

Why Informed Consent Matters

Bypassing patient autonomy hurts people living with HIV

Background

Under current law, medical providers in New York State are required to give verbal notice to patients before administering an HIV test. Providers are required to offer HIV testing to all New Yorkers ages 13 and up. A [bill introduced](#) by State Senator Brad Hoylman-Sigal to amend provisions of New York’s HIV testing law would fundamentally change how patients in New York are notified about HIV testing by removing the provision for affirmative informed consent.

Indirect notice is no notice at all

Notices on the walls of busy clinics, waiting rooms, and emergency departments are not an effective way to inform a person presenting for care that they must assert an objection at some point to avoid being tested for HIV. For instance, many New Yorkers don’t read or speak English, or the other languages signs may be posted in, and many of us live with disabilities that affect our vision or reading comprehension. Furthermore, patients often present in the kind of physical distress from acute pain or illness that precludes simultaneously understanding that at some unidentified point, they must object or they will be tested for HIV.

Ending direct notice is a drastic step based on little or no evidence

Replacing direct, oral notice before HIV testing with indirect notice has not been shown to



create better HIV care outcomes. To date, we still do not know if the root problem in New York is patients declining a test after being advised by their provider or if medical providers are failing their mandate to offer testing in the first place. However, there is research showing nonconsensual testing discourages patients from engaging in healthcare; just because a person learns their status does not mean that they will be willing to, or be in a position to, enter into and remain in long-term care.¹

Testing people without their notice or consent will dissuade people from accessing healthcare

The groups of New Yorkers who have the highest rates of new diagnoses are marginalized groups—Black and brown New Yorkers, sex workers, and transgender people—groups that traditionally

¹ See Alison Wringe et. al., “HIV testing experiences and their implications for patient engagement with HIV care and treatment on the eve of ‘test and treat’: findings from a multicountry qualitative study,” available at <https://pubmed.ncbi.nlm.nih.gov/28736389/>; (When they told me that I am HIV positive... I believed the results I had no choice. I wouldn’t argue with them, whatever they say I must do I will do it. I did all what they wanted me to do like taking bloods, attending sessions, and initiated by Nurse, but at the end... what they want me to do [take ART]... I will not do it!! (Female, lost to follow-up, Southern Africa)).

have a significant lack of trust in medical providers due to historic and ongoing racism, transphobia, and abuse by medical professionals. To remove a person's agency in their medical care is to further erode that trust, and risk further distancing them from medical care. Indeed, rather than increasing access to HIV treatment, perversely testing people without their knowledge or consent risks alienating them from pursuing further care. Patients may think twice about seeking medical treatment again, including HIV treatment, for fear that they will be subjected to further testing or interventions without their notice and consent. This is especially important given the history of mistrust between some of the most vulnerable communities affected by HIV and the healthcare system—we should right that wrong.



Testing people without their knowledge or consent can have collateral consequences

For those who are undocumented, testing for HIV without effective notice or consent while being treated for an acute healthcare need may place their ability to stay in or return to this country in

peril.² And, testing without effective notice or consent poses risks for people in mental health crisis, especially Black and brown people, who are brought into an ER for injuries sustained after “resisting arrest”; with this proposal, arresting officers may have access to HIV test results, which can turn a mishandled arrest into a felony charge for the arrested individual.

The proposed changes are out of step with medical ethics and standards of care for other diseases, and conflict with state and federal law

The Patient's Bill of Rights, enshrined in the Public Health Law, entitles patients to receive complete information about their diagnosis, treatment, and prognosis. Patients also have the right to refuse treatment, and these values are fundamental recommendations of the Centers for Disease Control and Prevention among others. Nonconsensual HIV testing is inconsistent with these values and the letter of the law. Rather than weaken peoples' right to make their own healthcare choices in the name of “helping” them, there are other changes that might address the issue of late or concurrent HIV/AIDS diagnoses. For example, we could require that providers be trained in how to have these conversations so they feel fully equipped to engage in them or increase the frequency by which tests must be offered to capture people at different stages of their lives. At a minimum, we need the Department of Health to attempt to enforce existing laws requiring pre-test and post-test counseling before stripping people of their rights.

Enforce Informed Consent, Don't Abolish It

² See “Immigration to the US, Women, and HIV: Facts and Resources” The Well Project, available at <https://www.thewellproject.org/hiv-information/immigration-us-women-and-hiv-facts-and-resources>; See also “HIV Criminalization Against Immigrants in California” The Williams Institute, available at <https://williamsinstitute.law.ucla.edu/publications/hiv-criminalization-immigrants-ca/> (“Based on the data available, it did appear that there were some individuals who had deportation proceedings brought immediately after an HIV-specific criminal conviction or police interaction.”).

CONTACT

Amir Sadeghi, Policy and Advocacy Manager, CHLP, amir@hivlawandpolicy.org