Public Health, the Learning Health System & Law

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Public Health and the Learning Health System: A National Meeting
Law

» Standards established by government that govern our conduct as organizations, professionals and workers, and individuals.

» Legislative, Executive, and Judiciary Branches all “make” law

» Law enables policy • Policy is used to implement law

» Ethics – the decent thing to do
Law: Friend or Foe?

» HITECH – Promotes meaningful use of electronic medical records

» Affordable Care Act – Extends and expands quality and effectiveness programs; Requires enhanced collection and reporting of data related to health disparities

» HIPAA regulations – establishes national privacy and security standards

» HHS human subjects protection regulations

» Anti-discrimination laws

» Public health confidentiality laws
Public Health Databases

- **Birth Records**
  - Birth date, birth weight, sex, mother/father age, address, maternal prenatal care and behaviors

- **Birth Defects Registry**
  - ICD-9 diagnostic codes; procedure codes (already linked with live births) and thus additional variables also available

- **Disease Surveillance System**
  - Infectious disease reports

- **Michigan Care Improvement Registry**
  - Birth date, address, sex, immunizations received, immunizations overdue, provider who administered, adverse reactions

- **Newborn Screening**
  - Birth date, birth weight, specimen date/age, sex, single/multiple birth order, NICU, transfusion status, ethnicity, mother’s address, hepatitis antigen

- **WIC**
  - Child and maternal data, pregnancy and post partum health history, breastfeeding, medications, weight, medical/nutritional conditions, marital status, education level
More Public Health Databases

- **Cancer Registry**: Patient demographics, cancer site and stage, family history information, laboratory information, method of confirmation, treatment data.
- **Early Hearing Detection & Intervention**: Hearing screen results (pass/fail); confirmed hearing loss (linked with live births and thus additional variables also available).
- **Children’s Special Health Care Services**: Mother’s name, address, primary enrollment diagnosis (ICD-9 codes), treatment and procedures (CPT codes).
- **Medicaid**: Birth date, address, racial heritage, diagnosis (ICD-9 codes), providers, procedures (CPT codes), pharmacy claims.
- **Childhood Lead Screening**: Child name, address, test results.
- **Death Records**: Age, birth date and place, death date, immediate and underlying cause of death, ancestry, race, education, occupation, parents’ names, autopsy.

Public Health and LHS March 12, 2013
Consent and datasharing

"Yeah, I see him too...But nobody wants to talk about it!"
Consent

» Legal issues
  » What does the law require?
  » Right to informational privacy
  » When is information de-identified?

» Policy issues
  » Data stewardship
  » How do we balance individual interests and public benefit?
  » Secondary Additional uses: Quality assurance & improvement, surveillance, research
  » Impact of consent on research
DATA USES

A difficult balancing act

Goal: Promote the common good while respecting the individual
Tradeoffs: Individual rights & protections vs. promotion of uses that
benefit the public.
>> Ethics
   » Respect for individual
   » Beneficence
   » Justice

>> The Common Good –
   » What are our responsibilities as members of a community and society to contribute to the common good?
Thank you for listening

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