

Issue: Recommendations for Retention of Names for HIV Reporting Systems and Recommendations for Expanded Laboratory Reporting in Washington State

Background and National Perspective

CDC has revised their recommendations regarding HIV reporting from advising a name-based system to strongly encouraging a name-based system. CDC steadfastly refuses to include data from code-based and name to code-based HIV reporting systems in the national HIV data base and to construct a plan for adequately evaluating these systems at the national level.

It is expected that the reauthorization of the Ryan White CARE Act (anticipated in September 2005) will include a requirement to allocate funds based on reported cases of HIV. The current statutory language of the Ryan White CARE Act includes amendments from the 2000 reauthorization stating that Ryan White eligible areas will submit HIV case data by fiscal year 2007 and that this data would be reported and confirmed by the Director of the Centers for Disease Control and Prevention.

Recently NASTAD (National Alliance of State and Territorial AIDS Directors) convened a conference call that included 10 of the 14 states that currently have non-name-based HIV reporting systems. Most of these states are considering changes to comply with a name-based reporting system;

- One of the five states with a name to code reporting system is already moving forward with the process to convert to a system of names retention by the first of 2006.
- Two of the ten states with code-based reporting systems are planning to move forward with the process to convert to a name-based reporting system.
- One state is 'holding out' in an effort to maintain their existing system. This state's representatives were asked whether they would maintain their current system and suffer a potential loss of future funding. They agreed that they would comply with the national movement of converting to a name-based HIV reporting system.

Existing Washington State Reporting System

As of August 12, 2005, 15,395 AIDS or HIV cases have been reported to the Department. Of these, 11,907 or 77% are maintained in the surveillance system using name as the identifier, and 3,488 or 23% are maintained in the surveillance system using code as the identifier.

The Department relies primarily on lab-based reporting, which is conducted using the name as the identifier. Every time diagnostic tests are conducted on an individual, the results are reported, by name, to the Department by the lab. Even when the name has been redacted after the initial disease report, the name is constantly reintroduced to the surveillance system for those in care who receive diagnostic tests on a regular basis.

The name-to-code system performs well in regards to evaluation standards related to timeliness, completeness, accuracy, ascertainment of risk, and ability to match with other public health databases.

There have been no breaches of confidentiality in Washington State at the state or local level associated with the collection and retention of surveillance data.

Benefits of Converting to Retention of a Name-Based System

- Allows WA State HIV data to be included in the national reporting system by the CDC.
- Eliminates possible funding loss from the Ryan White Care Act if the funding formula is based on HIV case data.
- Eliminates the additional time and resources both at the state level and the local level to convert names to code, re-identify individuals for investigations that are conducted after the 90 day time frame, and eliminate intrastate and interstate duplicates.
- Eliminates the disparity of HIV reporting compared to all other notifiable condition reporting
- Allows local public health officials to more efficiently conduct communicable disease control procedures and compare data between reporting systems (e.g., HIV and TB)
- Some margin of improved ability of the surveillance system to meet national standards for interstate de-duplication
- Ability to more efficiently match case data to other public health data systems

Disadvantages of Converting to Retention of Name-Based System

- HIV reporting has a history of being a controversial issue by some persons with HIV or at high risk of HIV
- The change will be perceived by some as a retreat from an agreement to convert names to codes

Benefits of Expanding Laboratory Reporting

The Council of State and Territorial Epidemiologists (CSTE) recommends that states require reporting of all HIV related laboratory tests (CD4s, viral loads). If the Department makes the decision to pursue a name-based HIV reporting system it would also provide an excellent opportunity to expand HIV related laboratory reporting.

- Will more accurately catch all cases thereby more reliably portraying the extent of the epidemic in WA State.
- Can better describe and enumerate those who are doing well clinically (high CD4s, undetectable viral loads) versus those who are not in care.
- Will allow for improved interpretation of results of HIV incidence testing with information about levels of immunosuppression and viral replication.
- Will allow public health officials to identify people who are infected as early as possible in the course of infection and provide prevention and care services.
- Will decrease the burden for labs because they will not have to sort labs based on lab values (as they will send all values).

Disadvantages of Expanding Laboratory Reporting

- HIV reporting has a history of being a controversial issue by some persons with HIV or at high risk of HIV
- Some increase in the volume of reported lab results that require follow-up.

Program Proposal:

File CR-101

- **Name retention HIV reporting system – CDC recommendation**
- **Expand HIV-related laboratory reporting – CSTE recommendation**
- **Meet with WA stakeholder groups across state**

File a CR 101 to publicly announce that the Department and the Board are considering the change to a name retention HIV reporting system in response to CDC recommendations and requirements to be included in the national HIV surveillance system. Include the expansion of HIV-related laboratory reporting as recommended by CSTE in the CR-101 proposal.

Meet with existing groups and organizations to explain the rationale. These groups would be limited to the HIV Collaborative, GACHA, the Title 1 Planning Council, Laboratories, and the AIDSNET Council. Hold one public stakeholder meeting in Spokane and one in Seattle.

Based on community and partner feedback, file a CR 102 to adopt names retention and expanded laboratory reporting.