



**INCREASING ACCESS TO VOLUNTARY HIV TESTING:
A SUMMARY OF EVIDENCE OF THE IMPORTANCE OF
SPECIFIC WRITTEN CONSENT AND PRE-TEST
COUNSELING IN HIV TESTING**

Increasing the numbers of people living with undiagnosed HIV who get tested, so that they will learn their status and get into care earlier, has our support. But expanded testing should be done with specific, written consent and after some counseling, for the reasons summarized below.

WHAT THE CDC RECOMMENDS REGARDING CONSENT AND COUNSELING FOR HIV TESTING¹

- The CDC continues to state that:
 - Ø Testing must be voluntary and free from coercion.
 - Ø Patients must not be tested without their knowledge.
 - Ø Obtaining informed consent is an ethical obligation.²

- The CDC now recommends:
 - Ø Testing should be done with specific, written consent and after some counseling, for the reasons summarized below.

WHY SPECIFIC WRITTEN CONSENT AND PRE-TEST COUNSELING ARE BENEFICIAL

- The risk of testing patients without their knowledge is avoided by requiring specific, written consent for an HIV test.
 - Ø This is a real concern. Up to 16% of the pregnant women tested under an opt-out testing system without a written consent requirement in Arkansas did not even know that they had been tested for HIV.³
- Health care providers benefit from requiring specific written informed consent, by documenting that they have satisfied their ethical and legal obligations to obtain informed consent.⁴
- Communication between the patient a

- The significant emotional and legal dimensions to an HIV diagnosis – which make HIV infection different from many other diseases – can be addressed.
 - Ø There is no cure for HIV and anyone who tests positive will need to follow a care regimen -- often very complicated, expensive, and with significant side effects -- for the rest of his or her life.
 - Ø The significant legal consequences include mandatory confidential reporting of the names of anyone diagnosed with HIV; in order to give truly informed consent, people should be informed of those and be informed that in many states they have the option of anonymous testing.

- Stigma still attaches to an HIV diagnosis and people living with HIV still experience discrimination.
 - Ø 26% of adults with HIV believed they had experienced discrimination from a health care provider since being diagnosed.

- Ø A 2005 study revealed that 33% of male respondents and 46% of female respondents incorrectly believed HIV transmission could occur through unprotected sex between two uninfected men.¹⁹
- Ø The Kaiser survey found that those with misconceptions about HIV transmission were much more likely to express discomfort with working with someone with HIV.²⁰

MANY MORE PEOPLE CAN BE TESTED AND LEARN THEIR STATUS WITHOUT ELIMINATING SPECIFIC CONSENT AND PRE-TEST COUNSELING

- Patient concerns about specific consent and pre-test counseling are not significant barriers to testing.
 - Ø A 2006 Kaiser Family Foundation survey found that the biggest reason people reported for not getting tested is that they did not think they were at risk.²¹ This shows the need for more information, not less.
 - Ø The same study showed that most people did not think that they would experience stigma because they were tested for HIV. However, the study found that stigma against those who test positive still exists and roughly half of those surveyed said that there is a lot of discrimination against people with AIDS.
 - Ø Offering testing to everyone, rather than offering it only to those considered at risk, will reduce or eliminate any stigma associated with testing.

- There are successful models that result in more people being tested without abandoning safeguards ensuring that testing is informed and voluntary.
 - Ø New York City Health and Hospitals Corporation (HHC) increased the number of patients tested in HHC hospitals by 63% in 2006, by using rapid testing and streamlining pre-test counseling, while continuing to use HIV-specific written consent, which is required by New York law.²²
 - Ø Authors of one study found that routinely recommending HIV counseling and testing can be feasible and effective in an emergency department setting, despite the time constraints present in that setting, and concluded that emergency room testing can be increased by streamlining counseling and providing some information in writing, as well as by involving non-physician staff in counseling.²³

¹⁹ Herek, G. *et al.* (2005) When Sex Equals AIDS: Symbolic Stigma and Heterosexual Adults' Inaccurate Beliefs about Sexual Transmission of AIDS, *Social Problems*, 52(1), 15-37.

²⁰ Kaiser Public Opinion Spotlight (2006); *see also* Herek, G. *et al.* (2002) HIV-Related Stigma and Knowledge in the United States: Prevalence and Trends, 1991-1999, *American Journal of Public Health*, 92(3), 371-377 (discussing link between misinformation about HIV and stigma against people living with HIV).

²¹ Kaiser Public Opinion Spotlight (2006).

²² NYC Health and Hospitals Corporation, *Rapid Testing and More Routine Testing Reaches Patients Not Commonly Known to Be at Risk, Including More Women and Teens*, Oct. 3, 2006 available at <http://www.nyc.gov/html/hhc/html/pressroom/press-release-20061003.html>

²³ Rothman, R. (2004) Current Centers for Disease Control and Prevention Guidelines for HIV Counseling, Testing, and Referral: Critical Role of and a Call to Action for Emergency Physicians, *Annals of Emergency Medicine*, 44(1), 31.

- Ø Perinatal transmission of HIV has been virtually eliminated in the United States, including in states that require specific written informed consent, such as Massachusetts, Pennsylvania and Michigan.²⁴

²⁴ Massachusetts STD and HIV/AIDS Surveillance Report: 2005, available at http://www.mass.gov/dph/cdc/aids/2005_surveillance.pdf; HIV/AIDS Surveillance Biannual Summary: Commonwealth of Pennsylvania, June 2005, available at http://www.dsf.health.state.pa.us/health/lib/health/epidemiology/biannual_summary_june2005.pdf; Status of the HIV/AIDS Epidemic in Michigan, 2005, available at http://www.michigan.gov/documents/Review_MI_05_final_161086_7.pdf