Anonymous vs. Confidential Testing

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Since 1985, when antibody testing was licensed in the United States, most publicly funded testing in California has been done anonymously. In 1991, for the first time, the number of confidential tests performed in the state exceeded the number of anonymous tests. Because these testing approaches coexist and are both valuable, it is vital for counselors to understand the differences between them and the process through which clients go to choose the approach that will serve them best.

This article presents an overview of the advantages of each type of testing and describes techniques counselors can use with clients to distinguish between confidential and anonymous testing. It then explores programmatic issues related to evaluating the success of confidential and anonymous counseling and testing.

Anonymous testing refers to testing and counseling in which clients are not required to identify themselves in any way to test site staff. A client receives a code before testing, and presents this code—which is linked with the blood sample—prior to receiving test results. California policy requires implied or verbal consent by clients at anonymous test sites.

Confidential testing refers to testing and counseling in which clients identify themselves—at the very least to test counselors—by name, and perhaps by address or other personal information. At various stages in the testing process, for instance when blood is drawn and sent to a laboratory, a client may not be identified but in general the test result and the client’s name are noted together. California policy requires written consent before a confidential test is performed.

Confidential Testing

In order to understand the occasions when one type of testing is more appropriate than another, it is important to identify the characteristics associated with each type. For instance, confidential testing can facilitate stronger counselor-client relationships that allow health care workers to track clients, work more closely with them in the process of notifying sexual partners, and perform more extensive research.

Tracking. By knowing a client’s identity, test site staff can locate a client who has not returned for a test result or can monitor a client’s progression through the health care system. Such tracking can be used to determine if the client is receiving health care and other services, and can facilitate case management. Knowing a client’s identity enables counselors to be more involved in planning follow-up care, and this knowledge may be especially important in some settings, for example, prenatal health care facilities and sexually transmitted disease (STD) clinics.

Partner Notification. While the process of partner notification can be begun in an anonymous setting—because the identity of an infected partner is not revealed during actual notification—some counselors believe it is better initiated in a confidential setting. Because confidential counseling and testing can include repeated visits that increase rapport with clients, it facilitates the process of discussing the names of a client’s sexual partners and then contacting these partners, or supporting the client in doing so.

Documentation. Clients who request documentation of a test result, perhaps in order to access assistance from a social service agency, must test in a confidential setting because such documents cannot be provided in an anonymous setting. It is important to note, however, that some confidential test sites do not provide clients with documentation of results.

Research. Some researchers and testing administrators find that confidential testing enables them to gather more detailed information about the characteristics of clients being tested.

Anonymous Testing

Clients testing at anonymous test sites may be willing to discuss personal concerns more honestly, maintaining their anonymity while reserving the choice to disclose personal identity in the future. In addition, an anonymous counseling and testing program is often easier to administer.

Protection of Identity. Clients may seek to protect their anonymity for a variety of reasons, and some may not know that HIV infection, unlike AIDS, is not “reportable” to government agencies, or they may fear that there will be a time when this policy changes. Concerns about protection of identity may be especially prevalent among undocumented immigrants, people in rural areas, and gay men. They may focus on fear of employment, housing, or insurance discrimination. Higher infection rates among clients at anonymous compared to confidential test sites indicate that people who suspect they are infected seek anonymous testing. In 1991, 2.8 percent of clients testing at the state’s anonymous Alternative Test Sites were antibody positive compared to 1.6 percent at sites that perform primarily confidential testing.

Ease of Administration. Anonymous testing requires significantly less paperwork than confidential testing. Also, because the identity of clients is not known, fewer administrative measures need to be taken to protect a client’s privacy.

Ability to Become Confidential. A client who tests at an anonymous site may choose at a later point to test at a confidential one. However, a client who tests confidentially once will have created a record with his or her name on it.

Counseling Implications

It is important for clients to be aware in the pre-test counseling session of the availability and value of both confidential and anonymous testing. It is important for counselors to realize that the testing decision may be based less on any of the factors described above than on which form of testing is most available or convenient.

Begin counseling by asking clients if they are aware of the differences between the types of testing. Explain, if necessary, that the primary difference between anonymous and confidential testing relates to what is done with information regarding the client’s identity. Help clients understand the potential implications of their testing choices. For instance, a client seeking
testing at an anonymous test site in an insular community may find that anonymity is nonetheless sacrificed when client and counselor already know each other. And, a client counseling at a confidential test site, particularly a primary care clinic, should be aware that the presence of an antibody test on a medical record may affect his or her chances of receiving life and disability insurance and, despite laws forbidding the use of results by health insurers, even health insurance.

Learn how information related to a client’s identity is handled at the confidential test sites to which you might refer clients. In a confidential setting, for example, only those who provide direct test site care to the client, and not ancillary personnel, should be aware of the client’s test results. It is also generally recommended—and in some facilities it is an official policy—that information related to a client’s serostatus be kept separate from other health information in a client’s file. Explain to clients that their results may be noted in their medical records.

Tell clients that their records may be shared with other members of the health care team located at the test site, for instance, if the confidential test site is also an early intervention center or family planning clinic. When a counselor wishes to disclose an antibody test result to someone who is not a member of the health care team providing diagnosis, treatment or care to the client, it is necessary to receive written consent from the client.

After offering basic definitions, focus on the client’s specific needs. Is he or she concerned about anonymity? Convenience? Being closely managed by a care provider? Having documentation of the test result? Knowing these things, begin to describe characteristics of each type of testing as they relate to these needs.

For example, a client at a confidential site who is concerned about losing his or her job due to a positive test result may benefit from learning that employers and other outsiders do not have access to test results. Despite this safeguard, it may be useful to state to concerned clients that anonymous testing may be a more comfortable alternative.

While the decision of where to test belongs to the client, there are occasions when counselors may believe one form of testing might be more useful to a particular client. For instance, a counselor at an anonymous test site may suspect that a client will not return for a test result or that a client will not be able to access care without help. For such a client, discuss the difficulty some people have in returning for results or in seeking needed medical care. Ask the client if he or she has had difficulty following up on seeking medical or personal care in the past. Ask whether returning for a test result will be difficult.

Describe the availability of confidential testing and the role that a confidential test site counselor may play in helping the client. Suggest that clients ask their friends to remind them about the return appointment. Through this discussion, counselors give clients a chance to voice their concerns about receiving test results.

Regardless of whether clients test confidentially or anonymously, it is important to make them aware that future health or social services are rarely anonymous. The meaning of “confidentiality” and the handling of client medical information may be far different outside the HIV test counseling setting. Physicians and other early intervention providers may record detailed personal and medical information in client files, and there are reports that some even photograph HIV-infected patients. While this last practice, in particular, follows the letter of the law, it may push ethical boundaries. Help clients understand the ethical concerns and complexities associated with the protection of confidential information outside the test counseling session.

Programmatic Concerns

Client return rates and the effect of counseling and testing on behavior change are often carefully scrutinized in order to measure the success of antibody counseling and testing. The extent to which this varies depends on whether a test is confidential or anonymous. Can determine which type of test program administrators offer to clients.

Test sites at which 80 percent of clients return to receive their test results are generally considered to have acceptable return rates. Acceptable rates are sometimes based on populations being served by test sites. For instance, acceptable rates might be lower at sites that have large numbers of clients who have traditionally received poor health care. Anonymous test sites are anecdotally considered to have lower return rates than confidential sites, although this is not true at all sites. When return rates fall below 80 percent, or levels that are considered acceptable, administrators might ask questions such as: Does the test site have a reputation for being a trustworthy place? Are test site staff members discreet in their handling of client identity and confidentiality? How can administrators ensure the professional, legal, and ethical handling of test-related information?

In terms of behavior change success, counselors can make use of the unique characteristics of confidential and anonymous testing to encourage behavior change. In anonymous settings, the protection of anonymity may help clients feel more willing to share their personal sexual histories; in confidential settings, clients may become detailed in their histories as they develop a relationship of trust with the counselor over several sessions. It remains unclear which type of site is more effective in promoting behavior change or how to measure such efficacy, but researchers may prefer confidential testing because efficacy is easier to study in this setting.

Conclusion

There are clear advantages for health agencies to provide both anonymous and confidential testing and counseling. While client tracking needs and partner notification programs may continue to lead to more confidential testing, public demand for the privacy of anonymous testing will likely mean that both sites should and will continue to be offered.
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