

# Surveillance, Consent & Public Health: Save Lives or Stand on Ceremony?

**RADx-Rad ELSI Office Hours**

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# Foundations

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Population health science has always been

- Information-intensive
- Able to presume the consent of its beneficiaries
- Utilitarian

# History

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- Hippocrates
- Paracelsus
- Graunt
- Farr
- Snow
- Watson?

# Privacy vs. Science?

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- Privacy and confidentiality were never seriously considered to be hard barriers to sharing and analysis
- Biomedical research has long relied on the work of trusted entities to collect health information; thus
- Security, de-identification, anonymization, pseudonymization

# Is Big Data Special?

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- With adequate governance, Big Data should not foster new concerns as regards risks to people who are the sources of data.
- More urgent concerns are of decisions made based on bad data, inferior programming or inappropriate uses and users.

# That is ...

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Ethical concerns should focus on

- Decision support – given variable data and database quality, uncertainty, software of questionable quality, etc.
- Appropriate uses
- Appropriate users

# This is not to say ...

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... that concerns about privacy, confidentiality, stigma, etc. are no longer worthy of attention.

It is to say that Big Data itself, all other things being equal, raises no new privacy challenges.

# Privacy

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- Is not an absolute right
- Must therefore be balanced against other rights (including a “right to benefit from science”\*)
- Is often mistakenly invoked by individuals

\* <http://www.ohchr.org/EN/Issues/CulturalRights/Pages/benefitfromscientificprogress.aspx>



# Information Free-Riders

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- Emphasize privacy over public health
- Risk little if anything
- Benefit from others' contributions of information

# Analogues

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- Vaccine refusers
- Organ donation refusers
- Infrastructure support refusers

# ↑ Health ≠ ↓ Privacy

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- Smart laws and policies; nimble governance at professional and social levels
- Recognition of duties to collectives, and that such duties do not violate individual rights
- Trust

# Surveillance

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- Essential for identifying emerging disease, disease in the population, future disease
- Failure to perform surveillance would be blameworthy
- Surveillance reduces morbidity, mortality

# Consent

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- Required for most research, clinical care
- Would undermine public health if required
- Hence tacit, latent, implied consent

# Trust

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- Most people in most civil societies trust public health scientists
- Distrust has been increased by surveillance for marketing, politics, etc.
- Distrust has been actively fostered by ideologues and zealots

# Now what?

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- Just when we need robust surveillance, trust is at a nadir
- Opportunity to improve public health literacy and education, e.g., RADx-Rad
- Outreach, communication, transparency