



**NEW YORK STATE
DEPARTMENT OF HEALTH:
SECURITY AND CONFIDENTIALITY
OF HIV SURVEILLANCE DATA**

October 27, 2014

DETERMINANTS OF NEW YORK STATE HIV/AIDS SURVEILLANCE DATA CONFIDENTIALITY AND SECURITY POLICIES

- New York State laws
 - HIV-specific laws are most important but other laws may be applicable
- New York State regulations
- CDC Guidelines required as a condition of grant funding
- “Overall Responsible Party” (ORP) approval
 - The ORP is a high-ranking official who accepts overall responsibility for implementing and enforcing data security, confidentiality and sharing
 - Dr. Guthrie Birkhead, Deputy Commissioner, Office of Public Health, serves as the NYSDOH ORP
- AIDS Institute staff assessment of risk – benefit ratio, practicality, and beneficial redundancy
 - Information technology, legal or other expertise may be sought



NEW YORK STATE HIV REPORTING AND PARTNER NOTIFICATION LAW

- June 2000 to April 2010
 - HIV surveillance data to be used for HIV epidemiology and partner notification
 - Sharing of information for other public health purposes not allowed
- April 2010 to present
 - Within health departments, use of surveillance data with identifiers is expanded
 - To direct program needs
 - To assess comorbidity
 - To assess completeness of reporting
- April 2014 to present
 - Use of surveillance data with identifiers is further expanded to allow sharing with health care providers for purposes of patient linkage and retention in care



HIV SURVEILLANCE DATA AND CONFIDENTIALITY: CHAPTER 308 OF THE LAWS OF 2010

*The Law: “2135. Confidentiality. All reports or information secured by the department, municipal health commissioner or district health officer under the provisions of this title shall be confidential except:

- (a) in so far as is necessary to carry out the provisions of this title;
- (b) when used in the aggregate, without patient specific identifying information, in programs approved by the commissioner for the improvement of the quality of medical care provided to persons with HIV/AIDS; or**
- (c) when used within the state or local health department by public health disease programs to assess comorbidity or completeness of reporting and to direct program needs, in which case patient specific identifying information shall not be disclosed outside the state or local health department.”**

*Text of law available at <http://www.nyc.gov/html/doh/downloads/pdf/ah/ch308.pdf>.
Red text color and bold font added for emphasis.



EXCERPTS FROM NYS REGULATIONS

PART 63.4(C) ADOPTED 2/22/2012*

Confidentiality. Such reports and additional information maintained by the commissioner or his/her designated representative, including all information generated by contact notification and domestic violence screening activities, shall be kept confidential as required by Public Health Law, Article 21, Title III, and shall not be disclosed except ...

--for conducting **accurate and complete epidemiological monitoring** of the HIV/AIDS epidemic and for **conducting contact notification** activities...

--information may be disclosed to public health officials in other jurisdictions when necessary to notify the contact or for purposes of **de-duplication**;

--Reports and information may be used ...with patient identifiers when used within the state or local health department by public health disease programs to **assess co-morbidity** or **completeness of reporting** and **to direct program needs**, in which case patient identifiers shall not be disclosed outside the state or local health department.

--Nothing contained herein shall prevent the department, municipal health commissioner or district health officer from informing physicians and other persons authorized to order diagnostic tests or make medical diagnoses or their agents that there is **no need for additional follow-up** by such provider for such individual.

* Full text available at http://www.health.ny.gov/diseases/aids/providers/regulations/amended_part63.pdf.
Red text color added for emphasis



NYS PUBLIC HEALTH LAW SECTION 2135 AMENDED APRIL 1, 2014

- *“§ 2135. Confidentiality. All reports or information secured by the department, municipal health commissioner or district health officer under the provisions of this title shall be confidential except: (a) in so far as is necessary to carry out the provisions of this title; (b) when used in the aggregate, without patient specific identifying information, in programs approved by the commissioner for the improvement of the quality of medical care provided to persons with HIV/AIDS; (c) when used within the state or local health department by public health disease programs to assess co-morbidity or completeness of reporting and to direct program needs, in which case patient specific identifying information shall not be disclosed outside the state or local health department; or **(d) when used for purposes of patient linkage and retention in care, patient specific identified information may be shared between local and state health departments and health care providers currently treating the patient as approved by the commissioner.**”

[*http://public.leginfo.state.ny.us/LAWSSEAF.cgi?QUERYTYPE=LAWS+&QUERYDATA=\\$\\$PBH2135\\$\\$@TXPBH02135+&LIST=LAW+&BROWSER=EXPLORER+&TOKEN=38638169+&TARGET=VIEW](http://public.leginfo.state.ny.us/LAWSSEAF.cgi?QUERYTYPE=LAWS+&QUERYDATA=$$PBH2135$$@TXPBH02135+&LIST=LAW+&BROWSER=EXPLORER+&TOKEN=38638169+&TARGET=VIEW)

Red text color added for emphasis.



REGULATIONS TO IMPLEMENT PUBLIC HEALTH LAW SECTION 2135

- Revisions to Part 63 regulations under development
- Who can share data? Health departments? Health care providers? Between? Among?
- Who are health care providers?
- Who is the health care provider “currently treating the patient”?
- What does “as approved by the commissioner” mean?
- Programmatic and procedural questions not answered by regulations: Which data? How much data? How to verify provider identity? Role of local health department? Role of AIDS Institute units outside of surveillance program? Providers’ re-release of data?



IMPLEMENTATION* OF 2014 CHANGES IN NYS LAW SECTION 2135 PENDING REGULATION APPROVAL

- AIDS Institute Director Dan O'Connell has been designated the Commissioner's agent pending approval of regulations and internal DOH policies
 - Any request for surveillance data from health care providers should be directed to the Bureau of HIV/AIDS Epidemiology (518-474-4284)
 - Requests are evaluated on a case-by-case basis
- Planning is underway for an electronic module that will allow standardized exchange of information with medical providers

*As of October, 2014



CDC GUIDANCE 2011

Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Programs: Standards to Facilitate Sharing and Use of Surveillance Data for Public Health Action

- <http://www.cdc.gov/nchhstp/programintegration/docs/PCSIDataSecurityGuidelines.pdf>
- 64 page document



TEN GUIDING PRINCIPLES FOR DATA COLLECTION, STORAGE, SHARING, AND USE TO ENSURE SECURITY AND CONFIDENTIALITY

1. Public health data should be acquired, used, disclosed, and stored for legitimate public health purposes.
2. Programs should collect the minimum amount of personally identifiable information necessary to conduct public health activities.
3. Programs should have strong policies to protect the privacy and security of personally identifiable data.
4. Data collection and use policies should reflect respect for the rights of individuals and community groups and minimize undue burden.
5. Programs should have policies and procedures to ensure the quality of any data they collect or use.
6. Programs have the obligation to use and disseminate summary data to relevant stakeholders in a timely manner.
7. Programs should share data for legitimate public health purposes and may establish data-use agreements to facilitate sharing data in a timely manner.
8. Public health data should be maintained in a secure environment and transmitted through secure methods.
9. Minimize the number of persons and entities granted access to identifiable data.
10. Program officials should be active, responsible stewards of public health data.

Available at <http://www.cdc.gov/nchhstp/programintegration/docs/PCSIDataSecurityGuidelines.pdf>.

Adapted from: Lee, LM, Gostin, LO. Ethical collection, storage, and use of public health data: a proposal for national privacy protection. JAMA 2009;302:82–84.



CDC GUIDELINES

- Applicable to HIV, STD, hepatitis, and tuberculosis surveillance data and expanded to include HIV program data collected for specified CDC grants
- Adherence to the guidelines is a condition of funding under several CDC grants
- Key themes include written policies and procedures, Overall Responsible Party (ORP) designation, staff training, staff attestation, physical and electronic security, procedures for handling breach of confidentiality, and emphasis on sharing minimum data necessary for task



CDC GUIDELINES – DATA SHARING

- Section on “Benefits, Risks and Costs of Data Sharing” includes recommended components of written data sharing plans
- “STANDARD 3.3 Ensure that any public health program with which personally identifiable public health data are shared has data security standards equivalent to those in this document.”

