



# Preserve the Right to Written Informed Consent for HIV Testing in Illinois

Illinois law requires patients to give their written, informed consent in order to receive HIV testing as a safeguard to ensure they understand fully the test's benefits and limitations.

At least eight bills\* pending before the Illinois General Assembly would eliminate the right of Illinois residents to written, informed consent for HIV testing. Promoting the public's trust—particularly among vulnerable populations where HIV education and testing are most urgently needed—remains a compelling reason to retain current written, informed consent requirements.

## Written, Informed Consent Promotes Ethical Medical Practice:

- The legal precedent for written, informed consent is enshrined in the nation's modern medical and legal history as a safeguard against unauthorized and/or uninformed medical procedures affecting a person's body and wellbeing.
- Written, informed consent is required when the benefits and risks are not well known. Given the myriad social and legal consequences of an HIV diagnoses—including stigma, eviction, workplace discrimination, violence, criminal transmission charges, uninsurability, etc.—HIV diagnoses warrants written, informed consent before testing is provided.
- The infamous medical abuses of the Tuskegee Syphilis Experiments of 1932-1972 underscore the need for the highest ethical standards in medicine. Tuskegee continues to generate mistrust in the medical establishment to date.
- The American Medical Association tells its members: "Informed consent is more than simply getting a patient to sign a written consent form. It is a process of communication between a patient and physician that results in the patient's authorization or agreement to undergo a specific medical intervention. To protect yourself in litigation ... it is important that the communications process itself be documented. Good documentation can serve as evidence in a court of the law that the process indeed took place."

## What Illinois Law Requires Currently:

Illinois requires healthcare providers to obtain written, informed consent before administering voluntary HIV testing:

- The patient must document that informed consent has been granted with his/her signature.
- The consent form must address HIV testing *specifically*.
- Specific consent for HIV testing may be included on the same form as general consent for healthcare.
- Examples of specific consent language:
  - "I am informed of and accept voluntary HIV testing."
  - "Unless I have declined HIV testing in the option provided above, I understand that I will receive voluntary HIV testing."

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\* HB 193 (Flowers); HB 890 (Ford); HB 1340 (Flowers); 1341 (Flowers); HB 1634 (McAuliffe); SB 1505 (DeLeo); HB 546 (Flowers); HB 1759 (Flowers)

- Illinois requires healthcare providers to make available the following pre-test information to individuals offered voluntary HIV testing:
  - Meaning of test results include its purpose, potential uses, and limitations
  - Voluntary nature of the test and the right to withdraw consent at any time
  - Right to anonymous testing and confidentiality
  - If appropriate, availability of additional or confirmatory testing
  - If appropriate, availability of referrals for further information or counseling

**Written, informed consent IS NOT a barrier to testing acceptance:**

- The vast majority of people counseled about the benefit of HIV testing will accept it.
- 61% of those surveyed said the leading reason for not being tested was not written informed consent but that they didn't feel they were at risk (Kaiser, 2006).
- Smaller shares of those who haven't been tested say it is because their doctor never recommended it (21%) or they worry about confidentiality (10%).
- The offer and acceptance of voluntary HIV testing dramatically increased (63%) in New York City hospitals in 2006 without eliminating the requirement of written consent. Illinois expanded testing acceptance among pregnant women and newborns from 73% to nearly 100% in 2006 with outreach, training, and technical assistance for clinicians.

**The general public, which lacks basic information about HIV transmission, benefits when offered testing with written, informed consent:**

Far too many people lack basic knowledge about how HIV is and is not transmitted. According to a 2006 national survey conducted by the Kaiser Family Foundation:

- 37% mistakenly believed that HIV could be transmitted through kissing.
- 22% mistakenly believed that transmission could occur through sharing a drinking glass.
- 16% mistakenly believed that transmission could occur through touching a toilet seat.
- And more than 4 in 10 adults held at least one of the above misconceptions about HIV transmission.

**Removing written, informed consent requirements increase the risk for involuntary and uninformed HIV testing:**

- Uninformed, involuntary HIV testing is unethical and exposes patients to psychological and social harm that can be avoided.
- Uninformed, involuntary HIV testing puts HIV-negative patients at risk for future HIV transmission by failing to educate the patient about HIV and risk reduction strategies.
- In most settings, greater than 99% of patients tested will have HIV-negative results but may need accurate HIV information and counseling about ways to reduce their risk.

**Removing written, informed consent is no guarantee that testing acceptance will increase unless more medical providers are equipped and funded to recommend voluntary HIV testing in their practice.**

Additional information:

AIDS Legal Council of Chicago: [www.aidslegal.com](http://www.aidslegal.com)

AIDS Foundation of Chicago: [www.aidschicago.org/prevention/news.php](http://www.aidschicago.org/prevention/news.php)

Pregnant Women and Newborns: [www.aidschicago.org/advocacy/perinatal.php](http://www.aidschicago.org/advocacy/perinatal.php)