

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

Epidemiology Congress of the Americas 2016

Miami FL

June 22, 2016

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Presidential Commission for the Study of Bioethical Issues

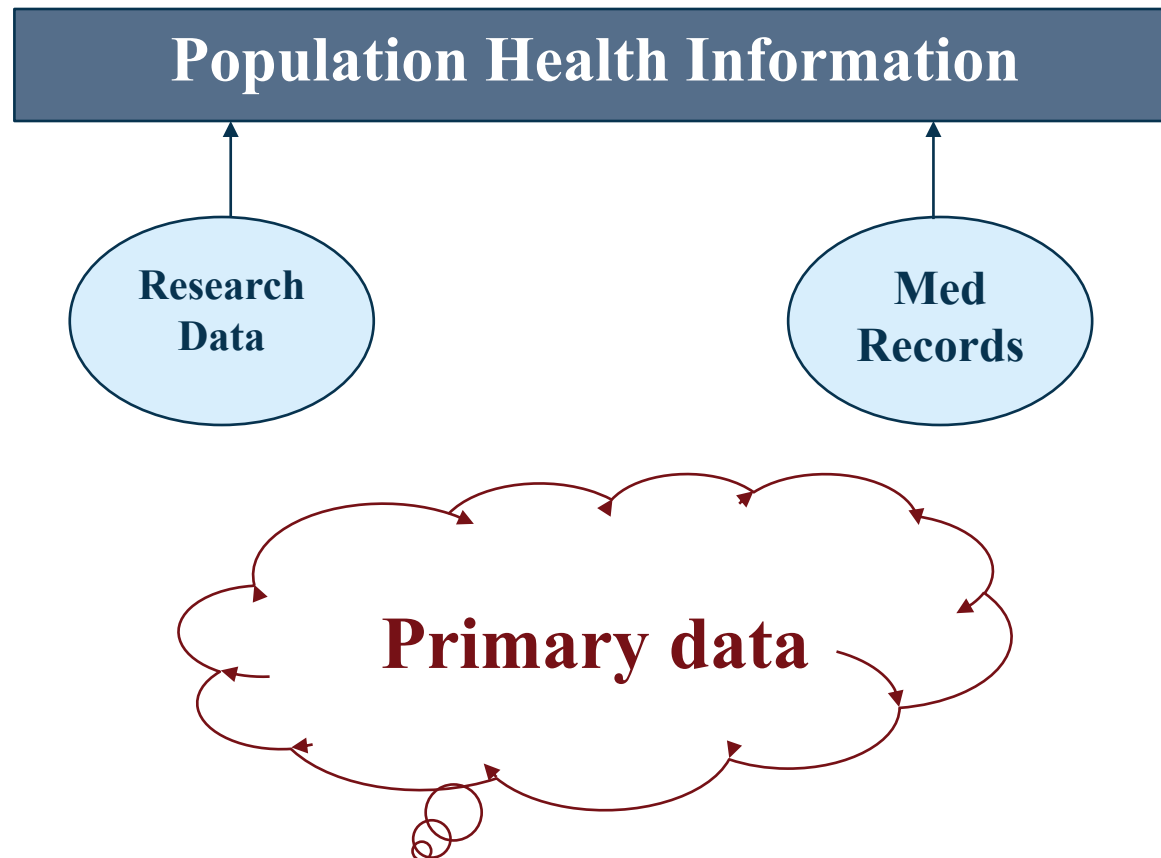
The findings and conclusions reported here are those of the author and do not necessarily represent the official positions of the Presidential Commission for the Study of Bioethical Issues or the US Government.

Outline

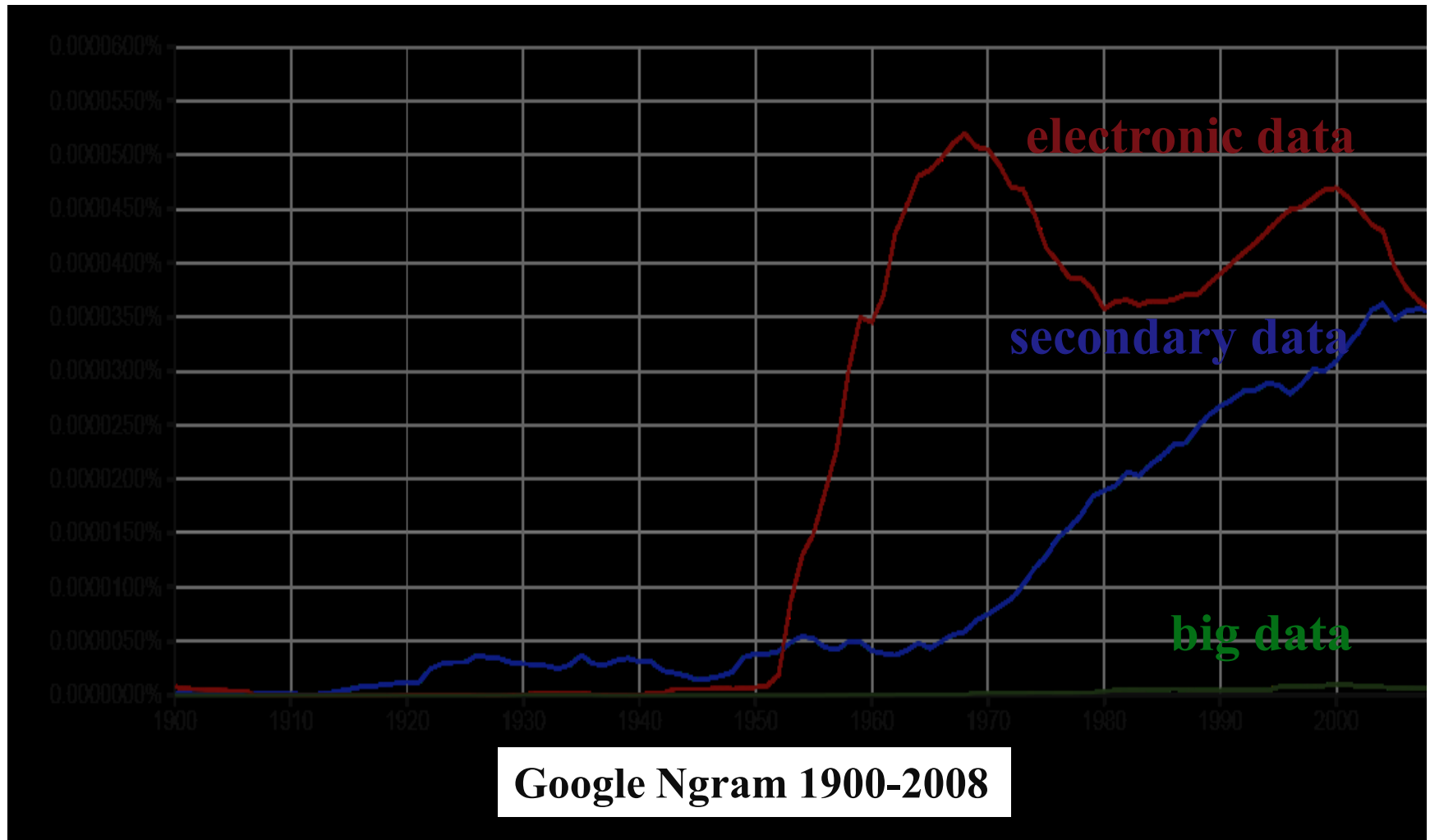
- Then: Defining secondary data & secondary use
- Now: Big data & ubiquitous data
- Ethical implications for population health research

Then

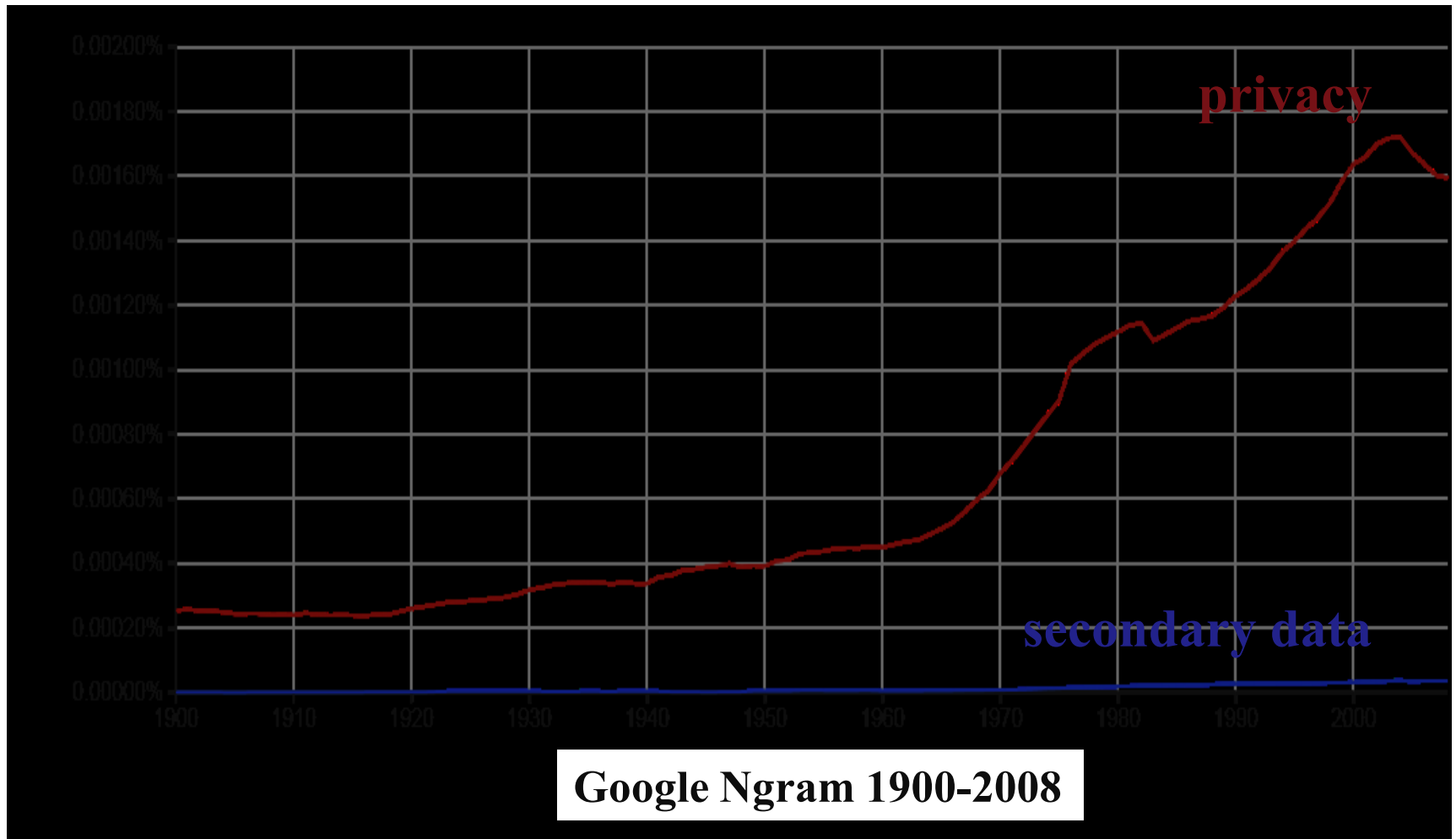
Sources of health information



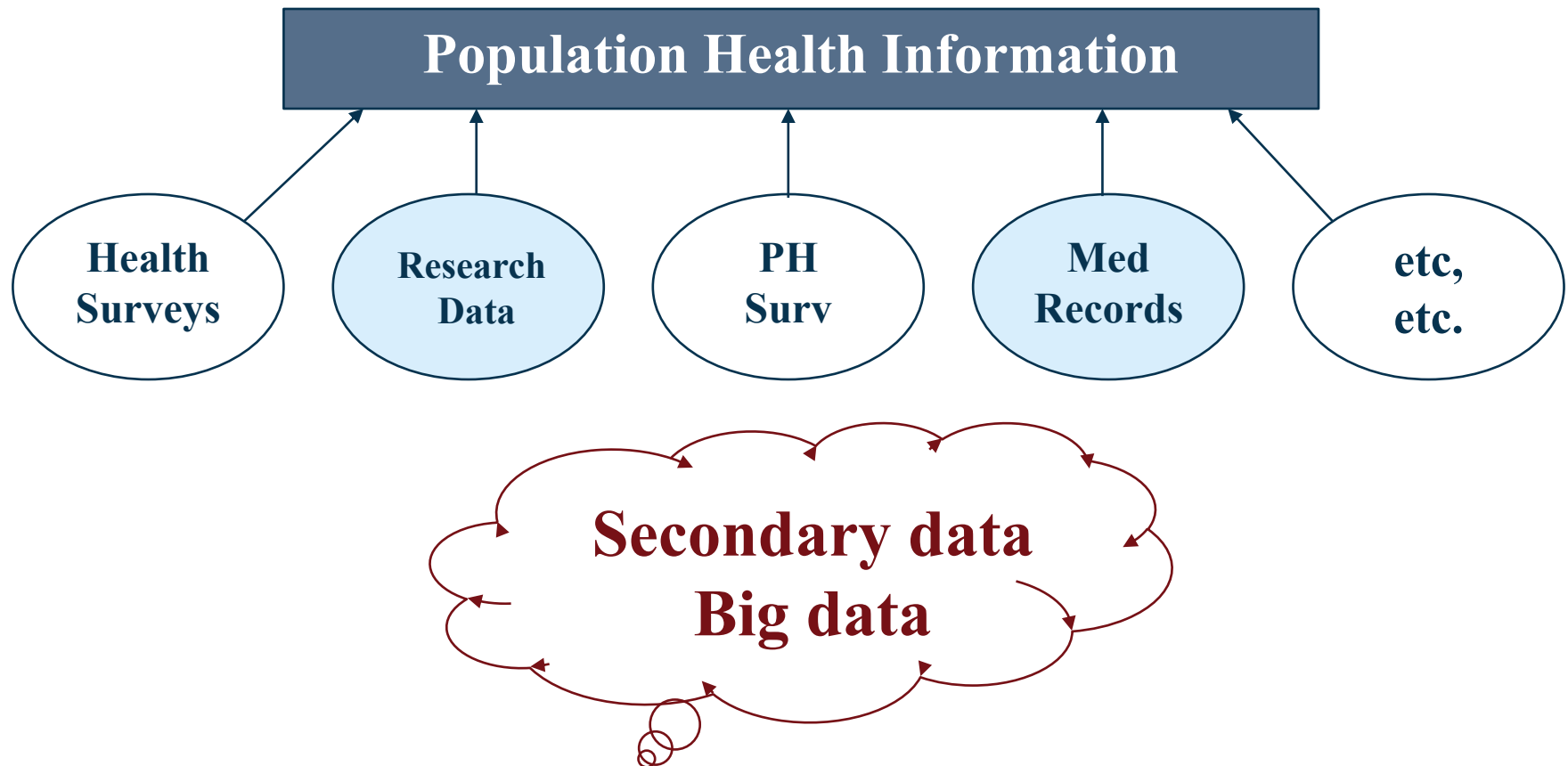
Background



Background



Sources of health information



Now

“Bigger Data”

Financial Information

Social Media

Health Care Encounters

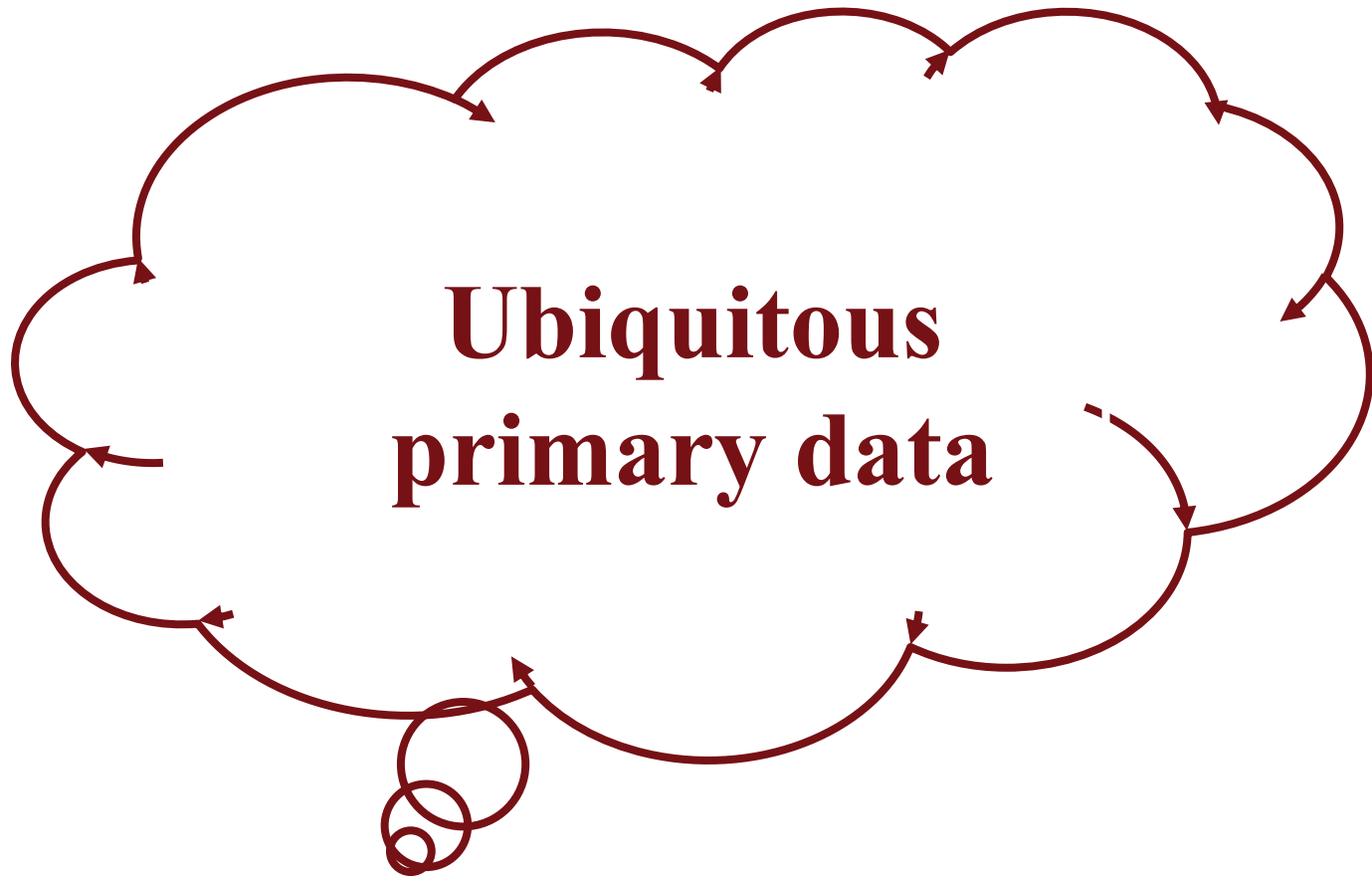
Pharmaceuticals/prescriptions

Public Health

Web Activity

Shopping Habits

Etc., etc.



“Bigger Data”

Financial Information

Social Media

Health Care Encounters

Prescriptions

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Web Activity

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Etc., etc.

Connected

Ubiquitous

Accessible

Integrated

Multisectoral

Permanent

Unprotected

“Bigger Data”



Financial Information

Social Media

Health Care Encounters

Pharmaceuticals/prescriptions

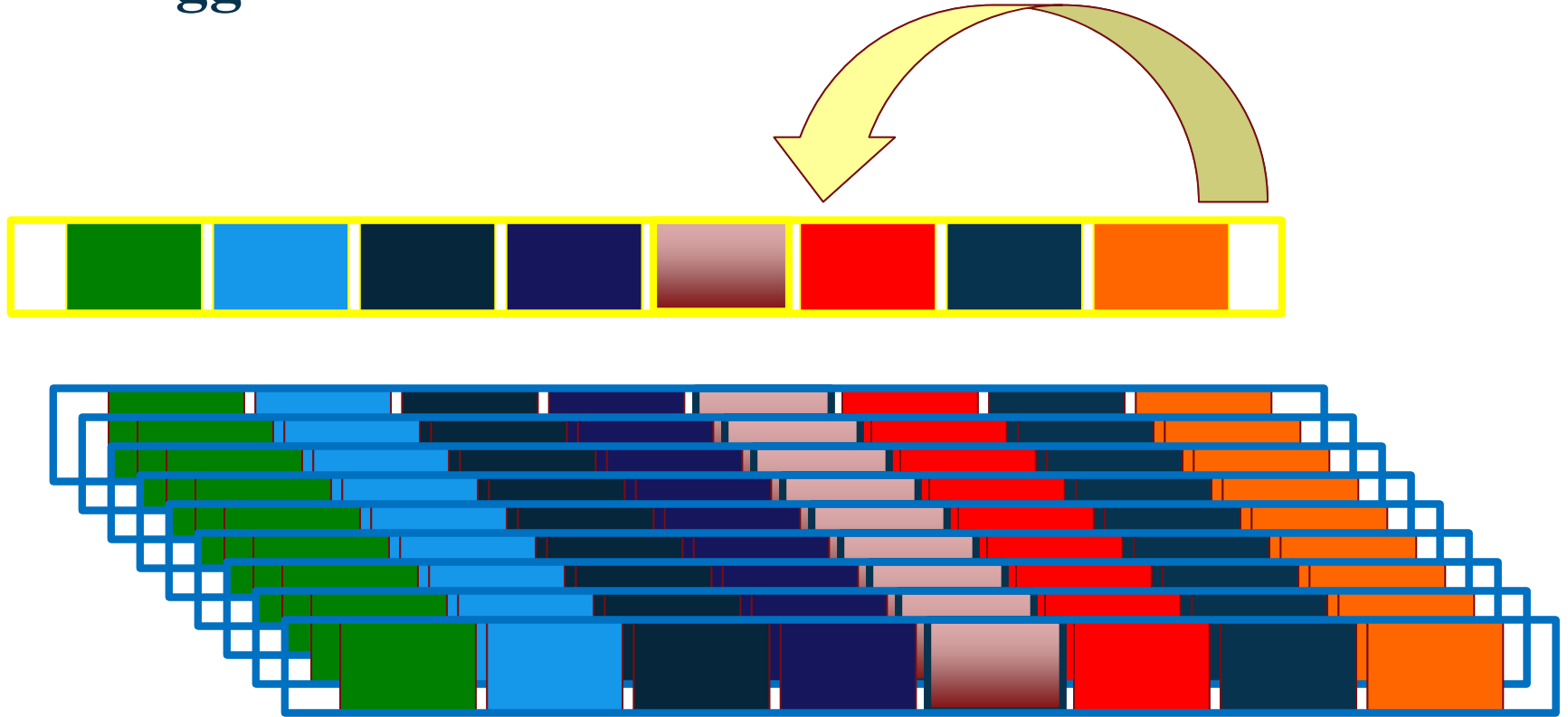
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“Bigger Data”



Ethical implications in population health

“Bigger Data”



Financial Information

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Etc., etc.

What is old is new again

HARVARD LAW REVIEW.

VOL. IV.

DECEMBER 15, 1890.

NO. 5.

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."

WILLES, J., in *Millar 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