Challenges with Sharing Public Health Information Through a Health Information Exchange

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What is PH surveillance?

- Public health surveillance is the ongoing, systematic collection, analysis, and interpretation of health-related data ...
  - Prevent or control disease or injury,
  - Identify unusual events of public health importance, and
  - Disseminate and use information for public health action.

Public Health Model

- Define the problem
  - Collection/surveillance

- Identify causes
  - Risk factor identification

- Develop and test interventions
  - Evaluation research

- Implement intervention
  - Training
  - Public awareness
We need to move from Sherlock Holmes
To the Matrix
Combined with The Minority Report
Public Health Informatics has been defined as the systematic application of information and computer science and technology to public health practice, research.

Need for Epidemiology trained informaticists

Effectively and efficiently using technology to improve data collection and surveillance
Why is this important?

- Initiatives such as
  - Meaningful Use
  - Electronic Lab Reporting (ELR)
- Proliferation of EMR systems
- Need to do more with less
Computers have made us somewhat more efficient and timely, but

- Data is relatively poor quality
- Limited data analysis and interpretation
- Lack of coordination among LHD/State and Feds
Public Health Data

Neolithic revolution
Petabytes of data

- 1000 Kilobytes = Megabyte
- 1000 Mb = Gigabyte
- 1000 Gb = Terabyte
- 1000 Tb = Petabyte

Expectation that electronic data exchange will process hundreds of petabytes of data daily
Current State/local Challenges:

- Current and projected large increases in volume of lab and case reports from healthcare (estimated increase 400-500%)
  - Data deluge
- Maintain and upgrade surveillance systems with limited PH resources
- Reduced funding = fewer staff
- Need new approaches for data management, analysis, and visualization
Current Federal challenges:

- Reduced funding = fewer staff
- Lack of interoperability/standardization
  - Use of same case definitions
  - Collect same data elements
  - Pendulum swing away from state/local autonomy
- Silos of data
- Goals of surveillance are different at local, state, and federal levels.
Health Information Exchange (HIE)

- Process of reliable and interoperable electronic health-related information sharing conducted in a manner that protects the confidentiality, privacy, and security of the information
### Domains for use of an HIE in Public Health

<table>
<thead>
<tr>
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<th>Domain</th>
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<tbody>
<tr>
<td>1</td>
<td>• Mandated reporting of laboratory diagnoses</td>
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<td>2</td>
<td>• Mandated reported of physician-based diagnoses</td>
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<td>3</td>
<td>• Public health investigation</td>
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<td>4</td>
<td>• Disease-based non-reportable laboratory data</td>
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<td>5</td>
<td>• Antibiotic-resistant organism surveillance</td>
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<tr>
<td>6</td>
<td>• Population-level quality monitoring</td>
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Benefits of using an HIE

- Single interface for multiple facilities
- More control of detection rules
- Potentially more standardization of vocabulary
- Large amount of clinical data
- Aids in investigation
- Current patient contact information
Challenges with using an HIE

- HIE first priority is to support clinical exchange
- Differences in coding/vocabulary
  - Same code may be used for different tests
- Data availability
  - Lag in sending data to HIE from EHR system
- Patient consent issues
  - Where does filtering occur?
- Cost to providers to use HIE for reporting?
HIE first priority is to support clinical exchange

- HIE will code based on volume, not what is reportable
  - ie, CBC, chemistries, cholesterol, etc..
- Public health is generally a lower priority, so changes will take longer
Differences in coding/vocabulary

- Not all codes are equal
  - Incorrect codes
  - Different codes for same test

- Vocabulary issues
  - Different uses for same vocabulary by different facilities

- Many different ways to say the same thing
Interoperability
Standards and Interoperability

- **Standards** – the use of a vocabulary with unambiguous meaning between two entities (ex: case definition that says the patient must have a “fever”; lab report that defines a specimen as “S”)

- **Interoperability** – the ability for two entities to exchange data with unambiguous meaning.
Vocabulary versus Structure

- Vocabulary refers to the meaning of the message part.
- Syntax or structure refers to the order in which the message was sent
  - I knew a man with a wooden leg named George
  - I almost wrote a check for $1000
  - I wrote a check for almost $1000
Data availability

- Facility may batch import data to the HIE
  - Immediately reportable conditions may be delayed
- Some facilities may participate in the HIE and other may not
  - Incomplete record or lab/clinical findings
- Data retention/removal policies
  - How long is data available
Patient consent issues

- Is there an opt-in or opt-out policy?
- Who manages consent
  - Centrally at the HIE
  - Locally within each facility
- When consent is changed are all stakeholders notified
- Where does data filtration occur?
Data filtration

- Can occur at:
  - The sender
  - The trusted third party (e.g. HIE)
  - The receiver

- Handshakes?
Costs of using HIE for reporting?

- Cost related to:
  - Money
  - Time
  - Data quality

- Costs to providers or public health

- The benefit of using the HIE must outweigh the burden of independent interfaces
Case Investigation

"Your recent Amazon purchases, Tweet score and location history makes you 23.5% welcome here."
Vision

- Automated acquisition of primary investigation data
- Cloud data
- Reduced investigator workload
- Probabilistic determination of who gets investigated
Data collection becomes ability to evaluate data streams, select appropriate streams, and merge them

Use probability determinations to determine if we investigate a case

- Pertussis – DFA (5%), PCR (40%), cough (10%), current vaccination (-20%)
- 50% threshold for investigation
Challenges

- Accuracy
- Integration of investigation data
  - Data standards
  - Linking data (think changing addresses)
- Master patient index
- Temporary technology means mandatory changes in process
- Data ownership and control
- Possible loss of creativity
Data collection

- It costs money to collect and store data!
  - Vision is to do neither!
  - Shop at Costco, let others do the fishing and hunting and
  - Goal should be to eliminate data collection/storage as a public health function
Take-away

- Engage HIE early
- Encourage facilities to join HIE to ease burden of reporting requirements
- Make sure codes important to public health are included in the HIE mapping tables
- Increase infrastructure in public health to handle increase of data
- Train more epidemiologists in informatics
Resources

- AMIA 10x10
- CSTE Scholarship for Public Health Informatics Online Certificate Program
- Public Health Informatics Institute (PHII)
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