

December 20, 2006

## **HIV TESTING, COUNSELING AND INFORMED CONSENT**

### **Frequently Asked Questions about New York City's Proposed State Legislation**

HIV can now be readily detected by reliable, non-invasive screening tests. Wider use of these tests could save many lives by giving people timely access to treatment, care and counseling. Unfortunately, an antiquated New York State law discourages routine HIV testing by requiring that patients express their informed consent on written forms. Some 38 states – including California, Connecticut, New Hampshire and Ohio – allow oral consent. It is critically important that New York State catch up with them. The New York City Health Department's proposal recognizes the importance of informed consent and patient confidentiality. This legislation is not a step toward mandatory HIV testing. By making HIV tests more accessible, our proposal could help control a preventable epidemic that is still killing thousands of people in this state every year.

#### **1. Wasn't the New York State law on HIV testing designed specifically to protect patients' rights?**

Yes, the current state law was passed in the 1980s to protect the rights of people living with HIV/AIDS. It requires any care provider ordering an HIV test to have the individual receiving the test read and sign a written informed-consent form. The form – which is separate from the general consent form usually used to authorize a wide range of medical tests – explains the rights of patients and the danger that those testing positive for HIV will face discrimination and emotional turmoil.

#### **2. What has changed since the current law was enacted?**

Twenty years ago, people lived on average less than a year after receiving an AIDS diagnosis. Today, lifesaving treatment is available to all HIV-positive people in New York State – regardless of their income or insurance status – and people who know they are infected can take steps to reduce the risks of passing HIV to others. In other words, the benefits of knowing one's HIV status now greatly outweigh any risks. Rules that discourage testing no longer serve primarily to protect patients. Written consent is now a barrier to public health, and most states do not require it. Like the CDC and experts throughout the country, we at the New York City Health Department want to ensure that the fears of an earlier era don't hobble the fight against HIV/AIDS today.

#### **3. What exactly is the New York City Health Department proposing?**

DOHMH hopes to streamline the testing process to facilitate voluntary HIV testing. Our proposals would mandate informed consent for HIV testing but would expand the options for documenting consent. Some facilities may choose to continue to require separate written informed consent, while others may choose to document verbal consent in the

medical record or include consent for HIV testing in a general medical consent. Our bill has several key points.

- The bill does not eliminate the requirement for pre- or post-test counseling. It simplifies pre-test counseling requirements and allows informed consent to be expressed either orally or in writing.
- The bill preserves post-test counseling for everyone being tested, and it stipulates that those testing positive should be offered linkage to HIV care.
- The legislation stipulates that it may not be used to require any individual to be tested for HIV.
- The bill strengthens penalties for unauthorized disclosure of confidential HIV-related information and the conducting of HIV testing without consent.

**4. Your original draft legislation included provisions giving DOHMH the authority to gather and share certain patient information that could be used to identify PLWHA who have dropped out of care or are otherwise not responding to treatment. A11958 does not include these provisions—what happened to them?**

While the Department remains concerned about HIV positive individuals who never initiate care, drop out of care, or remain in care but don't respond to treatment, we have decided not to pursue these care-related activities. We will continue to work with our community partners and sister agencies to improve care for all PLWHA. Our current focus is on making it as easy as possible for those who want to be tested for HIV to do so.

**5. Why are you in such a hurry to get everyone tested for HIV? Aren't most people at fairly low risk?**

More than 100,000 New Yorkers are living with HIV today, but thousands still don't know they are infected. Each year, more than 1,000 first learn they have HIV when they are already sick with AIDS. These individuals often miss the opportunity to receive the care they need to stay healthy, and many spend a decade or more unknowingly spreading HIV in their communities. The current system for HIV testing works well for those who recognize that they may be at risk, but the epidemic is no longer confined to small pockets of the population. If we can make testing a normal part of medical care, rather than offering it only to people with perceived risk factors, HIV-positive people will learn their status earlier, fewer will infect their partners, and fewer will die prematurely.

**6. How do you know that written consent is a barrier to HIV testing?**

Some argue that written consent is not a significant barrier, especially because the New York State Department of Health streamlined the consent requirements last year. That was a step in the right direction, but research suggests that needless paperwork still discourages many physicians from offering HIV tests. During the summer of 2006, the

New York City Health Department surveyed 137 primary-care physicians in three of the city's highest-prevalence areas – the South Bronx, Central Brooklyn and East and Central Harlem. “If written consent were no longer required,” we asked, “would you offer more patients an HIV test?” Some 38% of the doctors answered yes. Thanks to new technologies, HIV testing is now a quick, simple procedure – one that caregivers could easily integrate into routine care. If 38% of New York City's primary-care physicians tested even one more person each week, more than 300 additional infections could be diagnosed annually – and many others could be prevented.

### **7. How do other states handle the consent process?**

HIV testing is being streamlined and expanded nationwide. New York is one of only 12 states that currently require separate written consent for an HIV test in general practice. The CDC recently revised its recommendations to say that HIV tests should become a routine part of medical care for Americans aged 13 to 64 and that requirements for written consent and pretest counseling should be dropped. The new recommendations, published in September 2006 (see [Morbidity and Mortality Weekly Report](#)), say that health care providers should test patients routinely until the detection rate falls below one infection per 1,000 people tested. Unlike the new CDC guidelines, which drop the requirement for written consent altogether, the New York City proposal would still require written documentation that each patient had consented orally to being tested. Yet current state law prevents New York City from taking even that modest step.

### **8. Is there any evidence that switching from written to oral consent actually increases HIV testing?**

Consider what happened at San Francisco County Hospital in 2006, when they changed their practice from written consent to documented oral consent, as New York City is now proposing. Within three months of the change, the hospital documented a 17% increase in HIV testing and a 36% increase in the number of HIV infections identified.

### **9. It seems unlikely that private physicians will rush to offer HIV testing as soon as the consent law changes. What other steps are you taking to encourage them?**

This change of law will make testing easier and less time-consuming for general-practice physicians. If those busy doctors are equipped with appropriate HIV information and materials, many of them will want to offer HIV testing to their patients. While working to remove procedural barriers, we are also working to supply the tools physicians need to counsel patients effectively and make appropriate referrals when patients test positive. The Health Department has conducted a public health detailing campaign to encourage routine HIV testing and offers free HIV testing training for providers.

**10. Aren't New York City's testing rates increasing already, despite the written consent requirement?**

Free, anonymous rapid testing is available at Health Department STD clinics in each of the five boroughs on a walk-in basis; results are available within 30 minutes. And the City's Health and Hospitals Corporation has expanded voluntary HIV testing in public hospitals by using HIV rapid tests and by offering HIV tests to a broader population of patients. The city's public hospitals tested 92,000 people during fiscal year 2006 – a 59% increase over the 58,000 tested a year earlier. Yet 92,000 is still less than 10% of all HHC patients.

Overall, 58% of New Yorkers surveyed last year said they had been tested for HIV at some time in their lives, up from 50% in 2002. But this is no cause for complacency. Despite this progress, nearly two-thirds of New Yorkers at high risk of HIV infection went untested last year, and a quarter have never been tested at all. The tragic result is that more than a third of the city's new HIV diagnoses involve people who are already sick with AIDS. Many of them have lived with the infection for a decade or more, going undiagnosed despite repeated contacts with the health care system.

**11. How will you ensure people aren't tested without their knowledge, and that test results remain confidential?**

The New York City Health Department recognizes the importance of informed consent and right of any patient to refuse HIV testing. Under our proposal, clinicians would still have to explain the consequences of HIV testing and obtain verbal consent, and patients could still decline to be tested. Testing or treating patients without informed consent would still be illegal under the New York City proposal, as would the release of confidential health information. The experience of other states suggests it is possible to maintain patient protections without separate written consent. We have heard no allegations of people being tested without consent in those states, or having their privacy violated.

**12. Teenagers may need extensive counseling to understand the implications of an HIV test. Under your proposal, caregivers would have no obligation to provide it. Couldn't the proposed policy pose hazards for adolescents?**

Adolescents are as varied as adults. Some may need extensive counseling to understand the significance of an HIV test, while others may not. Clinicians are responsible for ensuring that patients understand and consent to whatever tests they receive. Our testing proposal creates a floor, not a ceiling, for counseling and consent. If a clinician felt that a patient would benefit from extra consultation, the clinician could still recommend it. Adolescents are routinely tested for gonorrhea and chlamydia. HIV testing is every bit as important. There is no reason to make it less accessible.

**13. Why are you so focused on one state law? Aren't there many other barriers to address?**

Legislative reform is just one component of our comprehensive response to the HIV/AIDS epidemic. We are working with the health care system and community-based organizations to combat stigma, increase condom distribution, expand rapid testing programs, increase access to syringe-exchange programs, and improve HIV education in schools. Removing legal barriers to testing will strengthen these other initiatives. Opponents worry that as more New Yorkers learn their HIV status, more will be subject to stigma. We believe the opposite is true. If everyone is offered HIV testing, no one will feel singled out. Seeking out a test will become a sign of health awareness, not an acknowledgement of high-risk behavior.

**14. If HIV testing becomes part of routine care, isn't it possible that some people will avoid medical care to avoid being tested?**

When HIV testing was introduced as a routine component of prenatal care, there was no decrease in the number of women seeking care. The result was a historic decline in the number of newborns infected with HIV – from a high of 320 in 1990 to 5 in 2004. We want to make the offer of HIV testing a part of medical care for everyone. HIV testing has and will always be voluntary.

**15. Doesn't this measure have financial implications? How much will routine testing cost, and who will foot the bill?**

Increased testing may lead to more diagnosis, causing greater demand for care, support and treatment in the short run, but it will save money over time. Every new HIV infection costs the health system an estimated \$600,000 in services. By preventing new infections, our policy could help contain the epidemic and reduce the demand for costly treatment. While pursuing that goal, we will continue to monitor service needs and service gaps – and we'll work with a variety of partners to maintain a durable safety net.

**16. Has the New York City Health Department sought advice from the people most affected by this proposal – i.e., health care providers and the public?**

We have held numerous forums over the past year to solicit comments from health workers and the public. We have also presented our position to our two federally funded planning bodies – the NYC HIV Prevention Planning Group and the NYC HIV Health and Human Services Planning Council of New York – as well as the NYC Commission on HIV/AIDS.

**17. What concrete steps has the City taken to combat the stigma surrounding HIV/AIDS?**

The Health Department's staff works closely with the community to devise ways in which stigma can be addressed, taking into consideration the range of views regarding

HIV/AIDS in different communities throughout the five boroughs. The department recently awarded more than \$1.6 million to community organizations to support anti-stigma interventions – a first for the nation.