Tackling Tough Public Health Problems through Cross-Sector Data Collaborations

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  - Adults at Risk
  - Maternal and Child Health
  - Statutory and Regulatory Public Health
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  - Public Health Law
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Presenter

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  - Cross-Sector Data Sharing
  - Collaboration Building
Tackling Tough Public Health Problems Through Cross-Sector Data Collaborations

Jennifer Bernstein, JD, MPH
Deputy Director, Network for Public Health Law
Mid-States Region
So much data ....
Screening

» Childhood lead screening
» Newborn screening for metabolic diseases
» Early hearing detection & intervention
» Vision & hearing screening of school children

Health Plans

» Medicaid
» State Children’s Health Plan
» County Health Plans

WIC

Regulatory

» Restaurant inspection reports
» Septic, wells, other permits
» Clean indoor air act
» Burning ordinances
» Asbestos contractors
» Lead abatement contractors
» Health facilities
Vital Records
- Birth records
- Death records
- Marriage records

Registries
- Cancer
- Birth defects
- Traumatic injuries
- Immunizations

Disease Surveillance
- Infectious disease reports
- Syndromic surveillance
- Hospital acquired infections

Clinical Services
- Child & maternal health
- Immunization
- Dental clinics
- School-based clinics
- FQHCs or CHCs

Emergency Preparedness
- Health alert networks
- Volunteer registries
- Vulnerable people registries
And growing ....

» Amount of data
» Sources of data
» Data sharing partners
» Ways to transfer and exchange
» Linkages with other information
» Creation integrated databases
» Retention, reuse, and further sharing of the information
» Creation of public datasets
So many laws ....
Data Protection and Disclosure Laws + frequent condition for receiving funds

**Federal**
- HIPAA
- FERPA
- WIC
- Title X family planning
- Cancer registries
- Substance abuse treatment
- Federally supported research
- Social Security Act

**State**
- Health information
- Disease surveillance
- Registries
- Vital records
- Screening
- Drug monitoring
- Medicaid
- Clinical services
- Social security #
- Open records
Law governs every aspect of data

Collection  Use
Sharing  Protection

Law friend or foe?
- How does law help us to do our job?
- How is law a barrier?
General barriers to exchange

» State law applies – variation among states

» General vs. specific authority to exchange data

» Scope of sharing: prerequisites, conditions & limits

» Within a state – applicability of multiple laws, need to harmonize

» Variety and changing systems, manner of exchange, technological capability

-- Growing complexity, multiple points of data transfer, HIE laws
Navigating the law

**Creative Solutions:**
- Create exceptions in agreement to accommodate certain parties
- Meet legal requirements of most restrictive party’s law
- Change in law or regulation to accommodate sharing
- Have party with greatest authority act as a data clearinghouse
The Patchwork US Privacy Framework

Cason D. Schmit
Assistant Professor
Dept. Health Policy & Management
Privacy Officer
School of Public Health, Texas A&M University
Presentation Overview

• Outline
  ▫ Ethical context for using existing data for public health purposes
    • 2017 WHO Guidelines on Ethical Issues in Public Health Surveillance
  ▫ Overview of federal privacy laws
  ▫ Implications for leveraging existing data for public health purposes
  ▫ International model (GDPR)

• Objectives:
  ▫ Compare federal data protection laws across sectors.
  ▫ Analyze how different federal data protection laws facilitate or impede the use of cross-sector data for public health purposes.
Resources to Navigate Federal Data Protection Laws

- 22 Snapshots of different federal laws protecting data
- Annotated list of resources and guidance
- Coming Soon: Interactive online database of legal data sharing resources

https://www.networkforphl.org/topics__resources/topics__resources/health_information_and_data_sharing/federalPrivacy_laws/?blm_aid=21653
Abbreviations

- CIPSEA - Confidential Information Protection and Statistical Efficiency Act of 2002
- FERPA - Family Educational Rights and Privacy Act
- HIPAA - Health Insurance Portability and Accountability Act
- HHS - Department of Health and Human Services
- IDEA - Individuals with Disabilities Education Act
- NSLP - National School Lunch Program
- SBP - School Breakfast Program
- SMP - Special Milk Program for Children
- Title X - Population Research and Voluntary Family Planning Programs
- WIC - Women, Infants, and Children Supplemental Nutrition Program
- SNAP - Supplemental Nutrition Assistance Program
- VA - US Department of Veterans Affairs
Ethical Foundations for Public Health Data Use
A Public Health Ethics Lens
Ethical Data Use for Public Health

• Guideline 1. **Countries have an obligation to develop appropriate, feasible, sustainable public health surveillance systems.** Surveillance systems should have a clear purpose and a plan for data collection, analysis, use and dissemination based on relevant public health priorities.

Obligation to conduct public health surveillance
Ethical Data Use for Public Health

- Guideline 11. Under certain circumstances, the collection of names or identifiable data is justified.

- Guideline 12. Individuals have an obligation to contribute to surveillance when reliable, valid, complete data sets are required and relevant protection is in place. Under these circumstances, informed consent is not ethically required.
Ethical Data Use for Public Health

• Guideline 14. With appropriate safeguards and justification, those responsible for public health surveillance have an obligation to share data with other national and international public health agencies.

• Guideline 16. With appropriate justification and safeguards, public health agencies may use or share surveillance data for research purposes.
Federal Data Protection Laws and Cross Sector Data Sharing

- Federal agencies collect and use data for a variety of programs and initiatives across sectors.
- This data has significant potential to inform public health activities.
Legal Variation

- Unfortunately, there are different federal data protection frameworks depending on
  - Person or entity
  - Nature of the data
  - Why it was originally collected
  - Intended use or purpose
(A few) Federal Data Protection Laws

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<th>Federal Legal Framework</th>
<th>Citations</th>
<th>Sector</th>
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## How is identifiable information defined?

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<tr>
<th>Federal Legal Framework</th>
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<th>Unspecified information about individuals</th>
<th>Direct Identifiers</th>
<th>Indirect Identifiers</th>
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1. VA guidance applies the HIPAA identifiability standards.
2. States have flexibility to determine what information is protected.
3. Federal de-identification guidance exists.
Identifiability Defined by Deduction or Inference

- **FERPA**
  - “information that, **alone or in combination, is linked or linkable** to a specific student that **would allow a reasonable person in the school community**, who does not have personal knowledge of the relevant circumstances, to identify the student with **reasonable certainty**.”

- **42 CFR Part 2**
  - “information by which the identity of a patient... **can be determined with reasonable accuracy** either directly or by reference to other information.”

- **HIPAA**
  - “a **reasonable basis** to believe the information **can be used to identify** the individual.”

- **CIPSEA**
  - “**permits** the identity of an individual to whom the information applies to be **reasonably inferred** by either direct or indirect means.”
The Problem with Inference or “Reasonable Person” Identifiability

- Actually very difficult to apply
- Safe harbor de-identification standards (e.g., HIPAA) are low risk and easy to use
## Data Use Exceptions for Public Health and Research

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</table>

¹ Limited to educational studies
² Several HHS components list research as a permitted purpose
³ Restricts non-governmental research
But that’s not all...

- Tremendous variation and complexity in state laws dealing just with health information
Persistent Data Sharing Barriers

- Unfortunately, effectively leveraging this cross-sectoral data for public health purposes has remained elusive in part because the United States lacks a unified framework for sensitive data protection (i.e., privacy, confidentiality, and security).

- Legal data sharing barriers can be both real and perceived
  - Real legal barriers \(\rightarrow\) a law restricts a use or disclosure
  - Perceived legal barriers \(\rightarrow\) belief that a law prohibits a use or disclosure

- BOTH are actual barriers!
Implications of Legal Uncertainty

• Precautionary data stripping
  ▫ I.e., removal of useful data elements
• At best, legal uncertainty increases transaction costs for data sharing
• At worst, legal uncertainty impedes legal data uses
Model for an alternative approach

The European Union’s General Data Protection Regulation (GDPR)
GDPR(EU)

- “[A]pplies to the processing of personal data ... which form part of a filing system or are intended to form part of a filing system. ”

- “*personal data*’ means any information relating to an identified or identifiable natural person ....; an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier...”
GDPR and Public Health

- **Recital #54**
  - “The processing of special categories of personal data **may be necessary for** reasons of public interest in the areas of **public health without consent** of the data subject”

- **Article 9**
  - “1. Processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data ..., [health data or sexual activity data] shall be prohibited.
  
  2. **Paragraph 1 shall not apply** if one of the following applies: ...
  
  (i) **processing is necessary for reasons of public interest in the area of public health**”
GDPR Article 5: Principles relating to processing of personal data

• “Personal data shall be: ...(b) collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes;
• further processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes shall, in accordance with Article 89(1), not be considered to be incompatible with the initial purposes”
Conclusions

• Inconsistent federal statutes and regulations place different restrictions on how sensitive administrative data can be used.
• Understanding these federal laws is critical to understand how to leverage cross-sectoral data for public health purposes.
• The EU GDPR provides a workable model for a unified approach to data protection while permitting data to be used to promote population health.

• What are the ethical implications of the US data protection framework?
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- Acknowledgements
  - Network for Public Health Law
  - University of Michigan
  - Data Across Sectors for Health (DASH)
  - Denise Chrysler
  - Jennifer Bernstein
  - Melissa Moorehead
  - Amy Fairchild
Criminal Justice- Behavioral Health System Review

Data Collaboration with Public Health, Fire, EMS, Hospitals and Law Enforcement
Partnership for a Healthy Community: Tri-County Community Health Improvement Plan

- Four Core Priorities:
  - Behavioral Health
  - Healthy Eating Active Living
  - Cancer
  - Reproductive Health

Why Behavioral Health?

Perceptions of Health In Our Community

#1 Mental Health

72% of tri-county residents report overall good mental health, less than National Goal 80%.

8.4% (WC), 10% (TC), and 17.8% (PC) reported more than 8 days of "not good" Mental Health per month

9% of the population reported NO ACCESS to Counseling when needed

37% reported the reason being unable to afford co-pay.

Drug Abuse, Anger/Violence & Alcohol Abuse ranked in the Top 4 perceived Unhealthy Behaviors.

59 Drug-Induced Deaths within the tri-county in 2014.

40 Suicide Deaths in 2014

In 2012, the suicide rates for PC (12.2), WC (12.8) and TC (15.4) were above the state rate (10.1).

Ratio of Population to Mental Health Providers

Peoria County: 490.1, Tazewell County: 690.1, Woodford County: 3,560.1
# Behavioral Health

<table>
<thead>
<tr>
<th>Objective</th>
<th>Goal</th>
<th>Reduce Substance Abuse among tri-county residents, especially youth.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Objective 1</strong></td>
<td>Increase the proportion of adults reporting good mental health from 72% to 80% by 2019.</td>
<td>Reduce the rate of drug-induced deaths with the tri-county region by 10% from 16.3 per 100,000 tri-county residents to 14.7 per 100,000.</td>
</tr>
<tr>
<td><strong>Objective 2</strong></td>
<td>Reduce the suicide rate by 10% for the 11.0 deaths per 100,000 within the tri-county to 9.9 deaths per 100,000 tri-county residents.</td>
<td>Increase the percentage of 12th graders within the tri-county that disapprove the use of marijuana by 20% from 63% to 83%.</td>
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<tr>
<td><strong>Strategy 1</strong></td>
<td>Behavioral Health Primary Care Integration</td>
<td>Reduction of Opioid Abuse</td>
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<td><strong>Strategy 2</strong></td>
<td>Culturally adapted healthcare</td>
<td>Behavioral Health Primary Care Integration</td>
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<td><strong>Strategy 3</strong></td>
<td>Mental Health Benefits Legislation</td>
<td>Justice System Level Interventions</td>
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<td><strong>Strategy 4</strong></td>
<td>School-based Social and Emotional Instruction</td>
<td>Targeted truancy interventions</td>
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<td><strong>Responsible Leaders</strong></td>
<td>Behavioral Health Steering Committee</td>
<td>Supporting County Health Department - Peoria City/County Health Department</td>
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</table>
Organizational Structure

Partnership for a Healthy Community

Behavioral Health Committee

Education

Criminal Justice-BH System Review

Narcan Advisory Committee

High Utilizer Matrix Team

Healthcare
### Why Participate?

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<tr>
<td>Health Department</td>
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<tr>
<td>Homeless Services</td>
</tr>
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</table>
Common Story

• M. Hendrickson found trespassing, 911 called
• Behavior warrants transport to area hospital
• Release from hospital to county jail for arrest
• Initial hearing
• Release with notice to appear
• M. Hendrickson found trespassing
• Arrested for failure to appear and trespassing
• Initial hearing/courts
• Released
• M. Hendrickson demonstrating erratic behavior
• 911 contacted
• ERS respond and take to ED
• Released
• M. Hendrickson agitated at OSF-ED
CJ-BH System Review
Information Sharing

315 HIGH UTILIZERS
- Peoria County Jail – 250
- Human Service Center – 29
- AMT – 22
- Peoria Fire EMS – 11

- **Purpose 1:** Develop Community Care Plan to manage treatment options and prevent further use of emergency resources.
- **Purpose 2:** Identify financial impact of the broken system on the community as a whole.
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<thead>
<tr>
<th>Client</th>
<th>Peoria County Jail</th>
<th>EMS (Fire)</th>
<th>EMS (AMT)</th>
<th>HSC</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>8</td>
<td></td>
<td></td>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td>B</td>
<td></td>
<td>25</td>
<td></td>
<td>39</td>
<td>64</td>
</tr>
<tr>
<td>C</td>
<td>6</td>
<td></td>
<td>23</td>
<td>10</td>
<td>39</td>
</tr>
<tr>
<td>D</td>
<td></td>
<td>16</td>
<td>34</td>
<td>6</td>
<td>56</td>
</tr>
<tr>
<td>E</td>
<td>13</td>
<td></td>
<td>25</td>
<td></td>
<td>38</td>
</tr>
</tbody>
</table>
## Data Sharing Matrix Cost

<table>
<thead>
<tr>
<th></th>
<th>Peoria County Jail</th>
<th>EMS (Fire)</th>
<th>EMS (AMT)</th>
<th>HSC</th>
<th>OSF ED</th>
<th>UP ED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost</td>
<td>$134,000</td>
<td>$10,885</td>
<td>$169,708</td>
<td>$152,500</td>
<td>$2.1 M</td>
<td>$575,207</td>
</tr>
</tbody>
</table>

Total Cost in 2017: $3,008,434
Next Steps: Community Investment

- **Primary Response**
  - Expand capacities to engage at initial points of response, including on the street, availability at hospitals, and “sitters”

- **Case Management**
  - Individual to coordinate with healthcare and social services agencies to provide follow-up, linkage to resources, and support for certain cases.

- **Information Sharing Technology**
  - Develop technology to increase quantity, quality, and frequency of data sharing between community agencies to support informed interventions.
Contact Information

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Email: Kathleen.kelly613@gmail.com
Phone: 309-397-0496

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3. Type your question
4. Click “Send”
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March 28, 1:00 – 2:30 p.m. EST

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