Tribal Public Health Data and Surveillance: The Role of Law

November 5, 2015
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Tribal Public Health Data and Surveillance: The Role of Law

October 5, 2015
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  - Tribal Public Health Law
  - Federal Indian Law
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  - Public Health Enabling Authorities
Presenter

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  - Public health statutory and regulatory authority
  - Bed bugs
  - Newborn screening samples and research
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  - Tribal population health issues
  - Perinatal Improvement Project
Presenter

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  - Native American Health Law Issues
  - Violence Against Women Office
Tribal Public Health Data and Surveillance: The Role of Law

Denise Chrysler, JD
Director, Network for Public Health Law
Mid-States Region

Webinar, November 5, 2015
Overview

» **Basic terms and concepts**

» **The role of law in data sharing**

» **Analyzing data sharing issues**

» **Navigating law to share data to improve health of American Indian and Alaska Native (AI/AN) people**
Public health surveillance

» Collection, analysis, and use of data to target public health prevention

» Conducted by federal, state, and local health departments

» Essential to public health mission

» Depends on data from many and diverse sources – especially health data

» To impact population health, data and information must be disseminated to those responsible for prevention and control
Public health surveillance, continued

» Conducted by Tribal Governments and Tribal Epidemiology Centers (TECs)

» Work to elevate health status of AI/AN people

» Challenges in obtaining data from state and local public health for multiple reasons

» Law: actual and misconceptions and misinterpretations

» Navigating law to get to “yes” takes willingness and effort
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
» Electronic data
» Data sharing partners
» Ways to transfer and exchange
» Linkages with other information
» Creation integrated databases
So many laws ....
Law governs every aspect of data

- Collection
- Use
- Sharing
- Protection

Law friend or foe?
- How does law support data sharing?
- How is law a barrier?
Federal laws (examples)

» HIPAA Privacy and Security Regulations
» Family Educational Rights & Privacy Act (FERPA)
» 42 CFR Part 2 (substance abuse)
» Public Health Services Act (Title X family planning)
» Social Security Act (Medicare, Medicaid, SCHIP)
» VA Claims Confidentiality Statute
» WIC Regulations
» Federal Regulations for the Protection of Human Research Subjects
State laws (examples)

» Public health laws (e.g., reporting requirements, communicable disease investigations, HIV/AIDS, vital records, registries, confidentiality)

» Health information/medical records laws

» Health information exchange laws

» Identity theft protection; breach notification laws

» Freedom of information laws

» Data practices laws
Challenges in Sharing Meaningful Data

» Public health data – state law mostly governs (varies)
» Each data type may be controlled by own law, multiple laws, or no law
» Myths and misinterpretations (e.g. HIPAA)
» Legal interpretations necessary—when in doubt lawyers say “no”
» De-identification (HIPAA’s influence) & re-identification risk
  - No reasonable basis to believe that the information can be used to identify an individual
  - Lack of statistical expert
TECs access to HHS data

» Indian Health Care Improvement Act (IHCIA)

The Secretary of HHS “shall grant to each epidemiology center . . . access to use of the data, data sets, monitoring systems, delivery systems, and other protected health information in the possession of the Secretary.”

» HHS receives data from state and local public health departments

» BUT ... State and local data usually at high level, may lack specificity and level of detail to be useful
Analyzing an information sharing issue

To determine authority to share data:

1. Establish facts
   - Data
   - Participants
   - Flow
   - Map movement of data
2. Identify law
3. Apply law
4. Establish & document terms for sharing
 Covered entities are prohibited from using or disclosing PHI unless required or allowed by HIPAA privacy rule.

Rule provides numerous exceptions that permit disclosure without individual’s authorization.

Minimum necessary rule applies to most disclosures.

If another law provides greater privacy protection or greater rights to individual concerning his/her health information, must comply with the other law.
HIPAA – should not interfere with data sharing

» Permits disclosure of identifiable data to public health authorities and their authorized agents for public health purposes

» “Public health authority” – agency or authority of US, State, territory, political subdivision, Indian tribe, that is responsible for public health matters as part of its official mandate, or a person or entity acting under a grant of authority

Includes contractors, employees or agents to whom a public health agency has granted authority

» IHCIA – Designates TECs as “public health authorities” for purposes of HIPAA
State law is another matter …

» Authority to share identifiable health data written narrowly

» No authority specifically authorizing the sharing of identifiable health data with tribal authorities

» Privacy provisions that limit sharing of identifiable data (general or specific to data type or source)
  - Exceptions do not include tribal authorities
  - Exceptions apply to limited purposes or circumstances (e.g. disclosures allowed for disaster relief or suspected bioterrorism)
  - Disclosure allowed to state or local public health authorities; “local” not defined or defined as a subdivision of a state
Suggestions to improve data sharing

» Public health laws - Liberal construction to improve public’s health
» General powers may provide authority
» Written statement of legal authority for TECs to receive, use data
» MOU or data sharing agreement
» De-identified data sets or limited data sets when will serve purpose
» Collaborative strategies – e.g. use of honest broker or statistical techniques to create meaningful data while reducing risk of re-identification
Thank you!

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Acknowledgments and resources:

CDC Issue Brief, Tribal Epidemiology Centers Designated as Public Health Authorities

James G. Hodge, Jr., Torrey Kaufman, and Craig Jacques, Legal Issues Concerning Identifiable Health Data Sharing Between State/Local Public Health Authorities and Tribal Epidemiology Centers in Selected US Jurisdictions, Council of State and Territorial Epidemiologists, 1 (Nov. 8, 2011)
Tribal Epidemiology Centers (TECs)

Partnerships to Improve Public Health for American Indians and Alaska Natives (AIAN)
AIAN Population

• US Census 2010 Total AIAN population:
  • 5.2 million AIAN Alone or in combination

• Distribution (AIAN alone or in combination):
  • 41% in the West
  • 17% in Midwest
  • 33% in the South
  • 10% in Northeast

• Since Census 2000, grew by 28%

Source:
Population Estimates, Single Race
Tribes are **Sovereign Nations**
12 Tribal Epidemiology Centers (TECs)

- Established 1996 by Congress
  Indian Health Care Improvement Act (IHCIA)

- 2010 Affordable Care Act
  - Permanently reauthorized the IHCIA
  - TECs given “public health authority” status
  - HHS shall grant TECs access to HHS data systems and protected health information
  - CDC shall provide TECs technical assistance
  - Each IHS Area must have a TEC
* Covers all urban Indian health organizations and AI/AN urban populations across the nation
Core TEC Functions

• Collect and monitor progress toward meeting health status objectives
• Evaluate delivery systems
• Assist tribes and tribal organizations with Epi Data
• Make recommendations for service targets
• Make recommendations to improve health care delivery
• Provide TA to tribes and tribal organizations
• Provide disease surveillance
TEC Activities

• Collect and disseminate data...
  Provide analysis of health data
• Area/Tribal specific health status reports...
  Community Health Profiles
• Maintain/provide access to surveillance databases
• Conduct epidemiologic studies
• Support public health emergency response
• Assist Tribes in disease control and prevention
• Provide training... Epidemiology, Data Collection, and Public Health
Data Difficulties

- Social stigma
- Barriers to data sharing
- Small numbers issues
- Cultural norms and values
- Tribal borders
- Community Isolation
- Racial misclassification
Up to 45% of AI/AN may be misclassified

Puukka et al., “Measuring the Health Status Gap for American Indians/Alaska Natives: Getting Closer to the Truth”

Espey et al., “Methods for Improving Cancer Surveillance Data in American Indian and Alaska Native Populations”
Cancer 2008;113(5 suppl):1120–30
Partnerships

• Build new collaborations
• Expand existing collaborations
• Address data sharing and data access issues
• Address data quality
• Increase understanding of AIAN health issues
• Improve public health outcomes
TEC Reports and Products

• Data Reports
• Community Health Profiles
• Methods and Technical Reports
• Fact Sheets

www.npaihb.org/epicenter/project/reports
http://crihb.org/ctec/reports.html
www.glitc.org
TEC-State-Fed-Tribe Collaboration Success Stories

- CSTE Tribal Epidemiology Subcommittee
- H1N1 Deaths Among AI/ANs (MMWR)
- IHS Patient Index and National Death Index Linkage
- Model State Vital Statistics Act/Regulations change
- Analysis of PHI/PII Data sharing between States-TECs
- Multistate AI/AN PH Surveillance Assessment
- Environmental Public Health Tracking
TEC Approaches to Data Use

• OCAP principles: Ownership, Control, Access and Possession
• Data stewardship
• Levels of protection: individual (PHI) and community
• Data Use Agreements
  Specifies:
  • Purpose of data use
  • How data will be used
  • Data disposition
  • Data destruction verification
• Dissemination policies
Tribal Public Health Data and Surveillance

The Role of Law

Presenter: Debra Gee, General Counsel, the Chickasaw Nation
The Chickasaw Nation

Overview

• The Chickasaw Nation has over 61,000 citizens
• Jurisdictional territory includes 7,468 square miles in rural, south central Oklahoma
• Checkerboard jurisdiction which includes Indian Country and fee land
• Strong proponent of tribal sovereignty
• Internal system ensures that tribal policies and applicable laws are followed
The Chickasaw Nation
Chickasaw Nation Department of Health

• Chickasaw Nation Medical Center – new hospital opened July 2010
• Three satellite clinics
The Chickasaw Nation

Components of our healthcare system

- Diverse delivery of healthcare
- Chickasaw Nation Institutional Review Board
- Information technology infrastructure
- Works with number of federal, state and local agencies and private partners
- Responds to various public health surveys and shares information to extent applicable laws provide for this
Information Sharing Challenges

My observations:

• Tribal information sharing with state and local agencies may pose tribal sovereignty concerns when state law governs

• Lack of IT infrastructure may affect accurate tribal reporting

• Data collected by various federal, state and local agencies may lack coordination causing overlap

• Role of the Indian Health Service in this effort and differences between IHS-operated facilities vs. tribally-operated facilities
Recommendations to Address Challenges

• Be aware of the issues of tribal sovereignty which vary from tribe to tribe
• Be aware of the legal landscape between federal, tribal, state, and local governments
• Obtain tribal input at the beginning of tribal public health data projects in order to ensure tribal buy-in and that your project gets the needed support
• Engage the tribal IRB if appropriate
• Engage in tribal consultation with tribes when appropriate
Please type your questions in the Q&A panel.
Thank you for attending

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Thursday, November 19—1pm (ET)

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