The Ethics of Surveillance in Public Health

Presentation for the Public Health Infrastructure Steering Committee

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Declaration of real or potential conflicts of interest

Presenters:
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I have no real or potential conflict of interest related to the material that is being presented today.

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Our mandate

- – Support public health actors in their efforts to promote healthy public policies

Our areas of expertise

- – The effects of public policies on health
- – Generating and using knowledge about policies
- – Intersectoral actors and mechanisms
- – Strategies to influence policy making

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Overview

- What is public health (PH) surveillance?
- What is PH ethics?
- PH ethics: frameworks
- PH ethics and surveillance: what ethical issues arise when we apply ethical thinking to PH surveillance policies / programs / systems

(Time is limited but we will be available for discussion during the break: 2:40-3:00)

What is PH surveillance? (1 - why)

Surveillance is:

1. "The bedrock of outbreak and epidemic response";

2. A central factor for "understanding the increasing global burden of noncommunicable diseases";

3. "The foundation for initiatives to promote human well-being at the population level";

4. A contribution to the reduction of unjust health inequalities;

5. A key element to inform the development of healthy public policies.

(1-4: WHO, 2017, p. 10)

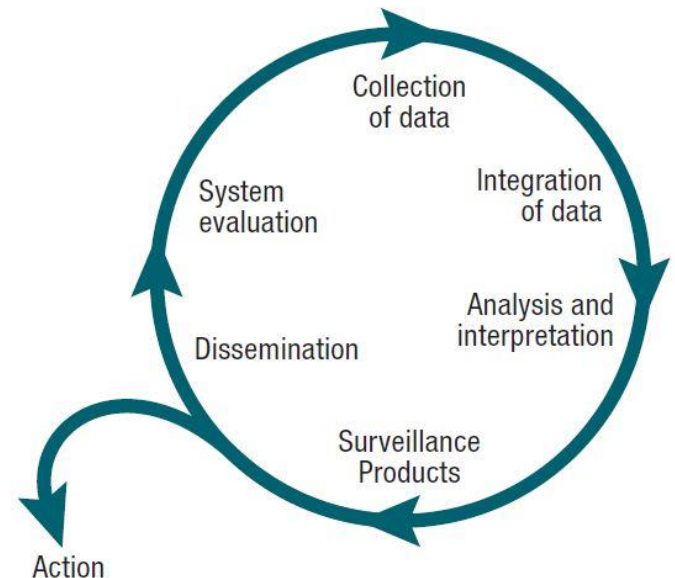# What is PH surveillance? (2 - what)

> Surveillance is the…
>
> "Systematic ongoing collection, collation and analysis of data for public health purposes and the timely dissemination of public health information for assessment and public health response as necessary "
>
> IHR – International Health Regulations (2005) in (WHO, 2016, p. 10)

"An effective surveillance system includes…
- Detection and notification of health events,
- Collection and consolidation of pertinent data,
- Investigation and confirmation of individual cases or injuries and outbreaks,
- Routine analysis and creation of reports,
- Feedback of information to those providing the data,
- Feed-forward (i.e., the forwarding of data to more central levels)"

Pan-Canadian Public Health Network, 2016, p. 6.
(Surveillance cycle graphic used with permission).

The surveillance cycle

What is PH surveillance? (3-how)

In practice: "phases in the surveillance life-cycle"

- **Background conditions (pre-phase)**
  - Preconditions favouring (or not) successful PH surveillance, including preexisting guidance and models

- **System design and implementation phase**
  - Priority setting, resources, and design +/- enhancing effectiveness

- **Data collection, analysis and storage phase**
  - Data accuracy and comprehensiveness, protocols and infrastructure for analysis and storage

- **Data reporting, sharing and use for PH action phase**
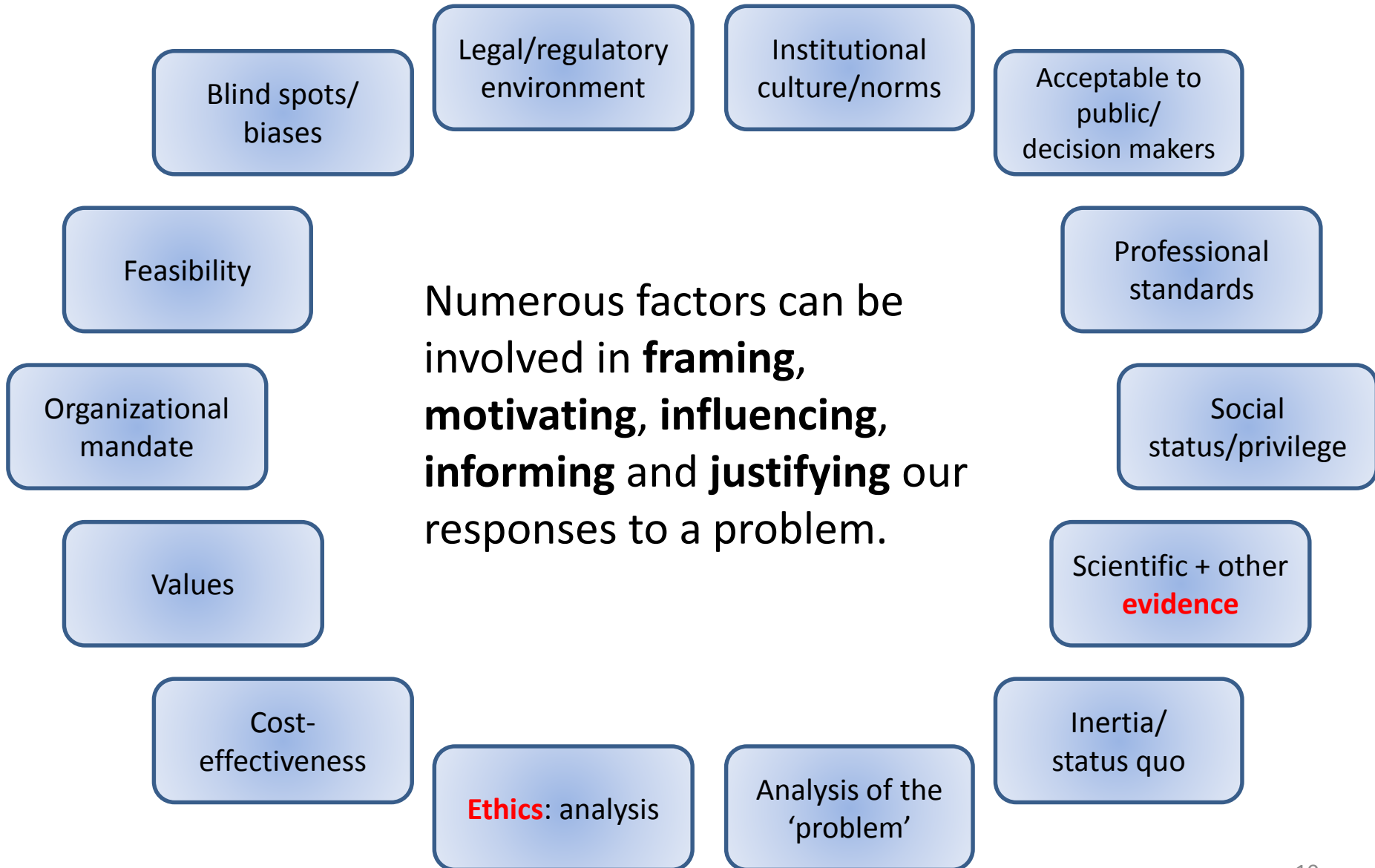 - Protocols for sharing, with whom, to what purpose and under what conditions

Based on Klingler, Silva, Schuermann, Reis, Saxena, and Strech, 2017, pp. 4-5.

Problematization and response

- What are the objects (health-related events) of surveillance? What is left out?

- What populations are the focus, or not?

- How is it set up, resourced and run?

- How are the protocols, mechanics and routines developed, implemented, evaluated?

These choices involve values.
Responses can be informed by ethical analysis.

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Ethics is one important dimension of informed decision-making

Blind spots/ biases

Legal/regulatory environment

Institutional culture/norms

Acceptable to public/ decision makers

Feasibility

Numerous factors can be involved in **framing**, **motivating**, **influencing**, **informing** and **justifying** our responses to a problem.

Professional standards

Organizational mandate

Social status/privilege

Values

Scientific + other **evidence**

Cost-effectiveness

Ethics: analysis

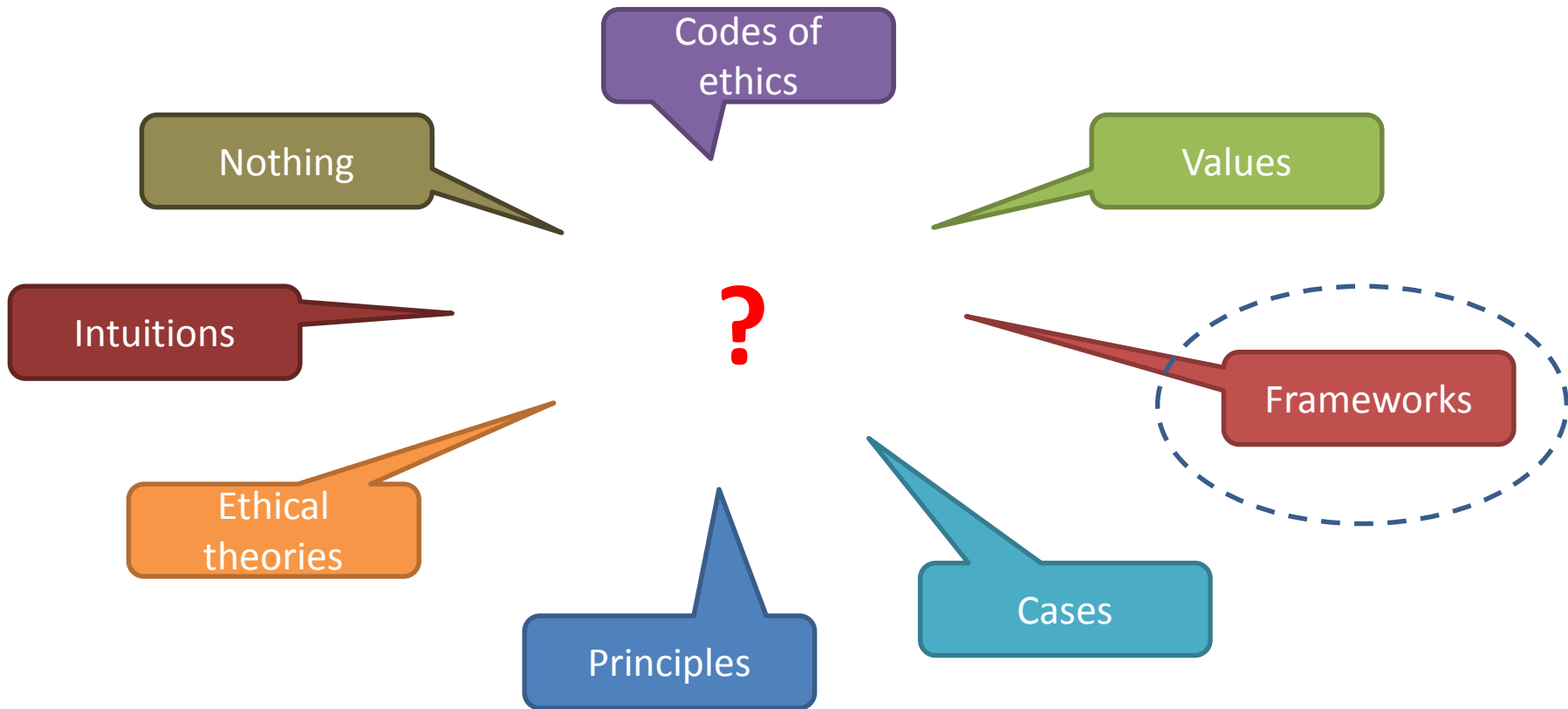Analysis of the 'problem'

Inertia/ status quo

These are just a few among many. All of these are important and call for critical attention.

What is PH ethics?

PH ethics is mostly about what should and shouldn't be done, collectively, to protect and promote the health of communities.

- It is normative, not descriptive
- It focuses on a collective (public) effort
- It focuses on populations, not individuals

What can we use to help us think about ethical issues in public health?

Codes of ethics

Nothing

Values

Intuitions

?

Frameworks

Ethical theories

Principles

Cases

What is an ethics framework?

A framework is a guide that can help to highlight ethical values and issues, and serve as an aid to deliberation and decision making.

What can it offer?

It provides an entry point and a structure for deliberation.

It can guide specialists in ethics as well as novices.

It provides a common language for addressing issues and values.

It provides a lens for looking at, and thereby seeing, ethical issues.

It helps to 'frame' issues.

What can it *not* offer?

It won't do the work or the thinking for you.

It won't replace your own critical perspective (and a note of caution … a framework can produce complacency).

It won't eliminate your cognitive and other biases, though if you deliberate in more diverse groups and use a framework, this might help to reduce their effects.

Inspired by: Dawson, 2010, p. 193, 200.

Using one will involve finding a balance and making trade-offs between perspicacity and usability (perfection-seeking vs over-simplification).

Ethical issues

Frameworks generally operate through directly appealing to or indirectly evoking ethical values (usually in the form of principles). If a well-chosen framework helps to highlight relevant values and raise ethical issues…

…what forms do those ethical issues take?

Conflict: tensions between values/principles
(e.g., individual privacy versus population health).

Risk: a value/principle is overlooked or not adequately considered
(e.g., a system design that leads to a low participation rate from a marginalized population can increase inequalities).

(Klingler et al, 2017, pp. 2-3)

Note: This is but one approach, and some approaches look very different from this.
Not all *ethical issues* take this form!

Variable characteristics of PH ethics frameworks: 1-5

Form	Principle-based ⟷ Question-based

Framing	Liberal / autonomy-based ⟷ Communitarian

Length	Short / cursory ⟷ Long / detailed / involved

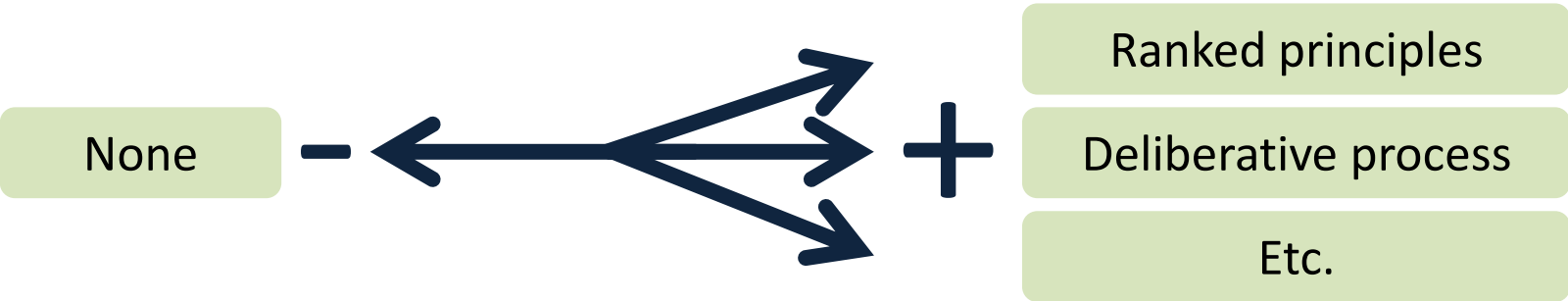| Scope	General / all purpose ⟷ Subject-specific

Scale	Macro (policy-level) ⟵ Meso perspective ⟶ Micro (individual-level)

Variable characteristics of PH ethics frameworks: 6-7

Practical guidance for how to proceed:

Just a list of principles/questions − ⟷ + Detailed step-by-step instructions

Normative guidance for resolving conflicts:

None − ⟷ +
- Ranked principles
- Deliberative process
- Etc.

PH ethics and surveillance

- Setting up for working with / road testing a new framework.

- Emphasis on values, guidance and considerations, and whether the result is an appropriately fine-tuned framework for the ethics of PH surveillance.

- Seeking a balance through trade-offs: not too much perfection-seeking in the name of perspicacity; not too much over-simplification in the name of ease of use.

Phases in the surveillance life-cycle

We will follow Klingler et al.'s literature review, in which these phases inform an overview of ethical issues that can arise in surveillance

Background conditions (pre-phase)
    Preconditions favouring (or not) successful PH surveillance, including preexisting guidance and models

System design and implementation phase
    Priority setting, resources, and design +/- enhancing effectiveness

Data collection, analysis and storage phase
    Data accuracy and comprehensiveness, protocols and infrastructure for analysis and storage

Data reporting, sharing and use for PH action phase
    Protocols for sharing, with whom, to what purpose and under what conditions

Based on Klingler et al., 2017, pp. 4-5.

Background conditions

Preconditions favouring (or not) successful PH surveillance, including preexisting guidance and models

Issues: Main themes

Subthemes (sample)

Issues related to choice of framework for conducting PH surveillance →

Misjudgment due to lack of ethics framework

Misjudgment due to using wrong ethics framework

Issues relating to sci. standards for evidence generation

Risk of not fulfilling preconditions for successful PH surveillance →

Risk of barriers to developing technologies, hindering effectiveness & efficiency of surveillance

Risk of not producing robust evidence on effective surveillance methods

Drawn from Klingler et al., 2017, p. 6.

System design and implementation

Priority setting, resources, and design +/- enhancing effectiveness

Issues: Main themes

Subthemes (sample)

Issue of deciding which PH surveillance system to build

→ Priority-setting conflicts between different PH programs (e.g., pandemic or chronic)

Issues of adequately designing a PH surveillance system

→ Risk of making poor choices of design of the surveillance system (e.g., priority-setting)

Risks involved in implementing and running a PH surveillance system

→ Risk of inadequate legal regulation and governance structures for surveillance project (e.g., no mechanism for ensuring ethical obligations are followed)

Further issues related to specific kinds of PH surveillance systems

→ Risks of surveillance systems relying on genetic profiles (e.g., inadequate focus on other factors leads to putting too much responsibility on the individual)

Drawn from Klingler et al., 2017, pp. 6-7

Data collection, analysis and storage

Data accuracy and comprehensiveness, protocols and infrastructure for analysis and storage

Issues: Main themes	**Subthemes (sample)**
Issues of protecting autonomy / the right to privacy	Risk of intentional/unintentional breaches of privacy (e.g., illegitimate authorities requesting or obtaining data)
Risk of producing inadequate information to guide PH activities	Risk of inaccurate/incomplete data (e.g., collecting from only certain groups); Risk of inadequate analysis/interpretation (e.g., evidence gaps, poor methods, slow work)
Risk of inadequately considering (vulnerable) subgroups in data collection	Risk of needs of subgroups not being made evident through poor analysis; Risk of stigmatization through targeting only subgroups
Risks related to specific data collection strategies	Risks related to using anonymous unlinked blood testing (e.g., forego potential for follow-up to help)

Drawn from Klingler et al., 2017, pp. 7-8.

Data reporting, sharing and use for PH action

Protocols for sharing, with whom, to what purpose and under what conditions

Issues: Main themes

Subthemes (sample)

Issues of adequately protecting the right to privacy / confidentiality in data reporting and sharing → Conflicts between protection of privacy/ confidentiality and realizing public benefit in sharing data with actors outside the surveillance system

Issues of inflicting harm or restricting freedom when labelling individuals / communities as suffering from health issues → Risk of inflicting physical, social or emotional harm (e.g., stigmatization, economic repercussions, foregoing care to protect privacy…)

Issues of foregoing PH benefits by not adequately putting data to use → Risk of not using data in time

Risk of not sharing data with other actors

Risk of not adequately sharing health risks to public

Drawn from Klingler et al., 2017, p.8

Thank you
Next we will try out the framework

For more discussion, please come and see us during the break
Visit us at **www.ncchpp.ca** for more resources

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