

Computational Epidemiology: Benefits, Risks and the Duty of Citizens to Contribute to Big Data

Epidemiology Congress of the Americas

Miami

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Foundations

Population health science has always been

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

Is Big Data Special?

Calm down! Nothing about Big Data should foster new concerns as regards risks to people who are the sources of data.

Rather ...

Ethical concerns should focus on

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

This is not to say ...

... 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

- 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

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

Analogues

- Vaccine refusers
- Organ donation refusers
- Infrastructure support refusers

Role of Ethics

- Illuminate the force, scope and limitations of rights
- Identify and balance conflicting rights, and rights and duties
- Identify and justify duties

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