

Public Health Surveillance Ethics

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Status Quo

Research Ethics Vs. Surveillance Ethics

Case Study

- MDRTB Surveillance Surveys

Additional Contexts of Concern

- Post marketing surveillance
- Name based reporting

Surveillance: Ethical Issues

- Standards of care (justice)
- Privacy/confidentiality
- Informed consent
- Risk to subjects (e.g., confinement, stigmatization, risky/experimental medical interventions)
- Conflict between individual and collective interests

Question

1. What is technical distinction between research and surveillance?

Standard Definitions

Research:

“a systematic investigation ... designed to develop or contribute to *generalizable knowledge*”

(US Federal Policy for Protection of Human Subjects)

Standard Definitions

Public Health Surveillance:

“the ongoing systematic collection, analysis, and interpretation of health-related data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know”

(US CDC)

Crucial Distinction?

CDC: *primary intention* of the activity in question.

Is it:

1. To generate generalizable knowledge?
2. To reduce disease/improve health?

Key Question

2. What, if any, are the *morally relevant differences* between research and surveillance?

Note key similarities:

Both involve investigation aimed at generation of information in order to improve health.

Need

1. Guidelines/oversight mechanisms for surveillance?

Two Options:

- a. Overarching guidelines/mechanisms that cover both research and surveillance
- b. Special/separate guidelines/mechanisms

Proposal:

Research and surveillance should be treated the same in cases when risk/benefit profiles are the same.

→ Like cases should be treated alike.

Note:

Reflection on surveillance ethics may reveal need for significant revision of research ethics.