

Information Sharing 101:

Protecting Public Health Data

NGA Solutions: Center for Best Practices
Homeland Security and Public Safety
In collaboration with the
Centers for Disease Control and Prevention
and the American Bar Association

December 12, 2019



Agenda and Speakers



Welcome

Moderator:

Gregory Sunshine, JD, Centers for Disease Control and Prevention



Expert Panel

Cason Schmit, JD, Department of Health Policy and Management at the Texas A&M School of Public Health



Rachel Hulkower, JD, MSPH, Public Health Analyst through Cherokee Nation Assurance with the Centers for Disease Control and Prevention's Public Health Law Program



Q&A

Today's Moderator Greg Sunshine, JD

Public Health Analyst
Public Health Law Program
Center for State, Tribal, Local, and
Territorial Support
Centers for Disease Control and
Prevention



Cason Schmit, JD

Department of Health Policy and
Management at the Texas A&M
School of Public Health



Rachel Hulkower, JD, MSPH

Public Health Analyst through
Cherokee Nation Assurance with
the Centers for Disease Control
and Prevention's Public Health Law
Program



HIPAA Basics for Emergency Situations

Cason Schmit, JD

Assistant Professor

Program in Health Law and Policy, Director

Department Health Policy & Management

Texas A&M University School of Public Health



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Health Insurance Portability and Accountability Act of 1996 (HIPAA)

- HIPAA Basics
 - Covered entities
 - Protected health information
 - General rule
 - Exceptions
- Key Take Away: HIPAA is friendly to public health activities
- Guidance for Emergencies:
 - **BULLETIN: HIPAA Privacy in Emergency Situations (Nov. 2014)**

<https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/special/emergency/hipaa-privacy-emergency-situations.pdf>

HIPAA Basics: Covered Entities

- HIPAA applies only to **Covered Entities and Business Associates**
 - **Covered Entities**
 - Health care providers
 - Health plans
 - Health care clearinghouses
 - **Business Associates**
 - “Perform functions or activities on behalf of, or provide certain services to, a covered entity” relating to protected health information
 - Ex: health information organization, E-prescribing Gateway

HIPAA Basics: Protected Health Information

- The HIPAA rules apply only to **Protected Health Information**
 - Individually identifiable health information
 - Created or received by a covered entity
- HIPAA permits covered entities to **de-identify** protected health information
 - De-Identified information is not subject to HIPAA

HIPAA Basics: General Rule

- A covered entity or business associate **may not use or disclose protected health information**, except as permitted...
- Permitted uses and disclosures.
 - A covered entity is permitted to use or disclose protected health information as follows:
 - (i) To the individual;
 - (ii) For treatment, payment, or health care operations...
 - (iv) ... pursuant to ... a valid authorization...

HIPAA Basics: Exceptions

- Do not need an authorization for the following uses/disclosures
 - Public health activities
 - To **public health authority** authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury or disability
 - At the direction of a public health authority, to **a foreign government agency** that is acting in collaboration with the public health authority.
 - To **persons at risk**

HIPAA Basics: Exceptions

- Do not need an authorization for **Disclosures to Family, Friends, and Others Involved in an Individual's Care and for Notification**
 - Examples:
 - Persons involved with patient's care
 - Disclosure necessary to identify, locate, and notify family
 - Disclosure to disaster relief organizations (American Red Cross) for the purpose of coordinating the notification of family or other persons involved in the patient's care, of the patient's location, general condition, or death

HIPAA Basics: Exceptions

- Do not need an authorization for uses/disclosures:
 - Imminent Danger
 - As necessary to prevent or lessen a serious and imminent threat to the health and safety of a person or the public
 - Required by law
 - Others...
 - **Key Take Away: HIPAA is friendly to public health activities**

STATE LAW DATA SHARING CONSIDERATIONS IN PUBLIC HEALTH INVESTIGATIONS

Rachel Hulkower, JD, MSPH

Public Health Analyst, Cherokee Nation Assurance

Public Health Law Program, CSTLTS

December 12, 2019

Disclaimer

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Public Health Investigations



Public Health Investigations

1.

- Disease surveillance and reporting

2.

- Disease investigation

3.

- Privacy protections, exceptions, and waivers

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Disease Surveillance and Disease Reporting

- National Notifiable Diseases Surveillance System
 - Enables all levels of public health to **voluntarily** share notifiable disease-related health information with the federal government
- States and localities can **require** reporting of dangerous diseases to the state or local health department
 - Accomplished through statutes, regulations, or both



www.cdc.gov/nndss

Examples: State Disease Reporting Requirements

Specific Diseases

- Ebola
- Tuberculosis
- Zika
- West Nile

Classes of Diseases

- Viral hemorrhagic fevers
- Arboviruses
- Severe acute respiratory syndromes

Dangerous Disease Catchalls

- “Any dangerous contagious or infectious disease”
- “Any cluster of illnesses”
- “Any unexpected pattern of cases, suspected cases, deaths, or increased incidence of any other disease of major public health concern, because of the severity of disease or potential for epidemic spread, which may indicate a newly recognized infectious agent, outbreak, epidemic, related public health hazard or act of bioterrorism”

Public Health Investigations

1.

- Disease surveillance and reporting

2.

- Disease investigation

3.

- Privacy protections, exceptions, and waivers

Disease Investigation

- Information is needed to prevent or control disease, injury, or disability
 - Examples
 - Reporting of a disease or injury
 - Reporting births or deaths
 - Conducting contact tracing
- Public health authorities may be legally authorized to receive such public health information from a variety of sources



Public Health Investigations

1.

- Disease surveillance and reporting

2.

- Disease investigation

3.

- Privacy protections, exceptions, and waivers

Privacy Protections and Exceptions

- When discussing limitations on disease investigation authority, three concepts are vital:
 1. Privacy protections
 2. Exceptions to privacy protections
 3. Waivers of privacy rights



Broad Protections for Individuals' Information

- 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

Exceptions to Privacy Protections

- Reporting tied to federal funding
- State mandates to report
 - Disease Reporting
- State laws authorizing public health to access information
 - Contact Tracing
 - Public Health Surveillance

Public Health Information Privacy Laws

- State privacy laws can dictate—
 - What exact information can be shared with public health authorities
 - When information can be shared with other government entities
 - Which government employees (or agents of the government) are allowed to access information
 - What information is subject to or exempt from public records requests

Examples of Public Health Information Privacy Laws

- State privacy laws can dictate the confidentiality of data reported for public health purposes

- Example from Maryland:

“(1) Any information that the Secretary receives [through the **disease surveillance system**] is **confidential** and may be used or disclosed only in accordance with this section.

(2) If the information requested . . . is **otherwise confidential** [under law] . . .the Secretary or person that receives the information **may not redisclose** the information **except**[:]

(3) A person may redisclose the information **to another health care provider or public official** provided that:

- (i) The health care provider or public agency to whom the information is disclosed will **maintain the confidentiality** of the disclosure; **and**

- (ii) The **Secretary** determines the disclosure is **necessary** to treat, prevent, or reduce the spread of the disease or outbreak believed to have been caused by the exposure to a deadly agent.”

Examples of Public Health Information Privacy Laws

- State privacy laws can dictate the confidentiality of data reported for public health purposes

- Example from Pennsylvania:

“Case reports submitted to the [state or local health department] are **confidential**. Neither the **reports**, nor any **information contained in them which identifies** or is perceived by the [state or local health department] as capable of being used to identify **a person named in a report**, will be disclosed to any person who is **not** an **authorized employee** or **agent** of the [state or local health department], and who has a **legitimate purpose** to access case information, **except** for any of the following reasons:

- (1) When disclosure is **necessary** to carry out a purpose of the act, as determined by the [state or local health department], and disclosure would **not violate another act or regulation**.
- (2) When disclosure is made for a **research purpose** for which access to the information has been granted by the [state or local health department].”

Examples of Public Health Information Privacy Laws

- State privacy laws can dictate the confidentiality of data reported for public health purposes
 - Example from Utah:

“Any individual or entity entitled to receive confidential information from the Department of Health or a local health department under this chapter, other than the individual identified in that information, who **violates** this chapter **by releasing or making public confidential information**, or by **otherwise breaching the confidentiality requirements** of this chapter, is **guilty of a class B misdemeanor.**”

Exceptions to Privacy Protections

- Privacy interests receive extensive protections
- However, there are instances where sharing personal information is essential to **protecting the public's health and well-being**
- Specific carve-outs provide **exceptions** to privacy protections for certain activities such as—
 - Public health
 - Disaster response
 - Law enforcement

Privacy Notices when Conducting Public Health Investigations

States might have requirements to provide privacy notices for informed consent. Privacy notices—

- Are given to individuals when they are asked to provide private or confidential information
- Enable people to make **informed decisions** about whether to give information about themselves to the government
- Convey to individuals when information must be provided

Minnesota's Tennessen Warning

- When a government entity collects data about an individual, notice, known as a “Tennessen Warning,” must first be provided
- Notice must include—
 - The reason for collecting the data
 - How data will be used
 - Whether the person is legally required to provide the data
 - Consequences if the person provides the data
 - Consequences if the person does not provide the data
 - The identities of people and entities that have access to the data by law

Rachel Hulkower
rhulkower@cdc.gov
404-718-6547

For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 www.cdc.gov

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Ethical Considerations in Data Sharing

Cason Schmit, JD

Assistant Professor

Program in Health Law and Policy, Director

Department Health Policy & Management

Texas A&M University School of Public Health



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Session Objectives

- Explore how ethics are used to identify and resolve dilemmas about *what should be done*
- Compare and contrast *Bioethics* with *Public Health Ethics*
- Explore the new WHO Ethical Guidelines for Surveillance



Moral Machine - Human Perspectives on Machine...



Watch later



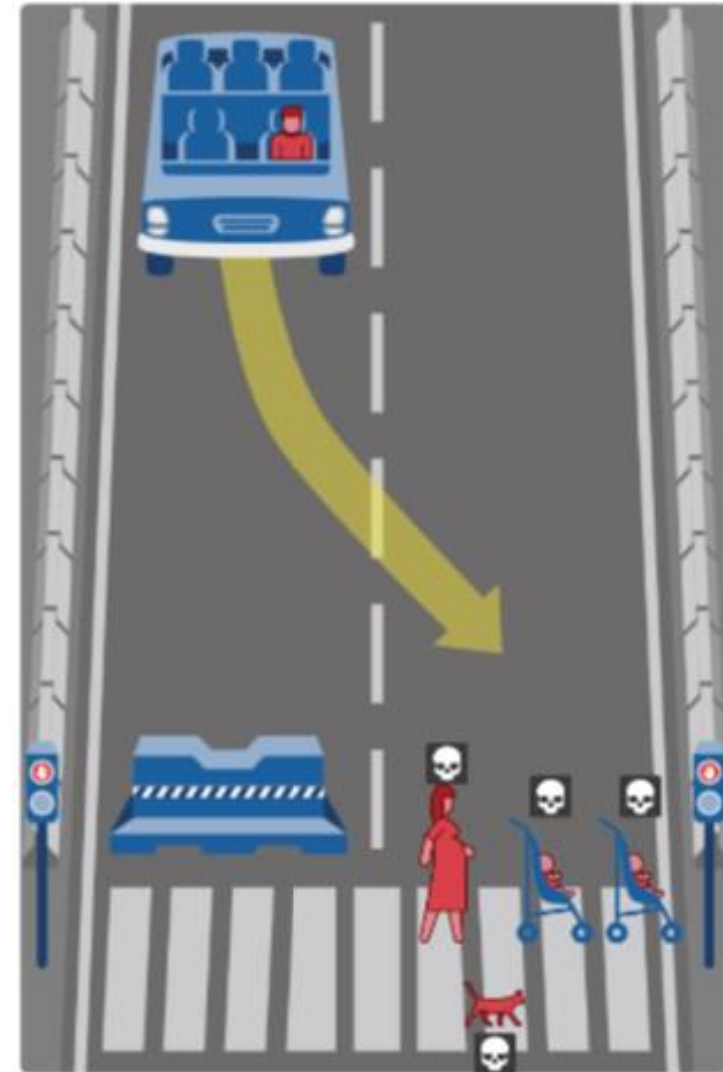
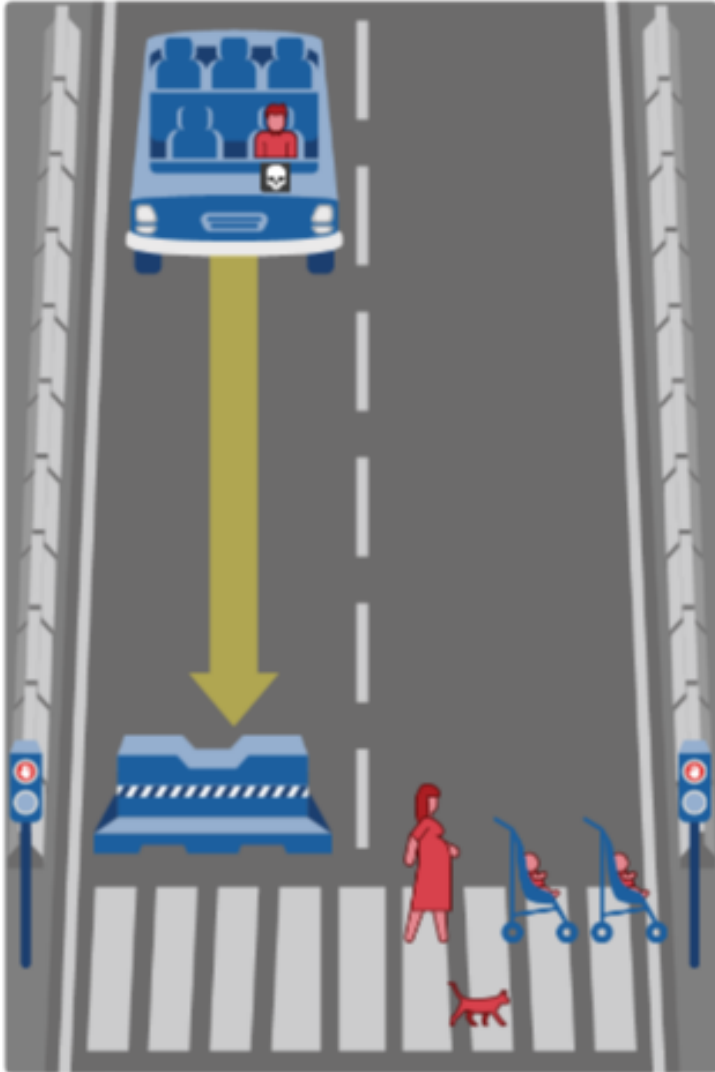
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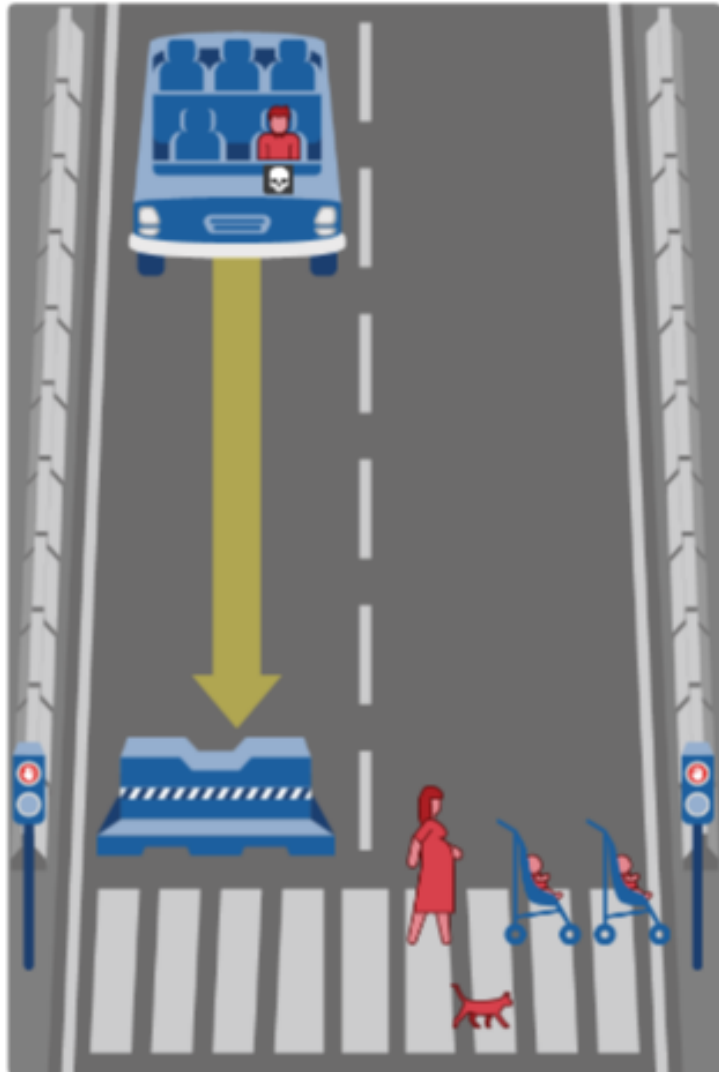
Welcome to the Moral Machine! A platform for gathering a human perspective on moral decisions made by machine intelligence, such as self-driving cars.

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

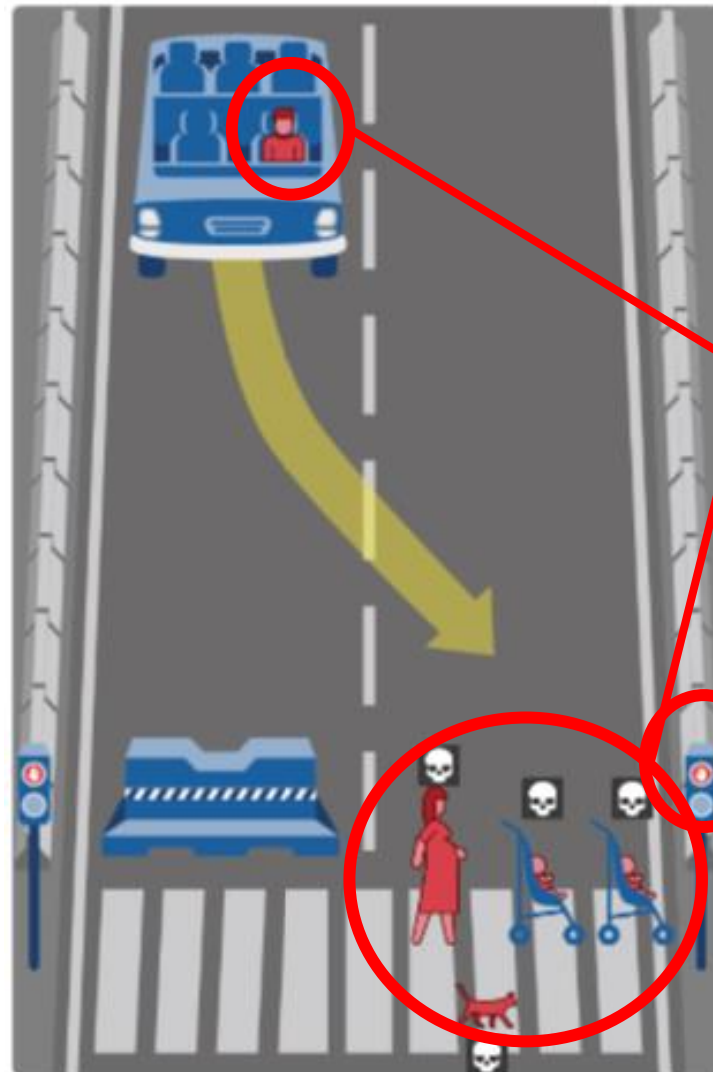
What should an autonomous vehicle do?



How Did You Decide?



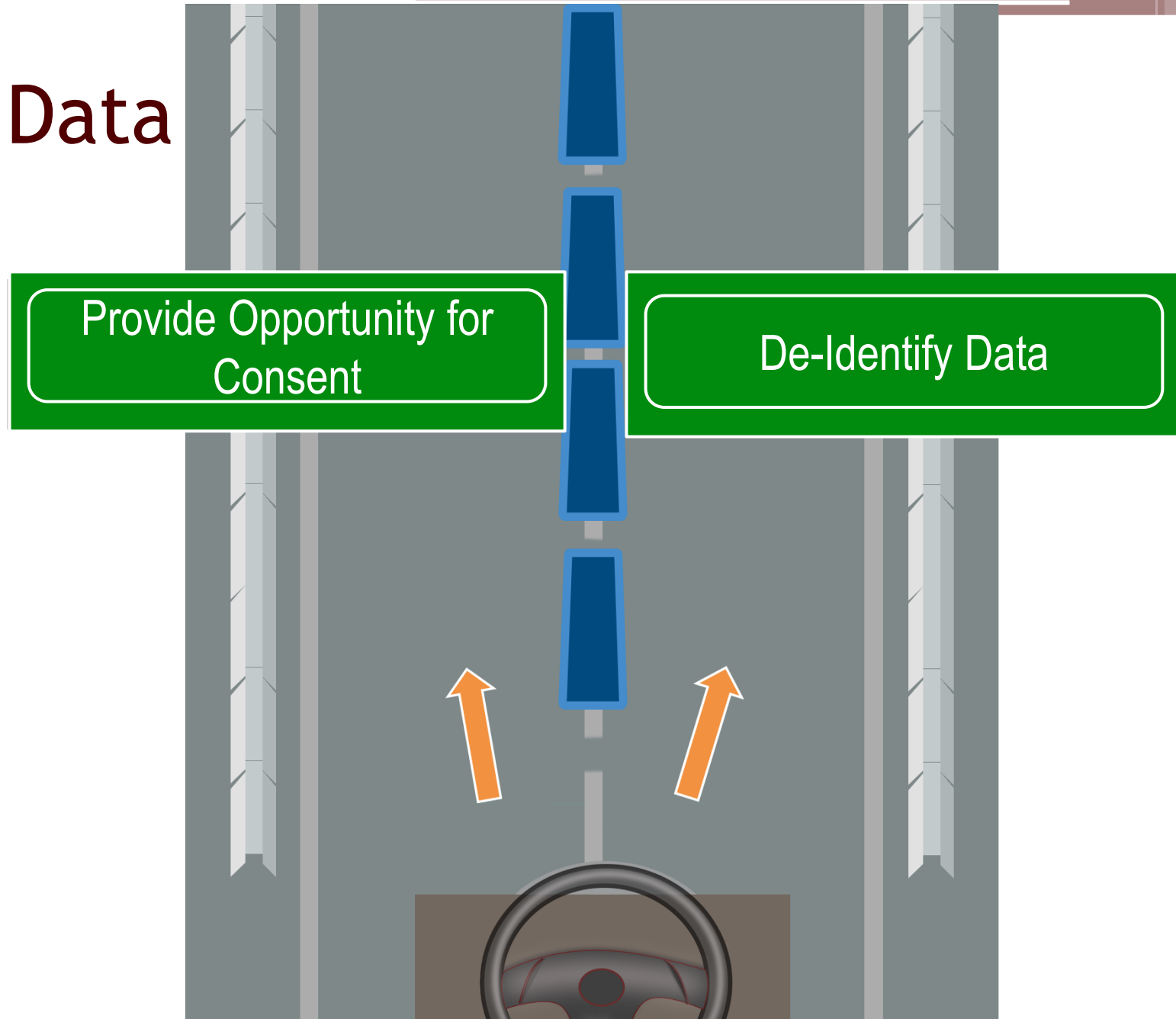
OR



- Utilitarianism
- Duty-based ethics
- Virtue Based Ethics

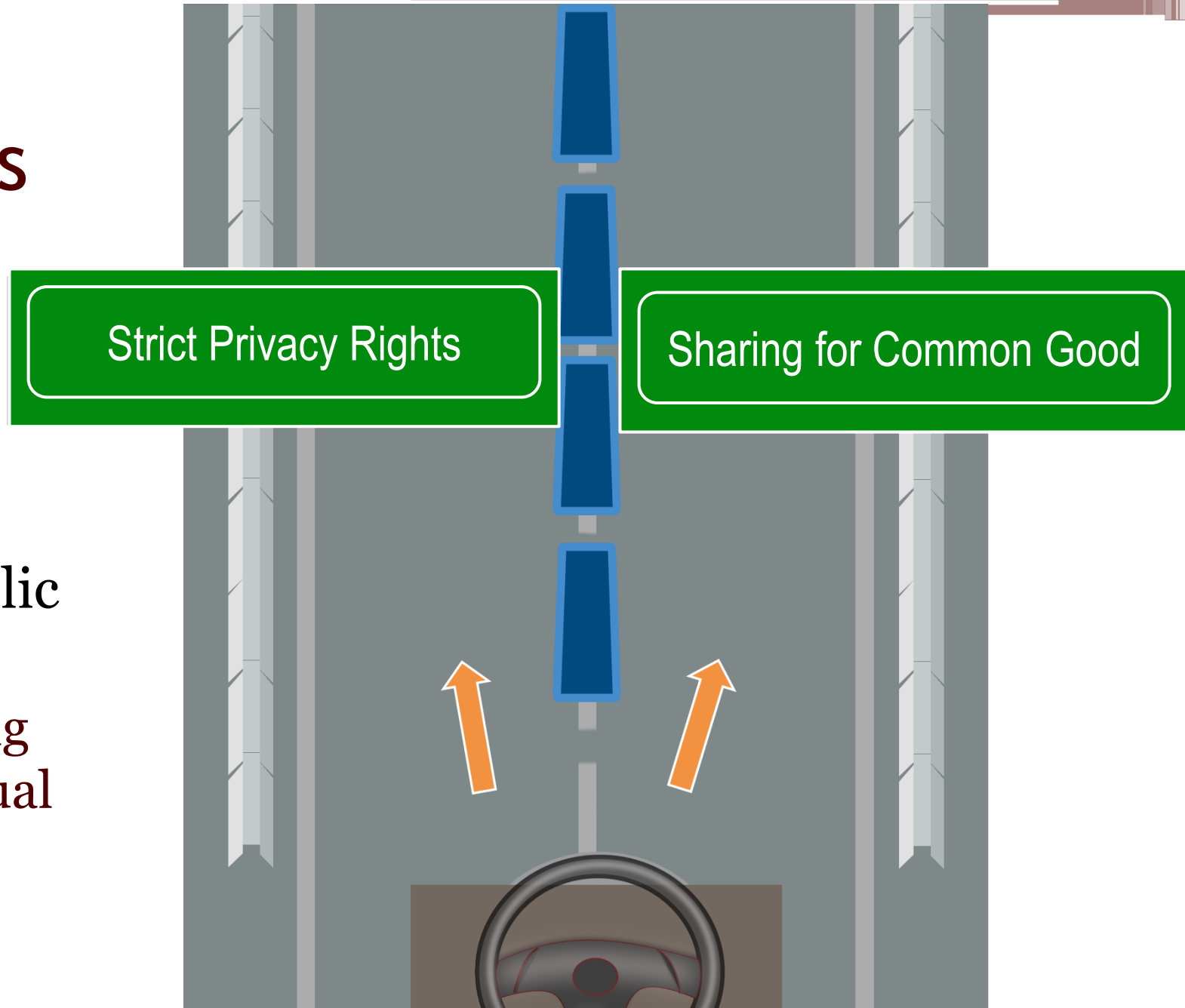
Let's Look at Some Data Examples

- Opportunity to Consent to Future Research
 - Seek informed consent if data will be reused for future research
- De-identification
 - Protect data subjects by removing identifiers from data



More Data Examples

- Strict Privacy Rights
 - Restrict data use without an individual's consent
- Limited data use for public benefit
 - Permit some data sharing where risk to an individual is low and the benefit to the community is high



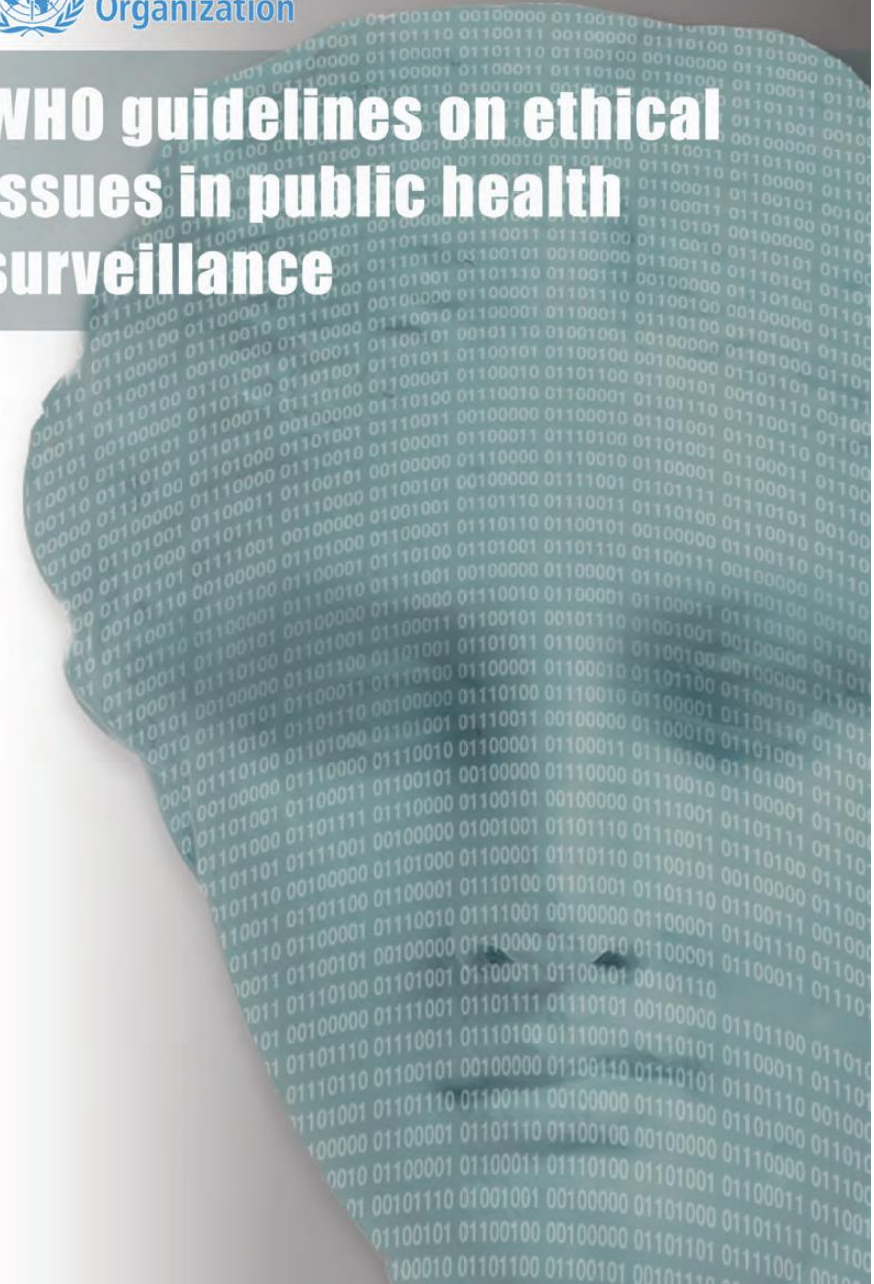


**WHO guidelines on ethical
issues in public health
surveillance**

Data Use Ethical Frameworks

Bioethics

Public Health Ethics



Bioethics

History and Context are Important!



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?

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





WHO guidelines on ethical issues in public health surveillance

Public Health Ethics

World Health Organization
Guidelines on Ethical Issues in
Public Health Surveillance

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

WHO Guidelines

- **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

Ethical Data Use for Public Health

- Guideline 1. **Countries have an obligation to develop appropriate, feasible, sustainable public health surveillance systems.** Surveillance systems should have a clear purpose and a plan for data collection, analysis, use and dissemination based on relevant public health priorities.

WHO guidelines on ethical issues in public health surveillance

Obligation to conduct public health surveillance

Ethical Data Use for Public Health

- Guideline 11. Under certain circumstances, **the collection of names or identifiable data is justified.**

Justification for collecting identifiable data

- Guideline 12. Individuals have an obligation to contribute to surveillance when reliable, valid, complete data sets are required and relevant protection is in place. **Under these circumstances, informed consent is not ethically required.**

Informed consent is not always ethically required

WHO guidelines on ethical
issues in public health
surveillance

Ethical Data Use for Public Health

- Guideline 14. With appropriate safeguards and justification, **those responsible for public health surveillance have an obligation to share data** with other national and international public health agencies.

Obligation to share data with public health

- Guideline 15. Guideline 15. During a **public health emergency**, it is imperative that all parties
- involved in surveillance **share data in a timely fashion.**

Timely sharing in emergencies

WHO guidelines on ethical issues in public health surveillance

Big Ideas

- Ethical frameworks guide decision-making
- The WHO Guidelines are extremely helpful when dealing with difficult data use issues

WHO guidelines on ethical issues in public health surveillance



Questions?

schmit@tamu.edu



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Questions?

