

Routine Testing for HIV: Public Health versus Patient Privacy

By Bruce Patsner, M.D., J.D.

Acquired Immune Deficiency Syndrome (AIDS) remains a devastating medical illness even in the U.S. where retroviral therapy has dramatically improved the life expectancy of many individuals with the disease.¹ AIDS is not curable but generally responds well to treatment, and some patients may have clinical remissions lasting a decade or longer. Infection with the human immunodeficiency virus (HIV) is the one essential prerequisite for an individual to develop AIDS, and all infected individuals will at some point early in the trajectory of their disease have an asymptomatic infection which can be detected by screening their blood for the presence of the HIV.² Inexpensive and accurate testing methods are readily available to detect occult infection.³ In the U.S., approximately 25% of asymptomatic HIV-positive individuals are unaware of their seropositive status.⁴ These people can, and sometimes do, unintentionally and unknowingly transmit the disease to their sexual partners.⁵

Without question, this situation represents a major public health crisis. Given the availability of effective treatment which can significantly diminish morbidity, and the data from some studies which suggest that at least some individuals will alter their behavior and potentially infect fewer people once they find out they are HIV-positive,⁶ there are good reasons to recommend routine screening for HIV to protect the public health. The critical questions are: Who should be screened for HIV? How aggressively should they should be screened? How much informed consent, if any, should be required prior to screening?⁷

Three potential strategies for screening for HIV for either the general population or higher-risk individuals have been advanced by public policy officials over the past ten years: (1) mandatory testing with no right of refusal; (2) voluntary testing with pretest counseling and specific informed consent (also known as “opt-in” testing); and (3) universal testing with patient notification that they will be screened for HIV unless they specifically refuse (know as “opt-out” testing). Barriers to routine screening without specific consent include concerns about low-yield and financial cost in non-high-risk populations; persistent stigma associated with HIV infection; fears that individuals who are HIV-positive will be discriminated against; laws in some states mandating counseling of individuals prior to drawing blood to screen for HIV as well as requiring a separate

¹ Kent A. Sepkowitz, *One Disease, Two Epidemics – AIDS at 25*, 354 N. ENGL. J. MED. 2411 (2006).

² *Id.*

³ Alexi A. Wright and Ingrid T. Katz, *Home Testing for HIV*, 354 N. ENGL. J. MED. 437 (2006).

⁴ Sepkowitz, *supra* note 1.

⁵ Centers for Disease Control and Prevention, *HIV Prevalence, Unrecognized Infection, and HIV Testing Among Men Who Have Sex With Men – Five U.S. Cities, June 2004 – April 2005*, 54 MMWR MORB. MORTAL. WKLY REP. 597 (2005).

⁶ Marks G, Crepaz N, and Janssen RS, *Estimating sexual transmission of HIV from persons aware that they are infected with the virus in the USA*, 20(10) AIDS 1447 (2006).

⁷ Sepkowitz, *supra* note 1.

informed consent in order to screen;⁸ reluctance on the part of the medical profession to perform diagnostic testing on patients without informing them of what they are being tested for;⁹ and case law favoring privacy concerns as well as disciplinary actions against physicians for non-consented HIV testing on competent patients.¹⁰

How Much Consent Should Be Required Before Testing for HIV?

The federal government already has determined that screening without consent is appropriate for certain populations. These include prospective recruits for U.S. armed services¹¹ and inmates in federal penitentiaries.¹² These federal screening policies have survived challenge in court. The U.S. also prohibits the admission of any alien into the U.S. if they are known to be HIV-positive,¹³ though there is no requirement that aliens seeking to enter the US be screened without their consent. Within the medical profession controversy still exists about mandatory or routine screening for pregnant women despite the potential to dramatically reduce the chance of HIV transmission from an infected woman to her child while still in utero.¹⁴ Some bio-ethicists have also suggested that HIV testing without consent be carried out in critically ill patients unable to consent to testing.¹⁵

The CDC (Centers for Disease Control and Prevention) in Atlanta has been issuing guidelines for routine HIV testing and counseling for years, and up until 2005 had recommended “opt-in” routine testing for HIV in areas and patient populations of higher prevalence, such as individuals with other sexually transmitted diseases, known intravenous drug users, or homosexual or bisexual men.¹⁶ The recommendations changed, however, in 2006.

The New Proposals for Routine HIV Screening

In 2006 the CDC published newer recommendations for HIV screening testing which advocated for “opt-out” testing. This change in policy clearly favors presumptive public health benefits over individual patient privacy and autonomy.¹⁷

⁸ John G. Bartlett, Bernard M. Branson, Kevin Fenton, et. al., *Opt-Out Testing for Human Immunodeficiency Virus in the United States*, 300 JAMA 945 (2008).

⁹ *Id.*

¹⁰ John Ellement, *Patient gets \$10,000 in settlement of suit over “secret” HIV testing*, THE BOSTON GLOBE, June 1, 1996 at A13.

¹¹ William E. Adams, Jr., Mary Anne Bobinski, Michael L. Closen, Robert M. Jarvis, and Arthur S. Leonard, AIDS. CASES AND MATERIALS (3rd ed. 2002).

¹² *Id.*

¹³ *Id.*

¹⁴ American College of Obstetricians and Gynecologists, Committee Opinion, *Prenatal and Perinatal Human Immunodeficiency Virus Testing: Expanded Recommendations, September 2008*, The American College of Obstetricians and Gynecologists, Washington, D.C.

¹⁵ Scott D. Halpern, *HIV Testing Without Consent in Critically Ill Patients*, 294 JAMA 734 (2005).

¹⁶ Centers for Disease Control and Prevention, *Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings*, 55(1)(RR-14) MMWR MORB. MORTAL. WKLY. REP. 1 (2006)

¹⁷ *Id.*

The new “opt-out” strategy – though a change from the previous purely voluntary and specific consented screening recommendation even for highest risk individuals – stops short of non-consented universal testing for all individuals in every potential medical care setting. The new CDC proposal acknowledges two fundamental truths about screening for occult HIV infection: (1) testing below a certain level of probability of finding a previously unknown positive result cannot be justified on economic grounds; and (2) some attention must be paid to informing patients that they will be tested.¹⁸

The new CDC recommendation is to screen all patients aged 13 to 64, at the time of any hospital admission and at the time they present for out-patient care in a clinical setting where the expectation is that at least 1 per 1000 patients (0.1%) will screen positive for HIV.¹⁹ This new screening strategy would be for everyone in the target age range, regardless of their risk of being HIV-positive.²⁰

Many, but not all, medical organizations have come out in support of this new screening recommendation. Since neither the survival rate nor general treatment approach for AIDS has changed in the past three years, and no new evidence has emerged that patients are altering potentially risky behavior, it is unclear why the CDC changed its policy on testing. Adding to the confusion is that new policy is at odds with laws in many states which require specific informed consent to screen for HIV and for patients to undergo AIDS counseling prior to being screened for HIV.²¹

Can the New Screening Guidelines Be Justified?

Although the exact reasoning used by the CDC is unclear, the new CDC recommendations may be the result of several factors, the cumulative effect of which has spurred CDC to take a more aggressive position on AIDS testing. First, AIDS and HIV infection from unknowing partners continues to be a problem despite voluntary programs. This is clearly a frustrating situation for public health officials. There has been no significant improvement in the new infection rate in the U.S. between the 2004 and 2006 recommendations, and perhaps the new recommendations belie a belief that population screening goals will not be met without further change in screening policy.

Additionally, there is now more support from medical organizations in favor of mandatory testing of patients who present for any type of medical care.²² There is also a general recognition that private, home testing availability has not resulted in a lowering of the incidence of new cases – if they are used at all – and an acknowledgement that fear of the results might prevent an individual from self-testing despite the possible risk to the public health. Lastly, it appears that the purely voluntary testing system is not working.

¹⁸ *Id.*

¹⁹ *Id.*

²⁰ *Id.*

²¹ Bartlett, *supra* note 8.

²² *Id.*

All of these CDC concerns may be completely legitimate from a medical point of view, but they provide no substantive basis as to why public health concerns should trump the recognized patient privacy and specific informed consent issues.

Overcoming the Medical and Legal Challenges

The recommendations/guidelines from the CDC carry some weight with public health policy experts but do not have the force of law. The United States Supreme Court has not yet faced the issue of whether it is constitutional to screen for HIV without obtaining an individual's specific informed consent or counseling on AIDS. Until 2005, specific consent for HIV testing was required in all fifty-three U.S. states and territories,²³ but the situation is now one characterized by a lack of uniformity of state laws. At present, the most that can be said is that an individual's likelihood of facing opt-out screening for HIV at a medical clinic or at the time of admission to the hospital depends on which state he or she is in at the time.

The primary argument for routine, non-consented HIV screening is that it offers individuals the opportunity to become aware of their HIV status and change their behavior so that infection of others might be prevented. Public health experience and patient behavior with other venereal diseases (e.g. syphilis, herpes, human papillomavirus infection) calls this basic assumption into question; this is one reason why some medical societies do not support "opt-out" screening of hospitalized patients. Even if behavioral data definitively supported a switch from "opt-in" to "opt-out" testing, it still begs the question of whether this public health concern should now trump traditional legal protections of patient privacy and due process rights. Apparently some states, the CDC, and many medical societies now think it should. Whether federal courts will answer this question the same way remains to be seen.

Health Law Perspectives (September 2008), available at:
<http://www.law.uh.edu/healthlaw/perspectives/homepage.asp>

²³ Halpern, *supra* note 15.