

# National Syndromic Surveillance Conference New York, NY

Track B Panel: Legal Perspectives/HIPAA  
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## Utah Case Study

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“In law, nothing is certain  
but the expense.”

~ Samuel Butler

# Outline

- Legal Authority for Syndromic Surveillance during the 2002 Winter Olympics in Salt Lake City
- Legal Authority for Syndromic Surveillance After the Games
- Impact of HIPAA on our Approach

# Making Syndromes Reportable for the 2002 Winter Olympic Games

- Statutory Authority enacted specifically for the 2002 Olympics
  - “Early Warning Reporting” rule
- Facilitated syndromic surveillance from Emergency Departments and Urgent Cares

# “Early Warning Reporting Rule”

- Definitions
  - “emergency center”, “encounter”, “diagnostic information”
- Reporting encounters
  - Public Health review or self-reporting allowed
- Encounter criteria (syndromes)
  - “Respiratory infection with fever”
- Report contents
- Epidemiological review

# Acute Care Surveillance Overview of System

- Total of 43 facilities participated
  - Chief complaint log confirmed by selective chart review (19)
  - Clinicians reported using special forms (4)
  - Electronic reporting based on electronic chief complaints (20)

# Acute Care Surveillance Log & Chart Review

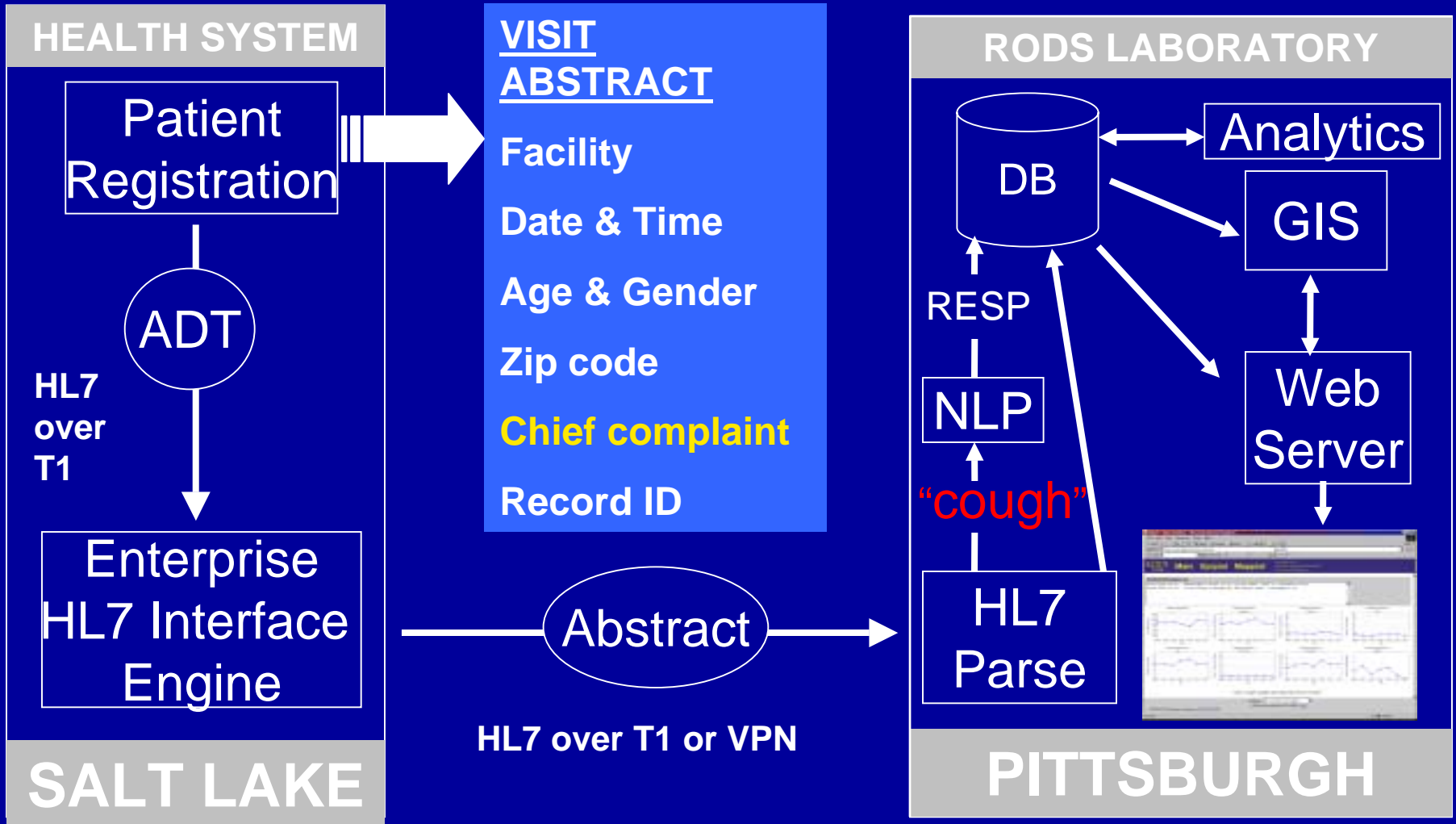
- LHD staff reviewed complaint logs & confirmed by chart review
- Data entered in database & transmitted to UDOH each morning via email attachment
- Analysis to detect aberrations
- Investigative follow-up for sentinel syndromes (e.g., Botulinic)

# Utah RODS Architecture

DATA

NETWORK

APPLICATIONS



# How RODS was different

- Relatively late addition
- “Black box” from Public Health perspective
- Syndromes were different
  - Respiratory with fever < Respiratory
- One health system decided to view it as a research project
  - IRB approval
  - Special “views” for public health

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# Utah's Detection of Public Health Emergency Act

- “Requires health care providers to report to public health when the health care provider suspects that an individual has been exposed to or harbors an illness or condition resulting from bioterrorism, an epidemic or pandemic disease, or other highly fatal infectious agent.”

# Utah's Detection of Public Health Emergency Act (continued)

- “Authorizes a health care provider to report certain emergency illnesses and health conditions.”
  - “Includes the diseases, conditions, or syndromes designated by the Utah Department of Health.”
- Syndromes will be designated in a separate Administrative Rule

# Utah's Detection of Public Health Emergency Act (continued)

- Authorized under ordinary circumstances
- Required upon declaration of public health emergency requiring it.
- Also requires pharmacies to report:
  - “an unusual increase in the number of prescriptions for antibiotics (e.g., Cipro)
  - “an unusual increase in the number of requests for information about or sales of over-the-counter pharmaceuticals”

# Authorization to report

- (1) A health care provider is authorized to report to the department any case of a reportable emergency illness or health condition in any person when:
  - (a) the health care provider knows of a confirmed case; or
  - (b) the health care provider believes, based on his professional judgment that a person likely harbors a reportable emergency illness or health condition.

# Utah RODS after the Games

- After the Olympics RODS has continued under a research agreement while we work out a sustainable model that is acceptable to public health and health care
- MOUs for Limited Data Set
- IRB approval from covered entities
- RODS Laboratory acting as Application Service Provider

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# HIPAA Privacy Rule

- Disclosures permitted if required by law
- Disclosures permitted for “public health activities and purposes”
- Consent not required, but rule doesn’t require PH disclosures

# Accounting for Disclosures for Syndromic Surveillance

- Required if PHI being disclosed
  - IHC has special Database
- Not required if:
  - Fully or statistically deidentified
  - Part of a Limited Data Set
  - Consent obtained

# Simplified Accounting for Disclosures to Public Health

- Repetitive disclosures to the same recipient for the same purposes (e.g., reporting syndromic encounters) can be simplified
- For an “accounting period”, CE need only:
  - Identify the recipient of such repetitive disclosures
  - Describe the purpose of the disclosure
  - Describe the PHI routinely disclosed
  - Include the date of first and last disclosure
- No notation needs to be in the patient record

# Health System Pushback

- “Is there any penalty for not reporting?”
- “If this activity is not required by law, then we can’t share data with public health.”
- “Due to the administrative burden of accounting for disclosures to public health, we don’t want to report.”
- “We can’t send information about all visits, just the ones we determine to have a syndrome.” (Denominator?)
- “Are the other guys reporting it?”

# What will drive the model?

- Lawsuits
- Public health events
- Public trust and community benefit
- Potential for dual-use of the data
- Experience from real-world deployments

# Resources

- Office of Civil Rights
  - <http://www.hhs.gov/ocr/hipaa/>
- <http://www.cdc.gov/privacyrule>
- <http://www.healthprivacy.org>
- Sample MOU available from <http://www.jamia.org/preprints.shtml>
- UT Detection of Public Health Emergency Act:
  - [http://www.le.state.ut.us/~code/TITLE26/26\\_19.htm](http://www.le.state.ut.us/~code/TITLE26/26_19.htm)