The Fallacy of “Secondary Use” and Its Effects on Population Health

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The findings and conclusions reported here are those of the author and do not necessarily represent the official positions of the Presidential Commission for the Study of Bioethical Issues or the US Government.
Outline

• Then: Defining secondary data & secondary use
• Now: Big data & ubiquitous data

• Ethical implications for population health research
Then
Sources of health information

Population Health Information

- Research Data
- Med Records

Primary data
Background

Google Ngram 1900-2008
Background

Google Ngram 1900-2008

privacy

secondary data
Sources of health information

- Health Surveys
- Research Data
- PH Surv
- Med Records
- etc, etc.

Population Health Information

Secondary data
Big data
Now
“Bigger Data”

- Financial Information
- Social Media
- Health Care Encounters
- Pharmaceuticals/prescriptions
- Public Health
- Web Activity
- Shopping Habits
- Etc., etc.
Ubiquitous primary data
“Bigger Data”

Financial Information

Social Media

Health Care Encounters

Pharmaceuticals/prescriptions

Public Health

Web Activity

Shopping Habits

Etc., etc.

Connected

Ubiquitous

Accessible

Integrated

Multisectoral

Permanent

Unprotected
“Bigger Data”

Financial Information

Social Media

Health Care Encounters

Pharmaceuticals/prescriptions

Public Health

Web Activity

Shopping Habits

Etc., etc.
“Bigger Data”
Ethical implications in population health
“Bigger Data”

Financial Information
Social Media
Health Care Encounters
Pharmaceuticals/prescriptions
Public Health
Web Activity
Shopping Habits
Etc., etc.
What is old is new again

THE RIGHT TO PRIVACY.

"It could be done only on principles of private justice, moral fitness, and public convenience, which, when applied to a new subject, make common law without a precedent; much more when received and approved by usage."

WILLIS, J., in Miller v. Taylor, 4 Burr. 2303, 2312.

THAT the individual shall have full protection in person and in property is a principle as old as the common law; but it has been found necessary from time to time to define anew the exact nature and extent of such protection. Political, social, and economic changes entail the recognition of new rights, and the common law, in its eternal youth, grows to meet the demands of society. Thus, in very early times, the law gave a remedy only
Ethical dimensions: Ubiquitous data & population health research

- Benefits and harms of various uses of data
- Benefits and harms of *not using* data
- Justice (inclusion, free riding, burden, and benefit)
- Scientific rigor (bad science is unethical science)
- Trust (professional ethics for the research enterprise)
- Reimagining informed consent
Possible next steps

• Renegotiating the public terms of data collection, storage, and use
  – Create a new norm that includes a learning health system to which all users contribute
  – Raise professional expectations of all who ‘touch’ data
  – Create comprehensive privacy policies that include swift and severe consequences for misuse
Thank you