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DATA LAW

AI in 2019: Authorized & Accountable

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Information is ‘Gold’

- Everyone wants it
- Often, the public gives it without thinking of the implications or who then owns and can use it; or for what purposes
- The imperative of ethics, data governance and accountability is upon us
- Biggest legal issues
    - not who gets sued if AI goes wrong
    - all about reliable data, that we have authority to use
    - data governance and data trusts

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The Problem?

- Current posture on data is

Don’t Ask (consent)

Don’t Tell (notice)

- Federal Privacy Commissioner of Canada “meaningful consent” rules in force Jan. 1, 2019 include:
  - Emphasizing key points (what data, what purpose)
  - Layered consent – giving detail plus a high level summary
  - Ongoing consent

Breathing new life into consent

- Under privacy laws, organizations are generally required to obtain **meaningful consent** for the collection, use and disclosure of personal information. However, **advances in technology** and the use of **lengthy, legalistic privacy policies** have too often served to make the control — and personal autonomy — that should be enabled by consent **nothing more than illusory**. . . Consent should remain central. But it is necessary to **breathe new life into the ways in which it is obtained**.

Consent in 2019 (with apologies to The Far Side)

- Blah blah blah blah blah privacy blah blah blah blah consent blah blah blah blah blah you blah blah we blah blah agree blah blah blah blah blah acknowledge blah blah blah blah blah blah blah blah blah understand blah blah blahblah blah blah blah privacy blah blah blah consent blah consent blah blah blah blah blah you blah blah we blah blah agree blah blah blah blah blah acknowledge blah blah blah blah blah blah limitation of liability blah blah blah understand blah blah blah blah blah blah blah privacy blah blah blah blah consent blah blah blah blah blah you blah blah we blah blah agree blah blah blah blah blah acknowledge blah blah blah blah blah blah blah blah blah understand blah blah blah blah blah blah blah privacy blah blah blah blah consent blah blah blah blah blah you blah blah we blah blah agree blah blah blah blah blah acknowledge blah blah blah blah blah blah blah blah blah understand blah blah blah blah blah blah blah privacy blah blah blah blah consent blah blah blah blah blah you blah blah we blah blah agree blah blah blah blah blah acknowledge blah blah blah blah blah blah blah blah blah understand blah blah worldwide affiliates blah blah blah blah blah privacy blah blah blahblah consent blah blah blah blah blah you blah blah we blah blah agree blah blah blah blah blah acknowledge blah blah blah blah blah blah blah blah blah understand blah blah blah blah blah blah blah disclose

I agree to the foregoing:

Signed: Dated: Witnessed:

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Legal challenges

- Do we need identifying information?
- If No, is it/can it be properly deidentified?
- What is the legal authority to collect, use and disclose the information?

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Legal challenges, cont'd

- Establishing what is a "meaningful" **consent** or by extension, a meaningful **notice**
  - What story do we tell? (i.e., tell the truth)
  - Otherwise, the public is left only with negative media stories
    - Facebook
    - Weather Channel weather app misuse of geolocation (including sale of data to third parties for retargeting and analysis of consumer behaviour)

". . . Intentionally obscured disclosures on how it uses geolocation data within a 10,000-word privacy policy"

- https://www.thestar.com/news/world/2019/01/04/weather-channel-app-accused-of-selling-users-personal-data.html

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And if we cannot seek consent

- Are we at a point where we say we literally cannot seek consent ("impractical", similar to research consent waivers from a research consent waiver) due to volume of data?
  - Research community already has an oversight framework, based on TCPS 2

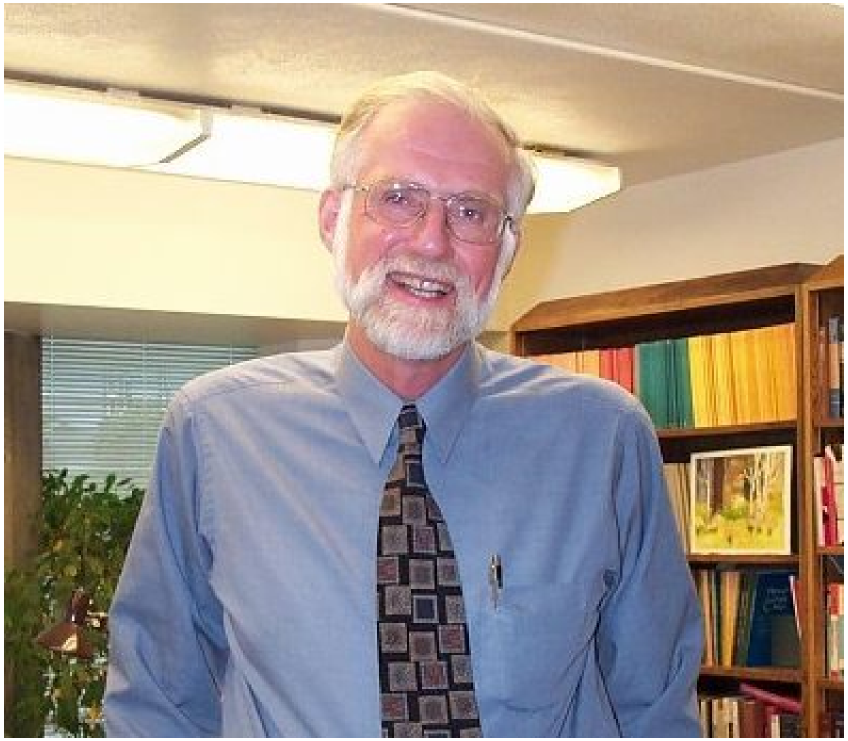
- Research ethics boards also challenged in the upward surge of 'overly' broad demands on data

- By parallel, it is all about the governance

McInerney v. McDonald

- Seminal case on access to health records, embedded in Ontario's *Personal Health Information Protection Act*
- Where the Supreme Court of Canada stated that while the record belongs to the health care provider, it is held in *fiduciary trust* on behalf of the patient

ACCOUNTABILITY & ENGAGEMENT



Dr. Michael McDonald, Professor Emeritus, Applied Ethics, UBC

- Constant mantra at Canadian Blood Services Research Ethics Board: we cannot be accountable if we do not engage patients
- CIHR Working Group on Ethics On Patient Engagement: http://www.cihr-irsc.gc.ca/e/51225.html (submissions closed January 28, 2019)
- “. . . treatment of patients as mere data source is out of step with the move toward patient engagement in research” and the same is true of AI

Data trusts

- Data trusts also rest on fiduciary duty
- Data trusts may bind parties contractually and create a framework for responsible use of the data (not to mention IP)
- It comes down to governance and accountability – and how we operationalize these

- Data governance framework is a must

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Thank you

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