deaths has already been felt, with July 1997 estimates showing that Texas 1996 AIDS deaths will fall by at least 10% compared to the previous year, it is likely that a similar effect will be observed in AIDS case reporting.

AIDS Case Counts by Year of Diagnosis and Race/Ethnicity: Texas, 1985-1996



* Adjusted for reporting delay; AIDS database updated through 9/22/97

Figure 1: AIDS cases by year of diagnosis, adjusted for reporting delay.

Unfortunately, different groups of the affected populations have varying degrees of access to these treatments, and the treatments are not equally successful with all patients. All of this means that overall case counts are expected to decline, although we have no indication that HIV infection is decreasing. Treatment breakthroughs mean the profile of those individuals who are diagnosed with AIDS, either through lack of treatment or treatment failure, will not be representative of the profile of people living with HIV infection as a whole. All of this points to a decreased role for AIDS case data in tracking HIV infection and targeting HIV prevention resources.

The Need for a Fully Functional System for Monitoring HIV Infection

Disease surveillance, the collection and analysis of disease reports, plays a vital role in public health, providing the information needed to identify, track, and respond to disease trends in an effective and timely manner. Nationally, statewide, and on a local level, the ability to protect and maintain the health of the community depends on the availability of accurate, reliable and complete data. Nowhere is this more true than with HIV.

What Can Good HIV Surveillance Provide?

If the public health system is to adequately respond to changes in the epidemic, making appropriate allocations of resources and targeting services and interventions to groups most in need, it is imperative that Texas have a *fully functioning* HIV reporting system in place. In this context, fully functioning means able to support **all** the functions listed below.

Timely Referrals to HIV Care and Services: Functional HIV reporting systems should ensure that services are provided to vulnerable individuals, in particular to those who might otherwise not receive these public health and personal health benefits until later in the course of their infection. Early entrance into care reduces or slows the development of disease, may lower the spread of infection in the community, and results in substantial health care savings for the individual and the community.

Accurate Minimum Estimate of Infected Persons: HIV disease reporting can be used in conjunction with AIDS case surveillance to provide an accurate estimate of the minimum number of persons known to be infected in a given area.

The Ability to Monitor Recent HIV Infection: HIV disease reporting should provide data regarding persons who acquired HIV recently, compared to data from reports of those already diagnosed with AIDS.

Evaluation of Prevention Interventions: A functional system of HIV disease reporting may also be used to target and evaluate specific HIV prevention interventions, such as the recommended procedures to reduce the risk of perinatal HIV transmission.

Accurate Epidemiologic Profiles for Community Planning: States conducting HIV reporting have presented HIV data together with AIDS surveillance data in their epidemiologic profiles for community planning. Community planning groups in areas without HIV reporting have expressed concern about the lack of data reflecting recent transmission patterns.

Assistance to Physicians and Public Health Professionals in Providing Disease Intervention Services: Confidential HIV disease reporting should enable public health professionals to assist physicians in locating and notifying patients who fail to return for their HIV test results and thus remain unaware of their infection. HIV disease reporting should also support voluntary partner notification efforts. The partner notification process increases the chances that women of childbearing age and others who do not perceive a personal risk for infection will become aware of their possible exposure to HIV. For those who are HIV-infected and pregnant, timely medical intervention can greatly reduce transmission of the virus to their newborns. Partner notification also allows targeted intervention for those at the highest risk of HIV disease - those exposed to the virus by a sex and/or needle-sharing partner. Those partners who are unaware of their infection will have the opportunity to access needed early intervention services much sooner only if they are provided information about their at-risk status. Uninfected partners can be supported in making behavioral decisions that will allow them to remain uninfected.

Epidemiologic Investigations/Supplemental Research Studies: Confidential HIV disease reporting should enable those in the public health system to conduct epidemiologic investigations of cases of special interest, including HIV-2 and cases of possible unusual modes of exposure.

Accurate Data for Funding Considerations: Confidential HIV disease reporting should lead to additional cases of AIDS being identified and should increase the amount of funding received by the state of Texas. Advances in treatment and the use of protease inhibitors has delayed the onset of AIDS diagnoses and may impact the level of funding for Texas. A strong confidential HIV reporting system will position Texas to benefit from likely shifts in funding formulas in the future (i.e., funding based upon HIV disease reports and not AIDS cases).

Although all the functions listed above are important, the bottom line is that reliable and accurate HIV infection data is the best basis for allocating and targeting funds within the state for HIV care and prevention services. As AIDS case data becomes increasingly less useful, current funding formulas will fail to recognize important shifts in disease burden that should drive the allocation of funds.

Who is Recommending and Using HIV Infection Monitoring?

In recognition of the importance of monitoring HIV infection, the CDC disseminated their *Strategic Plan for Prevention of Human Immunodeficiency Virus (HIV) Infection*, which called for "...all states and major cities to have in place confidential HIV infection reporting systems that are linked to medical, social and prevention services by 1995." Recently many expert and advocacy groups have developed recommendations for HIV infection reporting.

- σ The Council and State and Territorial Epidemiologists 1997 position statement recommends that "all states and territories should implement confidential HIV reporting

by name from health care providers and laboratories based on methods that provide accurate and representative data for all persons confidentially diagnosed with HIV infection."

- σ The Association of State and Territorial Health Officers (ASTHO) recommends "that all states undertake named HIV reporting. However, ASTHO opposes any federal mandate to collect the names of HIV positive persons."
- σ The National Alliance of State and Territorial AIDS Directors (NASTAD) has disseminated a October 1997 position statement recommending confidential HIV infection reporting by name.
- σ The National Association for People with AIDS (NAPWA) supports HIV reporting, although they oppose named systems of HIV surveillance.

Currently, 27 states mandate confidential HIV reporting by name for adults and children, and three states (Texas, Connecticut and Oregon) require confidential HIV reporting by name for children only. Two states, Maryland and Texas, have confidential Unique Identifier (UI) HIV reporting, although Maryland requires the reporting of names for symptomatic HIV infections. The remainder of the states have anonymous HIV reporting systems.

The History of HIV Reporting in Texas

Texas recognized the importance of tracking HIV infection in 1987, when the Texas Legislature made HIV infection a reportable condition. Between September 1987 and December 1989, HIV infections were reportable by age and sex only. In 1989, the Texas Board of Health approved new regulations for reporting HIV infection. The data to be reported was changed to include: race/ethnicity, county of residence, date tested (date blood drawn), date of birth (month and year) and sex. Only initial or first-time diagnosis of HIV infections, if made by or under the standing orders of a physician, and based upon acceptable laboratory test results, were to be reported.

In 1992, realizing this HIV reporting system did not meet public health needs, TDH proposed a named HIV reporting system to the Texas Board of Health. At that time, some communities raised confidentiality concerns regarding named reporting. In response, TDH considered and adopted the current experimental numeric based UI system for HIV reporting.

The Mechanics of the Unique Identifier HIV Reporting System in Texas

How the Current System Operates

Reporting of confirmed HIV infections by unique identifier (UI) for adolescents and adults began in March, 1994.¹ The UI reporting system in Texas is a dual system, with both test providers and laboratories required to report the four pieces of information of the UI for each individual with a confirmed HIV infection:

- σ the last four digits of the social security number (SSN)
- σ month, day, and year of birth (DOB)
- σ a numeric code for sex
- σ a numeric code for race/ethnicity.

These elements were chosen because, in theory, they are enduringly and consistently associated with each person. Mathematical modeling has demonstrated that combinations of these four elements usually allow true unique identification of an individual's report, and thus allow detection of duplicate reports. In addition to the UI information, test type, test date, test result, the zip code, city, and county of residence of the infected individual, and the name and address of the provider/laboratory reporting the infection is also required. No information on risk behaviors is routinely collected on HIV reports.

The new system was implemented with little additional infrastructure, with the exception of two dedicated positions for HIV surveillance funded at local health departments in Dallas and Houston. The system is predominately a passive reporting system, relying on providers and laboratories to submit reports to local health authorities, who in turn report required information to the TDH. Reports may be submitted in either paper or electronic form.²

Once a report has been submitted to the central database, a second process begins, depicted in Figure 2 on page 9. The report is examined for completeness of reporting elements. All electronic reports are added into the database, regardless of completeness of the UI. However, only those paper reports with two or more elements of the UI present are added to the database; starting in

¹Confirmed HIV infections in children 12 years of age and younger are reported by name.

²A new electronic reporting system, STD/HIV AIDS Reporting System (SHARES), was introduced in key local and regional STD reporting sites in 1995. SHARES allows these programs to report both STDs and HIV via one integrated software system. Encrypted reports are submitted via diskette or electronic data transfer to the TDH central office at the beginning of each month.

1995, paper reports with three or more UI element missing were considered ineligible for entry, eliminating an estimated 7,000 private laboratory reports from the data.

Although a report will be accepted into the database if any of the UI elements are missing, reports with missing UI elements are excluded from HIV infection case counts, for the UI cannot be compared against other cases to check for duplication of report. For purposes of surveillance, a report without a complete UI must be discarded. If the report has all four elements of the UI, it is compared against other complete reports. Reports with matching UI are examined for date of test, and the report with the earlier date of test is maintained in the records, with the second report discarded as a duplicate case.

Finally, UIs for cases of HIV infection are compared against UIs in the AIDS database to remove from HIV analysis sets any HIV infection cases which appear to have already progressed to AIDS. If the UI system was performing optimally, we would lose very few reports to element incompleteness or to appearance in the AIDS registry, and show a duplication ratio close to 50%.

Limitation of UI System: Provides Epidemiologic Monitoring Information Only

It should be recognized that the TDH was aware at the time the UI system was adopted that it could not support some of the core functions outlined previously. When HIV infections are reported, only the UI of the patient is forwarded through the system. Our experience is that UI reports are exceedingly difficult to trace back through the infection reporting system. If follow-back for public health purposes is impeded, then the system can no longer support four of the eight core functions of an HIV surveillance system: *timely referrals to HIV care and services, assistance in providing disease intervention services, support for epidemiologic investigations/supplemental research studies, and support for AIDS case finding*

In theory, the UI system should be able to provide epidemiologic data of acceptable quality, thus allowing the other four functions to be fulfilled, all of which hinge on complete and accurate reporting of known HIV infections. The system is, in effect, a *unifunctional* system, at best capable of providing only information for epidemiologic monitoring of HIV infection, and unable to systemically support patient referral and disease intervention services. This shortcoming was recognized but not resolved at the time of the system's design. However, because of the difficulty in following back incomplete infection reports using only a UI, the success of the UI reporting system in fulfilling the remaining surveillance functions is wholly dependent on providers and laboratories submitting *complete initial* reports.³

³Maryland, which also uses a UI system, requires providers to keep logs showing the name and UI for all HIV tests. This would allow the provider to supply additional information on cases. Maryland has not found this approach to be successful.

Per your conversation
with Sylvia. Just
thought you should
see what this
speaker presented
to the board during
the August meeting.

—

Except
FYI Only

4. The Department shall provide regular reports to the Board on the issuance of individual compliance schedules beginning in January 1999.
5. Enforcement of applicable Board standards should be appropriate to the individual compliance schedules.
6. Given the regulatory certainty provided by the Board's reaffirmation of the minimum health and safety standards set forth in WAC 246-358, and direction provided above for individual compliance schedules, we do not anticipate there being need for emergency rules in 1999 or subsequent years.

The Board is providing this direction to you regarding the 1999 cherry harvest now with the understanding that growers and communities will require time to consider and implement options for the housing of migrant and seasonal workers before the 1999 harvest season. As always, the Board is receptive and prepared to deal with individual exemption requests from growers as provided for under WAC 246-358-020, making use of the already existing process set up under the Interagency Agreement on Farmworker Housing. Exemption requests must include a description of how the intent of the regulation will be met.

The Board appreciates the Department's continuing efforts to ensure safe and healthful conditions licensed under provisions of WAC 246-358 and to implement Second Substitute Senate Bill 6168, Section 2, to adopt new standards for construction of temporary worker housing. We understand further that a solution to the housing needs of the agricultural industry will require the full and creative cooperation and partnerships among local, state, and federal agencies, the Governor and Legislature, non-profit organizations, industry and labor advocates, and communities. We look forward to working with all interested parties for the health of Washington and its people.

Motion/Second: Locke/Barnard. Carried by a vote of 7-2, with one abstention. The letter was signed by Mr. Reid.

FOLLOW-UP INFORMATION ON HIV/AIDS REPORTING (REFERENCE 12/97, 4/98)

Dr. Locke introduced Doug Hamacker, Reporting Manager, HIV/STD Epidemiology Division, Texas Department of Health (TDH). Dr. Locke thought it especially appropriate at this time, given the WSPHR release, that the Board hear from a speaker on a topic related to the second State Priority Health Goal, Reduce the Incidence and Preventable Consequences of Infectious Disease. Dr. Locke recalled that the Board had heard about the need for HIV surveillance and various systems to carry it out. In late 1997, a Washington State Association of Local Public Health Officials (WSALPHO) representative presented the case for HIV name reporting. In April 1998, the Board heard about the State of Maryland's experience with a unique identifier (UI) system. The American Civil Liberties Union and other community groups also presented their concerns about HIV name reporting at that same meeting. Dr. Locke acknowledged the controversy surrounding the issue, but noted there is general consensus now about the need to do more than just AIDS case reporting. Given that there are strongly held views on both name and UI HIV reporting, Dr. Locke said it is appropriate for the Board to continue to serve as the public forum for airing these differences and talking about experiences with both kinds of reporting systems.

Mr. Hamacker pointed out that some of Texas' experience doing HIV surveillance, along with comparable data from Maryland, will be published in a future issue of *Morbidity and Mortality Weekly*. He shared this information as a handout to the Board. He began with a brief review of the public health structure in Texas. The state has 254 counties, 64 of which have local health departments. There is an

HIV/AIDS Reporting System, but only 10 local health departments, in addition to the state health department, have an active HIV/AIDS surveillance system. Texas reported about 47,000 AIDS cases in 1997. When Texas first began collecting data on HIV, it was done through a fairly rudimentary system of simply tabulating how many new cases each week came from each provider. It was not yielding much useful data, even when demographic information was added to the system in 1989. In 1992, TDH proposed name reporting, but community objections were so strong they developed a UI system instead, implemented in March 1994. Though the Texas UI system code was nearly identical to what Maryland had developed, the two systems were actually created completely independent of one another.

Mr. Hamacker said main requirements of the Texas UI system were that it had to be able to integrate with existing activities, and it had to allow for data collection, management, and analysis at the local level which then could be aggregated at the central office. At the same time, reorganization that combined HIV, AIDS, and STD into one group was implemented, allowing for a single surveillance system for all these diseases. TDH received about \$1 million per year to support the system, and began using some of their HIV prevention money to help support the system as well. CDC contributed another \$100,000, which permitted TDH to put two extra staff in each of the highest AIDS morbidity areas, Houston and Dallas.

Mr. Hamacker said they knew that creating a UI system would not support field followup for partner notification, but that it might allow epidemiologic monitoring. That is, it would provide a baseline figure of HIV incidence linkable to the AIDS database to track the progression from HIV to AIDS to death. This permits better resource allocation and understanding of the epidemic.

Texas' UI code, used instead of the client's name, was composed of the last four digits of the client's social security number, date of birth, and an indicator of race or ethnicity and gender. Additional information included was county of residence, health care provider, and test date. It was conceived as a locally driven system, requiring buy-in and cooperation of local health jurisdictions to make it work.

Three years after implementation, 32,000 reports were collected which yielded only 6,800 new, unreported HIV non-AIDS cases. The next step was to try to determine why so much data was collected and yet so few cases resulted. 10,000 reports were incomplete; 7,000 more were grossly incomplete with no social security numbers or birthdates or race information, representing more than half of the reported cases. The item most commonly missing is the social security number. 3,400 of the remaining 14,000+ cases turned out to be duplicates because positive test results are reported by both the laboratory as well as the physician. In addition, by comparing some of the HIV data to the AIDS data, for the number of AIDS cases present, TDH estimated they were missing approximately 74% of HIV cases from their UI system. Thus, trying to characterize the epidemic from their HIV UI surveillance system would have a serious bias to it. The ability to link the system to other databases, e.g. birth records, STDs, and tuberculosis, was also uneven.

A follow-back study of 765 HIV reports resulted in only 60% of those cases being traceable back to the medical provider. There was no ability to try to capture additional risk information on a majority of the HIV reports. Of those that were traced back, only 50% had race or ethnicity information, and only 40% had a true social security number. Most of the cases reported came from a public provider source.

Mr. Hamacker said three main issues became clear: 1) inability of private laboratories to report UI information required to construct the report, primarily the social security number; 2) inability of local health departments to complete incomplete reports, and thus, to do any followup on HIV positive results; 3) information from the UI system was not statistically valid or representative of the epidemic. Problems that are unique to a UI system include: a) if any piece of information is missing, e.g. date of birth or social security number, the UI cannot be created, thus the cases themselves cannot be counted; and b) even when

reports are complete, only 60% of the time can further information be obtained.

Mr. Hamacker said that HIV reporting is critical because AIDS cases have leveled off and AIDS deaths are declining, but new developments in treatment have made it necessary to identify HIV positive persons as early in their infection as possible. An accurate profile of the epidemic cannot be developed unless HIV as well as AIDS is reported. Using only AIDS data, Texas has begun to show significant changes in the profile of the epidemic with respect to different ethnic groups. Shortening the time between when a person becomes infected, gets tested, and begins treatment extends the period of time before the onset of full-blown AIDS and keeps the amount of virus in the infected person's body at a lower level. This, in turn, has exciting implications for degree of infectiousness and prevention of new infections.

As of December 1997, 27 states have begun HIV name reporting; since that time, both New Mexico and New York have also begun developing HIV name reporting systems. Texas would like to switch to name reporting, with TDH taking the lead in developing the rules for the system. Mr. Hamacker said the Texas Legislature convenes again in January 1999, and the TDH would like to develop their system before they are mandated to do so by the Legislature. He thinks it possible that there could be federal legislation mandating HIV name reporting. It would be preferable to be proactive at the state level.

TDH convened a workgroup in Fall 1997 to look at what needed to be done to improve the HIV reporting system. Starting from the premise that aggregate reporting using UIs had failed, other options were explored, mainly name reporting. They identified what a good HIV surveillance should ideally provide: infected persons would receive timely referrals and basic services; ability to monitor recent infections; ability to support planning and targeting of services; assistance to physicians in providing disease interventions; and assistance in public health investigations, including a data set that could support requests for funding.

TDH decided to merge their HIV reporting system with their existing AIDS name reporting system, thereby reducing development and infrastructure costs. Though there was a concern about confidentiality, TDH felt the AIDS reporting system had sufficient protections built into it if HIV name reporting were added to it. Mr. Hamacker stressed that a UI system does not create anonymity for the person being tested, only a system where the person's name is not seen, though the name can still be accessed. The TDH workgroup also felt that their UI system did not support public health interventions or assist with allocation of resources. The recent CDC guidance on evaluating a surveillance system stresses sensitivity, simplicity, timeliness, and flexibility, and while it stops short of recommending name reporting system, it does conclude that name reporting systems perform better based on these criteria.

TDH then convened a number of stakeholder meetings around the state to create a dialogue and solicit input on named versus UI reporting systems. Concerns from the infected community centered around the issue of confidentiality, but in Texas, as elsewhere, in general, only about 2% of people are aware of how reporting is currently done, whether it is by name or UI. The typical reasons for people to delay HIV testing are not related to the kind of reporting system used, but instead to fear of test results. TDH sees value in retaining the option for anonymous testing, which is provided for in Texas law, and will be reinforced in the rules being proposed for HIV name reporting.

Confidentiality of reported information continues to be a concern. Mr. Hamacker has been spending much of his time visiting local health departments around Texas to review their security standards. Another concern is that people who test positive for HIV disease are not guaranteed services or access to the drugs that may deter or prevent the onset of AIDS. Instead, the primary objective of an improved HIV surveillance system would be to provide the safety net of basic public health functions and services to those who need them. TDH established a community consultation group of diverse stakeholders in June 1998 to assist with this, and

assigned a coordinator to assure a single point of contact. TDH envisions an active role for their local health departments in implementing the name reporting system, recognizing their own capacity and resources.

TDH plans to evaluate the HIV name reporting system, possibly even trying to ascertain a point in time after which the system no longer needs to retain individuals by name but instead by an encrypted code. Much time is currently being spent on responding to inquiries about the new system, including putting information out on the Internet.

Mr. Hamacker emphasized that even if Texas' UI system could be made to work, it would still be a unifunctional system limited to characterizing the epidemic. It appears to underrepresent the private sector with the biggest barrier being presented by private laboratories. Given that certain patients and providers appear to be unwilling to provide or collect certain information (e.g., migrant workers and illegal aliens either have no social security numbers or do not want to provide them), the UI system offers few prospects for meeting certain performance criteria. Another barrier is increasing local participation in a unifunctional system. Despite the public health system's inability to guarantee services to all who test positive for HIV, a named reporting system would provide the ability to at least inform everyone tested of their HIV status. Such a system would also provide the ability to direct attention in a more meaningful way to those at highest risk for HIV: sexual and needle-sharing partners of those who test positive for HIV.

Responding to Ms. Reeves, Mr. Hamacker said the system does not interface with other databases via modem. Using modems would not meet TDH's strict confidentiality and security provisions. Public health remains uncertain about how to recapture those HIV infected individuals for whom protease inhibitors have proven to be ineffective, as well as those who seem to have some HIV resistance. Ms. Reeve related how the Washington State prison system has made protease inhibitors available to inmates who need them, and how they have discovered the different factors that influence a patient's drug compliance. Availability is not the only factor. Mr. Hamacker pointed out that in Texas, the UI system was not able, even in the prison system, to capture all the information needed to do followup on those inmates whose HIV test results were positive. Mr. Reid thanked Mr. Hamacker for his informative presentation.

OPEN PERIOD TO TAKE PUBLIC TESTIMONY ON ANY HEALTH ISSUES

Mr. Reid invited citizens to testify on health issues of their own choice.

Judith Billings, Ph.D., Governor's Advisory Council on HIV/AIDS (GACHA) Chair, said she also chaired GACHA's taskforce on HIV surveillance. The taskforce took six months to examine activities in other states, receive written comments, and hold community forums around the state. Dr. Billings also serves on the President's Advisory Council on HIV/AIDS, and on the boards of the Northwest AIDS Foundation (NWAf) and National AIDS Fund.

Dr. Billings noted that there is universal agreement on the need for HIV surveillance. Without it, there is little reliable data to plot changes in the epidemic, now infecting women, young people, and people of color in increasing numbers. Surveillance would help ensure prevention resources are directed in the right direction. Dr. Billings urged the Board to act expeditiously. She said there is a need for information, which she hopes can be gathered without names being kept on a list in perpetuity. She cited proposed legislation in Illinois which would have given a list of infected persons to the legislature so they could inform health care workers and others about their HIV status. Dr. Billings noted there have been no leaks from DOH of names of people with AIDS. However, when she was diagnosed, newspapers got the story even before she had told her family. People's privacy concerns are legitimate in a society where discrimination still exists.

Kim Colaprete, NWAf Statewide Community Organizer, indicated NWAf has been working

Evaluating the Performance of the UI System

Completeness of UI Reporting Elements Is Unacceptably Low

The performance of the UI system in its first three years has been poor. As Figure 2 shows, only **21%** of the estimated 32,094 HIV reports submitted between April 1994 and June 1997 have been counted as cases of HIV infection not believed to have progressed to AIDS.⁴ The primary problem with the UI reporting system lies in the estimated 17,839 reports submitted with incomplete UI information. As Figure 3 shows, this means that **56%** of the reports submitted between April 1994 and June 1997 were missing at least one element of the UI.⁵ By comparison, the proportions of reports eliminated as duplicates (11% of the estimated total) and as cases of infection which have already progressed to AIDS (12% of the estimated total) are small.

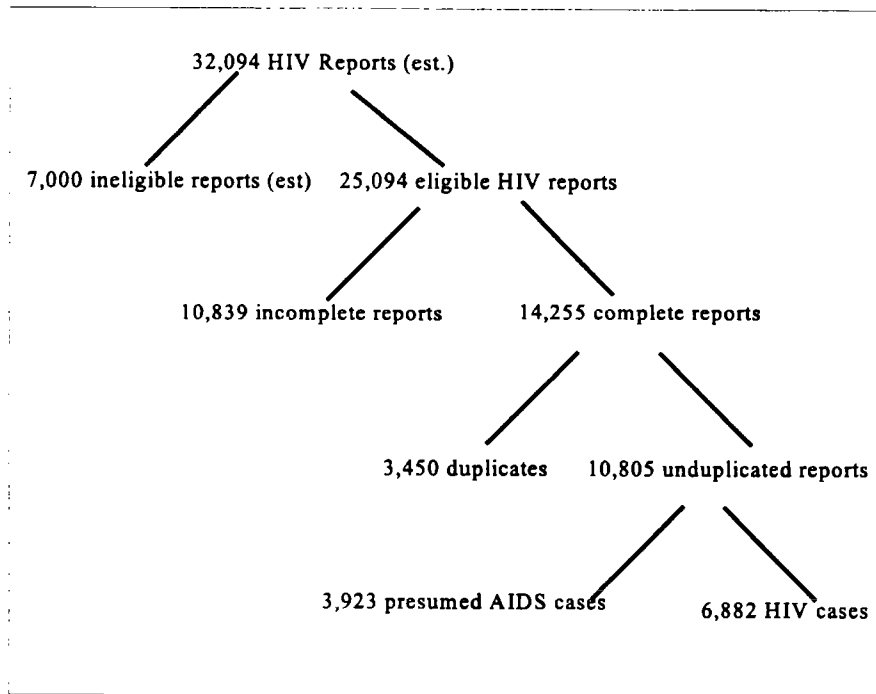


Figure 2: HIV Reporting Flowchart

When only the reports entered into the infection database are considered, the proportion of reports with complete UIs has improved over time. Figure 4 shows proportion of reports with complete UIs by date of test; these figures are not adjusted for reporting delay. The proportion of tests

⁴These estimated totals and estimated number of incomplete reports referred to subsequently include the estimated 7,000 private laboratory reports eliminated from entry into the system due to gross incompleteness of UI.

⁵If only the reports entered into the system are considered, 57% had at least one piece of UI information missing.

with complete UIs rose from about 30% for tests with test dates in the first six months of 1994 to around 60% in late 1994 and throughout 1995. Tests run in 1996 showed the proportion of completes rising from 64% among tests performed in the first quarter to approximately 70% complete for the third and fourth calendar quarter of that year.⁶

This improvement in report completeness means that missing genders, birth dates, and race/ethnicity indicators have all but been eliminated. Missing social security numbers now make up

almost all of the missing information, with 28% of the reports with test dates in 1996 missing SSN, as compared with 2% missing sex, 3% missing birth date, and 4% missing race/ethnicity.

Proportion of Reports with Complete UIs

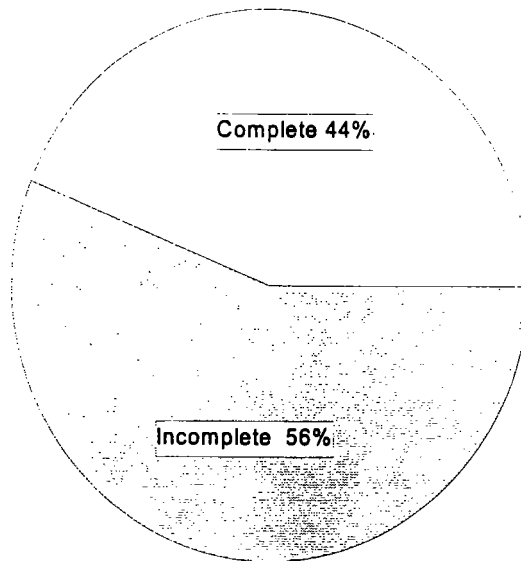


Figure 3: Estimated Proportion of HIV Reports Submitted from 4/94 - 6/97 with Complete UIs

Some of the increases in the proportion of complete reports are due to actual improvements in reporting. For example, the implementation of an updated laboratory form at TDH may partially account for the early upswing observed in early 1995, and the introduction of an electronic HIV reporting system for major public reporting facilities in 1996 explains some of the improvement in completeness seen in that year. However, as important as it is to note these improvements in reporting, the elimination of grossly incomplete reports from entry into the reporting database, which began in 1995, increased the proportion of complete reports by simply lowering the total volume of reports into the system. It is also important to note that the best performance of the system still allows about 30% of the reports received at TDH to be laid aside due to item incompleteness.

⁶1997 tests are omitted from this analysis due the small numbers of tests in the database at this time; we have not yet received data on 1997 tests from the TDH lab. Until those reports are entered, any data on completeness are not representative.

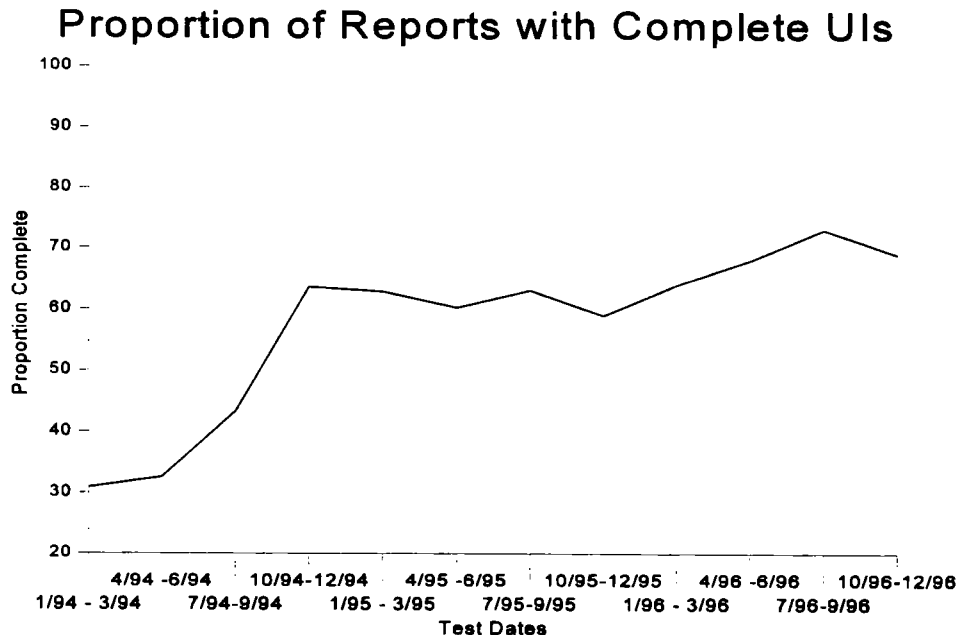


Figure 4: Changes in Proportion of Reports with Complete UIs

Limited Prospects for Improving Item Completeness through Surveillance System Follow Up

In terms of element completeness, the performance of the system is far below acceptable levels for surveillance purposes. If the current HIV reporting system is to provide valid, usable data, the proportion of complete reports must be increased dramatically. However, our experience suggests that using field follow up to complete reports submitted with an incomplete UI is not feasible.

In order to estimate the difficulty of tracing back reports, the TDH attempted to trace back a sample of reports from representative reporting sites in six areas of the state. The providers fully cooperated in this project. Only 60% of the complete case reports could be linked with a client/medical record at the source of report. Success was even more limited when only incomplete infection reports were considered: staff were able to match only 31% of all incomplete HIV reports to source records.⁷ Once the records were located, they were examined to abstract missing case information on each report. Although almost all the missing information on sex and date of birth was easily recovered from the providers' case records, only 50% of the reports

⁷40% of the successful locations used the UI elements only to find the desired record; the remainder relied on the combination of UI information with other information provided on the infection report, such as residential information or local identifiers.

missing information on race/ethnicity and 40% missing SSN were found to have this information available in the source reports. This experience suggests that field follow up to complete HIV reports would have limited success.

Current UI Reports Under-Represent Private Sources of Testing

The elimination of almost all private laboratory reports from entry into the system, necessitated by the gross lack of completeness of these reports, epitomizes the most basic limitations of these reporting data. They are incomplete in two important ways: the reports themselves contain missing elements, and the reports primarily represent infections detected through public sector testing. The low proportion of complete reports results in a significant artificial depression in the official HIV case counts for counties, regions, and the state as a whole. This depression can be illustrated by comparing the number of AIDS cases diagnosed in 1995 (5,010)⁸ to the number of non-AIDS HIV cases with test dates in 1995 (2,195). Analysis of completeness of HIV reporting in Texas conducted by matching UIs constructed for cases in the AIDS registry to UIs in the HIV registry suggests that the current system is capturing only **25%** of all HIV infections. This is in contrast to the 85% - 90% reporting completeness typically reported for AIDS surveillance systems.

Further, the reports currently entering the system are not representative of HIV infection, for current reporting sources are overwhelmingly public providers of testing. For all reports received between March 1994 and June 1997, only 6% were submitted by private physicians and hospitals, and 4% submitted by private laboratories. The public sector sources, the TDH laboratory and local health departments, submit 77% of the reports currently in the system.⁹ This distribution can be compared to the source of STD infection reports, which for Texas cases diagnosed in 1996 showed 46% of the reports coming from public sources, and 49% of the reports originating from private sources. As an HIV infection profile which is skewed towards the public sector is not representative of the epidemic as a whole, in terms of representativeness of reports, the performance of the HIV reporting system falls unacceptably short.

UI Elements Are Not Reported Consistently/Reliably

These two issues relate to the usefulness of reporting information. In this context, reliability and validity refer to the stability and accuracy of information as it flows through the system. Studies such as the field follow up described above and some analyses of information flowing through the HIV counseling and testing system (CTS) and laboratory data matching systems suggest that there

⁸AIDS figures adjusted for reporting delay for cases reported through 2/13/97.

⁹The remaining 13% were submitted by CBOs, CTS sites, and freestanding clinics, some of which are private, some public.

are unacceptable numbers of reports in the infection database which do not reflect information in the clients' records. There is also evidence that information on client race/ethnicity and sex is not consistently recorded/reported. For a system in which information on gender, ethnicity, and age are only ancillary data, this evidence would be disheartening. For a system such as Texas', which relies on these fields to make identification of cases, it destroys the very integrity of the data. If data are not accurate or at least reliable, then it is impossible to identify unique and duplicated cases, and counts of infection will be either over or underestimated in a way impossible to correct with statistical formulas.

Difficult to Eliminate Cases Already Progressed to AIDS

The differences in the information included in case reports of AIDS and HIV make it difficult to determine which reports of HIV infection represent cases which have progressed to AIDS. It is possible to generate UIs for most AIDS cases and remove cases of HIV which have matching UIs, thus creating an HIV database free of cases known to have progressed to AIDS. Unfortunately, the instability of the UI elements means that such a match can never ensure that all known AIDS cases are removed from the HIV data. As one of the primary purposes of HIV surveillance is to create a picture of the scope of HIV disease, especially newly acquired cases, a system which cannot easily distinguish between cases of HIV infection and AIDS is less useful than a system which would easily allow such a distinction.

Barriers to UI Reporting System Improvement

If the UI system is to function adequately as an epidemiologic monitoring tool, the barriers described below must be overcome.

Improving Ability of Private Laboratories to Report UI: From the very beginning of UI reporting, private (non-TDH supported) laboratories have had difficulty capturing, storing, and reporting UI information, with more than 85% of the reports in the first nine months of 1994 having incomplete UIs. Most private laboratories in Texas do not request information on SSN or race/ethnicity. They would also have to make costly changes to their data processing systems to capture, retrieve, and report the UI information. The TDH has no resources to underwrite the costs of these changes. Further, to ensure completeness of reporting items, the laboratories would either have to refuse to accept specimens from providers unless UI information was furnished, which is unlikely, or agree to accept the responsibility for calling providers to complete the UI information before passing the report on. This is even less likely, and would lead to increases in waiting times for results to be returned to tested clients. Although the latter activity is part of the UI reporting process in Maryland, it has had varying success in reducing incomplete submissions depending upon the laboratories' willingness to pursue the information and the providers' willingness and/or ability to provide it.

Enhancing Willingness of Providers to Report UIs and of Clients to Divulge It: Some providers and clients are unwilling to report UI information, particularly social security numbers, for fear that the information will be misused or because they do not trust the confidentiality of the information. Although their concerns are not supported by the excellent history of protecting confidential information by the public health surveillance system in this state, these perceptions are difficult to change.

Increasing Local Health Department Participation In and Support of the UI System: Local health authorities have little incentive to support the UI system, beyond faithfully fulfilling their legal responsibility to report HIV. A recent survey of key providers indicated that local health department surveillance programs found the UI reporting system inflexible and difficult to work into their current surveillance practices and standards, and 90% of those surveyed would not recommend the UI system to states/territories considering use of the system for HIV surveillance. Furthermore, the UI system does not give them the information needed to assure linkage to services. Finally, public (and private) health providers are aware that UI reporting does not perform well in meeting its primary function (to provide epidemiologic data) and that they can do little in terms of follow up to improve the quality of reports without reallocating scarce resources. All of these factors make it difficult for them to fully support the system and provide the resources (time, energy, person hours) necessary to improve the system and the data at a local level.

Conclusion: UI HIV Reporting Systems Are Not Fully-Functioning HIV Reporting Systems

The analysis of our current unique identifier HIV reporting system has shown that it does not provide us with reliable and accurate data on the number of persons infected with HIV infection in Texas. As a consequence we are unable to carry out informed planning for prevention programs and clinical and social services, and are unable to use our reporting system to appropriately allocate funds or other resources. As discussed earlier, this system also prevents health professionals from performing many core public health functions at the local health department level, such as linking clients to needed care and services and providing important partner notification assistance. With new treatments for HIV infection continually emerging and the consequent understanding that earlier identification and treatment can mean longer survival for the HIV infected person, having a system that can identify persons early in their disease is imperative. Likewise, such a system will best ensure that resources are allocated wisely so that treatment and other crucial services such as ongoing support for behavioral change are available where and when they are needed.

Although it does protect the confidentiality of infected individuals, the results of our evaluation of the current system indicates that the UI reporting system cannot be considered a satisfactory tool for monitoring HIV infection. Problems of completeness and reliability of UI elements and representativeness of reports (e.g., public vs. private sources of testing) are not easily solved.

Seeking to improve reporting, the TDH has undertaken consultations with local and regional health department surveillance staff and worked with the TDH laboratory to improve completeness and representativeness of HIV UI reporting. However, even with intensive infusions of resources, the system will never support all the functions expected of an infection monitoring system.

Before leaving this topic, however, we should note that the unsatisfactory performance of the UI system is not wholly attributable to the way the system was implemented in Texas. Maryland, the other state current using a UI system, instituted a reporting structure very different from Texas', with only laboratories charged with reporting HIV infections. Even with this difference, they report similar problems with reporting item completeness and completeness of reporting/representativeness. Other states have also considered and rejected non-named alternatives for reporting of HIV and CD4+ counts. In Connecticut, providers were unwilling to take on the added reporting responsibilities which a UI brings, while New York was unable to develop an acceptable non-named reporting system. After experimentation with non-named "uniform identifiers", New Jersey rejected this system in favor of named HIV reporting in 1992.

Proposed System for Confidential Reporting of HIV Infection by Name

Because of the serious shortcomings identified in the UI reporting system, and the urgent need for accurate and reliable information on HIV infection, the Bureau of HIV and STD Prevention is considering moving to a confidential named HIV reporting system. Based on experience with other surveillance methods, the named AIDS reporting system, the current UI system and evidence in the surveillance literature, we believe named HIV reporting would greatly improve HIV surveillance in Texas, and ultimately improve the health of Texans while protecting the confidentiality of infected persons. The decision to alter the reporting system must ultimately be made by the Texas Board of Health and would require a reporting rule change.

What Can a Named System Do That UI System Can't?

Named systems of HIV reporting can fulfill all eight of the core functions of HIV surveillance, including support of timely linkage/referral of infected individuals to care and services, and support of disease intervention services and voluntary partner notification efforts. These functions are of vital importance to reducing HIV infection in Texas, for they ensure that services are provided to vulnerable individuals, in particular to those who might otherwise not receive public health and personal health benefits until later in the course of their infection. We believe that a named reporting system will not be as susceptible to the problems of incompleteness and representativeness which have rendered the data UI system unacceptable. Due to the similarity of named HIV infection reporting to AIDS and STD reporting, we also believe that the system could be established and maintained more efficiently than the current UI system. Finally, the states' experience with named AIDS and STD reporting suggests that named reporting for HIV infection could be carried out with no loss of confidentiality or privacy.

What Would Named HIV Reporting System Look Like?

A partial HIV disease reporting system already exists: the AIDS case reporting system. Moving to a full named reporting system itself would not require significant changes, with the exception of adding the required data elements to reporting forms. The trigger for report would simply move up in time, from confirmed diagnosis of AIDS to confirmed infection with HIV. The proposed changes to the HIV reporting system **WOULD NOT** be retroactive. There would be no requirement to go back and report persons with past HIV positive tests by name.

If a named reporting system is implemented in Texas, we propose that HIV reporting become primarily a laboratory based surveillance system. Laboratory reports would flow in two different ways: from the lab into the local or regional health department or from the lab directly into the TDH Austin office. To function best, all Texas laboratory reports would go directly to local or regional health departments. This would allow local areas to act in a timely manner to verify completeness of the data, eliminate duplicate reports, provide Prevention Counseling and Partner Elicitation (PCPE) services (as needed), provide referrals for early intervention services, and forward the report to the TDH central office. HIV infection reports submitted by laboratories located out of the state of Texas would be sent directly to the Bureau of HIV and STD Prevention Austin office for processing and then forwarded to the appropriate local/regional health departments for evaluation.

HIV reporting would also be done directly by local health care providers. Providers would report HIV positive tests to their local/regional health departments using a standard report form. The local/regional health department would then handle the reports as described above and then forward them to the TDH Austin office.

How would the Confidentiality of the System be Ensured?

This proposed system would be identical to those already in place for other important reportable communicable diseases such as tuberculosis, syphilis, and measles. Within the Bureau of HIV and STD Prevention, this system would use the existing disease reporting structure in place for chlamydia, gonorrhea, HIV by unique identifier, AIDS, syphilis and other reportable sexually transmitted diseases.

Assuring the continuing security and confidentiality of case reporting information is one of the major charges of the Surveillance Branch of the Bureau of HIV and STD Prevention. This branch has taken specific proactive and protective actions at the TDH Austin office to protect the identity of those individuals reported under current named and non-named reporting systems. These actions range from requiring employees to sign assurances of confidentiality, securing electronic and paper copies of reports, and limiting access to identified case reporting information, and are discussed in detail below. Further, the TDH requires each local and regional health department

which handles confidential disease reports to maintain protective measures which afford levels of security comparable to that found in the TDH Austin office.

Assurances of Confidentiality: All Surveillance Branch employees have received a copy of the *Texas Communicable Disease Prevention and Control Act* addressing confidentiality and penalties for breaches of confidentiality. Additionally, all members of the Bureau of HIV and STD Prevention are required to read and sign a *Statement of Confidentiality* stating that they have read and understand the provisions of the act and the penalties, including dismissal, for any violation of confidentiality. The TDH also requires a statement of confidentiality to be signed by all local and regional surveillance personnel having access to HIV/AIDS case files and computer diskettes.

In addition, state law specifies that medical records and testing records are confidential under all circumstances. The Texas Health and Safety code provides for a Class A misdemeanor in cases where a person releases or discloses a test result or other information or allows a test result or other information to become known.

Limiting access to confidential reporting information: In both the TDH Austin surveillance office and all local and regional surveillance offices, paper or electronic forms containing potentially identifying information are maintained in spaces with limited, controlled access. In the TDH Austin office, entrance to the surveillance area is monitored by a magnetic card access system. In regional and local health department offices, access to registry files, paper or electronic, is limited to persons directly involved in case reporting.

Securing Paper and Electronic Reporting Information: At all levels, computers and software used to manipulate confidential reporting data are password protected. Paper forms and computer disks containing reporting information are maintained in locking file cabinets when not in use. All paper copies or computer discs which must be hand carried are kept in locking briefcases which the staff member maintains with them at all times until it can be secured in a locking cabinet or other secure environment. Telephone conversations in which staff must use or discuss patient identifiers or other confidential information are made in secure areas, such as in the Surveillance Branch suite. Finally, any oral or written presentations of these data, whether at a local or state level, include only aggregate data.

As always, no reportable communicable disease information is sent to the CDC by name and therefore, names of HIV positive persons would not be forwarded to the CDC.

How Would Linkage to Care and Voluntary Partner Notification Services be Handled?

Under the proposed system, when a positive HIV test result is received by the local or regional health department, staff would contact the provider to obtain permission to speak with the patient for purposes of referral to services to support care and/or prevention needs. In addition, health

department staff would provide prevention counseling and partner notification assistance. If the provider gives approval, local/regional health department trained professionals then contact the patient. If the provider does not wish the health department to contact the patient, assistance would be given to the provider to ensure that appropriate referrals, counseling and partner elicitation and notification occurs.

How Would Availability of Anonymous Testing be Affected by Movement to Named System?

The proposed system will not eliminate anonymous HIV testing. Anonymous testing is an effective adjunct to a confidential name reporting system. The continuation of anonymous testing is appropriate, as long as steps are taken to assure that persons testing positive will be referred for medical care and other needed services.

What Would the Cost of the HIV Named Reporting System be?

The Bureau of HIV and STD Prevention anticipates that changing the existing HIV reporting system to HIV named reporting would not require a significant addition of new funds. However, local health departments may need to reevaluate the current level of integration of their reporting systems and to prioritize their existing resources. As more accurate reports of HIV infection increase, additional monies may eventually be needed to fund increased early intervention services, targeted HIV prevention efforts and pharmaceutical costs. These decisions would be addressed through existing planning processes.

What Are the Primary Concerns about Adopting Named HIV Surveillance?

Concerns about Confidentiality

Named HIV surveillance would include the name of the reported person at the local and State health department level. Therefore, some communities have voiced concern that there is a potential for malicious or inadvertent disclosure of patients' identities from surveillance registries or by authorized surveillance personnel. Community representatives state that the potential consequences of breaches in confidentiality of HIV case surveillance are more significant than for AIDS case reporting since persons are reported earlier in the course of their infection, live longer after they are reported and are more likely to be employed.

The Bureau of HIV and STD Prevention shares these concerns and has instituted many security precautions to prevent the disclosure of confidential information about any of the diseases for which we maintain surveillance databases, including the named-based AIDS surveillance registry and our UI HIV Surveillance registry. Surveys of state laws and practices have found that state health departments have an unparalleled record of maintaining sensitive data on persons reported with HIV and AIDS in a highly secure and confidential manner.

Potential Deterrent to HIV Testing

Community representatives have expressed concerns regarding the potential negative impact of named HIV case surveillance on the willingness of persons to seek HIV testing. A preliminary analysis of counseling and testing data trends in five states before and after implementation of named HIV reporting suggests the number of tests increased or remained stable in most groups, with greater increases observed in women compared to men and decreases in testing among men noted in some states. However, these temporal trends may not be directly related to changes in reporting policies.

Our experience after UI was instituted indicates no discouragement of testing. Our Counseling and Testing System (CTS) figures actually show a decrease in both the number and proportion of anonymous tests from July to December 1994 as compared to July to December 1993: from 24,313 anonymous tests (28.5%) in 1993 to 20,106 (22.8%) in 1994. There was no decline in the number of tests performed at CTS sites across those time periods, nor was there any change in the testing profile in terms of the modes of exposure of those presenting for testing. In both time periods, the modes of exposure with the greatest proportions of anonymous tests were male-to-male sex and male-to-male sex with injecting drug use.

Finally, information from the HIV Infection Testing Surveys (HITS) suggests that for most at risk individuals, confidentiality issues do not make or break a testing decision. HITS was conducted with men who have sex with men, active IDU, and high-risk heterosexuals. Interviews were conducted in gay bars, drug hangouts and buying sites, and STD clinics in Austin, Houston, Ft. Worth, and Tyler/Longview in 1996 and 1997. Of the 615 respondents, 83% had previously tested for HIV; 6% of the respondents whose results were included in the data set indicated that they were HIV positive.¹⁰

For most respondents, confidentiality concerns were not the main reasons for either delaying testing or declining testing. Among those who had tested for HIV, 1.6% reported that fear of disclosure had been the most important reason for putting off or delaying testing. Among those who had not tested for HIV, 0.3% listed confidentiality concerns as the most important thing keeping them from testing. It should also be noted that more than 67% of the sample responded "*don't know*" to all questions regarding the kind of surveillance system (named, UI, anonymous) in place in the state, which makes it even less likely that confidentiality concerns drive testing decisions.

Lack of Access to Care to Those People Identified as Infected

As a state health department, we cannot guarantee access to quality care for every person identified

¹⁰When HITS was conducted in 1997, responses from individuals who were HIV positive were not included in the final dataset.

by an HIV surveillance system. However, without an accurate, representative picture of the numbers and distribution of HIV infected persons in Texas we cannot begin to equitably allocate resources to provide access to quality care. Lack of a satisfactory epidemiologic profile will also inhibit our ability to compete for funds to increase HIV services where they are needed. Also, without an accurate understanding of how many people are infected with HIV and where they are located within our state, we cannot monitor our HIV services contractors to ensure that they are providing quality care to the people who need it.

Lack of Anonymous Testing Option

In Texas, publicly-funded providers of HIV testing are required to make anonymous testing available. Changes in the reporting system for HIV surveillance would not change the availability of anonymous testing. The Bureau of HIV and STD Prevention feels strongly that there is a continuing need for the availability of anonymous testing options. It should be noted that of the HIV tests reported from publicly funded HIV CTS sites in Texas, approximately 20-25% of HIV tests are done anonymously.

The Role of Community Input

While we believe that named HIV infection reporting is a positive step towards understanding the changing nature of the epidemic, this change alone is not enough. In order to effectively address the needs of infected individuals, improvements in surveillance must be accompanied by movement of affected individuals to test earlier in disease process, and increased dedication to ensuring early access to high-quality clinical care and other HIV services. We further believe that these changes will not be achieved without the input of our affected communities.

The Bureau of HIV and STD Prevention will begin a dialogue on the HIV reporting system with the communities that would be affected by a rule change. We will be presenting the proposed change to the HIV surveillance system and will be soliciting input and addressing the concerns of affected communities. Based on the results of this process, we may submit new rules on HIV reporting to the Board of Health in 1998.

Conclusion

A rapidly changing environment requires that the TDH take immediate action to position our programs for maximum effectiveness and efficiency in the future. Radical changes in the natural course of HIV disease resulting from improved treatments will continue to reduce the ability of our current AIDS case reporting system to provide the information needed to describe the epidemic, provide useful data to planning bodies and to appropriately allocate resources.

The UI HIV infection reporting system is not an acceptable alternative to our current reliance on the AIDS reporting system. With the UI system, HIV reporting is incomplete and provides an unreliable picture of the epidemic in Texas. Because of limitations inherent in the system, it is unlikely that it could ever provide the information needed, no matter how many additional resources were invested in improving the system.

It is critical that we adopt an alternative system for HIV infection reporting now. It is critical that such a system be as secure as the current AIDS reporting system, provide for follow-up to ensure access to prevention and treatment services for the infected person, and provide an accurate and reliable picture of the HIV epidemic in Texas.

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