



# Right to Informed Consent HIV Testing

## Article 27-f of Public Health Law

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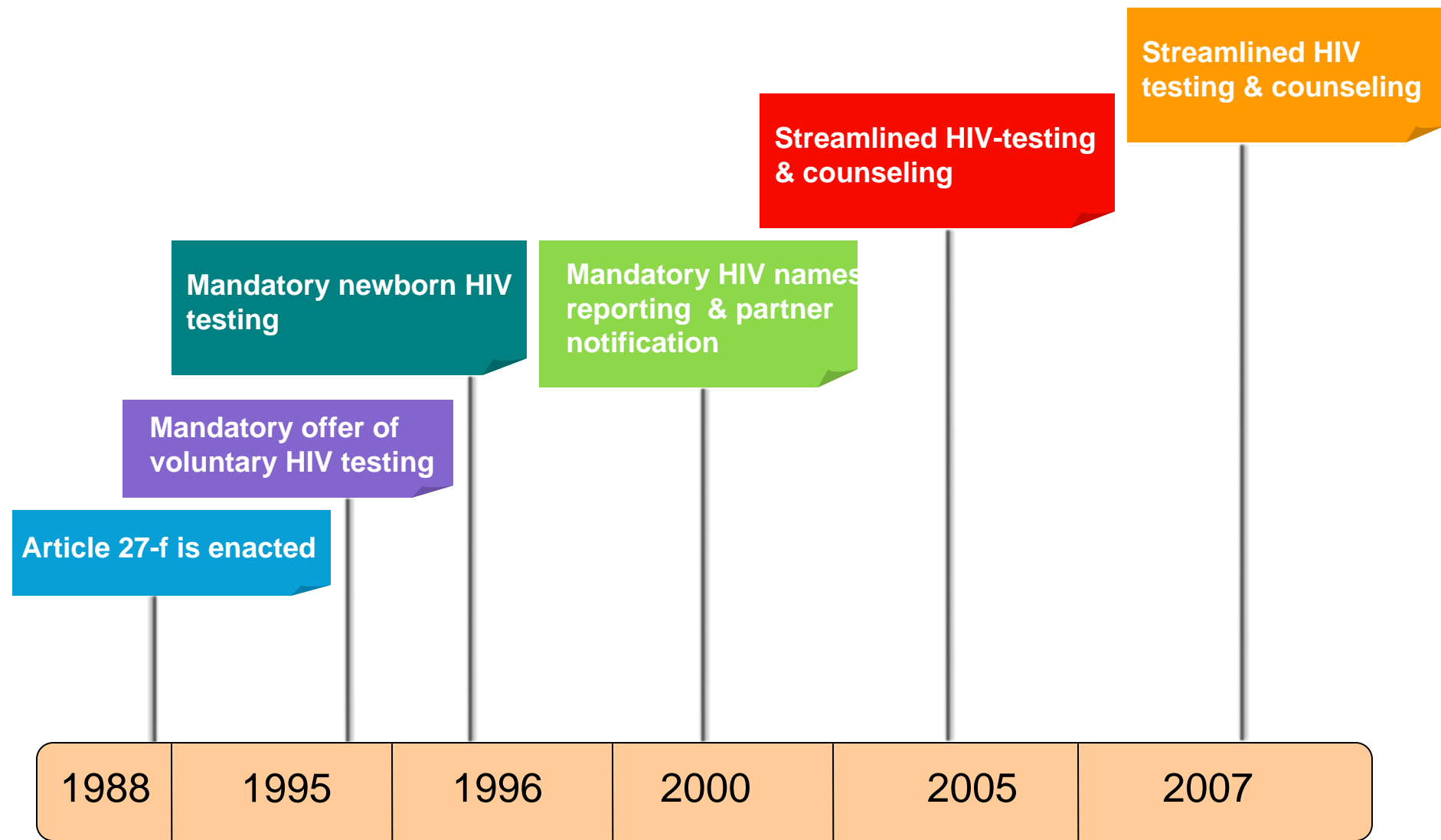
# 1988 NYS enacts PHL Art. 27-f

- Purpose:
  - To encourage voluntary HIV testing so people can learn their HIV-status
  - To enable people to make decisions regarding appropriate treatment
  - To encourage people to change behaviors that put them and others at risk of infection
- How Policy Achieves that Purpose:
  - Requires providers provide pre- and post-test counseling
  - Requires providers to obtain written consent for HIV testing
  - Enacts strict confidentiality provisions to protect HIV-related information, including whether or not an individual decides to have an HIV test



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# Timeline PHL article 27-f





# HIV Testing Subtext

- Stigma & discrimination surrounding HIV in the “early days” discouraged HIV testing
  - Art. 27-f policy directed at increasing voluntary HIV testing by protecting individuals testing for and diagnosed with HIV-infection
- How different is the social context today?
  - Is the policy still necessary?



# Problem Remains... Should Policy be Changed?

- **Fundamental Problem Remains in 2008:**
  - Too many people still do not know their HIV-status
    - Causes delays in decisions regarding appropriate treatment
    - Causes delays in behavioral changes that put people at risk of infection
  
- **Should Policy be Changed as a Result?**
  - Some people argue the policy is no longer needed, and/or it is part of the problem
  - Others argue the policy is sound and other policies are necessary to address the problem



# HIV Testing: What Art. 27-f Requires Today

- Requires that routine HIV testing to be integrated into medical care
- Requires pre-test counseling
  - Can be conducted by written material, video or face-to-face counseling
- Allows provider flexibility based on patient need & circumstances
- HIV consent form is one page
  - Contains all the necessary pre-test information



My health care provider has answered any questions I have regarding HIV testing and has given me written information with the following details about HIV testing:



- HIV is the virus that causes AIDS.
- The only way to know if you have HIV is to be tested.
- HIV testing is important for your health, especially for pregnant women.
- HIV testing is voluntary. Consent can be withdrawn at any time.
- Several testing options are available, including anonymous and confidential.
- State law protects the confidentiality of test results and also protects test subjects from discrimination based on HIV status.
- My health care provider will talk with me about notifying my sex or needle-sharing partners of possible exposure, if I test positive.

I agree to testing for the diagnosis of HIV infection. If I am found to have HIV, I agree to additional testing which may occur on the sample I provide today to determine the best treatment for me and to help guide HIV prevention programs. I also agree to future tests to guide my treatment. I understand that I can withdraw my consent for future tests at any time.

**For pregnant women only:**

In addition to the testing described above, I authorize my health care provider to repeat HIV diagnostic testing later in this pregnancy. I understand that my health care provider will discuss this testing with me before the test is repeated and will provide me with the test results. The consent to repeat diagnostic testing is limited to the course of my current pregnancy and can be withdrawn at any time.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_  
(Test subject or legally authorized representative)

If legal representative, indicate relationship to subject: \_\_\_\_\_

Printed Name: \_\_\_\_\_

Medical Record #: \_\_\_\_\_

Except for expedited HIV testing on labor units, this form replaces other HIV testing consent forms as of June 1, 2005.

**NOTE:** this form is intended to be used in conjunction with DOH-2556i, Part A.



# Should Art. 27-f be Changed?

## YES

- Stigma and discrimination are no longer a problem and AIDS “exceptionalism” (reflected in the policy) should end
- While stigma may still exist, the policy actually has the effect of discouraging voluntary testing -- written consent poses a barrier to testing
- People assume they are being tested for HIV anyway
- People have the right to “opt-out” – so if they really don’t want to be tested they can choose not to be tested

## NO

- Stigma and discrimination still HUGE problem for people living with and at risk for HIV infection & the policy remains necessary
- Human & civil rights advocates argue people have a fundamental right to give informed consent prior to medical testing or treatment – Art. 27-f preserves this right
- Written, informed consent does not deter testing from a patient’s perspective
- Problem is not policy, problem is providers not offering the test routinely

# Proposed Policy Change #1



## Eliminate separate written informed consent

- Replace with oral consent and a notation in patient's medical chart
  
- Eliminate pre-test counseling
  
- Eliminate post-test counseling for negatives
  
- Increase civil penalties for unlawful HIV-test or disclosure of confidential HIV related information
  
- This bill did not pass out of the Assembly health Committee
  - Likely to be reintroduced 2009 legislative session



# Proposed Policy Change #2



- Mandatory offer of HIV-test by medical practitioners in Article 28 facilities
- Elimination of separate written informed consent for HIV-test (replaced with general durable medical consent with “opt out” provision)
- Retains pre-test counseling (eliminates requirement of standard written materials)
- Retain post-test counseling
- Provides for HIV testing without consent in certain cases of “occupational exposure”
- Authorizes collection of additional data by DOH



# HIV Stigma Today

- People diagnosed with HIV still subject to STIGMA, harassment and discrimination in
  - The workplace
  - Health care settings
  - Community and family

People diagnosed with HIV are:

- Since 1990, there has been no change in the share of Americans who incorrectly think that HIV might be transmitted through kissing, sharing a drinking glass or touching a toilet seat.
- Subject to prosecution under criminal laws because of their status



# Written informed consent is NOT the barrier to HIV testing

- Absence of reliable data that written informed consent is a barrier to HIV testing and care
- All patients fill out multiple forms- medical history, HIPPA, and insurance forms
- Data shows that OFFERING test strongest predictor of HIV testing



# Written informed consent is NOT the barrier to HIV testing

- 2006 Kaiser Family Foundation survey found that 61% of those who had never been tested had chosen not to be tested because they did not consider themselves to be at risk
  - Problem due in part to general acceptance on behalf of patients and providers alike of “risk-based” – which fails to distinguish between risk (which we all have) and HIGH risk (which some people have)
- 21% said their doctor had never offered them a test
- 13% said they were nervous about confidentiality



# Routinizing offer of HIV-testing while retaining written informed consent leads to good outcomes

- Kings County Hospital Scaled-up HIV testing program offered every adult outpatient an HIV test in 2006
- Patients watched an informational video in the waiting room, and gave written informed consent using NYSDOH streamlined form
- Over all, NYC HHC increased HIV testing in its hospital system 63% in 2006
- Under state law mandating the offer of voluntary HIV testing in Illinois correctional facilities, testing conducted after counseling and informed consent were given, increased 475% between 2004-2006



# General Consent is NOT the Same as Informed Consent

- A general consent covers procedures whose risks and benefits are generally known
- According to the AMA, “informed consent is ... a process of communication between a patient and physician that results in a patient’s authorization or agreement to undergo a specific medical intervention....”
- Studies have established that patients’ trust of their physicians is strongly related to their use of preventive services, adherence to treatment recommendations, and continued participation in care



# Opt-out testing is NOT informed consent

- “Opt out” testing systems rely on a default rule that testing will be performed absent specific objection by the patient and fail to ensure that testing will be performed, particularly in high volume settings, with consent that is informed
- The CDC found that nearly 16% of pregnant women tested in Arkansas under an “opt out” testing system without a written consent requirement did not even know that they had been tested for HIV



# Policy Recommendation

- Preserve Article 27-f of the Public Health Law
- Enact regulatory changes that require all Article 28 health facilities to offer HIV testing routine, irrespective of perceived risk
- Engage in public health social marketing campaigns in high-incident communities about the need for everyone to have an HIV test
- Improve provider's understanding of the law and its parameters
- Encourage providers to partner with their patients in fighting this public health problem



# Delay & Entry into Care

- People cannot enter into HIV care if they do not know their status
- Just knowing HIV status will not solve the problem of access to appropriate, high quality HIV care
  - Concerns about stigma and rejection and fears of social and legal consequences of revealing HIV status or risk behaviors
  - Distrust of medical system based on prior experiences of inadequate care and feeling disrespected and unwelcome
  - Misunderstanding about HIV disease processes, accessibility of treatment and the role of medications



# Other Causes of Delay & Entry into Care

- “Denial” of illness
- Drug use
- No social support
- No source of regular medical care
- homeless



# Recommendations to facilitate entry to care

- Distribute realistic information
- Improve the ease, speed and convenience of HIV testing
- Ensure pre and post-test counseling adequately prepares the individual for a positive result
- HIV testing sites actively facilitate entry to care
- Bring HIV testing and health care to stigmatized populations
- Incorporate testing and medical referrals into housing programs



# Routine offer of HIV testing and fully resourced medical care

- Focusing on ensuring providers offer HIV tests routine is KEY
  - elimination of written informed consent is a misguided panacea for the crisis that faces us is shortsighted
  - Unnecessarily deprives people of their human right to give consent for medical care and services
- Creating a system that recognizes the complexity of HIV-testing and the ethical responsibility to develop a responsive medical care system is the challenge- one that we must all be engaged in



# HIV Law Project

[www.hivlawproject.org](http://www.hivlawproject.org)