Since the first HIV antibody test was developed in 1985, HIV testing has always been a critical component of both HIV prevention and care efforts. Today, with more effective treatments and better partner notification efforts, this is truer than ever. Yet many individuals do not know their HIV status, and the Centers for Disease Control and Prevention (CDC) suggests that it is this lack of knowledge that may be driving up to half of the new cases of HIV in the United States each year.1

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The CDC recommends that about 25 percent of HIV-positive Americans are not aware of their status, and that it is transmission between these individuals and their partners that accounts for about 54 percent of new sexually transmitted HIV infections.2 People who know that they are HIV-positive change their behavior to reduce transmission risk to others,2 and can receive HIV-specific treatment earlier.

In 2006, the CDC recommended expanding HIV testing efforts to include routine screening in health care settings. The CDC guidelines suggested that all people between the ages of 13 and 64 should be tested at least once and that individuals at “high risk” should be tested at least annually.4

Whereas the CDC previously recommended testing in medical settings with at least a 1 percent HIV prevalence rate, it now describes routine testing as cost-effective in populations with a prevalence rate as low as 0.1 percent. At the same time as it has recommended expanding testing in medical settings, the CDC has sought to promote new models for testing outside of medical settings.5 This Research Update explores the many settings, both medical and nonmedical, in which people can test and learn their HIV status, as well as some of the aspects of testing that may differ among settings, including anonymity, type of consent required, and whether prevention counseling is offered.

Where Do People Test?

According to a 2006 nationally representative survey of 2,517 people by the Kaiser Family Foundation, 55 percent of adults in the United States report that they have been tested for HIV at least once, and 21 percent...
reported having been tested within the prior year. People test at a variety of public and private settings, including counseling and testing sites, health departments, hospitals, private doctors' offices, and STD clinics. CDC-funded sites (including California State Office of AIDS-funded sites) conduct more than 2 million HIV tests per year. See “Sources of HIV Tests and Positive HIV Tests” on page 3. The rate of HIV-positive tests at California State Office of AIDS-funded sites is 1.9 percent.

In the Kaiser study above, 40 percent of respondents wanted to know how to protect their privacy when testing, and 21 percent said they believed that people would think less of them if they knew that they had been tested (regardless of the test result). While 66 percent thought that HIV should be treated as any other disease, with routine screening as part of regular medical checkups, 27 percent said they believed that HIV testing should require special procedures, such as a patient's written permission. Among those who had never been tested, 61 percent said they had not tested because they did not think they were at risk, and 21 percent said that it was because their doctor had not recommended it, but 13 percent said that they had not tested because of concerns about confidentiality.

How Venues Differ

The concerns expressed by some in the Kaiser survey suggest that different venues may be appropriate for different testers. Besides setting, three key distinctions between types of test sites are whether they offer anonymous or confidential testing (or both), whether the consent for testing is on an “opt-in” or “opt-out” basis, and whether prevention counseling is offered with HIV testing.

Anonymous versus Confidential. At anonymous test sites, clients are not required to give their names to test, and client test results are not linked with the client's name. At confidential sites, clients are asked for their name, birth date, Social Security Number, and, possibly, other contact information. This allows for follow-up contact and makes it easier to integrate testing with other client services, such as case management or medical services. The names of clients who test HIV-positive at all confidential sites are forwarded to the California State Office of AIDS. Both confidential test sites and the California State Office of AIDS protect the confidentiality of clients by not sharing their names with other parties.

Opt-In versus Opt-Out. Historically, most HIV testing was done on an “opt-in” basis. This means that an individual had to sign separate, written, HIV-specific consent to receive an HIV test. Now, a growing number of test settings, particularly medical settings, use an “opt-out” model for obtaining consent. This means that the provider conducting the testing notifies the client that HIV testing will be done unless the client objects. The CDC has suggested that opt-out counseling is appropriate in some settings, arguing that treating HIV more like many other diseases reduces stigma and other barriers to testing, and that opt-out screening increases testing rates.

Critics of opt-out testing express concerns that, without a written, HIV-specific consent, it will be unclear whether clients really know that they are being tested for HIV, making it less likely that they will be emotionally prepared for an HIV-positive result. Some suggest that clients may feel uncomfortable refusing testing even when they do not want it. They also point out that some medical tests (for example, genetic testing) require a specific, opt-in, written consent, because the outcome may be stigmatizing or may lead to unwelcome negative health information.

Counseling with Testing. HIV prevention counseling, defined as an “interactive process to assess risk, recognize risky behaviors, and develop a plan to take steps that will reduce risk,” has been a key weapon in the fight against new infections for more than 20 years. While there is clear evidence that people change their HIV transmission-related behaviors when they discover that they are HIV-positive, the evidence that people change behaviors when they receive an HIV-negative test result is less clear. Thus, the CDC’s 2006 recommendations state that HIV testing in certain settings, such as health care settings, does not require HIV prevention counseling.

The model most counselors are familiar with, that of the California State Office of AIDS-funded test site, always uses opt-in testing, and requires some risk assessment to determine the need for prevention counseling. Some Office of AIDS-funded sites offer anonymous testing, some offer confidential testing, and some offer both. At many sites, clients at higher risk for HIV receive higher-level counseling services, while those at lower risk receive lower-level prevention services.

The following sections describe HIV testing in several environments, most of which are not Office of AIDS-funded sites. The settings discussed below are not the only ones in which HIV testing is offered; for a discussion of HIV testing in prenatal care, substance abuse treatment, and rural areas, see the September 2002 issue of PERSPECTIVES. The integration of STD and HIV testing services is explored in the Winter 2008 issue of PERSPECTIVES. Tuberculosis clinics and refugee health centers are among the other emerging HIV testing settings.

Medical Settings

Most HIV testing in the United States is done in medical settings (see “Sources of HIV Tests and Positive HIV Tests,” page 3). The further expansion of testing in medical settings seeks to build on the tremendous success of prenatal HIV screening, which has led to dramatic reductions in mother-to-child transmission in the United States. Yet much of the HIV testing done in these settings in the past happened when patients were already ill.
Physicians state that a variety of factors have prevented them from testing their patients routinely. One 2007 analysis of 17 published and unpublished studies found several barriers to testing that were identified by providers across medical settings: insufficient time; burdensome consent process; lack of knowledge or training; lack of patient acceptance; pretest counseling requirements; competing priorities; and inadequate reimbursement. The CDC has sought to reduce many of these barriers by eliminating the prevention counseling requirement, and allowing opt-out, general consent, rather than HIV-specific consent. Reimbursement plans to reduce the cost of massive new testing are also being explored.

In January of 2008, the California State Assembly passed Assembly Bill 682, which eliminated the requirement that health care providers obtain written consent from patients before ordering an HIV test. Instead, providers must: inform the patient that an HIV test is planned; provide information about the test; inform the patient that several treatments for HIV exist; advise patients that routine testing is recommended for those who test HIV-negative; advise patients that they have the right to decline the test; and, if the patient declines HIV testing, note the refusal in the patient’s medical file.

Medical settings are diverse, and, because testing in many settings is not based on patient risk, HIV-positivity rates vary tremendously by setting. The higher the prevalence of HIV in the group of people being tested, the more cost-effective the testing is. Some of the key medical settings where HIV testing is conducted are described below.

### Doctors’ Offices

HIV status is a key aspect of health status, and when both patients and medical providers know the patient’s HIV status, it facilitates more appropriate care and referrals. If doctors routinely tested all their patients, the proportion of people who had taken an HIV test would increase dramatically, because many people who visit the doctor do not seek out specialized HIV counseling and testing services.

Despite these benefits, conducting routine testing of adult patients presents challenges. Medical staff must ensure that patients understand that they are being tested for HIV, and that they consent, even on an opt-out basis. Although HIV prevention counseling is not required in medical settings, medical providers must be prepared to respond to any HIV-related questions, and to support clients who test HIV-positive.

Providers must also decide how best to disclose HIV test results to patients. In the traditional HIV test counseling model, counselors disclose both HIV-negative and HIV-positive results in person. The CDC states that in health care settings, HIV-negative results may be disclosed to patients “without direct personal contact,” but that HIV-positive results “should be communicated confidentially through personal contact.”

### Hospitals and Emergency Departments

While HIV testing in doctors’ offices reaches many individuals who would likely not otherwise test, it cannot effectively reach those who do not have a regular source of medical care, either because they do not have insurance or because they face other barriers. The Kaiser Family Foundation estimated in 2004 that 45 percent of people living with HIV lacked health insurance, and that 30 percent receive health coverage through Medicaid (called Medi-Cal in California). Emergency departments are the primary source of health care for many of these people, and are an increasingly promising site for detecting new HIV infections, since one review of studies found HIV prevalence rates among emergency department clientele of between 2 and 17 percent.

HIV testing is not yet done routinely in emergency departments nationwide, but a number of states (including California, Massachusetts, Michigan, New Jersey, New York, and Ohio) have piloted such testing. A 2004 national survey found that 57 percent of hospitals provide at least some HIV testing in the emer-
Outreach Venues

A large proportion of Americans do not have access to regular health care, or may not choose to receive an HIV test in a medical setting. As part of its strategy to increase the number of people who know their HIV status, in 2003 the CDC announced its plan to “implement new models for diagnosing HIV infection outside medical settings.” Outreach venues, especially mobile testing sites, are critical to this effort, and rapid HIV testing in the field has made mobile testing even more effective.

In contrast to routine testing, outreach efforts target groups of people at higher risk for HIV infection, so the venues chosen as test sites are usually places where people at higher risk congregate. For example, testing in bathhouses, gay festivals, parks, dance clubs, and bars can target gay and bisexual men, and testing at needle-exchange sites can target injection drug users. In California, the Office of AIDS often funds these testing efforts.

Between 2004 and 2006, the CDC funded a demonstration project aimed at testing racial and ethnic minority individuals and others at high risk for HIV infection in outreach and other community settings. In seven major U.S. cities, trained HIV counselors tested and counseled 23,900 people, 30 percent of whom had never tested before. Approximately 1 percent of the people tested had newly diagnosed HIV infection. Forty percent of participants had not visited a health care provider in the preceding year, so without this outreach effort, they might have missed the opportunity to learn their HIV status.

Also between 2004 and 2006, the U.S. Conference of Mayors and the CDC partnered to sponsor behavioral risk assessment and HIV testing of racial and ethnic minority men at gay pride events in nine U.S. cities. Of 133 gay or bisexual men of color tested, eight (or 6 percent) had confirmed, newly diagnosed, HIV-positive results. Lack of staff and client unwillingness to wait for available staff are among the challenges of testing in such venues: only about one quarter of those who said they were willing to be tested actually were tested.

Home Testing

The FDA has approved only one consumer-controlled kit for HIV (the Home Access HIV-1 Test System, available without prescription). It is not really a “home test,” but rather a home collection kit. Consumers prick their fingers with a special device, place drops of blood on the kit’s specially treated card, and mail the card in for testing at a licensed laboratory. Consumers call for their results, using a special identification number.

Counseling is not required, but customers have the option of speaking to a counselor before, during, or after the test, and HIV-positive people are offered referrals for follow-up confirmatory tests and to care. This method has the potential to be extremely private and convenient, since the consumer does not have to leave home or interact face-to-face with others. Drawbacks include the possibility of misunderstanding test results (for example, believing an HIV-negative test result to be accurate after a very recent exposure), the possibility of a negative emotional reaction to an HIV-positive result, and the cost (about $50).

Conclusion

Testing plays an increasingly important role in HIV prevention. Clients today have more choices about where to test than ever before—including the option to test in a variety of medical and community settings. While some barriers to routine testing have been reduced, other challenges remain—including finding the financial and staff resources necessary to implement such testing. In the context of expanded testing, Office of AIDS-funded counseling and testing sites remain a critical prevention resource.
Implications for Counseling

In many places, clients can choose between different types of settings when taking an HIV test. Each setting has its advantages. HIV test counselors at state-funded sites can explain some of these options and advantages to clients. This information can help clients decide which setting is most appropriate for them. Some of the key differences among sites include whether the site offers anonymous or confidential testing (or both), whether the site is affiliated with the client’s medical providers or health insurance, and whether the site offers HIV prevention counseling.

Anonymous or Confidential?

Publicly funded anonymous and confidential counseling and testing sites are similar in that they both tend to follow the guidelines of client-centered counseling, and clients’ identities and test results are not recorded in their primary care medical or insurance files. Confidential sites keep a record of client names.

Anonymous sites gather and record client information without identifying the client. Many clients prefer to share personal information about their sexual or drug-using behaviors if they can do so anonymously. Anonymous testing also offers people who are concerned about potential discrimination (as a result of taking an HIV test or testing HIV-positive) the opportunity to test without the fear of being identified.

Confidential counseling and testing sites gather information about each client and record it with the client’s name, which makes it possible to follow up with clients if they do not return for test results. Confidential sites can also maintain ongoing relationships with clients. This allows counselors to direct clients to other services and more easily follow up on referrals. This is especially useful for clients whose behaviors put them at higher risk for HIV and clients who test HIV-positive. Confidential testing is also more appropriate for clients who want a record of their test results, which they may need, for example, for immigration purposes, to show sex partners, or to obtain services if they test HIV-positive.

In anonymous testing, the counselor tells the client the result, but the client does not receive a written record.

Some venues are more appropriate for either anonymous or confidential testing. For example, HIV testing in a sex club or at a needle exchange site is more compatible with anonymous testing. Medical clinics usually offer confidential testing, so that clients can be easily referred into further medical care and other services.

Medical Settings

For some clients in regular medical care, making an HIV test part of their annual checkup may be a convenient way to monitor their HIV status. Certainly, if the client is experiencing other health problems that may be related to HIV, it is useful for medical providers to know if the client is HIV-positive when creating a treatment plan. Another advantage of testing in a medical setting is that it facilitates quick and easy referrals within that system of care, contributing to quality treatment for HIV-positive individuals.

As discussed above, most testing in medical settings is confidential, not anonymous. For example, in a private physician’s office or an emergency department, this means that the client’s HIV status becomes part of his or her medical (and often, insurance) records. Clients who do not feel comfortable having their test results as part of these records may choose to test elsewhere anonymously. Of course, when a client tests HIV-positive, it is important that he or she seek appropriate medical care as soon as possible, at which point his or her HIV status becomes part of the medical record.

What About Counseling?

Medical settings vary in the degree to which they offer HIV prevention counseling with HIV testing. The CDC urges medical providers to move toward a “screening” model in which HIV testing is routine. Therefore, CDC does not require prevention counseling in these settings. This may be appealing to some clients who do not want counseling. For example, some clients who believe that they are at very low risk for HIV may not see the point in receiving HIV prevention counseling, while others who have tested many times before may believe that they have “heard it all.”

However, client-centered counseling goes beyond education. Counselors help clients explore the psychological and social factors that influence their behaviors and discuss their feelings and thoughts about their risk behaviors. Counselors then help clients think through the next steps clients can take to reduce their HIV-related risk level.

When working with a client who is reluctant to receive counseling, a counselor may say: “I don’t want to waste your time. This won’t be a lecture, and I won’t tell you things you already know. Instead, I’d like to talk with you about what you think is going on in your life that may put you and your partners at risk for HIV.” At state-funded sites that use the two-tiered testing model, client-centered counseling is reserved for clients at higher risk for HIV, while clients at lower risk receive a less-intensive educational intervention, such as a brochure to read or a video to watch.

Other issues that may determine the right setting for the client are the amount of time the client wants to spend in the testing session and the place the client would feel most comfortable receiving an HIV-positive result. If the client has a number of questions about HIV testing,
Outreach and Mobile Testing

In many communities, HIV counseling and testing services are available at temporary sites in the community—for example, in tents at street fairs, in a partitioned area of a sex club or bar, or in mobile testing vans at a needle exchange site. The advantage of this type of setting is that it brings HIV testing to events with large numbers of people who might not otherwise have tested, and makes counseling and testing accessible. In the past, one of the challenges of this type of setting was that many clients did not return to receive their test results. Rapid, single-session counseling and testing has resolved much of this problem.

Mobile test sites still present counselors and clients with challenges. Programs must develop procedures to protect client privacy despite the thin walls of a tent or the cramped quarters of a van. Counseling sessions may be interrupted by distractions in the environment.

Most people do not come to such venues with HIV testing on their minds. While this makes such outreach settings an especially effective tool for testing people who could not otherwise be reached, it also means that many people may not have thought through the consequences of receiving a preliminary HIV-positive result in a sex club, at the needle exchange, or during the street fair. At a late-night or

References


weekend venue, potential referral sites may not be open.

Counselors can assess client readiness to test in such settings by asking a few key questions: “What would it be like if your result comes back preliminary positive today?” “Are you here with other people?” “What were you planning on doing for the rest of the night?” Some clients may not want to receive their results and then go back to a street fair or may not want others at the needle exchange to see them testing.

Sometimes clients at outreach sites are intoxicated. When a client is so intoxicated that the counselor believes that he or she cannot give informed consent and participate in the counseling session, the counselor should tell the client to return when he or she is more coherent.

Home Testing

Home specimen collection tests offer an accessible, private, and convenient way to test for HIV. Results are given over the telephone, and clients can speak to a counselor or can choose not to use counseling.

One advantage of telephone counseling is the increased anonymity for clients when talking about their sexual and drug-using practices. Since counseling is not required, clients who do not desire it may also prefer this option. If a client asks a test site counselor about home testing, it is important that the counselor lets the client know that at this point, only one test is approved by the U.S. Food and Drug Administration (FDA) for home use, and that the sample must still be sent to a lab for the results.

Conclusion

Client concerns about convenience, privacy, linkage to medical care, and the availability of HIV test counseling, as well as other factors may all guide decisions about where to test. HIV test counselors can help clients weigh these factors and direct them to the sites where they feel most comfortable testing.
Test Yourself

Review Questions

1. The CDC estimates that transmission between HIV-positive people who are unaware of their status and their partners accounts for what proportion of new sexually transmitted HIV infections? a) approximately one-fourth; b) more than half; c) more than two-thirds; d) three-fourths.

2. True or False: In California, all health care providers must obtain a separate, HIV-specific written consent from clients before testing the client for HIV.

3. In contrast to targeted HIV testing, routine HIV “screening” refers to: a) testing large numbers of individuals without informed consent; b) testing large numbers of individuals without regard to HIV risk; c) testing individuals most at risk for HIV; d) both a and c.

4. The CDC recommends that which group of people be screened for HIV? a) children under 12; b) young people aged 12 to 25; c) people between 13 and 64 years old; d) adults aged 18 to 65 years old.

5. Emergency departments may be a promising new venue for HIV testing, because: a) they are a primary source of health care for uninsured people, and early studies show a relatively high prevalence rate; b) routine testing has recently been implemented nationwide; c) both a and b; d) none of the above.

6. True or False: The FDA has approved several home HIV tests that allow consumers to test themselves for HIV in a way that is similar to how home pregnancy tests work.

7. Testing in outreach settings allows prevention efforts to reach people who: a) belong to groups that are at high risk for HIV; b) might not otherwise think of testing; c) may or may not have regular medical care; d) all of the above.

Discussion Questions

1. Why might some clients choose to test in their doctors’ offices rather than at another location?

2. What are the advantages and disadvantages of offering HIV testing without prevention counseling in medical settings?

3. What are some of the advantages and disadvantages of HIV testing in the emergency room?

4. What are some of the challenges involved in delivering mobile HIV testing services? What unique opportunities does mobile HIV testing offer?

5. What do you see as the costs and benefits of using a “screening” approach to testing, rather than a “targeted” approach?

Answers to Review Questions

1. b

2. False. In January 2008, California State Assembly Bill 682 eliminated the requirement that health care providers obtain written consent from patients before ordering an HIV test.

3. b

4. c

5. a

6. False. The FDA has approved only one consumer-controlled kit for HIV. It is not really a “home test,” but rather a home collection kit.

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