



California’s HIV Surveillance System: Ensuring that it fully reflects case load

Executive Summary: In order to develop a surveillance system for California that best serves public health needs and assures the state of obtaining its “fair share” of Ryan White funding, this policy brief recommends: 1) expanding outreach efforts; 2) erasing the distinction between HIV and AIDS status to redeploy resources used in reclassification; 3) assuring that all persons receiving RW services are listed in the names-based registry; 4) providing local health jurisdictions with limited access to the state HIV registry; 5) collecting more information at the time of a preliminary positive HIV test; 6) publishing data on numbers of HIV cases receiving care in California, but first diagnosed in another state and listed in that state’s registry.

Background: It is critical that California’s Names-Based Reporting System be as robust as possible in order to insure that California receives its fair share of federal HIV/AIDS resources. How the federal government allocates these resources is based on the number of cases in the HIV/AIDS names-based registry. Cases are reported by physicians or laboratories to the County in which they are located, and the County confirms a case and then reports the

person’s name to the state. The state collects these names in its registry and reports numbers of confirmed HIV/AIDS cases to the federal government, but does not report the names themselves. California has collected AIDS cases by name since 1982, but put in place in 2002 a code-based system for reporting non-AIDS HIV cases that did not include names. However, beginning in 2006, California became one of the last states to adopt names reporting for non-AIDS HIV cases. This change was made not only for sound public health reasons, but because beginning in 2013, Ryan White Comprehensive AIDS Resources Emergency (CARE) Act (RWCA) funding, including the funding for the AIDS Drug Assistance Program (ADAP) will be based solely on cases reported by name to the state.

Recognizing the importance of this issue, the California Legislative Analyst’s Office (LAO), which advises the Legislature, published a report in February of 2010 that explained the names-based reporting system and offered recommendations for improvement. The report noted that there is no systematic requirement to assure reporting the names of individuals receiving drugs through ADAP to the state’s surveillance database. The LAO estimated that

several thousand HIV-positive persons may now be receiving various state services but are not yet counted by name in the surveillance system. The LAO report concluded that “...the State’s fairly recent shift to a names-based surveillance database means that its data on the number of HIV cases is not complete, putting it at a major disadvantage in receiving federal funds to combat the disease. Efforts to enhance the number of cases reported will increase the State’s competitiveness for federal funding for HIV and AIDS....We [LAO] recommend that the OA develop a process to cross-check the records of individuals in state-supported HIV and AIDS programs to ensure that they are included within the surveillance database and modify electronic reporting rules that apply to other diseases to HIV cases.” OA responded to the LAO’s recommendations, stating that “Current gaps in the surveillance system as noted in the LAO report may be due more to statutory and regulatory limitations rather than from surveillance practice inefficiencies or missed opportunities” and went on to add that “We [OA] expect that California will be able to switch to submitting only names-based HIV counts in the federal year 2012 award cycle (beginning October 1, 2011). This cycle will use 2010 data, and we [OA]

Funding provided by the California HIV Research Program





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anticipate that our 2010 names-based data will be as or more complete than the combination of code-based and names-based cases.”

A second factor that may result in California’s not receiving its fair share of funding is the Center for Disease Control and Prevention (CDC)’s policy of attributing a case to the state in which the person was diagnosed, without taking into consideration migration between states. Thus, a person diagnosed with HIV in Massachusetts who subsequently moves to California continues to be counted in Massachusetts’ registry, although California may be providing ADAP and other HIV-related care services for that individual. California may greatly benefit from changing policy to attribute HIV cases to the state in which the HIV-infected individuals are being treated, since it is likely that California is a net immigration state for people with HIV, given the admirable 25-year history of providing generous benefits for people with HIV and AIDS.

Methods: UCLA and APLA undertook a study to determine what changes were being made, or could be initiated, in the surveillance system in order to ensure that HIV case numbers accurately reflect the HIV burden within the state.

Results: Our study concluded that through enhanced efforts at the local and state levels, California has achieved a robust names-reporting system in which the majority of

persons with HIV in care are now included in the HIV case registry. Nonetheless, there remains room for significant improvement.

Active case follow-up at the local level has helped California close the gap between code based reports (41,155) and names-based reports (40,590). However, Counties reported a number of continuing challenges:

- Insufficient staffing for active outreach.
- Costly re-classification of persons with non-AIDS HIV at time of AIDS diagnosis.
- Lack of coordination between publicly funded services and the Registry, e.g., some current ADAP clients are not listed in the Registry.
- Lack of centralized statewide reporting structure, such as exists in smaller states, which could reduce duplication of County efforts.
- Preliminary positive test does not result in a full names report.
- Migration from state of first diagnosis means some receiving services in California are not registered.

Recommendations: In order to meet the ambitious goals set by OA so that California does not face penalties as a result of a flawed names-based reporting system, and to ensure that the state obtains its “fair share” of federal Ryan White funding, our report makes the following

recommendations:

- Expand outreach efforts, which cost/benefit analysis shows is cost-saving.
- Reward agencies with high rates of return for confirmatory results or that successfully link HIV-positive clients to care.
- Encourage CDC to erase reporting distinction between HIV and AIDS status to redeploy resources used for case reclassification.
- File registry reports for all new and recertifying ADAP enrollees.
- Provide local health jurisdictions limited access to the state HIV case registry to reduce duplicative efforts.
- Collect more extensive information at the time of a preliminary positive HIV test.
- Publish the number of a state’s reported HIV cases that were previously reported in another state.
- Modify CDC reporting to separately list state of origin for HIV cases and for diagnosed AIDS cases, if the distinction between HIV and AIDS persists.
- Distribute to local health jurisdictions data on persons who have received an HIV or AIDS diagnosis in California and are currently receiving care in the state but who are listed in another state’s registry.

For further information: The entire report will be posted on the APLA and CHIPTS websites in April, 2011.

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