Novel Uses of New York State HIV Surveillance Data

Albany Medical Center
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Outline

• Overview of HIV in New York State

• New York State HIV Surveillance Data
  • What HIV surveillance data does the state collect?

• Legal and Regulatory Safeguards of HIV Surveillance Data
  • How is the confidentiality of the individuals and the security of the data protected?

• Novel uses of HIV Surveillance Data in New York State
  • How is the state broadening its use of HIV surveillance data to “End the Epidemic” or “Get to Zero”
Trends in HIV and AIDS Cases*
New York State, 1984 - 2012

*Data as of April 2014
HIV named reporting began in NYS in 2000; deaths among HIV and AIDS cases are reported starting in 2000.

Newly Diagnosed HIV Cases by Transmission Risk
New York State, 2002-2012*

*December 2013
Cascade of HIV Care
New York State, 2012

- Estimated HIV Infected Persons: 154,000
- Persons Living w/ Diagnosed HIV Infection: 132,000
  86% of infected
- Cases w/any HIV Care during the year*: 86,000
  56% of infected
- Cases w/continuous care during the year**: 75,000
  56% of PLWDHI
- Virally suppressed (n.d. or ≤200/ml) at test closest to end-of-year: 68,000
  44% of infected

* Any VL or CD4 test during the year
** At least 2 tests, at least 3 months apart

Viral Suppression among Persons Living with Diagnosed HIV Infection by Risk and Race/Ethnicity: New York State, 2012

- % viral suppression
  - White non-Hispanic: 48%
  - Black non-Hispanic: 51%
  - Hispanic: 56%
  - Asian/PI: 56%
  - Native Amer.*: 65%
  - Multirace**: 51%
  - MSM: 79%
  - IDU: 56%
  - MSM-IDU: 56%
  - Female Pres. Het.: 56%
  - Blood Products: 79%
  - Pediatric Risk: 79%
  - Unknown: 44%

*Based on a small number of persons (n=100).
**Multirace care measures are likely less reliable due to the method used to calculate multirace status.
Summary: New HIV Diagnoses in New York State

- Data shows 28% decrease from 2007 to 2012
- Racial and ethnic disparities persist
- An increasing percentage of new diagnoses are among MSM
- New diagnoses among young MSM of color have increased markedly over the last decade, but numbers over the past few years appear to be reaching a new plateau

Summary: New AIDS Diagnoses in New York State

- Data shows that 23% of new HIV diagnoses have a concurrent diagnosis of AIDS
- Within each passing year, a lower percentage of persons newly diagnosed with HIV are developing AIDS within a given time period after HIV diagnosis
Clinician Reporting Requirements

- Public Health Law, Article 21, Title III requires clinicians to report by name
- Initial or previously unreported diagnoses of HIV infection
- HIV illness – new to the practice or returning to care after extended time
- Initial or previously unreported AIDS diagnoses
- If available, contacts of persons with HIV or AIDS
  - Protocol exists for identification and screening of victims of domestic violence
- Requirement is to report within 14 days of diagnosis

- Reporting via
  - Medical Provider HIV/AIDS and Partner/Contact Report Form: DOH-4189
  - For assistance with obtaining or completing the PRF, please call 518-474-4284.

Three Key Purposes of the Medical Provider and Partner/Contact Report Form

- Important source of data for confirming HIV case surveillance eligibility and documenting risk of infection
  - Data is used nationally to determine the allocation of prevention and care funding to states and localities
- Key source of variables used in the CDC methodology to estimate HIV incidence
  - Particularly testing history and treatment information
- Important link of patients to Health Department partner services and a key source of named partners/contacts
Laboratory Reporting Requirements

Laboratories conducting HIV-related testing for NYS providers and/or residents are required to electronically report any laboratory test, tests or series of tests approved for the diagnosis of HIV or for the periodic monitoring of HIV infection:

- All reactive initial HIV immunoassay results AND all results (e.g., positive, negative, indeterminate) from all supplemental HIV immunoassays (HIV-1/2 antibody differentiation assay, HIV-1 WB, HIV-2 WB and/or HIV-1 IFA)
- All HIV nucleic acid (RNA or DNA) results (qualitative and quantitative)
- All CD4 counts/percent of total lymphocytes (unless known to be not HIV related)
- Genotype nucleotide sequence (protease, reverse transcriptase and integrase)
- Positive HIV detection tests (culture)

Exceptions: testing known to be performed for the sole purpose of clinical trials, IRB-approved research or for insurance risk assessment; reporting by federal facilities is “in the spirit of cooperation”.

Determinants of New York State HIV Surveillance and Partner Services Confidentiality and Security Policies

- New York State laws
  - HIV-specific laws are most important but occasionally other laws may be applicable
- New York State regulations
- CDC “guidelines” required as a condition of grant funding
- Overall Responsible Party approval – Dr. Birkhead, Deputy Commissioner, Office of Public Health, NYSDOH
- AIDS Institute, Division, and Bureau assessment
  - Risk – benefit ratio
    - Information technology, legal or other expertise may be sought
  - Practicality
  - Ensuring redundancy
New York State HIV Reporting and Partner Notification Law

• Implemented June 2000
• HIV surveillance data to be used for HIV epidemiology and partner notification
• Sharing of information for other public health purposes not allowed

HIV Surveillance Data and Confidentiality: Chapter 308 of the laws of 2010

“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.”

• Use of surveillance data with identifiers expanded
  • To direct program needs
  • To assess comorbidity
  • To assess completeness of reporting

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.


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=$$PBH2135$$&TXPBH92135
MULTI-LIST=SPORTS+&BROWSER=EXPLORER+&TOKEN=38638169+&TARGET=VIEW
Red font added for emphasis
CDC NCHHSTP 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


64 page document

NYSDOH/AI/BHAЕ

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.

November Uses of HIV Surveillance Data

- The goal of utilizing HIV surveillance data in new ways is to insure linkage and retention in care and viral suppression.

- Implementation of 2014 Changes in NYS Law Section 2135.

- Creation of a “Provider Feedback Loop” via the NSYDOH Health Commerce System.

Implementation of 2014 Changes in NYS Law Section 2135

- Dan O’Connell, the AIDS Institute Director, has been designated the Commissioner’s agent pending approval of regulations and policies

- Any request for surveillance data from providers should be directed to BHAE Director/Assistant Director and/or DEER Director who will obtain approval from AI Director prior to release of information

- With case-specific approval of Commissioner’s agent, information has been provided to a small number of physician practices to assist with linkage and retention in care.

- Regulations and standard operating procedures for managing these requests are in development.
Leveraging Current DOH resources

- Planning underway for electronic module that will allow standardized exchange of information with medical providers.
- Providers could query the HIV Surveillance System for patient-level information via the Health Commerce System.
- BHAE is also in the process of creating an electronic version of the Provider Report Form (ePRF).

Questions?

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