Secondary Use of Healthcare Data for Public Health

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Agenda

• NCPHI Overview
• Three disparate secondary uses of clinical data for PH
• Present and Future States for PH
• Summary
Public health informatics is the systematic application of information and computer science and technology to public health practice, research and learning.
NCPHI MISSION:

To protect and improve the public’s health through science and service in health information technology and informatics
NCPHI provides national leadership

- Developing and promoting the science of public health informatics
- Supporting the necessary research and workforce bases for this growing discipline
- Establishing strong partnerships and facilitating coordinated activities
- Ensuring strong representation for public health in all national Health IT initiatives
NCPHI: Guiding Principles

- Public health/healthcare integration
- Application of best practices
- Applied science
Public Health Uses of Clinical Data - Federal Perspective

• Surveillance
• Case and Outbreak Management
• Population Health Assessment
• Population Health Interventions
Public Health Surveillance

- Allowed by state and or local law
- Protected under HIPAA
- Provider burdens
  - Active submission of data
  - HIPAA requirement to account for release to patients
## Public Health Surveillance

<table>
<thead>
<tr>
<th>Accountability</th>
<th>Ineffective civil</th>
</tr>
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<tbody>
<tr>
<td>Transparency</td>
<td>Unaware, many suspect</td>
</tr>
<tr>
<td>Permission</td>
<td>None required</td>
</tr>
<tr>
<td>Identity Protection</td>
<td>Cultural</td>
</tr>
<tr>
<td>Oversight</td>
<td>Governmental self monitoring</td>
</tr>
<tr>
<td>Laws/Regulation</td>
<td>State and Local</td>
</tr>
<tr>
<td>Standards</td>
<td>Partially used</td>
</tr>
<tr>
<td>Benefit</td>
<td>Public’s protection</td>
</tr>
</tbody>
</table>
Public Health Statistics

• Sources:
  • From States
    • (covered under data use agreements)
      • E.g., Vital Records
  • From direct CDC Surveys
    • (covered under consent, IRBs, and PH law)
      • E.g., NHANES
# Public Health Statistics

<table>
<thead>
<tr>
<th></th>
<th>States</th>
<th>CDC</th>
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<tbody>
<tr>
<td>Accountability</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>Transparency</td>
<td>Unaware</td>
<td>Aware to Unaware</td>
</tr>
<tr>
<td>Permission</td>
<td>None</td>
<td>None to IRB</td>
</tr>
<tr>
<td>Identity Protection</td>
<td>De-identification</td>
<td>De-identification</td>
</tr>
<tr>
<td>Oversight</td>
<td>Data Steward</td>
<td>Ownership/control</td>
</tr>
<tr>
<td>Laws/Regulations</td>
<td>State/Local</td>
<td>None to Federal</td>
</tr>
<tr>
<td>Standards</td>
<td>Fully addressed</td>
<td>Partially used</td>
</tr>
<tr>
<td>Benefits</td>
<td>Public</td>
<td>Public</td>
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</table>
Specifically Funded Programs

- Systems - e.g., BioSense
- Data Repositories - e.g., Cancer Registries
- Research activities (covered under IRB)
- Others
## Specifically Funded Programs

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<tbody>
<tr>
<td>Accountability</td>
<td>None</td>
</tr>
<tr>
<td>Transparency</td>
<td>Unaware to fully</td>
</tr>
<tr>
<td>Permission</td>
<td>Consent</td>
</tr>
<tr>
<td>Identity Protection</td>
<td>None to de-identified</td>
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<tr>
<td>Oversight</td>
<td>Control</td>
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<tr>
<td>Laws/regulations</td>
<td>Yes-Funding &amp; Mission</td>
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<tr>
<td>Standards</td>
<td>None to fully</td>
</tr>
<tr>
<td>Benefits</td>
<td>Public &amp; research</td>
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</tbody>
</table>

Unaware to fully, Consent, Control, None to fully, Public & research.
Present vs. Future State

• Now
  • Data Collection via agreements and law
  • Many aspects - manual process
  • Early integration efforts

• The Future
  • New data sources
  • Semi to Fully automated process
  • Significant data linkage issues
  • New techniques to protect data (eg., filtering, de-identifying)
Public Health Uses of Clinical Data
Present vs. Future State

• What's the same?
  • Need to protect the data
  • Balancing the risk vs. the benefit of the data sharing
Public Health Use of Clinical Data Federal Prospective

• Summary:
  • PH with variety of needs for secondary use of clinical data
    • Disease surveillance, health statistics, and CDC-funded programs
  • New challenges to be addressed
    • Access to and best use of novel data sources
    • Automated Collection
      • Increased of volume of data
    • Data integration (linkage) issues
    • Privacy & Security assurance
Thank you!

Questions?

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