

HIV REPORTING IN CALIFORNIA

Questions and Answers for Health Care Providers
Preparing for Compliance to the California
HIV Reporting Regulations

May 2002

Regulations to report HIV infection without clinical AIDS have been developed by the California Department of Health Services (DHS) using a non-names code.

The new reporting system will be in effect July 1, 2002. This document provides the answers to "Frequently Asked Questions" about this new reporting system. Further information is available from the San Diego County Health and Human Services Agency Office of Public Health, Community Epidemiology Division, HIV/AIDS Epidemiology Unit, (619) 515-6675.

Questions
&
Answers

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Acquired Immunodeficiency Syndrome (AIDS) is already reportable. Why is HIV reporting needed?

Tracking cases of clinical AIDS, the progressive disease characterized by opportunistic infections and cancers resulting from HIV infection, has been the cornerstone of epidemiologic surveillance since it was first recognized in 1981. Clinical AIDS (as defined by the CDC (Centers for Disease Control and Prevention)) has been reportable to California DHS since 1983. In recent years, advances in the treatment of HIV infection have significantly reduced the likelihood that an HIV-infected individual will progress to AIDS. For this reason, focusing surveillance on AIDS cases alone no longer provides a good picture of the extent of the HIV epidemic, or trends among groups of people affected. Because resources, including federal funds to fight the disease and provide services, are distributed in proportion to an area's needs it is important to monitor the total number of people living with HIV infection.

How will the cases be counted?

Under the regulations, the individual's name is not included when a case of HIV infection is reported. Instead of names, cases will be coded using bits of personal information, such as gender and date of birth, that are not sufficient to directly reveal an individual's identity. Coding cases without actual names serves two important purposes:

- 1) it protects individual privacy in a manner consistent with current California Health and Safety Codes (H & S 120975 - 121035)
- 2) it provides a mechanism to match and unduplicate case reports.

How likely is it that reported information, including the non-name code, would be able to identify an individual?

The coding elements are insufficient to reconstruct or definitively confirm an individual's identity.

What are the chances that duplication of case reports will occur using this non-names based system?

An evaluation team reviewed the stability of different combinations of potential variables and determined that with the above group, the duplication rate is likely to be less than two percent.

Will AIDS still be reportable?

Yes. All diagnoses of AIDS (according to the current CDC surveillance definition) will continue to be reportable, by name, as currently required. This will enable California DHS to continue monitoring trends in the development of AIDS statewide. Cases of AIDS and HIV infection (without AIDS) will be reported using the same form.

Who is mandated to report cases of HIV infection?

The regulation defines mandated reporters as:

- health care providers licensed by the State (MDs, osteopaths, nurse practitioners, etc.)
- designees acting under the general supervision of a physician and surgeon
- designees of the local Health Officer such as counselors in a County Confidential HIV Testing Program

Facilities with large HIV caseloads should consider developing a coordinated reporting plan and designate an individual to be the responsible reporting party.

What tests should be reported?

The regulation now defines "Confirmed HIV test" as a procedure which verifies the presence of HIV infection as determined by any clinical laboratory test or examination used to detect the presence of HIV, a component of HIV, or antibodies or antigens to HIV, including the HIV antibody (HIV-Ab), HIV p-24 antigen, Western blot (Wb), and immunofluorescence antibody tests; or all tests used to monitor HIV infection, including HIV nucleic detection.

For which of my HIV-positive patients should I file a report? What if my patient is also seeing another health care provider?

You should submit a report for all patients already known to have HIV infection who are receiving primary health care from you. The new surveillance system can identify duplicate reports, so reporters do not need to be concerned about patients being reported more than once by different providers. To ensure completeness and accuracy of surveillance data: "When in doubt, report."

How do the proposed regulations interface with existing regulations and statutes?

Existing California Statutes prohibit health care providers from disclosing HIV test results without specific, written, informed consent of the patient. Under the HIV reporting regulations, an individual's consent is not required prior to reporting test results. The HIV reporting regulations specify that case reports will not include a patient's name or other personally identifying information. The regulations do not violate confidentiality provisions when a health care provider reports a person living with HIV infection (non-AIDS) in a manner that prevents actual identification of the patient.

How will the security and confidentiality of reported information be assured?

Both the County of San Diego, Health and Human Services Agency, HIV/AIDS Epidemiology Unit and the California Department of Health Services, Office of AIDS, HIV/AIDS Epidemiology Branch, which will receive the HIV case reports, have strong security procedures in place to protect the confidentiality of HIV-related data. Only a few specific employees, who must take an oath of confidentiality, have access to the data. Security measures protect the building, room and computer systems. Data are released only in aggregate form with no information that could identify individuals. Since California DHS initiated the collection of AIDS-related information in 1983, the data have been kept fully secure and confidential.

Will anonymous HIV testing still be available?

Yes. Anonymous testing is an important part of HIV prevention efforts. Free, anonymous HIV testing will continue to be available at sites throughout the state so that no individuals need delay or avoid testing out of privacy concerns. Anonymous tests are not reportable under the HIV reporting regulations.

What is the difference between anonymous and confidential HIV testing?

Anonymous HIV testing is performed without any record of a patient's identity. Because information required for reporting HIV is not available in anonymous programs, no case reporting will originate there. In confidential testing, test results are recorded in the individual's medical chart. For people who test positive at confidential test sites, a case report will be sent to the County of San Diego, Health and Human Services Agency. People who initially test positive at anonymous test sites will be reported to the County of San Diego, Health and Human Services Agency, by non-name code, once they begin treatment with a health care provider.

The HIV/AIDS case report form indicates it should be used for patients age 13 and older. How do we report HIV infection in children?

If providers are concerned that a child in their care has not been reported, they should report the case (using the pediatric form), or call the local health department in the county where the patient resides for guidance. San Diego County, Office of Public Health, HIV/AIDS Epidemiology (619) 515-6675.

What if I don't have all the information I need to complete the case report?

Missing information is not a reason not to file an HIV case report. Reporters should make all reasonable efforts to obtain this information, including contacting the medical records department or the health care facility's patient information system. If the missing information cannot be obtained, complete the report form as fully as possible. If the last four digits of the Social Security Number are not available, four digits of zero (0000) should be used.

How was the HIV reporting system developed?

The California DHS, Office of AIDS encouraged participation from various groups including impacted community groups and professional groups. The proposed regulations were drafted by the Office of AIDS and made available for a period of public comment. More than 100 comments were received and considered.

How will the reported information be used?

Information from disease reporting -- also called "surveillance" data -- is used to guide disease prevention, treatment and service programs. Specifically, HIV surveillance data will be used to:

- ◆ track the scope of, and trends within, the HIV epidemic in San Diego County and all of California.
- ◆ target and evaluate HIV prevention efforts.
- ◆ estimate needs for health care and other services.
- ◆ allocate resources for HIV prevention and treatment.
- ◆ qualify for federal funds that are distributed based on local statistics.

Information from HIV reporting will be used for epidemiologic and public health planning purposes only. Data used for public health planning are presented in aggregate form only. No identifying data is ever released regarding an individual case.

How do I obtain case report forms and other materials?

For supplies and information,
Call the San Diego County Office of Public Health,
HIV/AIDS Epidemiology Unit
at the San Diego County Health and Human Services Agency:
(619) 515-6675

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County of San Diego
Health & Human Services Agency