



<b>DEPARTMENT</b>	1501 Capitol Ave., Suite 71.6101	<b>PHONE</b> 916.440.7594	<b>Roberta Lawson</b>
<b>OF HEALTH</b>	P.O. Box 997413, MS 7003	<b>FAX</b> 916.440.7595	RDH, MPH
<b>SERVICES</b>	Sacramento, CA 95899-7413	rlawson1@dhs.ca.gov	<i>Executive Administrator</i>

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Sandra Shewry, Director  
Mark Horton, M.D., M.S.P.H., State Public Health Officer  
California Department of Health Services  
1501 Capitol Avenue, MS 0000  
Sacramento, CA 95814

Dear Director Shewry and Dr. Horton:

The California Conference of Local Health Officers (CCLHO) has recently been informed of communications coming from the Office of AIDS to local surveillance staff regarding HIV names reporting. We are very concerned about the direction the Office of AIDS appears to be taking regarding the process of HIV names reporting.

CCLHO acknowledges that there remains sensitivity around this disease. CCLHO, itself, has struggled for many years to gain consensus on the reporting issue. It was only in the last few years that we came to agreement and decided to pursue legislation to implement HIV names reporting. CCLHO was a sponsor of SB 699. It was the intent of that legislation to regularize the reporting of HIV and to discontinue a difficult and complicated process that did not work well.

CCLHO has an advisory capacity to the California Department of Health Services (CDHS). We want to be as clear as possible in our advice to the Department. Since there are probably a number of practices that will have to be changed, we give our advice as a series of principles that should guide this implementation.

The following are the principles that CCLHO feels are important as we carry out implementation of HIV names reporting.

- **Principle #1 - HIV is an STD and a blood-borne pathogen.**
- **Principle #2 - There should be no barriers placed on the reporting of HIV by name from local providers to the local health department.**
- **Principle #3 - Confidentiality around HIV is not an unusual challenge for local health departments.**
- **Principle #4 - It is incumbent upon us to accurately describe the changing**

**epidemiology of the HIV epidemic in California.**

- **Principle #5 - Large amounts of funding come into our state for HIV services. Funding coming into California is dependent upon good data.**
- **Principle #6 - CDHS must distinguish contractual obligations they have with the Centers for Disease Control and Prevention (CDC) and the legal obligations of SB 699.**
- **Principle #7 - Destruction or purging of data is not appropriate.**
- **Principle #8 - The staff doing HIV surveillance work at the local level are employees of local health departments.**
- **Principle #9 - The state is not in a position to dictate disciplinary action for employees of local health departments.**
- **Principle #10 - The Office of AIDS staff must not threaten or otherwise intimidate employees of local health departments.**

**Principle #1 - HIV is an STD and a blood-borne pathogen.**

All diseases have their unique aspects, such as incubation periods, modes of transmission, and pathologic manifestations. HIV has its unique aspects as well. But when it comes down to the basics of preventing transmission and treating disease, HIV is not that unique. As we reflect on the 25 years since we became aware of the epidemic, it is time to stop treating this disease as something more unique than it is.

**Principle #2 - There should be no barriers placed on the reporting of HIV by name from local providers to the local health department.**

Barriers to reporting include special forms required of providers, special or different ways of communicating information from providers to the local health department than are required for other diseases, or special software requirements, including encryption requirements. The initial communication from provider to local health department should be on the CMR form or another appropriate means of getting the local health department the information we need to complete the case report. Labs should report HIV results in the same fashion that they report all other communicable diseases. Local staff will be responsible for filling out the HIV/AIDS case report form, as has been the practice in the past.

In addition, AIDS has been reportable by name for decades and there are a number of systems that have clinical and financial data on those with both HIV and AIDS, such as the Medi-Cal database and the ADAP database. These systems do not require extraordinary means of communication, HIV reporting shouldn't either. We are not aware of breaches of confidentiality with these systems and do not expect such breaches with HIV names reporting.

Any barriers placed on the reporting of HIV, even in the name of confidentiality, is not appropriate and will do a disservice to the people of California.

**Principle #3 - Confidentiality around HIV is not an unusual challenge for local health departments.**

Almost everything a local health department does in relation to disease control is based in confidentiality. Every day local health departments deal with confidential information. Staff are trained on confidentiality and understand its significance. This is not a new concept to them.

**Principle #4 - It is incumbent upon us to accurately describe the changing epidemiology of the HIV epidemic in California.**

Just like every other disease, we use data to describe the characteristics of that disease in the population. We then use that data to develop intervention techniques. Lack of complete data severely inhibits our ability to intervene in the transmission of communicable diseases.

**Principle #5 - Large amounts of funding come into our state for HIV services. Funding coming into California is dependent upon good data.**

This has never been as important as it is now. As of April 17, 2006, we have no cases of HIV to report to the CDC. It is very important that over the next year or so, we reconstruct the data that we had when HIV was reported by soundex, so California's funding is not critically curtailed. In addition, since we are now starting at zero cases, a fair allocation of HIV cases, for the purposes of funding, must be discussed further.

**Principle #6 - CDHS must distinguish contractual obligations they have with the CDC and the legal obligations of SB 699.**

The legal requirements that flow from SB 699 are distinct from contractual or other obligations that the Department has with the CDC. These two issues should not be conflated when issuing regulations or directives to local health departments.

**Principle #7 - Destruction or purging of data is not appropriate.**

We will not destroy or purge data that may be helpful in describing the local epidemiology of HIV. This suggestion goes against every basic epidemiologic principle.

**Principle #8 - The staff doing HIV surveillance work at the local level are employees of local health departments**

Appropriate communications strategies between the Office of AIDS and local health department staff must be developed.

**Principle #9 - The state is not in a position to dictate disciplinary action for employees of local health departments.**

That the above two principles even need to be stated indicates that an unclear line of authority exists between the Office of AIDS and local health department staff. These are local staff who, while they may have a relationship with the Office of AIDS, are not supervised or managed by the Office of AIDS. The Office of AIDS must not communicate directly to line staff around policy issues, such as HIV names reporting,

without first consulting with the administration of local health departments, which include both CCLHO and the County Health Executives Association of California (CHEAC).

**Principle #10 - The Office of AIDS staff must not threaten or otherwise intimidate employees of local health departments.**

Again, while we think this should go without saying, we have received numerous reports from our staff that information contained in the bill regarding breaches of confidentiality has been communicated to them in a threatening and intimidating manner. This must stop.

CCLHO recommends that the office of AIDS develop an ad-hoc committee over the next month to deal with this implementation process and in the development of regulations. Membership in the committee should be from the Office of AIDS, CCLHO, CHEAC, and the California Conference of Local AIDS Directors (CCLAD).

Sincerely,

*(Original signed by:)*

Glennah Trochet, M.D.  
President, CCLHO

cc: Barbara Bailey, Assistant Chief  
Office of AIDS  
California Department of Health Services

Kevin Reilly, D.V.M., M.P.V.M.  
Deputy Director, Prevention Services  
California Department of Health Services

Kevin Hutchcroft, President CCLAD  
HIV/AIDS Prevention and Control Program  
770 South Bascom Avenue  
San Jose, CA 95128

Gayle Erbe-Hamlin, President CHEAC  
El Dorado County  
Director, Public Health Services  
931 Spring Street  
Placerville, CA 95667

Judith Reigel, Executive Officer  
CHEAC  
1127 11<sup>th</sup> Street, Suite 309  
Sacramento, CA 95814