



# NYCLU

NEW YORK CIVIL LIBERTIES UNION

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## **Reproductive Rights Project**

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VIA E-Mail  
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Mr. William Johnson  
Department of Health  
Division of Legal Affairs  
Office of regulatory reform  
Corning Tower, Room 2414  
Empire State Plaza  
Albany, NY 12237

Dear Mr. Johnson:

The New York Civil Liberties Union (“NYCLU”) and the American Civil Liberties Union (“ACLU”) submit these comments to the New York State Department of Health’s (the “Department”) proposed amendment regarding 10 N.Y.C.R.R. Part 63, “HIV Laboratory Reporting.” In particular, we wish to point out a number of significant civil liberties concerns implicated by the regulations as currently proposed.

First, the proposed regulations violate New York Public Health Law § 2130(1), which permits physicians and diagnostic laboratories to report only: (1) an *initial determination* that a person is infected with HIV; or (2) an *initial diagnosis* that a person is afflicted with AIDS; or (3) an *initial diagnosis* that a person is afflicted with HIV-related illness. The statute does not authorize mandatory reporting of HIV-related tests beyond the initial determination or diagnosis, nor does it authorize the reporting of HIV subtype data or antiviral resistance testing data.

Moreover, the additional data reporting mandated by the DOH Commissioner is outside the scope of the authority of the statute. Mandatory reporting of such highly personal information violates an individual’s right of privacy and due process, which is protected by the New York State law and the State and federal Constitutions. With respect to any information beyond the initial determination or diagnosis of HIV infection, an individual should be given the opportunity to opt out of any reporting regime. At a bare minimum, an individual must be told that his or her results will be reported to the Department of Health, so that the individual can

make an informed decision about whether to proceed with confidential testing at that location or to seek an anonymous testing site.

Second, the proposed regulations also provide for the repeal of the regulatory promulgation of the previous HIV consent form, which was compliant with the statutory requirements for informed consent. *See* Public Health Law § 2781. The revised consent form, currently in use, fails to comply with those statutory requirements. The form neither specifies the HIV tests to which a person is consenting, nor makes clear to whom the consent has been given. In addition, the form purports to serve as consent for all tests that may be conducted in the future. A “one time for all time” consent form violates both the letter and the spirit of the Public Health Law.

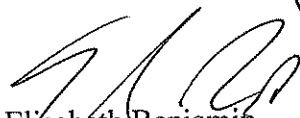
While obtaining information to help guide HIV prevention programs is an important component of HIV public health, patients have a right to be specifically informed as to whom their identifiable personal health information will be provided, and the right to decline to provide a specimen to be used for prevention efforts or other research. By linking testing for treatment and prevention efforts, patients can only access the former by agreeing the latter. This requirement inappropriately imposes a coercive element into the provider-patient relationship.

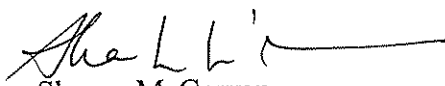
The revised consent form is also problematic to the extent that it does not make clear specifically to whom consent is being granted. This form provides authorization to anyone who comes into possession of this document. We believe that all of these important safeguards are essential elements of any informed consent form.

The NYCLU and ACLU share the Department’s goal of ending the devastation of HIV/AIDS by enhancing HIV treatment and prevention. Community stakeholders, however, must be involved in the conversation concerning drafting and implementation of regulations such as these from the outset. We also note that, although the Department is seeking public comment concerning the proposed amendment, there is no hearing scheduled. We urge the Department to schedule public meetings in locations throughout New York State to allow for meaningful input by community members.

Thank you for your time and attention to this matter. Should you have any questions, please do not hesitate to contact us at the numbers below.

Very truly yours,

  
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