

# Building Public Trust in Big Data Analytics for Health Policy

**Don Willison Sc.D.**

Institute for Health Policy, Management & Evaluation, DLSPH

Dept. of CE&B, McMaster University

[don.willison@utoronto.ca](mailto:don.willison@utoronto.ca)

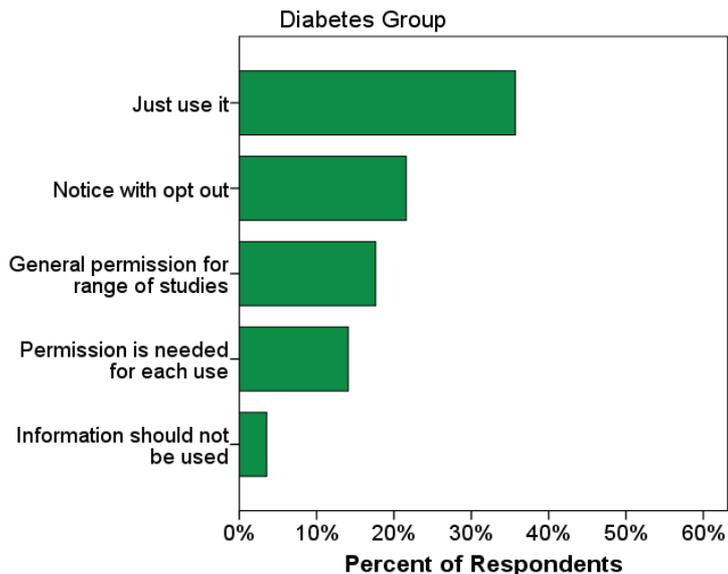
# “Bottom Line”

- Research linking health records with data on SDH has tremendous potential to improve population health
- The general public is not yet onboard with these kinds of secondary uses of data
  - Connection of income, education etc. with health
  - Concern over potential stigma and discrimination of individuals / groups
  - Who is making decisions over acceptable uses/users?
  - What safeguards are in place?
- Need to build public trust through transparency, accountability, and governance

# Linking health data with biological samples vs. education, income & employment

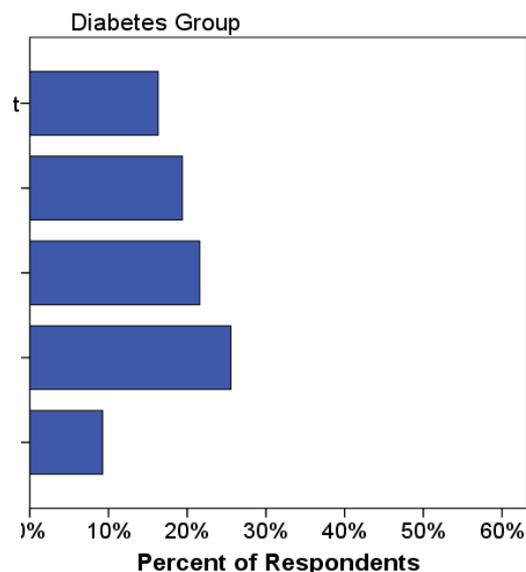
Scenario 1:

Health Information for Quality Improvement



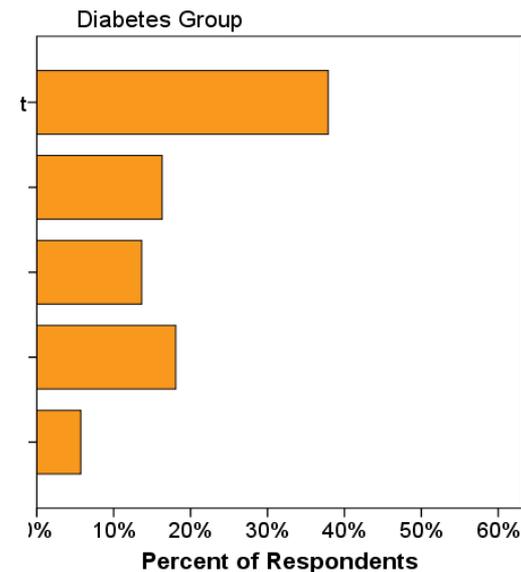
Scenario 3:

Linking Health Information to Work, Education or Income



Scenario 4a:

Linking Health Information with Biological Samples with No Profit

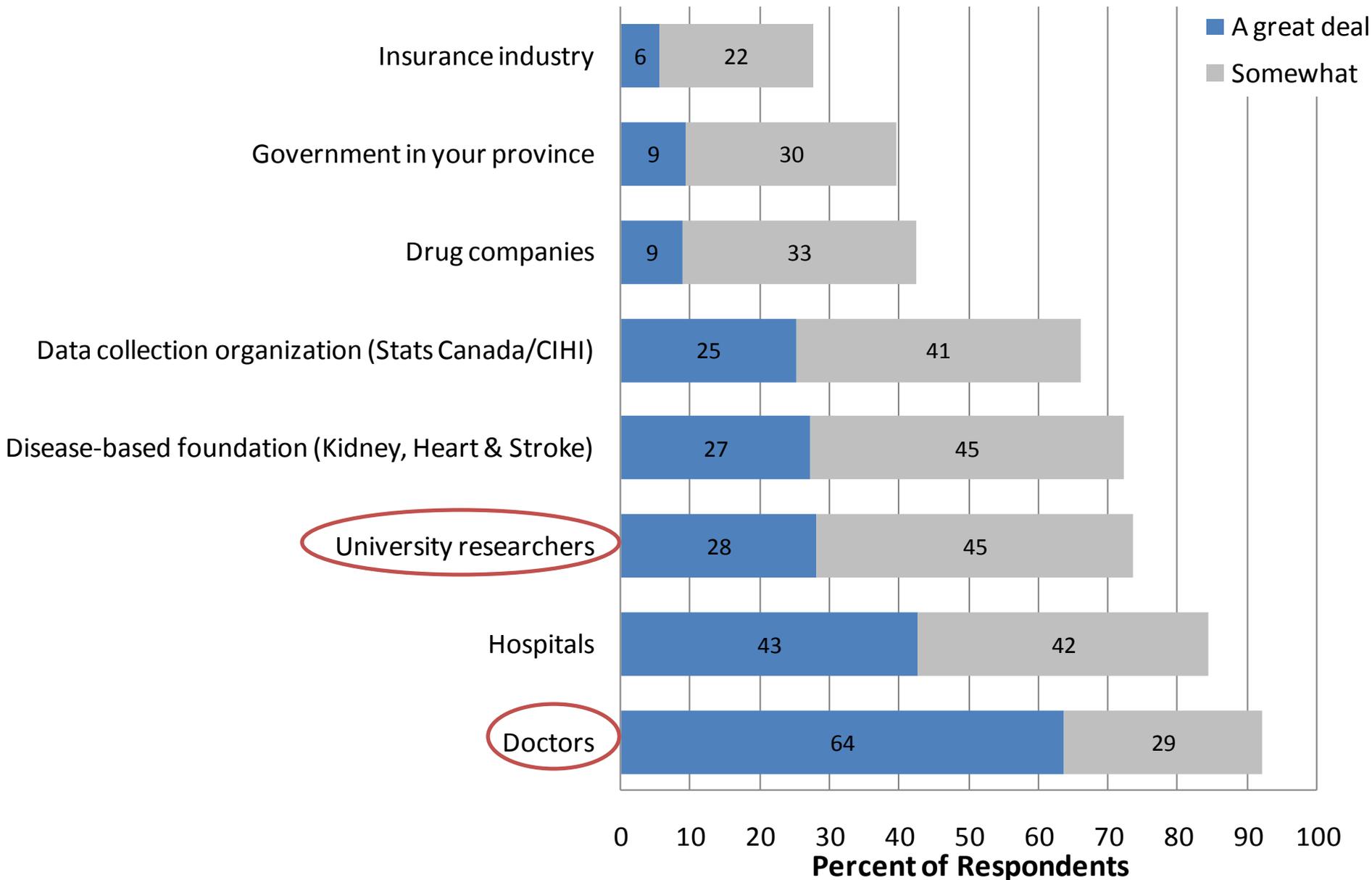


“I think the simple answer is that physical tissue sample is just a piece of *what* you are, what you might be... where the rest of the information [education, income, employment] is more of *who* you are. People are more afraid of the revelation of *who* you are than *what* you are.”

HIV-Participant 8, male

Willison et al (2009) BMC Medical Ethics. *Consent for use of personal information for health research: Do people with potentially stigmatizing health conditions and the general public differ in their opinions?*

# How much do you trust the following individuals, organizations or groups to keep any health information they may have about you confidential?



# Building Public Trust

- Trust in what?
  - Safeguards in place
  - Use of data in the public's interest
- How?
  - Greater transparency
    - Kinds of research being done, public benefit and governance over uses
    - Where to find more information
    - “Just the facts”
  - Governance and accountability
    - What are the limits on uses (and users)?
    - Consultation with potentially affected persons, when research has potential for stigmatization or discrimination