

**Office of AIDS
HIV Reporting Stakeholders Meeting Summary
Sacramento, California
April 9-10, 2008**

I. ACKNOWLEDGEMENTS

The California Department of Public Health (CDPH), Center for Infectious Diseases, Office of AIDS (OA) wishes to extend its thanks to the many participants in the HIV Reporting Stakeholders Meeting. This meeting was attended by professionals from a broad range of disciplines including:

- Organizations focusing on HIV prevention, advocacy, and services to HIV-positive persons:

AIDS Project Los Angeles; American Academy of HIV Medicine; Beyond AIDS; Bienestar; GCG Rose and Kindel; AIDS Health Foundation; Los Angeles Gay and Lesbian Center; Netherland Healthcare Consulting; Project Inform; San Francisco AIDS Foundation; University of California, San Francisco, Center for AIDS Prevention Studies; Women Organized to Respond to Life Threatening Disease; and the Los Angeles County, Department of Public Health, Office of AIDS Programs and Policy, Educational Services Division.

- Professional and public health organizations:

California Conference of Local Health Officers; California Conference of Local AIDS Directors; and the California Medical Association; Los Angeles County, Department of Public Health, Sexually Transmitted Disease (STD) Program and CDPH's STD Control Branch, Division of Communicable Disease Control.

- Health care systems, health care providers, and laboratories:

Quest Diagnostics; Kaiser Permanente Northern California; California Medical Facility, Clinical Services; San Ysidro Health Center.

- Local HIV/AIDS surveillance programs:

Cities of Berkeley and Long Beach; Counties of Alameda; Contra Costa; Del Norte; El Dorado; Fresno; Imperial; Kern; Lassen; Los Angeles; Madera; Marin; Orange; Placer; Sacramento; San Bernardino; San Diego; San Francisco; San Joaquin; San Mateo; Santa Clara; Solano; Sonoma; Stanislaus; Sutter; and Yuba.

II. PURPOSE OF THE MEETING

During the HIV name-based reporting emergency regulations process, OA received comments representing a wide spectrum of opinions, concerns, and requests. To provide an opportunity for consensus-building discussion regarding the current HIV reporting process, OA held the HIV Reporting Stakeholders Meeting at the Holiday Inn Capitol Plaza Hotel in Sacramento, California, on April 9 and 10, 2008. This meeting convened stakeholders from local health departments (LHDs), governmental public health agencies at the state and local level, private laboratories, health care providers, and private organizations that serve the needs of HIV-positive patients.

III. TOPICS DISCUSSED

Day One

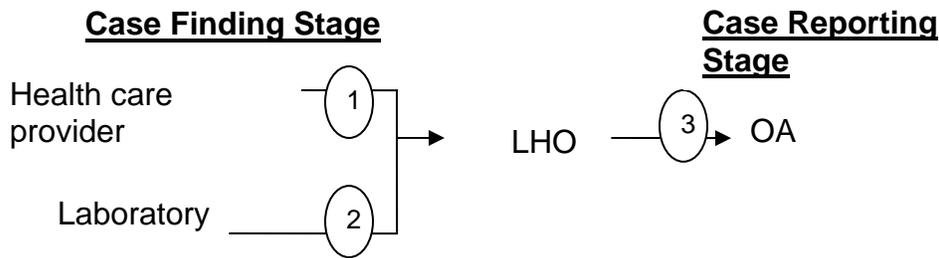
- What is working at the state and local levels?
- Data transmission: encryption, faxing, and mailing options.
- Office of Administrative Law Technical Recommendations for HIV Disease Reporting Consistency.

Day Two

- Centralized laboratory reporting (CLR).
- Uses of HIV/AIDS data for public health purposes.
- Policy and funding implications of including HIV/AIDS reporting in other communicable disease reporting regulations.

IV. SUMMARY OF STAKEHOLDER GROUP DISCUSSION

Disease reporting regulations provide specificity to statutes that govern the reporting of HIV and other diseases. Because provider systems and health jurisdictions are impacted by a unique set of operational, economic, legal, and political influences, the sharing of common goals and how to best meet those goals frequently took divergent paths. Shared opinions often aligned with stakeholders' respective roles in the HIV reporting process. The following diagram was helpful for clarification, particularly when discussing issues specific to the three separate points of data transmission: Case Finding Stage – 1) health care provider to the local health officer (LHO); and 2) laboratory to LHO; and Case Reporting Stage - 3) LHO to OA.



During the two-day conference, the following emergent themes were identified:

Common language: Stakeholders suggested a need to develop a common language for some routinely used HIV/AIDS surveillance terms and differences in terminology were often seen between stakeholders representing different stages in the HIV reporting process. The definition of ‘case report’ for example, varied depending on the perspective of the stakeholder. Some stakeholders viewed laboratory reports and other surveillance prompts as ‘case reports’ while others reserved the term only for completed HIV/AIDS Case Report Forms. There was an agreement upon case finding and case reporting terminology as represented in the previous diagram.

Security and Confidentiality: Confidentiality is a concern among all stakeholders. A breach impacts not just the individual provider or government agency, but the integrity of the entire public health care system.

Cost effective use of resources: HIV/AIDS surveillance has historically relied heavily on active surveillance, which is relatively labor intensive. Efforts to improve HIV reporting should focus on making things simpler, more routine, and cost-effective, while preserving high standards of security and confidentiality.

Quality and utility of HIV reporting information: Quality and completeness of HIV reporting is of great concern. National standards exist both for completeness of reporting and completeness of specific data on the case report form. Further, unlike other diseases, HIV case counts are tied to allocation of Federal dollars for care and treatment of HIV-infected persons. Assessing completeness of reporting is complicated by the fact that jurisdictions and health provider systems have arrived at different decisions regarding reporting of previously reported code-based cases.

A. Encryption

Encryption is a method used to ensure security of information transmitted electronically. Encryption technologies, including encrypted e-mail and facsimile (fax), have been suggested as one way of streamlining transmission of HIV case information between health care providers, laboratories, and LHDs.

Recurring themes in the discussion of encryption centered on cost, LHD capacity, and differing views on the need for specificity in regulations to govern encryption standards. OA is working with the Office of Regulations to increase our understanding of regulatory requirements and limitations in this area.

Cost

- Electronic transmission is cheaper than paper and is compatible with other technology already in use (e.g., the Confidential Morbidity Report [CMR] system used by a few counties and laboratory standards).
- It is not always easy for laboratories or providers to incorporate encryption software into their data systems.
- Many providers are using Electronic Medical Record reporting systems, but this technology is not available to all.

LHD Capacity

- All LHDs do not have the same level of capacity and some LHDs may not be able to receive information electronically.
- Restrictions based on jurisdictions with lowest capacity may have forced the process to the lowest level.

Security

Concerns were also expressed about the presumed superiority of paper-based over electronic systems in terms of confidentiality protection, particularly as electronic transmittal offers some protections, such as access tracking and encryption that paper-based systems do not.

In summary, participants urged OA to explore the maximum flexibility allowed in statute, regulations, and policy to enable the use of encryption technologies while preserving the highest standards of protection of confidentiality.
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B. Data Transmission Issues

Stakeholders generally expressed interest in secure Web-based systems and e-mail for data transmission, which were seen as cost efficient and potentially safer than paper-based systems. Secure data transfer is in place in some, but not all jurisdictions.

Stakeholder opinions diverged on the issue of faxing. Some stakeholders expressed an interest in having encrypted faxing be an option for health care providers reporting to LHDs as faxes are routinely sent to pharmacies and other entities. Other stakeholders urged caution in allowing this technology as dial faxing is not secure.

Recurring themes in the discussion of data transmission issues revolved around definitions of terms, specific needs at different points in the data transmission process, and varying technological capacity within each level of the reporting process.

Language in regulations:

- Questions arose regarding the definition of terms like ‘person-to-person’ communication and ‘secure fax.’ Can ‘person-to-person’ communication involve phone calls? Is a ‘secure fax’ the same as an encrypted fax?

Issues differ for different points in the data transmission process:

- The level of comfort with transmission technologies (fax, e-mail, Secure Data Network) differs at each stage of the reporting process.
- OA will identify policy, regulatory, or statutory barriers to the use of specific technologies at each level of the HIV reporting system.

Capacity issues:

- Variation exists between large and small provider systems. Private providers without access to significant technology, need equally viable options to ensure reporting from their offices is secure.
- Some LHDs already have a system into which HIV can be included.
- Because care of HIV-positive patients involves laboratory testing to monitor infection and all HIV-positive tests are reportable, it is not uncommon for laboratories to send multiple test reports to the LHO for a single individual. Perspectives on the utility of laboratory test results beyond the first confirmatory HIV test (e.g., multiple viral loads, CD4 counts) differed among stakeholders.

In summary, participants urged OA to explore the maximum flexibility allowed in statute, regulations, and policy to enable the use of electronic data transfer technologies (especially secure Web-based systems and encrypted e-mail) while preserving the highest standards of protection of confidentiality.

A workgroup was established to work on these issues.

C. Regulation Recommendations for HIV Disease Reporting Consistency

Discussion on this topic centered around the question of how HIV data are treated differently than AIDS data under the law. HIV regulations were based initially on standards in place for AIDS reporting and codify policy that is not codified for AIDS reporting.

Some stakeholders expressed reluctance to expand HIV-associated restrictions to AIDS case reporting. Other stakeholders noted that the large volume of laboratory reports for HIV tests makes HIV reporting more prone to a breach in confidentiality.

Other comments: If regulations are changed to make AIDS reporting and HIV reporting specific, it was suggested that OA revisit the Confidentiality Agreement, which includes a provision that the agreement is not valid unless signed by OA's HIV/AIDS Case Registry Section Chief. The intent of this provision was to allow OA to be aware of who was accessing HIV/AIDS surveillance information. Some LHDs noted that many staff sign, but few actually have access. It was suggested that OA change this form and replace OA's Chief's signature with the LHD Overall Responsible Party or Privacy Officer.

In summary, it would be ideal for HIV and AIDS reporting regulations to be merged. However, it would be critical for each issue to be evaluated carefully and the least restrictive (but secure) option be adopted. Thus, AIDS could not be "dropped in" to the HIV regulations or visa versa. The time and resources required to make such changes need to be weighed against the potential benefits. If other issues are identified that will require regulatory amendments, then this issue should be seriously considered.

D. CLR

Stakeholders generally expressed support for CLR. However, there were three distinct perspectives, one from regional laboratories, another from large counties with existing, functional systems in place, and a third from smaller LHDs without their own systems. There was also concern over the development of a separate system for HIV reports when the state is in the process of developing a laboratory reporting system for other communicable diseases. Concern was also expressed regarding OA's current capacity to handle the large volume of laboratory reports quickly and efficiently.

- Regional laboratories generally found CLR desirable and less burdensome, given that the regional laboratory does not have to address a host of LHD-specific standards. At least one laboratory stakeholder supportive of CLR noted that in terms of efficiency, CLR eliminates a lot of work.

- Large counties with functional systems expressed concern over the creation of another layer in the reporting process.
- Smaller counties without their own systems expressed interest if the process could be shown to be effective and efficient. Some LHDs using laboratory data for unmet needs assessment asked if the laboratories could send all laboratory reports both directly to LHD and OA. Other stakeholders expressed a desire to have OA unduplicate reports before distributing information to local health jurisdictions.

In summary, participants urged OA to explore this option, taking into consideration the need for OA to provide appropriate reports back to local health jurisdictions in a timely manner for both surveillance and other local health department purposes.

A second workgroup was established to work on these issues.

E. Use of HIV/AIDS Surveillance Data for Public Health Purposes

Discussion of the use of HIV/AIDS surveillance data for public health purposes centered mainly on partner services and secondarily on case management. There was a range of support for using HIV/AIDS reporting data for partner services. There were also significant concerns about this suggestion and several participants referred back to the historical development of the current regulations and promises that may have been made about not using these data for non-surveillance purposes. Although there was a lack of consensus on this topic, the following were noted:

- Acceptability of using case-level surveillance reports for partner service vary from one jurisdiction to another.
- This issue should not be considered only from a public health perspective. Dialogue should engage the community.
- Information on effective programs, for example those that embed public health workers in high-volume HIV service sites, could be used to guide discussion.

In summary, OA is committed to moving slowly, thoughtfully, consistently, and deliberately with further exploration in this area.

A third workgroup was established to work further on these issues.

F. Policy and Funding Implications of Including HIV/AIDS Reporting in Other Communicable Disease Reporting Regulations

There was some question among stakeholders of the benefit including HIV/AIDS reporting with other communicable diseases and an overall sense this issue may not have as much traction as it previously did.

In summary, it was agreed that there was no need to follow up further on this issue.

V. OUTCOMES AND FOLLOW UP

The following three workgroups will be convened for in-depth discussion of issues surrounding the following major topic areas:

- Data Transmission Issues

UPDATE:

The Data Transmission Issues workgroup convened their first teleconference on June 25, 2008. Although participants had previously identified three data transmission topics: secure Web-based systems; data transfer via fax; and data transfer via e-mail, the first meeting consisted of a discussion on Web-based transmission of HIV/AIDS information. Discussions of e-mail and fax transmission of HIV/AIDS case information are to be addressed at a future date. Although the Centers for Disease Control and Prevention (CDC) plan to deploy Enhanced HIV/AIDS Reporting System (eHARS) in May or June 2009, OA has participated in numerous meetings regarding the integration of eHARS and Web-CMR.

- ***Issues related to eHARS and Web-CMR will be discussed at the second Surveillance Stakeholders Meeting on December 3, 2008.***

- Other Uses of HIV/AIDS Data for Public Health Purposes

UPDATE:

The Other Uses of HIV/AIDS Data for Public Health Purposes workgroup convened their first teleconference on July 15, 2008. Discussions centered on the facilitation of partner services (PS) using individual-level surveillance data rather than aggregate surveillance data. On August 26, 2008, OA hosted a technical assistance site visit with CDC PS representatives. Technical assistance was requested for OA, STD, Tuberculosis, and representatives from selected LHDs. At this meeting, CDC presented PS draft guidelines, specifically the security and confidentiality requirements. A mutual interest was expressed regarding exploring the possibility of conducting three PS pilot programs in select counties. There was a general consensus that it is

important to create a timeline and process to obtain stakeholder, provider, and community support and input.

- ***Considerations regarding such a pilot project will be discussed at the second Surveillance Stakeholders Meeting on December 3, 2008.***
- CLR
- ***Considerations regarding implications within the context of HIV Incidence Surveillance (as well as scale-up of HIV and integration of HIV and core surveillance) will be discussed at the second Surveillance Stakeholders Meeting on December 3, 2008.***