

# Surveillance (Versus Research) 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: Obvious Ethical Issues

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

# 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?

# The 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.

Note:

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