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HIV Reporting - The Time Has Come (?)

AIDS has been reportable to the state health department since 1985. AIDS case data, along with other data such as HIV antibody testing conducted through the State Section of Laboratories, scientific information about HIV, and data on national trends, are used to help characterize the HIV/AIDS epidemic in Alaska and to guide public health efforts.

In the absence of effective treatment, HIV-infected individuals develop AIDS an average of 10 years after initial infection. AIDS case data therefore present a snapshot of the HIV epidemic approximately one decade earlier. AIDS case data for 1996 and 1997 show that advances in treating HIV infection are delaying infected individuals' progression to AIDS. This encouraging trend is expected to continue. As a result, however, AIDS case data will provide less and less information about recent patterns in the epidemic. Although the behaviors which transmit HIV are well known, the prevalence of and changes in these behaviors within various populations are not. More current data on the occurrence of HIV infection are essential to target and marshal support for prevention activities.

The Alaska Division of Public Health is currently updating its disease reporting regulations. The Division is proposing to add HIV infection to the approximately 45 conditions for which health care providers and laboratories are required to report identifying information to the Section of Epidemiology.

A number of professional organizations have recently recommended that all states implement HIV case reporting. The Centers for Disease Control and Prevention (CDC), the Council of State and Territorial Epidemiologists (CSTE), the Association of State and Territorial Health Officers (ASTHO), and the National Alliance of State and Territorial AIDS Directors (NASTAD) have all taken positions supporting name-based HIV surveillance. Support for HIV reporting (but not necessarily for reporting by name) has also come from national advocacy groups such as the National Association of People with AIDS (Washington, DC), Gay Men's Health Crisis (New York), and AIDS Action Council (Washington, DC).

While there is growing support for national HIV reporting, the nature of the HIV/AIDS epidemic, injuries suffered by many affected individuals, and punitive legislative proposals introduced in some areas have raised a number of serious concerns about HIV named reporting. Some of these concerns, and alternatives considered, are discussed below.

Will HIV reporting discourage people from getting tested?

In recent years, many people have expressed concern that the perceived social risks resulting from making HIV a reportable condition would deter some people, especially those potentially at highest risk, from seeking testing. Some also believe HIV reporting might increase the number of people seeking anonymous, rather than confidential, testing. Results of several recent studies indicate the impact on testing is likely to be less than anticipated.

Are reported HIV/AIDS data secure?

State public health departments have an excellent record for protecting confidentiality of HIV/AIDS data. There have been no reported breaches of name-based HIV surveillance. Access to, and uses of, Alaska data collected for public health purposes are severely limited. A report which identifies cases, or establishes characteristics of the status of an identifiable patient with a reportable condition, is confidential and may not be disclosed to the public (7 AAC 27.890).

Are there feasible alternatives to name-based reporting?

Decisions about approaches to report HIV cases other than by name need to weigh the purposes and relative benefits of disease surveillance. Disease surveillance systems, such as the reporting system now proposed for HIV, are designed to help monitor disease trends, to provide information sufficient to target appropriate public health services, and may improve timely treatment and preventive services. By their nature, these systems are most effective if they place a relatively low burden on reporting providers, produce accurate and verifiable data, allow for necessary follow up, and are relatively low cost.

CDC recently published an evaluation of two existing state systems (Texas and Maryland) which use a unique identifier for HIV case reporting. The evaluation found that the systems tested provided much less complete information than name-based systems; could not reliably eliminate duplicate case reports; greatly increased the complexity of health department follow up with providers to complete risk and other information; precluded integration of HIV data with other relevant name-based public health surveillance data (for example, TB); and might not diminish risks for breaches in confidentiality since providers had to keep logs of patient names to match with assigned identifiers.

The process proposed changes to regulations must follow:

All interested individuals are urged to provide verbal or written comments on the proposed changes to the Section of Epidemiology so that they are received no later than April 10, 1998. Additionally, any interested person may present oral or written comments at a hearing to be held in Room 515, Frontier Building, 3601 C Street, Anchorage, AK, from 5:00 pm to 8:00 pm on March 25, 1998. Oral testimony also may be presented on March 26, 1998, from 1:00 pm to 4:00 pm, by calling toll free 1-888-869-5955.

Copies of the proposed regulations may be obtained by writing to the Section of Epidemiology, 3601 C Street, Suite 540, PO Box 240249, Anchorage, AK 99524-0249, by calling 907-269-8000, by faxing 907-561-6588, or by e-mailing to epiwebmaster@health.state.ak.us.