

# Public Health Departments as Data Providers for Community Driven Change

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# Who are we and what do we do?

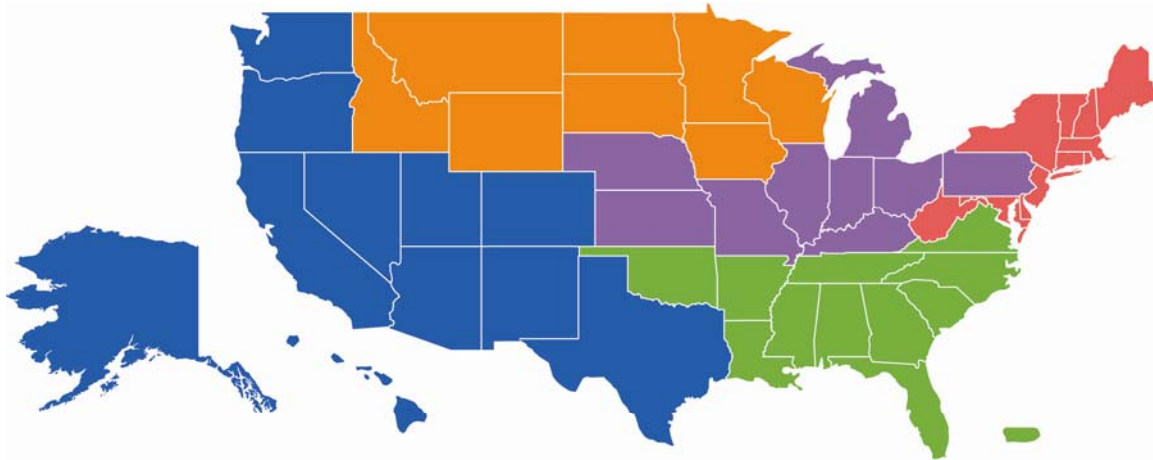
**At no cost, the Network provides public health legal support:**

- » **Technical assistance**
- » **Resources**
- » **Opportunities to build connections**

*With a single point of entry to experts on a wide-range of topics, it's practical, reliable and seamless.*

# National Scope with Local Expertise

- » **Provide support across the country**
- » **Divided into 5 Regions to provide local and state support**
- » **Contact your region for assistance**



# Who can use the Network

**Anyone committed to public health can join the Network:**

- » **Local, state, tribal and federal public health officials**
- » **Public health practitioners**
- » **Attorneys**
- » **Policy-makers**
- » **Advocates**

# Public Health Topics

Working with experts around the country, the Network provides support on a variety of topics:

- » **Cross-border public health**
- » **Emergency legal preparedness and response**
- » **Environmental public health**
- » **Food safety**
- » **Health reform**
- » **Health information data sharing**
- » **Injury prevention and safety**
- » **Obesity prevention**
- » **Public health agency accreditation and shared service delivery**
- » **Public health statutes and regulatory information**
- » **Tobacco control**
- » **Tribal public health law**
- » **And other topics**

# Health Information Data Sharing

- » **TA requests**
- » **Resources**
- » **Blogs**
- » **2012 Public Health & the Law Conference  
– Data sharing track**
- » **State PH privacy officer listserv**
- » **Public Health and the Learning Health  
System National Mtg (Mar 2013)**

# 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

## Newborn Screening

Birth date, birth weight, specimen date/age, sex, single/multiple birth order, NICU, transfusion status, ethnicity, mother's address, hepatitis antigen

## Immunization Registry

Birth date, address, sex, immunizations received, immunizations overdue, provider who administered, adverse reactions

## 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



Too big ...Too difficult

# Big ....Difficult



**with many legal, policy, and  
technical issues to resolve**

How can the federal govt take us from “too big, too difficult”

to simply “big and difficult”?

# Challenges in Liberating Data

- » **PH data – state law mostly governs (varies)**
- » **Each database may be controlled by own law**
- » **Legal interpretations necessary – when in doubt say “no”**
- » **Deidentification (HIPAA’s influence) & reidentification risk**

No reasonable basis to believe that the information can be used to identify an individual

Lack of statistical expert

Ideas for avoiding issue – e.g. honest broker

# Michigan's HIV confidentiality law

Sec. 5131.

(1) All reports, records, and **data pertaining to testing, care, treatment, reporting, and research**, and information pertaining to partner notification under section 5114a, that are associated with the serious communicable diseases or infections of HIV infection and acquired immunodeficiency syndrome **are confidential**. A person shall release reports, records, data, and information described in this subsection only pursuant to this section.

# Public health, trust, transparency

- » **Shining a light – the downside**
- » **Law grants PH broad power to collect data – what is PH's authority re sharing, secondary uses by others**

Do not want to jeopardize public health's functions and services

- » **Consent models (beyond individual consent)**
- » **Connections to fellow travelers**

Health in All Policies

# Michigan's BioTrust for Health

- » **Parallel opportunities and challenges**
- » **Many legal, ethical, and policy issues – issues are intertwined**
- » **Addressing issues is neither fast nor easy**
- » **Don't think you can fly below public radar**
- » **Choice matters (even if data are de-identified)**
- » **Balancing common good & respect for individual**

Reciprocity

Privacy advocates and absolutists



# Thank you for listening

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