DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333

September 30, 2005

Dear Colleague:

On July 5, 2005, the Director of the Centers for Disease Control and Prevention (CDC) disseminated a "Dear Colleague" letter about HIV reporting to state and local health departments and other relevant public health partners. In this letter, CDC recommended that all states and territories adopt confidential name-based surveillance systems to report HIV infections. The letter also noted that it is critical that all areas move as quickly as possible to an integrated, confidential name-based HIV/AIDS reporting system, and stated a commitment on the part of CDC to provide technical assistance for this transition.

As one part of this technical assistance, HIV Incidence and Case Surveillance Branch (HICSB) of CDC has developed the CDC Policy on Acceptance and Use of HIV Case Surveillance Data for States Converting from Non-named to Name-based Reporting Systems, which we will be including as an Appendix to HIV/AIDS Surveillance Guidelines. We have disseminated this to areas transitioning from non-name-based to name-based HIV reporting. I have included this policy as attachment with this letter, and will be making it available on the secure HICSB website (http://www2a.cdc.gov/hicsb). If you have any questions about this policy, please contact your area's core surveillance technical assistance epidemiologist. If you are not sure who this person is, please find the state assignments on the secure HICSB website under "Branch State Assignment List" or contact HICSB at (404) 639-2050.

Sincerely,

Lisa M. Lee

Lisa M. Lee, PhD
Acting Branch Chief, HIV Incidence and Case Surveillance Branch
Division of HIV/AIDS Prevention – Surveillance and Epidemiology
National Center for HIV, STD, & TB Prevention

Attachment

CDC Policy on Acceptance and Use of HIV Case Surveillance Data for States Converting from Non-named to Name-based Reporting Systems (an Appendix to HIV/AIDS Surveillance Guidelines)

Attachment

Appendix to HIV/AIDS Surveillance Guidelines: CDC Policy on Acceptance and Use of HIV Case Surveillance Data for States Converting from Non-named to Name-based Reporting Systems

CDC has had and will maintain a policy to accept only HIV case surveillance data collected, reported, and maintained in state/local HIV/AIDS surveillance systems using confidential name-based methods. CDC will continue to ensure that HIV surveillance data reported to CDC are consistent with the ongoing policy.

Acceptance of Case Data from Jurisdictions Transitioning to Confidential Name-Based Reporting

Code-based Systems

1. The only cases that will be accepted are those entered into local HARS/eHARS systems after the implementation date of the change to name-based HIV reporting.
2. Each area has to submit and have approved by HICSB their plan to implement name-based reporting:
    a. This plan must state that only name-based reports/documents will be entered into local HARS/eHARS.
    b. This plan may include options for retrieving some data previously collected under code-based reporting and attaching to name-reported cases.
    c. All "newly reported" HIV cases from these areas must undergo rigorous de-duplication with other jurisdictions. CDC will assist with this task by providing sites with a list of potential duplicates through the routine deduplication process run monthly. The transition plan must include planning for the resolution of these potential duplicates.
    d. This plan must include steps that will be taken to ensure that newly reported HIV cases are investigated to determine correct HIV diagnosis date.

Name-to-Code-based Systems

1. The only cases that will be accepted are those entered into local HARS/eHARS systems after the implementation date of the change to name-based HIV reporting.
2. Each area has to submit and have approved by HICSB their plan to implement name-based reporting:
    a. This plan must state that only name-based reports/documents will be entered into local HARS/eHARS.
    b. This plan may include options for retrieving some data previously collected under name-to-code-based reporting.
        i. If areas have a variable or other marker that indicates that name was never removed from the record, these records may be immediately imported back into HARS/eHARS.
    c. All "newly reported" HIV cases from these areas must undergo rigorous de-duplication with other jurisdictions. CDC will assist with this task by providing

sites with a list of potential duplicates through the routine deduplication process run monthly. The transition plan must include planning for the resolution of these potential duplicates.

d. This plan must include steps that will be taken to ensure that newly reported HIV cases are investigated to determine correct HIV diagnosis date.

Use of Data from Jurisdictions Transitioning to Confidential Name-Based Reporting

When name-based cases are reported to and entered into HARS, the resulting records are processed by HARS for submission to CDC. Names and other personally identifying information are removed, and the data are then sent via the Secure Data Network.

When a state submits data that is accepted in the national HIV/AIDS surveillance system, CDC immediately includes them in the "reported cases" tally. Cases are counted in all data runs using reported cases that go to HRSA and are included in any subsequent national surveillance reports.

Other uses of the data, including descriptions of the epidemic, examining trends over time, and counting cases adjusted for reporting delay, use "estimated diagnosed cases." In order to estimate the number of cases reliably, a system must have reporting in place 4 years before the data can be adjusted statistically and included in such tables.

Examples of this can be found in our recent surveillance reports. These reports include examples of how data from states that have recently implemented name-based HIV reporting have been processed and displayed (independent of whether it reflects a transition from another reporting scheme). Examples of areas that have recently implemented include Georgia (new implementation) and Puerto Rico (transition). Data from these areas are included in the 2003 surveillance report. Please see http://www.cdc.gov/hiv/stats/2003SurveillanceReport/table16.htm.