NASTAD Consultation: HIV Data Privacy & Confidentiality in the Era of Data Modernization

March 8, 2018
Overview: NASTAD Legal Research Project on HIV Data Privacy and Confidentiality
NASTAD Legal Research Project:
Ten Focus States
NASTAD Legal Research Project

- Threshold research questions:
  - What is extent to which state laws and regulations permit or compel health departments to share personally identifiable HIV data with various entities?
    - When is patient consent required?
    - Under what circumstances can data be shared without consent and for what purposes?
    - With whom can data be shared (e.g., other health department programs, medical providers, community-based organizations, Medicaid programs, law enforcement)?
  - What is extent to which HIV data privacy and confidentiality protections are addressed in health department written policies, data-sharing agreements, and internal processes?
  - How are data privacy protections are applied to HIV data held by external entities flowing to the health department?
Research Methods

Phase One
Ten-state legal/regulatory review using search term query in Westlaw

Phase Two
Analysis of internal health department policies and data sharing agreements

Phase Three
Informant interviews with health department staff across HIV Prevention, Surveillance, Care, and Legal Counsel
Limitations for data use and sharing varied by state, but overwhelming majority of statutory schemes provide broad discretion to health department and/or legal counsel to make data sharing decisions.

Most statutes and regulations do not explicitly address emerging data sharing practices (e.g., data-to-care, Medicaid data sharing and molecular HIV surveillance use).

As a result of statutory/regulatory breadth, health department data sharing practices varied based on legal counsel and/or health department interpretation.
## When HIV PII May Be Shared Without Consent

<table>
<thead>
<tr>
<th>State</th>
<th>Confidentiality Statute</th>
<th>Statutory breadth for disclosure without consent (not including court order)</th>
</tr>
</thead>
<tbody>
<tr>
<td>IL</td>
<td>Hybrid</td>
<td>To “provide a vital foundation for a concerted State effort to reduce the incidence of HIV and AIDS in this State”</td>
</tr>
<tr>
<td>IA</td>
<td>HIV specific</td>
<td>To investigate sources of HIV infection and “use every appropriate means to prevent the spread of HIV”</td>
</tr>
<tr>
<td>LA</td>
<td>Hybrid</td>
<td>When “necessary to carry out ... investigation, control, or surveillance of disease, as determined by the office of public health”</td>
</tr>
<tr>
<td>MA</td>
<td>Hybrid</td>
<td>Names of people with HIV may not be shared with the federal government, any state or local department, or with any other program in the state health department</td>
</tr>
<tr>
<td>MI</td>
<td>HIV specific</td>
<td>To protect the health of an individual, to prevent further transmission of HIV, or to diagnose and care for a patient</td>
</tr>
<tr>
<td>TN</td>
<td>Communicable diseases</td>
<td>To enforce laws and regulations governing control and treatment of STDs and to carry out the purposes of laws and regulations related to control of communicable diseases</td>
</tr>
<tr>
<td>UT</td>
<td>Communicable diseases</td>
<td>To control communicable diseases and epidemic infections</td>
</tr>
<tr>
<td>VA</td>
<td>Hybrid</td>
<td>If pertinent to an investigation, research or study or when “threat to public health”</td>
</tr>
<tr>
<td>WI</td>
<td>Hybrid</td>
<td>To treating provider and for surveillance, investigation, control of communicable disease</td>
</tr>
</tbody>
</table>
**Patient Consent**

- Jurisdictions varied on the extent to which clients were asked to consent to their HIV-related data being used and/or shared by the health department:
  - Most states do not require consent for the health department to collect surveillance data
  - Most states have consent procedure in place for when clients present for testing
    - Those that don’t mandate consent have informal verbal education procedures that inform clients of how testing data will be used
  - All states had some form of consent process for Ryan White Program/ADAP clients that included the ability to share data for the purposes of insurance assistance, care coordination, or monitoring and evaluation
Looking at the Statutes

Most restrictive

Health departments may not share HIV PII without consent

Massachusetts

Tennessee

Least restrictive

Health departments may share HIV PII for very specific purposes

Iowa

Health departments may share HIV PII for broad “public health” purposes

Illinois

North Carolina

Louisiana

Wisconsin

Michigan

Virginia

Utah
Data Gatekeepers

Data sharing is challenging:
- Governed by different statutory/regulatory schemes
- Accountable to different missions and purposes
- Variable data sharing agreement requirements

Department of Public Health
- Bureau of Infectious Disease
- Other Public Health Programs
  - Hepatitis Program
  - STD Program
  - HIV Surveillance Program
  - HIV Prevention Program
  - HIV Care Program

DPH Legal Counsel

Medicaid Agency
- All Payer Claims Database
- MCOs
- Health Information Exchange
- Medical Providers
- Researchers
- Other State Public Health Departments

Local Health Departments
- Law Enforcement

Other Public Health Programs
- Bureau of Infectious Disease
- Other Public Health Programs
  - Hepatitis Program
  - STD Program
  - HIV Surveillance Program
  - HIV Prevention Program
  - HIV Care Program

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1) Data-to-Care Data Sharing

- **Themes and variations**
  - Data sharing among HIV programs almost always possible without a data sharing agreement
  - Most jurisdictions limit the extent to which surveillance data is shared for the purpose of linkage-to-care
    - Only share out-of-care data
    - Share viral load information with treating provider only
    - Restrict access to HIV data to health department staff or “designees” (could include local health departments and/or contracted agencies)

- Only health department may access care and surveillance data
- Health department may share limited information with specified entities
- Health department may share surveillance data, including viral load, with providers
2) Medicaid Data Sharing

Themes and variations

- Formal data-sharing agreement required in all cases
- Jurisdiction-specific limitations on what type of data can be shared with Medicaid:
  - Share PII on HIV viral load directly with Medicaid agency who is allowed to re-share with Medicaid managed care organizations (MCOs)
  - Share aggregate data (viral load and/or diagnosis) as a result of surveillance/Medicaid match with state Medicaid agency
  - Share aggregate data (viral load and/or diagnosis) as a result of surveillance/Medicaid match with individual MCOs

Health department may not share surveillance data with Medicaid

Health department may share limited/aggregate information with Medicaid

Health department may share PII surveillance data, including viral load and diagnosis, with Medicaid and MCOs
3) Law Enforcement Data Sharing

- Themes and variations
  - All jurisdictions allowed for some data sharing with law enforcement specified in statute
  - Jurisdiction-specific limitations on under what circumstances and what type of data can be shared:
    - Only share data as a result of court order and/or pursuant to specified state criminal statutes
    - Only share data following legal counsel review; case-by-case decision on when and what gets shared
    - Only share limited pieces of health department data with regard to HIV diagnosis
    - Statutes do not specifically address molecular HIV surveillance
Next Steps

- NASTAD will publish final report with findings, including legal/regulatory summaries
- Aim is to identify themes and connections between the state legal/regulatory scheme, internal health department policies, and data sharing and use practices
- Identify considerations for balancing patient privacy and confidentiality protections and data sharing and use innovation