

HIV COUNSELOR PERSPECTIVES

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HIV NAME-BASED REPORTING

California has long sought to protect HIV-related information, and currently has some of the strongest HIV-related confidentiality laws in the United States. Since April 17 of this year, the names of people who test HIV-positive have been reported to the state. This change allows better tracking of the epidemic and responds to federal requirements and funding needs. This issue of PERSPECTIVES discusses the history of AIDS and HIV case reporting in California, explains the new system, and addresses potential client and counselor concerns regarding confidentiality and stigma.

Research Update

The Centers for Disease Control and Prevention (CDC) estimates that 40,000 new HIV infections occur every year in the United States.¹ To better understand trends in the epidemic, the CDC recommended, in 1999, that states begin reporting cases of HIV by name. AIDS cases have been reported by name since 1983. At first, California declined to use the name-based system, instead creating a coded reporting system. This year, however, California has shifted its approach.

Tracking HIV cases, rather than AIDS alone, allows public health officials to better understand where and in which populations new HIV cases are occurring. This information will be used to help allocate federal and state funding for both prevention and care services.

Since 1983, California's physicians have reported AIDS cases by name to health departments at the local and state levels. Gathering information

about AIDS helped public health officials respond to the spreading epidemic. However, as the epidemic advanced, it became clear that knowing the number of people with AIDS without also knowing the number of people with HIV who had not yet progressed to AIDS provided only a limited picture of the scope of the epidemic.

The Limitations of AIDS Reporting

"Hidden" HIV cases made targeting prevention efforts especially difficult, because health policy makers could not see new transmission trends emerging until people actually became ill. Ironically, this difficulty increased when improved HIV antiviral treatment appeared, successfully delaying the progression from HIV to AIDS for many people. Care efforts were hindered as well, because it was hard to know where future AIDS cases would emerge. In response to these concerns, the CDC recommended tracking HIV in the same way AIDS had always been tracked—by using the name of the diagnosed person.

Some states—including California—were concerned that reporting names might discourage people from testing, particularly the people at highest risk for HIV infection. Others feared that reporting names would deter treatment, since reporting also occurs when clients access medical care. Some HIV-positive people had already lost employment or insurance coverage and experienced other stigma-related harms. (Since that time, however, both the federal government and the California state government have strengthened prohibitions against HIV-related discrimination.) These

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stigma-related concerns seemed to justify treating HIV as an “exceptional” condition, different from all other sexually transmitted diseases which were already reported by name.

At the same time, other states complied with federal recommendations by beginning to report names to state health departments, which then provided an estimate of unduplicated cases—not names—to the CDC.² By April 2006, 43 states had begun reporting HIV by name.¹

The History of HIV Reporting

California has a long history of considering HIV names reporting. The public voted against names reporting on ballot initiatives in 1986 and again in 1998, as did the legislature in each year between 1988 and 1999. The legislature eventually agreed to a coded system to be implemented in July 2002.³ The system—dubbed “non-name code reporting”—created a set of numbers and letters for each person who tested HIV-positive. The client’s last name was “Soundex-coded”—that is, encrypted into a letter and three numbers—then combined with the client’s gender, date of birth, and, when the client agreed to provide it, the last four digits of his or her social security number.

The California Office of AIDS designed the non-name code to be unique to each client and to be easy to re-create each time that someone tested for HIV antibodies or received a viral load count. The Office of AIDS could then follow trends in the epidemic throughout the continuum of care, as people moved from positive results in confidential test sites to initial and then ongoing tests of their immune functioning in doctors’ offices and public health clinics. The state could also collect data on the types and quantities of services HIV-positive people used, which helped the state and counties to plan and fund services appropriately.

Since July 2002, doctors, confidential test sites, HIV clinics, and laboratories have forwarded information about HIV to the Office of AIDS by non-name code. The last four digits of the social security number were held at local health departments, to be used as backup to identify duplicate cases. Only the Soundex code, gender, and date of birth were forwarded to the Office of AIDS, and only demographic information and prevalence data were reported to the CDC—not the actual code.

Although research initially supported the accuracy of code-based surveillance,^{4,5} experience with the system demonstrated that the data collected was inadequate. Even with the hiring and training of staff to de-duplicate cases, the coded system proved burdensome and inaccurate.⁶ One example of this difficulty occurred when the CDC sent back lists of possible duplicate cases to staff in each state. In these instances, the CDC suspected that one person, having tested or received care in multiple locations, had been incorrectly reported as multiple “cases” of HIV.

Further, de-duplicating these cases across state lines proved difficult. For example, if one client had tested in two states, and one state had used the client’s mother’s maiden name to create the Soundex code, and the other had used the client’s own name to create the code, one case of HIV would appear to be two. Soundex encryption is irreversible, that is, once encoded the original information—for example, the client’s mother’s maiden name—cannot be retrieved. This means comparing the two cases and discovering that they were, in fact, only one would be impossible. However, with every state using a name-based reporting system, states could easily de-duplicate cases, without ever revealing the client’s name. Because of the burden and inaccuracy of coded systems, the CDC refused to accept

SB 699, the California bill that mandates name-based reporting, was created with input from HIV service agencies and consumers.

estimates of HIV prevalence from states with coded surveillance.⁷

California’s HIV Reporting Law

Beginning October 1, 2006, the federal government stopped providing Ryan White CARE Act funds to states that do not report HIV by name. For California, this would have created a loss of approximately \$50 million each year.⁸ To prevent the loss of these critical resources, the state legislature passed SB 699, a bill drafted with input from HIV service agencies and consumers, “to ensure knowledge of current trends in the HIV epidemic and to assure that California remains eligible for federal HIV and AIDS funding.” Governor Arnold Schwarzenegger signed the bill into law on April 17, 2006.⁹

HIV name-based reporting became effective immediately. Confidential HIV test sites began forwarding the full names of clients with confirmed HIV-positive test results to the Office of AIDS in place of the non-name code. The development of final regulations is still in progress.⁹ Reporting additional information—such as the client’s full social security number—may be required in the future. However, SB 699 itself requires only that names be reported, so clients may decline to provide any additional information and still test in a confidential test site.¹⁰

SB 699 also requires the continued availability of anonymous testing at state-funded Alternative Test Sites, which exist in all California counties that also have a blood bank. People concerned about having their names reported if they receive a confirmed HIV-positive test will continue to have the option to test anonymously.^{9,11} However, medical tests used to monitor and treat people living with HIV, such as viral load tests, will also result in HIV reporting by name. That means that when people who receive a confirmed HIV-positive test in anonymous settings later seek medical care, their names will be reported.

Concerns and Safeguards

A 2006 telephone survey of 2,517 individuals by the Kaiser Family Foundation revealed that the protection of privacy regarding HIV testing is a key concern for many Americans. Forty percent of those surveyed stated they would like to have more information about how to protect their privacy when getting an HIV test; the numbers were higher for African Americans and Latinos, who are disproportionately affected by HIV. Among young people between 18 and 25 years of age, 51 percent identified privacy as a concern.¹ In order to protect HIV-positive people's private

Tracking HIV cases, rather than AIDS alone, allows public health officials to understand where new HIV cases are occurring—helping them better allocate resources.

Understanding Name-Based Reporting

- *On April 17, 2006, HIV became reportable by name*
- *Only confirmed HIV-positive results are reported*
- *Viral load tests are also reportable by name*
- *Federal funding regulations required that states transition from code-based to name-based reporting*
- *The same confidentiality and security measures protecting the names of people with AIDS also protect those of people with HIV*
- *In 20 years, there has never been a breach of the confidentiality of names held in the HIV/AIDS Case Registry*
- *Anonymous testing is still available in all counties with blood banks and Office of AIDS-funded testing programs*

information, including their names, the Office of AIDS has enhanced several safeguards that have been protecting the names of people with AIDS for more than 20 years.

How Might Clients Respond?

HIV name-based reporting follows the same confidentiality guidelines that protect people diagnosed with AIDS. As required by the CDC, California's HIV/AIDS Case Registry 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. California's case registry has never had a security breach. SB 699 adds new, more stringent penalties for security violations, including increased fines for breaches of confidentiality.^{12,13} In order to further protect confidentiality, only the demographic information for each case, not actual names or other identifying information, is forwarded to the CDC.¹⁴ This enables the CDC to compile gender, race and ethnicity, age, and route of transmission information for HIV cases in each state.

It remains unclear whether names reporting will change clients' testing practices or their initiation of HIV care. HIV is unlike many other communicable diseases: there is no cure, and the disease carries a significant stigma. On the other hand, some advocates for name-based reporting suggest that treating HIV like other communicable diseases actually helps reduce the stigma surrounding the disease. They argue that treating HIV as an exception to other infectious diseases only reinforces the notion that HIV is something that should be hidden. Further, while there is no cure, HIV disease has evolved into a treatable condition, making it more like other chronic illnesses.

While the actual effect of name-based reporting on HIV testing behavior is unknown, a handful of studies suggest that the effects may be different for different populations. One of the largest studies on the subject, conducted between 1995 and 1996, found that HIV reporting by name had virtually no impact on testing practices. The study sampled socioeconomically diverse groups seemingly most at risk for HIV

infection in eight states: heterosexuals receiving STD clinic services, men who have sex with men visiting gay bars, and injection drug users enrolled through street outreach.¹⁵ The study, however, did not sample people living in the states with the highest prevalence of HIV, such as New York and California, or determine whether participants actually engaged in high-risk behaviors. Other research—on a much smaller scale, in California—suggests that name-based reporting could have an impact on the testing practices of people most vulnerable to HIV infection.

Researchers in one San Francisco study conducted during 1997 and 1998 interviewed 130 men who have sex with men who were recruited from a confidential test site. Forty-four percent of the men said they would not test if name-based reporting were in effect. Of those who would test, two-thirds said they would not give their real names if name-based reporting were in place.¹⁶ Both the national and San Francisco studies, however, are almost 10 years old, and attitudes toward testing under name-based reporting since then may have changed.

A larger, more recent study of more

than 400 people conducted during 2002 and 2003 in four California counties examined the acceptability of three types of HIV reporting: name, name-to-code, and non-name code. Only 32 percent of the respondents said they would test at a confidential test site if the names of those who tested HIV-positive were reported. The preference for a non-name code was especially strong among men who have sex with men and those who had just tested anonymously.³

Both of the California-based studies suggest that some members of two groups—men who have sex with men and those who currently test anonymously—might have particular reservations about name-based reporting. This may be of particular concern, since men who have sex with men continue to account for the bulk of HIV infections in California.¹⁷

In contrast, some research shows that even people who test for HIV often generally do not know which reporting system is in place. In 2003, a year after California's implementation of non-name code reporting, one study found that only six percent of people exiting confidential and anonymous test sites

Name-based reporting
makes HIV surveillance
more accurate and
ensures that resources
get to populations with
rising rates of infection.

knew which reporting system had been implemented.³

Conclusion

Name-based reporting is intended to make California's HIV surveillance more accurate. This change focuses prevention in populations where infection rates may be rising and allows better tracking of services throughout the overall system of care. Some people, particularly clients at high risk for contracting HIV, may still have concerns about confidentiality. To address these concerns and encourage all Californians to know their HIV status, safeguards regarding the security of confidential testing have been reinforced, and clients retain the option to test anonymously.

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Implications for Counseling

In California, the recent shift to name-based reporting of HIV-positive test results challenges counselors to assist clients in several ways. Counselors must be prepared to address confidentiality concerns and to support clients' informed consent. To accomplish this, counselors must have current, accurate information about the new process, and allow clients to ask questions. Counselors can then address client concerns, including confidentiality. Finally, counselors can clarify the difference between anonymous and confidential testing, and offer these options to the client. With name-based reporting as with other issues, counselors must manage their own feelings so that they can remain client-centered in their approach.

Supporting Informed Consent

Prior to testing, many clients may be unaware of the change to name-based reporting or unsure about how this change affects them. When discussing the process with a client and obtaining informed consent, the counselor should let the client know that for confidential testing, he or she will need to provide his or her name and date of birth and that sharing his or her social security number is currently optional. Clients need to know that when a test result

is confirmed HIV-positive, the client's name and date of birth will be sent first to the local health department, and then to the state's Department of Health Services. At the state level, the information is turned into a code, and the code is sent to the Centers for Disease Control and Prevention (CDC). Since much of this information may be new to clients, counselors should make sure that clients understand the counselor's description of the process, possibly by asking clients to restate what the counselor has explained.

All consent paperwork and other relevant literature at the testing site should also explain the change to name-based reporting. At a minimum, a client needs to understand three things: that names and other identifying information are reportable to the state during confidential testing; that this information is protected by the state, encoded, and sent to the federal government; and that California continues to offer anonymous testing. During anonymous testing, counselors do not collect names or other identifying information, and no name-based reporting is required.

Addressing Client Concerns

Beyond this basic information, discussion should be guided by the client's concerns. Clients who have further questions about the new system are likely to focus on how their personal information is treated and how their confidentiality is ensured. Counselors are already sensitive to the fact that some people, especially those from marginalized groups, may distrust government agencies and feel wary about sharing personal information. Many people at heightened risk for HIV already endure discrimination as people of color, gay or bisexual men, substance

users, or members of other marginalized groups. It is understandable that they may want to avoid exposing themselves to the possibility of further stigma.

For these or other reasons, occasionally a client may react strongly to the issue of name-based reporting. In these cases, it is important to acknowledge the client's feelings, stay neutral and focused on the client's reasons for testing now, remind the client of his or her power to choose anonymous or confidential testing, and review the ways that the client's privacy is protected.

Clients may also find it helpful to hear why the change to name-based reporting is happening. Counselors can state that the new system will provide a better picture of the number of people living with HIV, who is becoming infected, and where they are living. Further they can state that this will allow continued federal funding for HIV-related services. Clients may be more willing to provide this personal information when they understand that this information can make a difference.

If a client asks "How do I know that my name will be kept confidential?" a counselor can explain the system's safeguards. A counselor might say: "The names of people who test confirmed HIV-positive are all kept in a separate, very secure database. Even though AIDS has been reportable by name since the 1980s, no one has ever broken into California's AIDS database or leaked information about the names in it. The laws against breaching that security have just been made even tougher, so if someone did violate the rules of confidentiality, he or she would face high fines and possible jail time. Does that address your concerns, or do you have others?" Some clients may be concerned that laws might change, and that their personal information could then be shared more widely. While counselors cannot predict the future, they can reassure clients that California has

A Counselor's Perspective

"When clients have a problem with name-based reporting, I offer them anonymous testing and return the focus to the client's risk behaviors."

historically supported strong protections regarding the confidentiality of HIV-related information.

Confidential versus Anonymous

When talking with clients about the change to name-based reporting, it is important to describe the difference between confidential and anonymous testing, and to explain that name-based

reporting occurs only in confidential settings. For example, at a test site that offers both types of tests, a counselor might say: “We offer both anonymous and confidential HIV testing. If you choose to be tested confidentially, I will ask you for some personal information, including your name, date of birth, gender, and demographic information. Giving your Social Security number is currently optional.

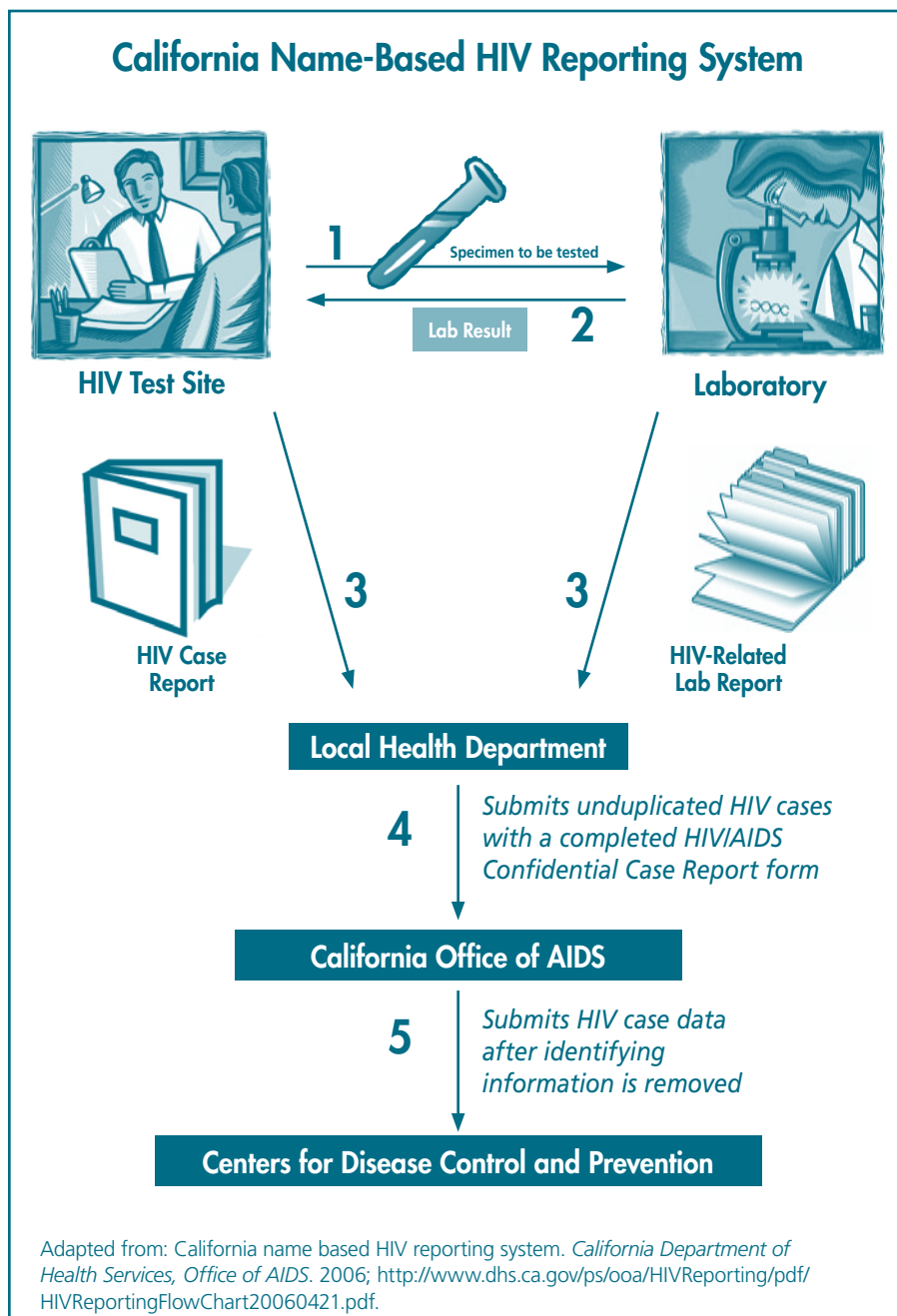
A Counselor’s Perspective

When I talk about name-based reporting with clients, I always explain why the information they are sharing is so important—how it makes a difference in our understanding of the epidemic.

All this information is kept private—we will only release it to authorized people. If you test confidentially, and your test result is confirmed to be HIV-positive, this information will be sent to the state. If you test HIV-negative, no information will be reported to the state. Testing confidentially also enables us to contact you and follow up to offer you specialized HIV health-related services. If you choose to test anonymously, I will ask you for some information, for example, about the situations that put you at risk for HIV, but I will not ask your name, or for any other identifying information.”

In this way, counselors can let clients know that confidential testing can facilitate linkage to other services, including HIV-specific medical services. It is important for a client to understand that even though he or she may initially avoid name-based reporting by testing anonymously, if the client tests positive and enters medical care, viral load tests will also trigger name-based reporting.

Many clients may be unconcerned about name-based reporting and continue to choose confidential testing. Others may switch to anonymous testing in order to avoid name-based reporting. Once the client understands the reporting implications of both forms of testing, he or she can decide which option makes



Case Study

Jaime is a 46-year-old Latino gay man living in San Francisco. He tells his counselor, Becky, that he gets an HIV test every year. Becky is a 49-year-old White lesbian who has been volunteering as a test counselor for 13 years. Becky welcomes Jaime and lets him know that he is at a site that offers both anonymous and confidential testing and that she would like to go over these options with him.

Jaime interrupts, saying “Thanks for covering this stuff, but I always use confidential.” Becky acknowledges Jaime’s expertise. Then she says, “Recently, there was a change in how confidential, confirmed positive HIV test results are reported. Now, when a person gets a confirmed positive test result while using confidential testing, his or her name is reported to the state Department of Health Services. You also have the option to test anonymously and not give your name. Would you like to go ahead and get a confidential test?”

Jaime replies, “I’m seeing a new guy, and we’re both getting tested so we can stop using condoms if we’re negative. I need my result in writing to show him. If I do test negative, will my name still be reported?”

Becky responds, “No, your name won’t be reported to the state if you test HIV-negative. And it is true that knowing your own status, especially if you talk about it with your partner, can help you both decide what risks to take, and this can help both of you reduce HIV risk.”

Jaime smiles nervously and asks, “I’m just wondering—do you think it’s safe to give my name? I get nervous whenever they start putting us on lists.”

Becky realizes that she has strong but mixed feelings about name-based reporting. Since the new law passed, she knows her county has no choice about reporting names, and she supports the ways that name-based reporting

helps track the epidemic, but she’s still not convinced that it is a positive change. She, too, gets nervous at the thought of lists of HIV-positive people being kept by the government.

At the same time, Becky remembers that her role as an antibody test counselor is to present the client with the information he needs to make his own decision. She makes a mental note to talk with Karl, another test counselor, about how he’s handling these questions. Then she says, “That’s a good question. What I can tell you is that the people in this program and the program at the state believe strongly that your confidentiality is important and they have designed an entire system to protect it. The information is kept very secure at the state level, and the state doesn’t release names to the federal government—they only report a code to federal officials. Also, it’s probably important to tell you that in 20 years, there’s never been a security breach of the California database that holds the names.

“Having said that, you still have the option to test anonymously, and I’m happy to do whichever test you’re most comfortable with. Do you know which type of test you’d prefer?”

“I think I’ll stick with confidential,” Jaime responds.

“Great.” Becky answers, “Now, about you and this new guy...”

the most sense. If a testing site does not offer both anonymous and confidential testing, counselors should have information about sites in the area that offer the type of testing the client desires. It is important to remember that the availability of anonymous testing empowers clients—even if they ultimately choose confidential testing.

Staying Client-Centered

In addition to addressing client concerns, counselors must manage their

own feelings about the change, and stay client-centered. Some counselors may have strong feelings about the new reporting system—feelings that at times may be much stronger than those of the clients they counsel. Some counselors may appreciate the way name-based reporting can help public health officials and policymakers track the course of the epidemic. Some may feel that name-based reporting helps remove the stigma of HIV by treating it more like other STDs. Others may

not be convinced that the value of better tracking data outweighs privacy concerns. While each of these reactions is understandable, it is important for counselors to stay focused in the session on the client’s issues. This does not mean that counselors should ignore their own beliefs and concerns. Talking with supervisors and co-workers can help counselors recognize and work through their own feelings about name-based reporting and separate them from the counseling session.

Test Yourself

Review Questions

1. True or False: The California database that holds the names of people with HIV has safeguards protecting confidentiality almost as strong as those of the database that holds the names of people with AIDS.
2. Which of the following was *not* a problem when California used non-name code reporting of HIV positive test results? a) other states used a different system; b) it was difficult to de-duplicate cases (identify when one case had been reported multiple times); c) it did not adequately protect confidentiality; d) the federal government preferred name-based information.
3. True or False: Many other communicable diseases, including sexually transmitted diseases, have been reported by name for some time in California.
4. Which of the following kinds of HIV test results is reported by name to the state Department of Health

Services? a) preliminary positive test results; b) anonymous test results; c) HIV-negative test results; d) none of the above.

5. True or False: Only state-funded test sites, not doctor's offices or other HIV test sites, are affected by the shift to name-based reporting of confirmed HIV-positive test results.
6. True or False: Once the names of people with confirmed, confidential HIV-positive test results have been reported to the state Department of Health Services, that department forwards the names to the Centers for Disease Control and Prevention.

Discussion Questions

1. What has the experience of shifting to name-based reporting been at your test site? What kinds of issues have come up with clients? With counselors? Have most issues related to confidentiality, or have there been other issues?
2. Is treating HIV more like other sexually transmitted diseases helpful in decreasing stigma? In what ways do you think HIV should or should not

be treated like other sexually transmitted diseases?

3. How might a counselor respond to a client's concerns about the confidentiality of name-based reporting?
4. How can counselors take the time to support informed consent and still maintain a focus on risk assessment and risk reduction?

Answers to Review Questions

1. *False. The same database, the HIV/AIDS Case Registry, holds the names of people living with HIV and AIDS. It has strong safeguards protecting confidentiality that have worked for more than 20 years, and have recently been strengthened.*
2. *c.*
3. *True. HIV is unusual among communicable diseases because it has not been reported by name in California in the past.*
4. *d.*
5. *False. Doctor's offices and medical clinics must also report confirmed HIV-positive test results, as well as viral load tests to the state Department of Health Services.*
6. *False. The names are turned into a name-based code, and that code, rather than the name itself, is reported to the CDC.*

Using PERSPECTIVES

PERSPECTIVES is an educational resource for HIV test counselors and other health professionals.

Each issue explores a single topic. A **Research Update** reviews recent research related to the topic. **Implications for Counseling** applies the research to the counseling session. Also included are a **Case Study** and two sets of questions for review and discussion.

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