



## Ethical Issues in Public Health Data Use



**Rachel Hulkower, JD, MSPH**  
Public Health Analyst,  
Cherokee Nation Assurance  
CDC Public Health Law Program



**Cason Schmit, JD**  
Assistant Professor  
Texas A&M University  
School of Public Health

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**Northwest Center**  
FOR PUBLIC HEALTH PRACTICE

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### Question for the Viewers

Describe your level of familiarity with public health data sharing laws:

- A. Expert
- B. Intermediate
- C. Novice
- D. Beginner

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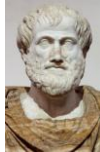
### About This Presentation




**PART I:**  
PH Data  
Sharing 101



**PART II:**  
Protections &  
Exceptions



**PART III:**  
Ethical  
Frameworks



**PART IV:**  
Data Sharing  
Ethics

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## DISCLAIMER

The contents of this presentation do not represent official CDC determinations or policies. The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of CDC. The contents are for educational purposes only and are not intended as a substitute for professional legal advice. Always seek the advice of an attorney or other qualified professional with any questions you may have regarding a legal matter.

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### Scenario: Disease Outbreak

Four new cases of hepatitis C virus (HCV) are diagnosed at a small, 100-bed hospital. It is quickly determined that all patients share a genetically similar strain of the virus, indicating a common source. The hospital noticed that the diagnoses occurred in close proximity to each other, the health care exposures were similar, and none of the patients had known or apparent HCV risk factors.

To prevent further HCV infections, the public health department came to the hospital and requested access to all patient electronic medical records to look for anyone suspected to be exposed, or a source. **The hospital denied access to any patient information in the EMRs without prior patient consent.**



**Consider:** In this scenario, is it legal for the provider to disclose the health information of these individuals?

- a. **Yes** - public health activities like this allow providers to disclose patient data.
- b. **No** - the patients have not given authorization.

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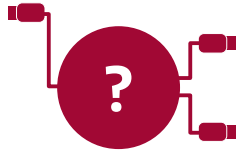
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### PH Data Sharing Guidance

How federal, state, and local public health data confidentiality laws apply to you depends on the following:

- **What** is in the data?
- **Who** has the data?
- **Who** wants the data?
- **Why** is the data being released?




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### Common Sources of Public Health Data



- **Immunization Information Systems**
- **Vital statistics**
- **Public health registries**
  - Treatment registries
  - Disease-specific registries
  - Registries used in preventive medicine

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### Examples: Disease Surveillance and Reporting

- **National Notifiable Diseases Surveillance System (NNDSS)**
  - Allows any PH entity to **voluntarily share** notifiable disease-related health information with the federal government
- **State and local laws**
  - Can **require** reporting of dangerous diseases to state or local health departments

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How Is PH Data Used?

- **Disease Investigations**
  - ❑ All state (and some local) health departments have authority to *investigate diseases and potential outbreaks*
  
- **Disease Control**
  - ❑ All state (and some local) health departments have authority to *implement disease control measures*
  
- **Other Uses**
  - ❑ Many state health departments have laws to use and release data for activities like: *treatment and coordination of care, partner notification or contact tracing, and public health research*

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Health Insurance Portability and Accountability Act (HIPAA)

HIPAA Privacy Protections:  
The General Rule

A **covered entity** can only use or disclose **protected health information** for **limited purposes** unless the individual authorizes the use or disclosure

45 C.F.R. § 164.502 et seq.




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Covered Entities: To whom does HIPAA apply?	
<b>Covered Entities</b>	<ul style="list-style-type: none"> <li>Healthcare providers "who transmit any health information in electronic form in connection with a transaction"</li> <li>Health plans</li> <li>Healthcare clearinghouses</li> </ul>
<b>Business Associates</b>	Provide services on behalf of covered entities requiring the disclosure of protected health information
<b>Hybrid Entities</b>	Activities include "covered" and "non-covered" functions

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**Protected Health Information: What does HIPAA protect?**


**Protected health information**

- Individually identifiable health information that is transmitted or maintained by covered entity

**Individually identifiable health information**

- Created or received by a covered entity and
- Relates to the health of an individual
  - Identifies the individual; or
  - Reasonable to believe information can be used to identify the individual

45 C.F.R. § 160.103



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Exceptions: When Do Covered Entities Disclose Data?	
<b>Must Disclose</b>	<b>May Disclose</b>
<ul style="list-style-type: none"> <li>Individuals requesting access to their protected health information</li> <li>US Department of Health and Human Services undertaking compliance investigation, review, or enforcement action</li> </ul>	<ul style="list-style-type: none"> <li><b>Public health activities*</b></li> <li>Law enforcement</li> <li>Serious threats to health or safety</li> <li>National security</li> <li>Disaster response</li> </ul>

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### HIPAA Permitted Use Exception: Public Health Activities



A **covered entity** may use or disclose **public health information** to a public health authority:

*"for the purpose of preventing or controlling disease, injury, or disability, including, but not limited to, the reporting of disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions"*

45 C.F.R. § 164.512(b)

Image courtesy CDC

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### State Laws: PH Data Sharing Protections

States generally have broad legal protections for individuals' information, including:

- Vital statistics laws** { **Example:** Vital records information may only be released to "public agencies administering health, welfare, safety, law enforcement, or public assistance programs" "when deemed in the public interest" 410 ILCS 535/2-3
- Public access laws** { **Example:** "Disclosure of a government record shall not constitute a clearly unwarranted invasion of personal privacy if the public interest in disclosure outweighs the privacy interests of the individual." HRS §92F-14
- Health information privacy laws** { **Example:** A healthcare provider may not disclose individuals' health information "to any other person without the patient's written authorization." MT ST 50-16-529, 530

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### State Laws: PH Information Privacy Laws



State privacy laws can dictate the following:

- **What** exact information can be shared with public health authorities
- **What** information is subject to or exempt from public records requests
- **When** information can be shared with other government entities
- **Which** government employees or agents may access information

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### Scenario: Disease Outbreak - Conclusions

This scenario demonstrates that we have laws which can protect the public's health and well-being. However...

- ✓ Private health information has broad legal protection
- ✓ When private health information is shared for public health reasons, context matters
- ✓ **Individual privacy and public health activities** are legal distinctions, *not necessarily* ethical ones

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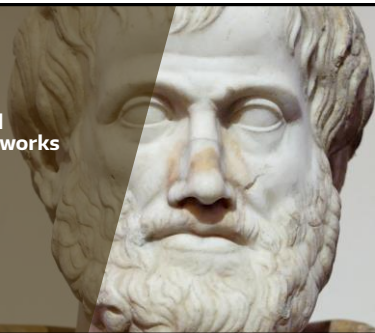
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### Part III: Ethical Frameworks



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### Guidance on Public Health Ethics

- How are ethics used to identify and resolve dilemmas about *what should be done*?
- How does *Bioethics* contrast with *Public Health Ethics*?
- Which ethical framework is more appropriate for public health and big data?

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### Ethics Example: The Moral Machine

MIT's **scenario-based approach** for applying human ethics to machine intelligence decision-making, including self-driving cars



moralmachine.mit.edu

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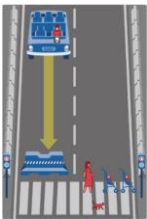
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### Who Should Die? Scenario 1



Driver

In Scenario 1,  
who should die?

- A. The driver
- B. The pedestrians



Pedestrians

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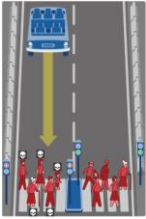
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Who Should Die? Scenario 2

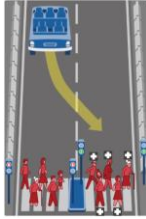


Group A

In Scenario 2, who should die?

A. Group A

B. Group B



Group B

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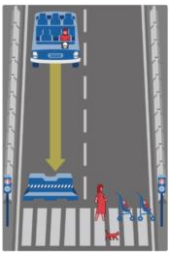
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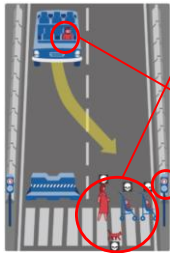
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How Did You Decide?



OR



- Utilitarianism
- Duty-based ethics
- Virtue-based ethics

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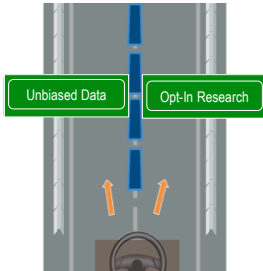
Data Examples

Unbiased data

- Prioritize the use of bias-free data

Opt-in model

- Give individuals choice to opt-in to secondary data research, but risk introduction of bias



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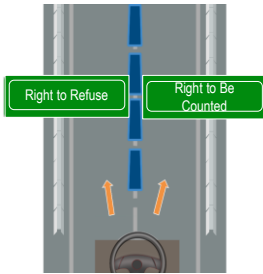
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### More Data Examples

- **Right to Refuse to Participate**
  - ❑ Right to be excluded from research/surveillance
- **Right to Be Counted**
  - ❑ Right to have your circumstances counted or assessed



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### Love Canal, NY – Right to be Counted

#### The Love Canal Disaster: 1893 – 1998

- **1950s:** Neighborhood and schools built on toxic dump
- **1970s:** Environmental contamination evidence
  - ❑ Governmental inaction frustrated community
  - ❑ Community mobilized, demanding a study of the health impact
  - ❑ Subsequent study compelled government action
- **1998:** Lawsuit settled; former residents compensated



Photo Source: EPA Flickr Page  
<https://www.flickr.com/photos/epa/5621420888/>

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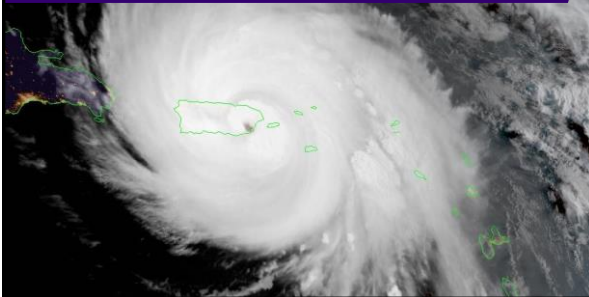
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### Hurricane Maria



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**What Isn't Counted Doesn't Count**

**The Right to be Counted – Key Takeaways:**

- Knowledge of harm is centrally important for asserting individual and human rights
- “Right to be counted” issues are relevant to “respect for persons”

**Do potential conflicts with consent models raise anticommons concerns?**

- Knowledge from community data is a resource
- Exercise of individual rights relating to data collection and use can frustrate efforts to use that knowledge for social good

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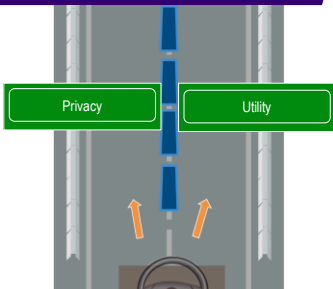
**More Data Examples**

**Stringent non-disclosure**

- Suppress data elements from secondary data use

**Data utility**

- Use more data elements to learn more from data




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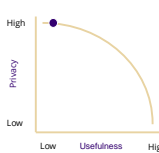
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**More Ethical Concerns: Privacy v. Utility**


**High Privacy**  
Low Usefulness



**Medium-High Privacy**  
Medium Usefulness



**Medium-Low Privacy**  
**High Usefulness**



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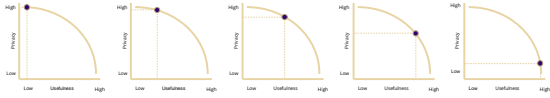
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More Ethical Concerns: Privacy v. Utility

Where would you strike the balance?



- A:** Very High Privacy, Low Usefulness
- B:** High Privacy, Med-Low Usefulness
- C:** Med-High Privacy, Medium Usefulness
- D:** Medium Privacy, Med-High Usefulness
- E:** Low Privacy, High Usefulness

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Part IV: Data Sharing Ethics




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The History and Context of Bioethics is Important



Nazi Germany Human experimentation early - mid 1940s



The United States Public Health Service Tuskegee Study 1932 - 1972

Photo Sources: National Archives <https://www.archives.gov/>

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**Bioethics (Belmont Report, Common Rule)**

**Respect for Persons**

- Treat individuals as autonomous agents
- Persons with diminished autonomy are entitled to protection

**Beneficence**

- Do not harm
- Maximize benefits and minimize harms

**Justice**

- Who ought to receive the benefits of research and bear its burdens?

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**Bioethics is an Awkward Fit for Public Health**

**CIOMS International Guidelines for Ethical Review of Epidemiological Studies (1991)**

- Acknowledges the insufficiency of the bioethical model for public health



Source: Council for International Organizations of Medical Sciences  
<https://cioms.ch/wp-content/uploads/2012/01/CIOMS-ETHICAL-GUIDELINES.pdf>

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**WHO Guidelines: Overview**

✓ **Common Good**

- Some benefits are fundamentally shared

✓ **Equity**

- Equitable conditions for humans to flourish
- Unfair risk distribution may require balancing resources

✓ **Respect for Persons**

- When possible, involve individuals in decisions affecting them
- Engage individuals in when considering population interventions

✓ **Good Governance**

- Accountability, transparency and community engagement

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WHO Guidelines: Ethical Data Uses for Public Health

- Obligation to conduct public health surveillance (*Guideline 1*)
- Justification for collecting identifiable data (*Guideline 11*)
- Informed consent is not always ethically required (*Guideline 12*)
- Obligation to share data with public health (*Guideline 14*)
- Appropriate to use data for research purposes (*Guideline 16*)
- Inappropriate to share identifiable data with agencies likely to take action against individuals (*Guideline 17*)

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Which Framework Should Apply?

Is the activity research or a public health activity?

- Historically, this has been a challenging distinction (partially addressed in recent Common Rule revisions)

What about big data analytics?

- Ongoing, systematic, data collection, and analysis of large number of individuals




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Big Data Ethics Theorem

- $n$  = Sample (of  $N$  pop) size
- $N$  = Population size
- $BD_e(x)$  = Big data ethics applied to 'x' situation
- $PH_e(x)$  = Public Health Ethics applied to 'x' situation
- $\lim_{n \rightarrow N} BD_e(x, n) = ?$
- $\lim_{n \rightarrow N} BD_e(x, n) = PH_e(x)$




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Yeah, but...

Remember the following  
*big caveat:*



What is ethical is not always legal;  
What is legal is not always ethical

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Action Items

- ✓ Data sharing practices are informed by the law **and** ethics. Understand the distinction!
- ✓ Consider which ethical frameworks guide your decision-making as a practitioner
- ✓ Use *public health ethics* for population-level data projects
- ✓ Refer to the **WHO Guidelines** (seriously...they are awesome...)

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QUESTIONS?



To ask a question, please click the  icon in the Zoom toolbar to open your Q&A Pod.

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Resources

**US Department of Health and Human Services Office for Civil Rights**

HIPAA and Public Health Fact Sheet:

[https://www.healthit.gov/sites/default/files/12072016\\_hipaa\\_and\\_public\\_health\\_fact\\_sheet.pdf](https://www.healthit.gov/sites/default/files/12072016_hipaa_and_public_health_fact_sheet.pdf)

**World Health Organization**

Guidelines on Ethical Issues in Public Health:

<https://www.who.int/ethics/publications/public-health-surveillance/en/>

**Massachusetts Institute for Technology**

The Moral Machine:

<https://moralmachine.mit.edu/>

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