



Navigating law to share ... **Environmental Health Data**

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Agenda

Introduction: Key Concepts + Goals



Overview of Legal & Policy Challenges

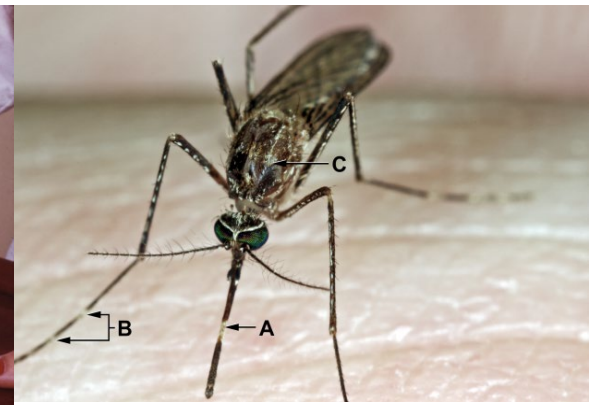


Case Study: Kent County Lead Poisoning Prevention Project

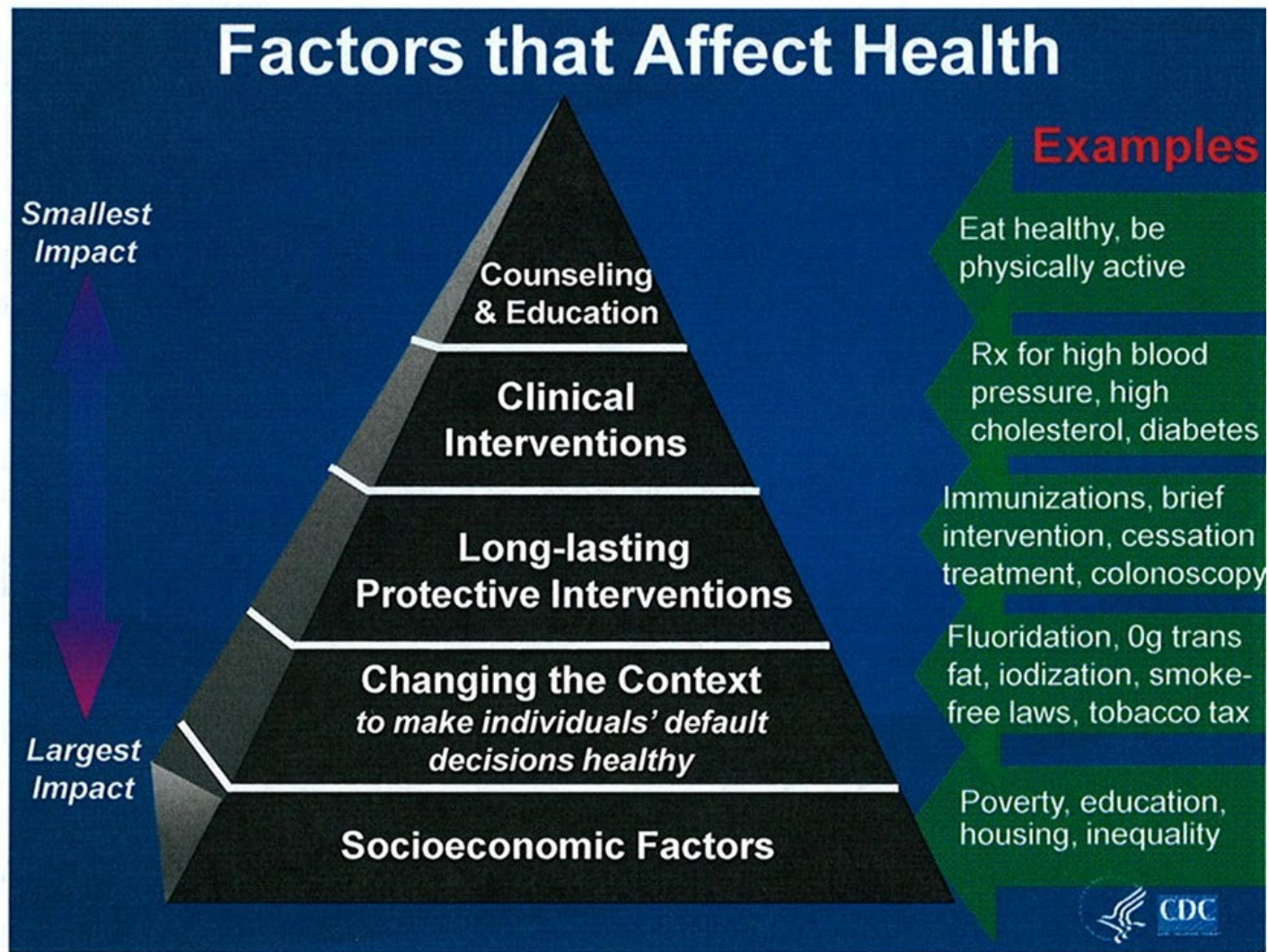
Introduction: Key Concepts + Goals

Law can protect the public

- Air quality
- Water quality
- Sanitation
- Injury prevention
- Safe food
- Workplace safety
- Environmental controls to prevent disease
- Mandatory vaccination



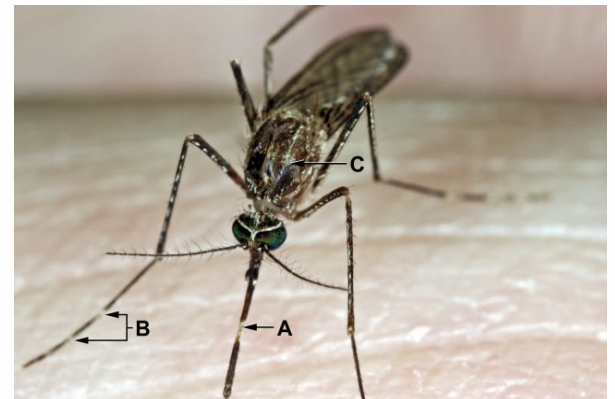
Health impact of interventions



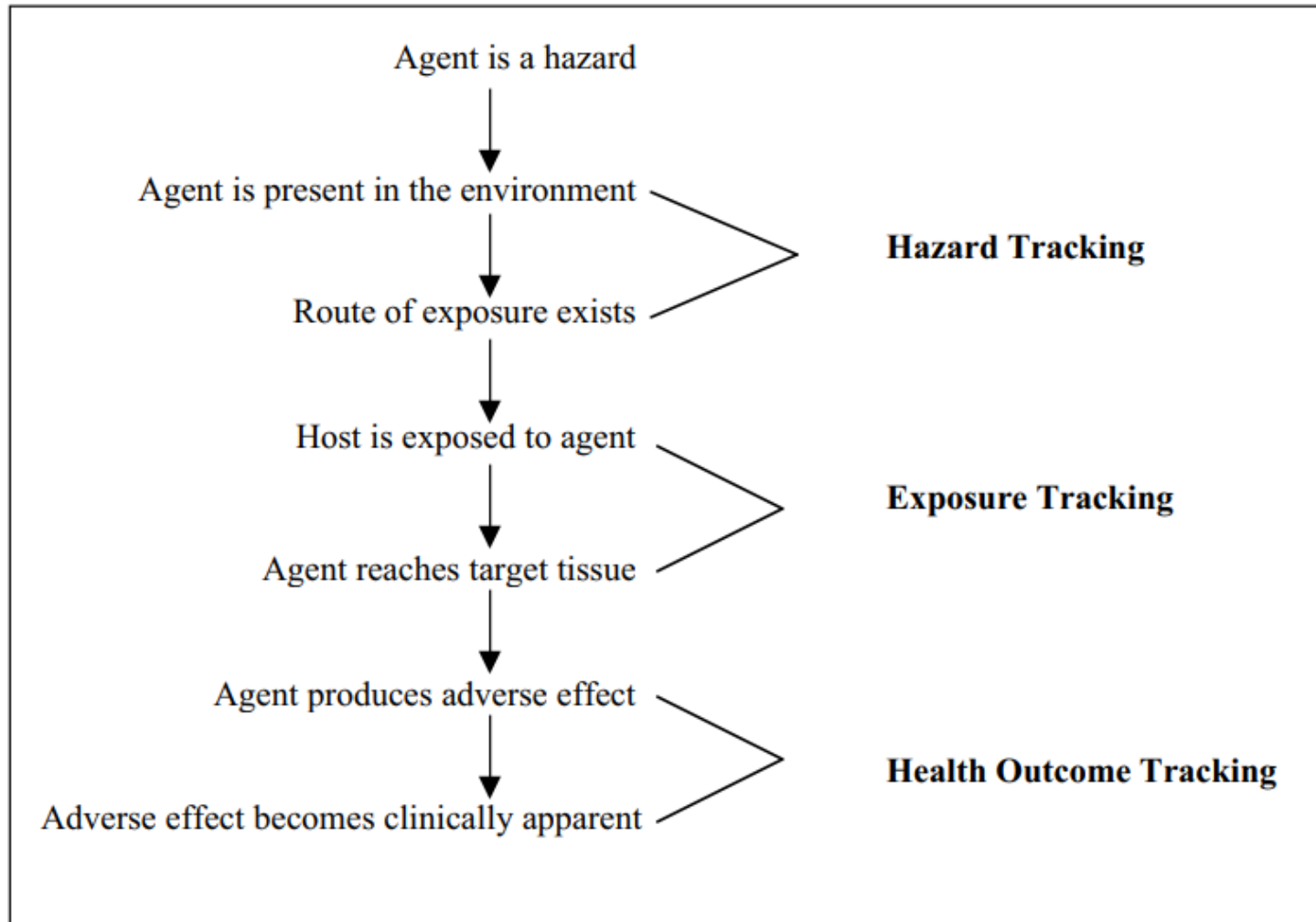
A Framework for Public Health Action, Thomas R. Frieden, AJPH, April 2010

What is environmental health?

- » **The branch of public health concerned with monitoring or mitigating those factors in the environment that affect human health and disease.**
- » **Factors may directly affect health or disrupt the ecological balances essential to long-term human health and environmental quality.**
- » **Factors may be natural or man-made.**

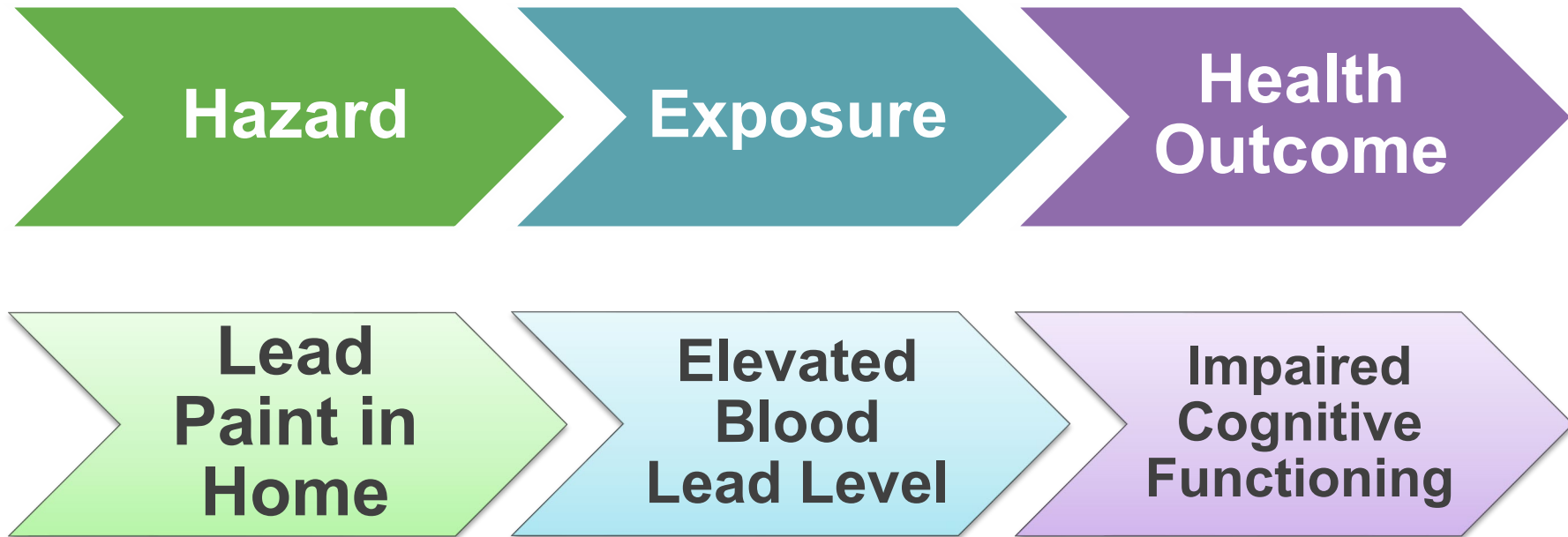


Three Types of Public Health Tracking for Adverse Environmental Threats



Johns Hopkins School of Hygiene and Public Health - Environmental Health Tracking Project Team, *America's Environmental Health Gap: Why the Country Needs a Nationwide Health Tracking Network* (2000), <https://www.jhsph.edu/research/centers-and-institutes/center-for-excellence-in-environmental-health-tracking/pew-technical-report.pdf> ("Johns Hopkins EH Report (2000)")

Three Types of Public Health Tracking for Adverse Environmental Threats: *Example*



What is environmental justice?

» **Fair treatment and meaningful involvement of all people regardless of race, color, national origin, or income, with respect to the development, implementation, and enforcement of environmental laws, regulations, and policies.** Source: EPA

» **Environmental justice & health in all policies (remedying the past + going forward)**

The conclusion

“The Flint water crisis is a story of government failure, intransigence, unpreparedness, delay, inaction, and environmental injustice.”

Flint Water Advisory Task Force Final Report
(March 2016)

3 CRISES

FINANCIAL

Loss of manufacturing ♦ People left
Tax base declined ♦ Revenue sharing cut
♦ Infrastructure crumbling

WATER

Water contaminated with lead ♦ System
compromised ♦ Community instructed to
drink bottled (unfluoridated) & filtered water

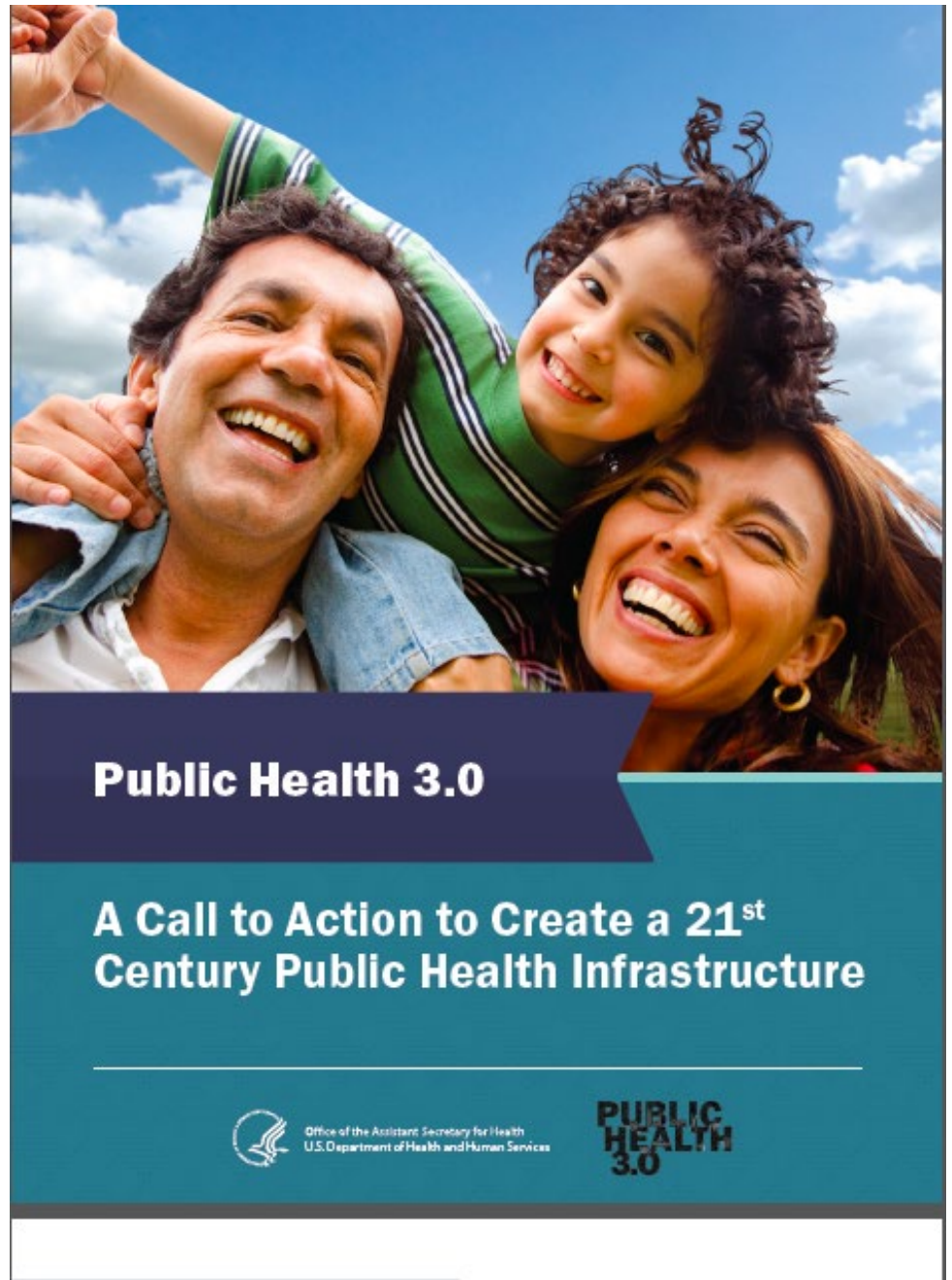
PUBLIC HEALTH

Thousands of children, adults, and pets
exposed to lead in the water ♦ Unknown
short and long term consequences

Public Health 3.0

recognizes that we need to focus on the social determinants of health in order to create lasting improvements for the health of everyone in America.

Public health + community organizations create conditions so that everyone has the opportunity to be healthy



Public Health 3.0 – Data are key

- » Requires access to timely, reliable, granular data (i.e. sub-county) and actionable data
- » Depends on data from many and diverse sources – including sources and types of data relevant to social determinants
- » Should have data that are accessible to communities throughout the country that are shared, linked, and synthesized while protecting data security and individual privacy
- » Needs clear metrics to assess impact and document success
- » **Environmental health is local!**

Sharing Environmental Data

- » **Empowers public health and public health advocates**
- » **Empowers communities**
- » **Empowers consumers**

App Tracks Restaurant Health Inspection Data State-by-State

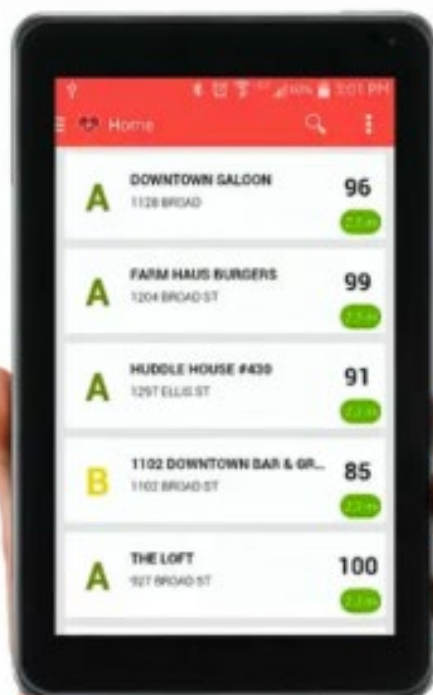
It's called What the Health.

by [Khushbu Shah](#) | Jan 22, 2015, 1:32pm EST

Via [App Puts Restaurant Health Reports at Your Fingertips \[WWL\]](#), [Yelp Joins Forces With Governments to Publish Restaurant Inspection Data \[E\]](#), and [All App Coverage](#)



SHARE



WHAT THE HEALTH

Juggling multiple roles and competing interests

- » **Protect the public**
- » **Protect and improve population health AND provide health screening and treatment**
- » **Protect individual privacy**
- » **Implement regulatory programs**
- » **Protect business reputation**
- » **Protect business proprietary information**
- » **Inform the public**



1854 Soho Cholera Outbreak

Science *plus* law

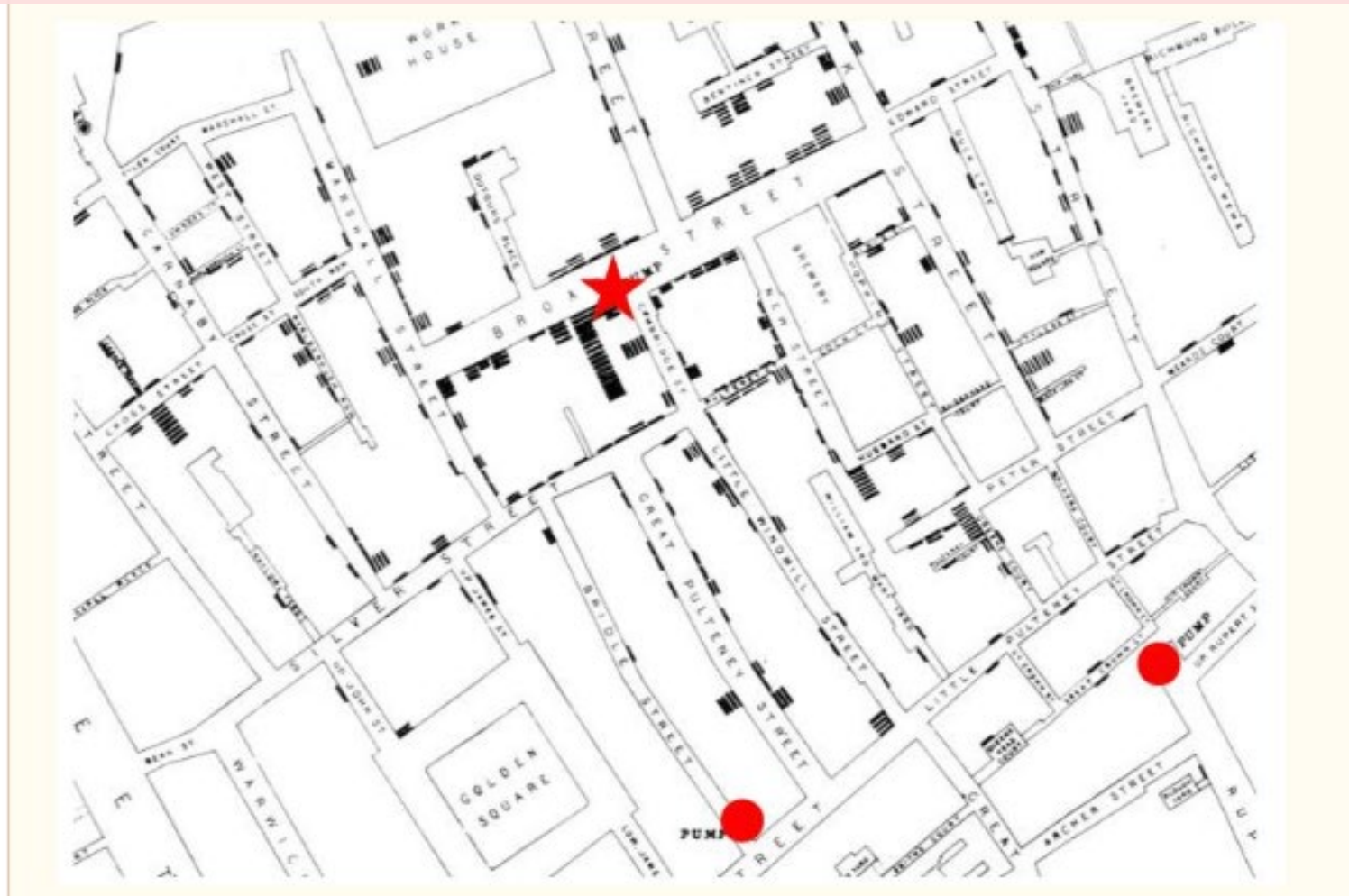
John Snow's
study of water-
borne cholera
cases essential

...as is

Local council's
action to remove
Broad Street Pump
Handle



John Snow's Map of the 1854 Cholera Outbreak in London.



The star indicates the water pump closest to the most deaths (black bars). The circles are other water pumps. Note that the map only solved the problem because of unique locations.

Source: Gutmann, M et. al. Providing Spatial Data for Secondary Analysis
Issues and Current Practices relating to Confidentiality, Popul Res Policy Rev. 2008; 27(6): 639–665. (Figure 2).

Today: Could John Snow map be publicly disseminated?

Why or why not?

Area near a closed industrial site. 22 out of 40 private wells tested positive for Dioxin wells – Map shows specific sites – disseminate publicly?

Why or why not?

What does your agency do?



Are aggregate data “protected health information” (PHI)?

[See handout]

Legionnaires' Disease in Genesee County 2019 Update

AS OF AUGUST 23, 2019

TOTAL CONFIRMED CASES: 14

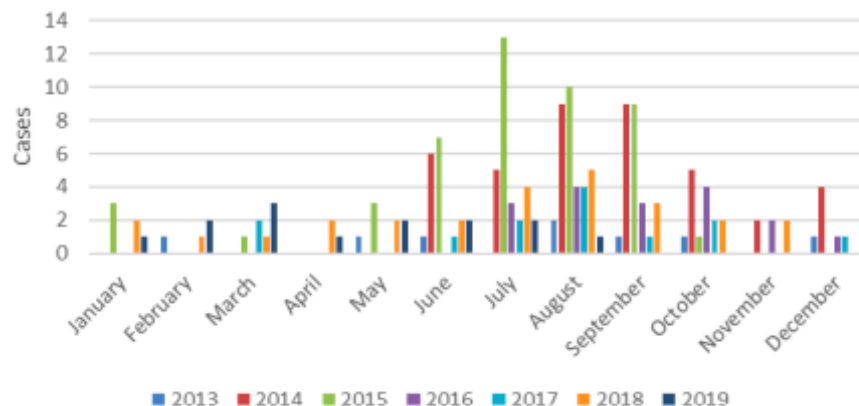
Age:

Range: 41-90 years

Average: 62 years

Median: 60 years

Legionnaires' Disease Cases by Month of Onset or Referral Date, Genesee County 2013-2019



Protected health information (PHI)

- » **Information, including demographic information:**
 - In any form: written, electronic or oral
 - Relating to past, present or future
 - Physical or mental health status or condition
 - Provision of health care
 - Payment for provision of health care
- » **That identifies the individual or for which there is a reasonable basis to believe can be used to identify the individual**

De-Identification – Safe Harbor

- » **HIPAA lists 18 identifiers that must be removed + very small risk that anticipated recipient could identify individual**
- » **Geographical identifiers: Smaller than a State, except for the initial three digits of a zip code if, combined area contains more than 20,000 people**
- » **Dates: All elements of dates (except year) for dates directly related to an individual, including birth date, admission date, discharge date, date of death; all ages over 89 may be aggregated into a single category of age 90 or older**

De-Identification – Expert Determination

- » **Person with appropriate knowledge and experience**
- » **Applies statistical or scientific principles**
- » **Determines very small risk that anticipated recipient could identify individual**
- » **May use mitigation strategies to reduce risk**
- » **Documents methods and results of analysis**

Legionella data: HIPAA does not apply.

This law does . . .

Communicable Disease Rules, R 325.181

- » Medical and epidemiological information which **identifies an individual** and which is gathered in connection with an investigation is **confidential** and is not open to public inspection without the individual's consent or the consent of the individual's guardian, unless public inspection is necessary to protect the public health as determined by a local health officer or the state health director.

Using law to protect the public's health

CAN I?

Legal question: Do I have authority?

MUST I?

Legal question: Does law leave me no choice?

SHOULD I?

Policy question: How should I exercise my discretion?

Navigating law **De-Identification**



might be a key to open doors

- » **If remove or obscure personally identifying information in a dataset**
- » **Then most laws do not prohibit release of de-identified information**

De-Identification as a solution

“Data can be either useful or perfectly anonymous, but never both.” Professor Paul Ohm

Concern: Data regarding small geographic size, specific populations, sparsely populated areas, identifying populations based on multiple characteristics or unique characteristics

Concern: Informing the public - Aggregate data can be identifiable

Concern: Sufficient identifiers needed to link and combine data across databases and data sources

Statistical de-identification techniques

- **Anonymizing/de-identifying data**
- **Generalization**
- **Restrictions on geographic detail**
- **Recoding into intervals and rounding**
- **Cell suppression**
- **Subsampling**
- **See de-identification toolkit**

Machines that read data

Digital Data

- Machine learning
- Decision support

Computer software

- De-identify data
- Merge identifiable data-sets without any person being able to view the data in identifiable form

Image Credit: CC BY 2.0 Jeff Golden



The Network
for Public Health Law

Ideas. Experience. Practical answers.

Overview of Legal & Policy Challenges

So many hazards...

- » **Drinking water contaminants – surface and groundwater sources**
- » **Air pollution, indoor air (e.g., carbon monoxide)**
- » **Food**
- » **Hazardous waste**
- » **Pesticides**
- » **Heavy metals (e.g., mercury, lead)**
- » **Radiation**
- » **Bioterrorism**
- » **Asbestos**
- » **Chemical spills**
- » **Housing quality issues**
- » **Bioterrorism**
- » **Agricultural waste (e.g., hog farms)**

So many health outcomes (suspected or confirmed environmental etiology) ...

- » **Respiratory/lung diseases (e.g., asthma, COPD, asbestosis)**
- » **Neurological disorders (e.g., encephalitis, Parkinson's, Alzheimer's)**
- » **Skin disorders**
- » **Chronic liver disease and cirrhosis**
- » **Heart diseases**
- » **Blood diseases**
- » **Birth defects (e.g., low birth weight, congenital anomalies)**
- » **Developmental disabilities**
- » **Reproductive disorders**
- » **Kidney diseases**
- » **Immune disorders**
- » **Cancer (e.g., leukemia)**
- » **Diabetes**

So many disconnected sources of data...

- » **CDC National Environmental Public Health Tracking Network:** <https://ephtracking.cdc.gov/>
- » **Regulatory processes** (e.g., inspections, permit applications, required reporting)
- » **Public health surveillance**
 - » Biomonitoring (e.g., blood lead levels, newborn screening blood spots)
 - » Routine disease reporting (e.g., mandated communicable disease reporting, syndromic surveillance)
 - » Disease/condition-specific registries (e.g., birth defects, cancer)
- » **Surveys** (e.g., Nat'l Health & Nutrition Examination Survey (NHANES))
- » **Vital Statistics**
- » **Electronic health records**
- » **Research and tissue repositories**

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Food-poisoning tweets get city follow-up

Health authorities seek out sickened Chicagoans, ask them to report restaurants

August 13, 2013 | By Monica Eng, Chicago Tribune reporter

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When Juan Anguiano fired off a tweet about a bout of food poisoning in April, he thought he might hear back from sympathetic friends or pick up a new follower.

"I wasn't expecting the city of Chicago to tweet me and ask me to file a report," said Anguiano, an editor for Univision.

So many laws. . .

to obtaining, using, and disclosing EH data

Law governs every aspect of data

Collection

Use

Sharing

Protection

Law friend or foe?

- How does law help us to do our job?
- How is law a barrier?

How do you analyze a data sharing issue?

One
bite at
a time



Analyzing a data sharing issue

1. Establish facts

-- What

-- Who

-- Why

2. Identify law

3. Apply law

4. Establish & document terms for sharing

The **WHAT**

- » **What do you want to address (what public health threat)?**
- » **What do you want to accomplish?**
- » **What is your level of focus?**
 - Individual (e.g. case management; care coordination; crisis intervention)
 - Systems (e.g. assessment and improvement; of individual organization or human services or health services delivery systems)
 - Population health (e.g. public health or community interventions)

The WHAT

» What do you want to address (what public health threat)?

Big picture: Children in the community have been exposed to a hazard. Health and social services are needed to mitigate harm.

» What do you want to accomplish?

Specific goals: Provide resources and linkages to care for children exposed to the hazard; translate learnings to prevent harm in other communities

» What is your level of focus?

- Focus is primarily on the individual: Connect children to needed services and care.

The **WHAT**

» **What data do you need to accomplish your goal?**

- Data Type
- Data Source
- Data Elements

» **Data needed from state health dept.:**

- » Medicaid claims data (potentially obtained through CMS or through state Medicaid program)
- » State Disease Surveillance System
- » Vital Records
- » Birth Defects Registry
- » Cancer Registry
- » Immunization Registry
- » Hazard-specific health department programs
- » Women, Infants, and Children (WIC) program

Analyzing a data sharing issue

1. Establish facts

-- What

-- Who

-- Why

2. Identify law

3. Apply law

4. Establish & document terms for sharing

Informed consent as a solution . . .
people just want to be asked

Concern: May not be easy to design or implement an informed consent process

Concern: reduce value of data

- Self-selection

- Justice – inclusion of under-represented and vulnerable groups

Concern: Need the population data for population health

Challenges in Sharing Meaningful Data

- » **PH data – state law mostly governs (varies)**
- » **Each data type may be controlled by own law**
- » **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

Courts Drawing Lines

Illinois Supreme Court



» **Southern Illinoisan v. Dept. of Public Health (2006)**

Illinois Public Health Dept. (IDPH) denied newspaper's FOI request for Cancer Registry information regarding incidence of neuroblastoma, including type of cancer, date of diagnosis, and zip code. Court ordered IDPH to release data, despite expert testimony regarding risk of re-identification, because the general public would not be able to re-identify.

Courts Drawing Lines

Ohio Supreme Court



» **State ex rel. Cincinnati Enquirer v. Daniels (2006)**

Health department must release lead risk assessment reports and lead-citation notices to newspaper under FOI, which contain specific household addresses. Were issued to property owners of residences with children with blood tests that indicated elevated lead levels.

Courts Drawing Lines

Ohio Supreme Court

» Cuyahoga Cnty Bd. of Health v. Lipson O'Shea Legal Group (2016)

Health department properly denied attorney's FOI request for "documentation or information of all homes ... where a minor child was found to have elevated blood lead levels in excess of 10 [mcg/dl]." House address was linked to a specific blood lead level and therefore "inextricably linked" to PHI.



Ohio Department of Health to publish homes that remain a lead hazard statewide

Updated Jan 11, 2019; Posted Mar 30, 2017

Comment



0
shares

By [Rachel Dissell, Brie Zeltner, The Plain Dealer](#)

CLEVELAND, Ohio - The Ohio Department of Health (ODH) will soon make public the location of homes with unaddressed lead hazards as part of its stepped up oversight on investigations of childhood lead poisoning cases, officials said.



ODH plans to release a list of all non-compliant cases on its website when this process is complete, Amato said.

The Plain Dealer received the information, which is current through October 2016, from Advocates for Basic Legal Equity (ABLE) Inc., a which requested it from the state as part of its efforts to advocate for lead-safe living environments for children in the Toledo area.





Ohio Lead Hazardous Properties

Description: Properties with Notices of Non-Compliance/Orders to Vacate for Lead Hazards

Category: Prevention

Last Updated: 9/27/2019

Actions	Address	City	County	Zip	Local Lead Jurisdiction
Map It	176 Wendell Ave B	Peebles	Adams	45660-2201	Ohio Department of Health
Map It	1207 N Main St	Delphos	Allen	45833-1147	Ohio Department of Health
Map It	1002 N Jefferson St	Lima	Allen	45801-4169	Ohio Department of Health
Map It	1131 1/2 W Wayne St	Lima	Allen	45805-2467	Ohio Department of Health
Map It	234 S Collett St	Lima	Allen	45805-3204	Ohio Department of Health
Map It	334 S Collett St	Lima	Allen	45805-3206	Ohio Department of Health
Map It	433 Franklin St	Lima	Allen	45804-1509	Ohio Department of Health
Map It	832 W Wayne St	Lima	Allen	45801-3933	Ohio Department of Health
Map It	15 Ferrell Ave	Ashland	Ashland	44805-4024	Ohio Department of Health

Harris County Lead Safe Housing Registry

Rental Occupied	Unit Address	City	Zip-Code	Lead Safe Date
Rental	3310 Carter	Pasadena	77503	August 2018
Rental	322 E. Wright	Baytown	77520	March 2018
Rental	3226 Nebraska	Baytown	77520	February 2018
Rental	13702 Longview	Houston	77015	February 2018
Rental	201 Bolster	Baytown	77520	January 2018
Rental	1705 Maryland	Baytown	77520	December 2017
Rental	300 W. Cleveland	Baytown	77520	December 2017
Rental	1705 Michigan	Baytown	77520	December 2017
Rental	500 E. Murrill	Baytown	77520	August 2017
Rental	323 FM1942	Crosby	77532	August 2017
Rental	10106 Chadwick	Jacinto City	77029	August 2017
Rental	201 W. Nazro	Baytown	77520	July 2017
Rental	409 W. Adué	Baytown	77520	May 2017
Rental	401 W. Adué	Baytown	77520	May 2017
Rental	1206 Azalea Ct.	Pasadena	77506	January 2017
Rental	2012 10 th	Galena Park	77547	January 2017

Non-legal challenges

to obtaining AND using EH data

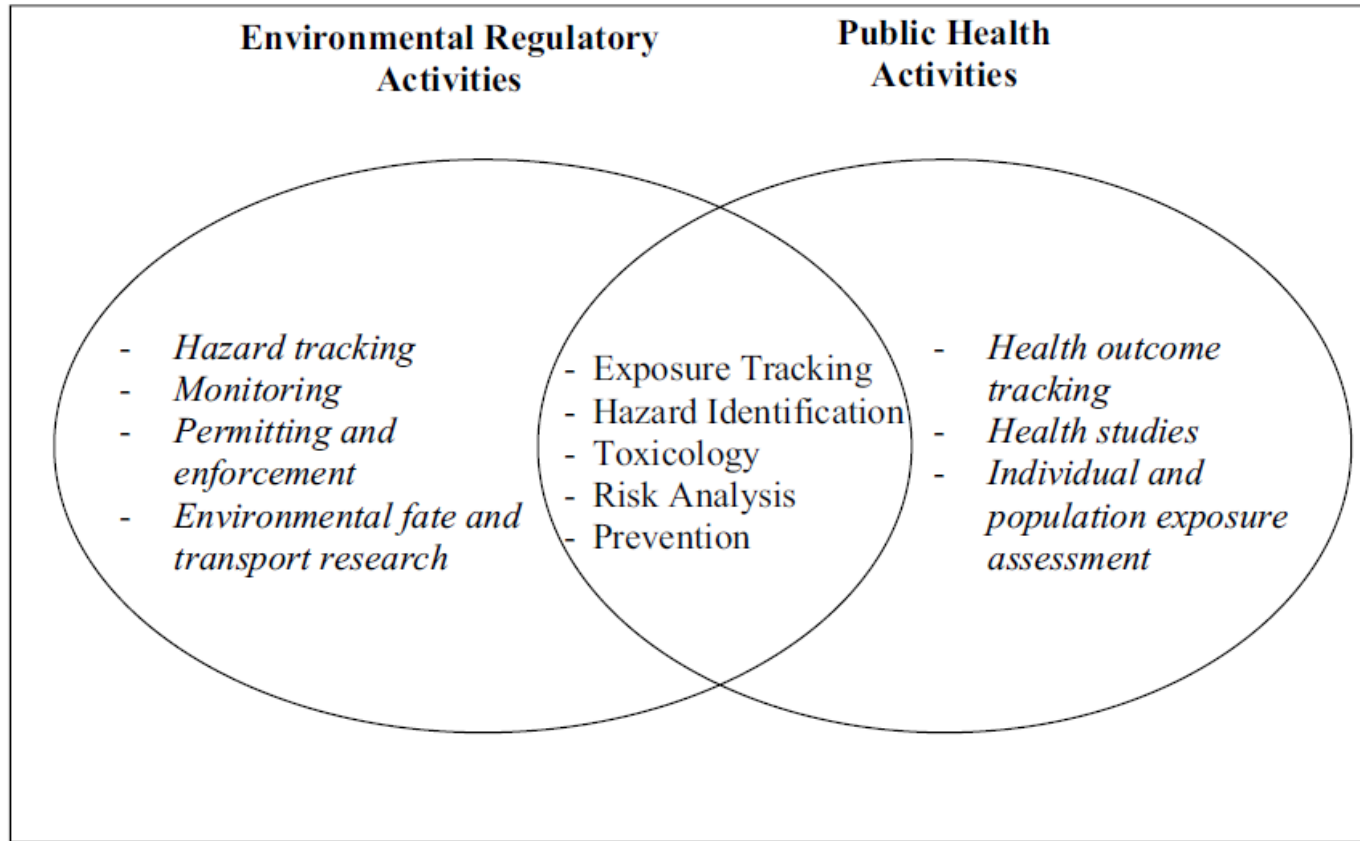
- » **Data is often too OLD to be useful**
- » **Data is often too GENERAL to be useful**
 - » May be available only at national or state level. Even when available at county level, may be still be too general; may need census tract, individual data to address threats.
- » **Lack of standardization across sources**
- » **DELAY between exposure and onset of symptoms**
 - » Logistical challenges with linking data
 - » Difficult to predict / calculate cumulative impact of prolonged, low-dose exposures

Policy challenges

to obtaining and using EH data

- » **Lack of capacity / funding to conduct routine surveillance relating to hazards & exposure**
 - » Activities may be limited to legally mandated regulatory/enforcement functions, rather than proactive monitoring
- » **Environmental health data is often not prioritized...** but how can we change that without data?
- » **Separation between environmental agencies and public health agencies → distinct purposes and cultures**

Core Environmental Health Activities



"The removal of environmental health authority from public health agencies has led to fragmented responsibility, lack of coordination, and inadequate attention to the public health dimensions of environmental issues (Institute of Medicine, 1988a)."

Ethical challenges

to obtaining, using, and disclosing data

- » **Disclosing hazard data without health outcomes may nevertheless reveal identities of affect persons**
- » **Potential for stigmatizing neighborhoods or communities**
- » **Will this action create/perpetuate inequities?**

Navigating Law to Share Data

Network for Public Health Law Resources

- Checklist of Factual Information Needed to Address Proposed Data Collection, Access and Sharing to Improve the Health of Communities
- Data De-Identification Toolkit
- Federal Privacy Laws – snapshots + annotated compilation
- HIPAA Hybrid Status Toolkit

https://www.networkforphl.org/resources/topics_resources/health_information_and_data_sharing/

Navigating Law to Share Data

Resources continued

Legal Bibliography



- *Data Across Sectors for Health*
- *Network for Public Health Law*

<http://legalbib.communitycommons.org/>

Thank you!

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