



UCSF AIDS Health Project

Training Program http://ucsf-ahp.org/HTML2/services_providers_training.html

Online Resources for the Basic I

HIV Reporting Laws: Anonymous versus Confidential Testing

CDPH/OA funded test sites provide either anonymous or confidential HIV testing. There are advantages and disadvantages to both systems of testing.

Anonymous Testing

Anonymous test sites are “dedicated” facilities: their main or only reason for existing is to provide the HIV antibody test. Clients come to the test site voluntarily and specifically to be tested for the HIV antibody.

At anonymous test sites, an individual is given a code number that is linked to his or her test result and lab slip. The person never gives any identifying information, such as name, telephone number or address, and the test result cannot be linked in any way with the individual.

Anonymous testing provides the highest possible protection of privacy. This is its main benefit and is a very important consideration for many clients. Unauthorized release of a person’s HIV test result could affect job security, housing, insurance benefits, child custody or other important elements of an individual’s life.

There are some disadvantages as well, however. A client often cannot receive a record of the test result, cannot have the result forwarded to a medical provider and cannot be reached for follow-up if he or she fails to appear for the test results or leaves a session in great psychological distress.

Confidential Testing

Confidential testing programs are part of larger service agencies (for example, rural health clinics, maternal-child health clinics, STD clinics, drug and alcohol treatment, and Indian Health Service facilities). There are also many community based organizations that run confidential test sites. In some confidential test sites, clients may come to the agency for many different reasons. HIV antibody testing may not be the concern that brings them there.

At confidential test sites, an individual provides identifying information, and the test result is linked to that person’s

identity in a confidential medical record. This record is protected by special laws in the State of California, and the CDPH/OA funded test sites employ an even higher standard concerning protection of confidential records than is required by law. This is because the CDPH/OA places a high value on privacy in this and other public health matters. In general, people working in HIV services share this strong commitment to protection of privacy and confidentiality.

However, there is always a possibility that when a person’s name is linked to a record, this information could be released. This might happen through a human error (someone mistakenly releases the record), because records are burglarized, or through an inadvertent disclosure (a result is lying on a desk in an office, and someone walking through the office sees the result). These kinds of releases would be illegal and are quite rare, but they are possible.

There are also important advantages to confidential testing. For example, a client can sometimes be counseled by someone familiar with his or her background and concerns, the counselor may be able to look over earlier medical or counseling records and provide more individualized services, the client may be able to enroll in follow-up services at the same site where test results are received, and counselors may be able to locate a client who has not returned for follow-up or has left a session in emotional distress.

For these reasons, confidential testing can be a good choice for clients who might be especially vulnerable to the stress of the testing process (for example, people in early recovery from chemical dependency, teenagers, people with pre-existing mental health problems or pregnant women).

HIV reporting by name: In April 2006, confidential test sites in California transitioned from reporting HIV by code to reporting HIV by name. Although research initially supported the accuracy of code-based surveillance, the coded system proved burdensome and inaccurate. Having



accurate information on HIV trends, risk factors and demographics allows the CDPH/OA to better target and evaluate education and prevention efforts. It will also help us to more accurately understand the scope of the epidemic and will impact future funding for people in California who are living with HIV.

When a client receives a confirmed HIV-antibody positive in a confidential test site, the full name—and possibly the full social security number when offered by the client—is forwarded to the CDPH/OA, which compiles data in the HIV/AIDS Case Registry System (HARS). This registry also contains the names of people diagnosed with AIDS since 1983. Other information, such as full address and telephone number may also be reported.

HIV reporting by name happens both for people who test HIV-positive in a confidential test site as well as for people living with HIV who test for viral load and CD4 cell count evaluation in a medical office or clinic. Cases of HIV for people who test anonymously will therefore be reported by name once anonymous testers enter confidential medical care.

The names of people living with HIV are never released beyond the CDPH/OA. Compiled data is kept in a secure, locked location, on an electronic server that is never connected to the Internet and is accessible only to authorized personnel. When reporting to the federal government, the CDPH/OA sends only a code and demographic information to the CDC, not names and not any other identifying information. According to the Office of AIDS, the case registry has never had a breach of confidentiality.

Which System Is Better?

There are advantages and disadvantages to both systems of testing. What is better for one client may not be a good choice for another. Counselors who understand the pros and cons of each approach will be able to provide the most useful support to clients who are deciding which test to take.

What is the Difference Between Confidential and Anonymous HIV Testing In California?

Anonymous HIV testing is performed without any record of a client's identity. Because information required for reporting HIV is not available in anonymous programs, no case reporting will occur. In confidential testing, names are recorded on consent-to-test forms and test results may be

recorded in the individual's medical chart. For people who receive a confirmed HIV-positive test result at confidential test sites, a case report will be sent to the local health department.

1. Identifiers: In confidential testing programs, clients' names can be matched with their test results. At anonymous test sites, no identifying information—only a number—can be matched with a client's test result.
2. Informed consent: In confidential testing programs, clients must give informed written consent before they can be tested. At anonymous test sites, consent is informed but not written (written consent would violate anonymity). In both settings, clients should be 12 years or older (13 years if using an oral OraSure Collection Device or the OraQuick ADVANCE rapid test) and of sound mind, should fully understand the risks and benefits of the test, and should choose to be tested freely, not through coercion.
3. Follow-up: In a confidential setting, where a client's name and address are usually known, it is possible to offer follow-up after HIV antibody testing with further counseling and intervention. At anonymous test sites, follow-up is more difficult; there is no locating information on the client, and anonymous sites are usually not funded to provide follow-up services.
4. HIV case report form: In order to complete an HIV case report form, the test site is responsible for collecting the following three documents:
 - a. completed "Consent to Test for HIV" form
 - b. completed Counseling Information Form
 - c. client's confirmed positive antibody test result.

For every HIV test site funded by the CDPH, Office of AIDS (OA), the county HIV coordinator should ensure that an individual is assigned the responsibility for reporting HIV from his/her test site. This person should be the liaison with the local surveillance program to ensure that case reports are submitted accurately and timely. They can assist with compiling the necessary forms needed to complete the case report forms. Reporting in anonymous and confidential test sites differ in that confidential test sites must report the names of clients who test HIV-positive;



anonymous test sites also report HIV-positive results, but never a name, since no name is known.

5. Anonymous test sites are “dedicated” facilities: their main or only reason for existing is to provide the HIV antibody test. Clients come to the test site voluntarily and specifically to be tested for the HIV antibody. Confidential testing programs can be part of larger service agencies (for example, rural health clinics, maternal-child health clinics, STD clinics, drug and alcohol treatment, and Indian Health Service facilities). Clients may come to the agency for many different reasons, and HIV antibody testing is not always the concern that brings them there.
6. HIV reporting by name: When a person living with HIV is confirmed antibody positive at a confidential site or receives medical care that involves a viral load or CD4 cell count test, that person’s name and—when consented—full social security number are forwarded to the CDPH/OA. Other information, such as full address and telephone number may also be reported. Anonymous test sites do not report HIV by name, since no name or contact information is ever known when a client tests anonymously. Counselors may, however, prepare clients who test positive in anonymous sites for the process that will happen when they receive confidential medical services or if they transition from an anonymous test to a confidential test at the same site.