Regulating the Use of Personal Health Information in Big Data Research

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Information and Privacy Commissioner of Ontario

Commissaire à l'information et à la protection de la vie privée de l'Ontario

Clinical Trials Ontario's 2018 Annual Conference

March 28, 2018

Who is the Information and Privacy Commissioner of Ontario?

- IPC/O is appointed by the Legislative Assembly of Ontario and provides independent review of decisions and practices of:
  - government and
  - organisations and individuals involved in health care sector

  that affect access to information and privacy.
- Mandate includes:
  - public education and publication of guidance,
  - consultations with government or organisations on legislative or policy initiatives,
  - investigation, mediation, and adjudication of privacy complaints or decisions to refuse access to information,
  - review of the practices and procedures of certain entities or organisations.

Ontario's Legislative Framework

Public Sector	Health Sector	Private Sector
Government e.g. ministries, agencies, hospitals, universities, cities, police, schools, hydro *Freedom of Information and Protection of Privacy Act* (*FIPPA*) *Municipal Freedom of Information and Protection of Privacy Act* (*MFIPPA*)	Individuals, organisations delivering health care e.g. hospitals, pharmacies, labs, doctors, dentists, nurses *Personal Health Information Protection Act* (*PHIPA*)	Private sector businesses engaged in commercial activities *Personal Information Protection and Electronic Documents Act* (*PIPEDA*)
IPC/O oversight	IPC/O oversight	Privacy Commissioner of Canada oversight

Big data trends in the province

- Governments want to **share, link, analyse data** across agencies to obtain new insights, to support
  - policy development
  - system planning
  - resource allocation
  - performance monitoring.
- Big data analysis is sometimes called **data integration.**
- Benefits of big data may be compelling. For example:
  - higher quality evidence
  - better public policy
  - better use of money
  - fraud detection.

Big data trends in the province

- There are risks involved in big data analysis, which include:
  - unexpected uses of personal information
  - invasive
  - inaccuracy in linkages or representativeness of samples
  - discriminatory.
- Big data analysis goes against expectation that governments and organisations collect personal information **directly** from individuals to whom the information relates, and the expectation that information is not shared with others except in limited circumstances.
- So far, legislative approaches to big data in Ontario have been piecemeal.
  - e.g., *Child, Youth, Family Services Act, 2017*

Regulatory approaches preferred by the IPC/O

- *FIPPA* treats government institutions as silos; indirect collection, sharing/linking across government not envisioned
- IPC/O maintains that big data analysis should occur within a **single dedicated unit**, to:
  - collect personal information across government
  - link records securely
  - de-identify
  - make de-identified data available to public bodies to inform policy and system planning.
- Modelled from approach in *PHIPA*, e.g., s. 55.9 in context of electronic health record systems.
- Allows institution to: (1) avoid **replicating databases** and creating **profiles** of sensitive personal information across government, (2) maximise security of personal information, including minimising and controlling access, and localising security infrastructure.

Regulatory approaches preferred by the IPC/O

- Centralised model has further advantages over decentralised system:
  - Allows for ethical review at outset, prior to big data analysis,
  - Facilitates an organisation's capacity to be transparent in its information practices (e.g., ensure public knowledge of purpose, methodology, algorithm)
  - Makes it easier for an independent regulator to oversee information practices (e.g., IPC/O, including order-making, audit, inspection powers)
  - Facilitates the use of expertise needed to carry out analysis and minimise privacy and security risks.
- IPC/O now in discussions with Ontario government about legislative reform.

Lessons for big data in *PHIPA* context

- Potential uses of big data analysis

1) for planning or delivering programs or services, **or** risk management, improving or maintaining the quality of care or the quality of a program or service. For example:
   - section 37(1)(c) – (d) [use by custodian],
   - section 39(1)(d)(iii) [disclosure to custodian who provided healthcare].
   - Section 39(1)(c) and 45(1) [disclosure by custodian to prescribed entity to analyse or compile statistical information with respect to managing, evaluating, allocating resources, or planning health system].
   - section 47(2) [disclosure by custodian to health data institute]
   - section 55.9 [collection by MOHLTC for planning analysis or detecting and preventing fraud]

- Centralised structures, de-identification, encryption, secure transfer and destruction, privacy policies and procedures and training, auditing and monitoring.

Lessons for big data in *PHIPA* context

- Potential uses of big data analysis

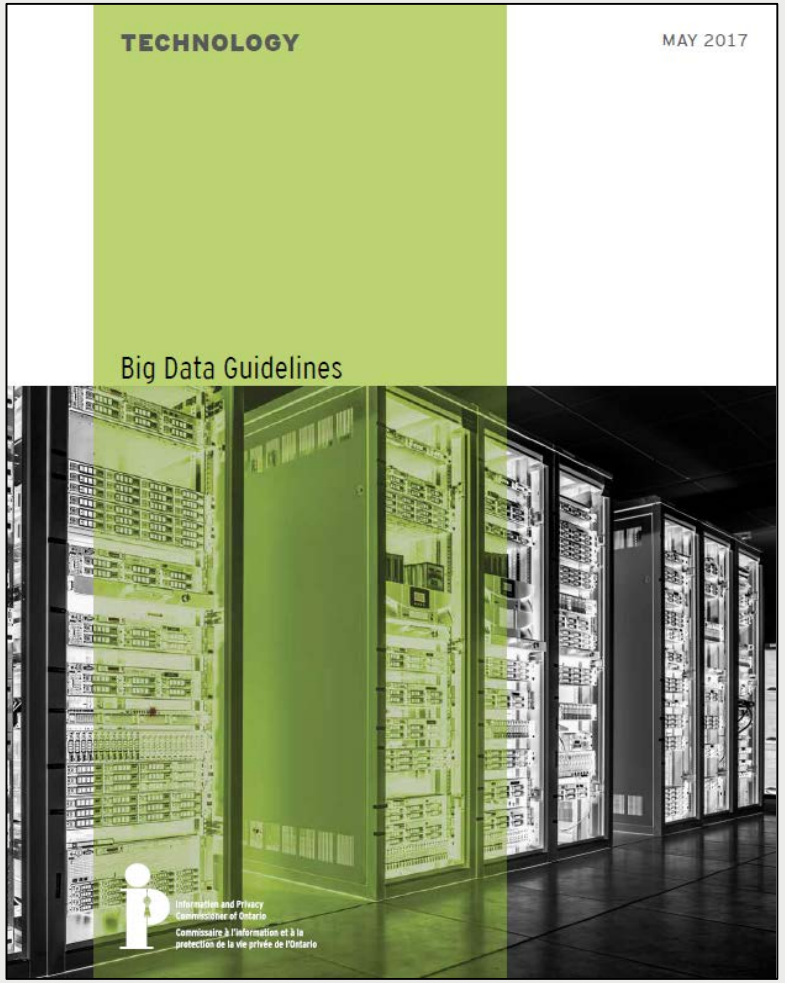
2) Research – in the sense of systematic investigation designed to develop or establish principles, facts or generalizable knowledge, or any combination of them.
    - sections 37(3) and 44.

- Follow conditions set out by REB process, follow limitations on further use and disclosure of identifying research data under *PHIPA*, limit and control access to identifying information with segregated or centralised organisational structures, de-identification, encryption, secure transfer and destruction, privacy policies and procedures and training, auditing and monitoring.

Lessons for big data in *PHIPA* context

- To minimise collection, use, and disclosure to what is directly relevant and necessary for achieving the specified purpose (section 30 of *PHIPA*), at a minimum, data elements collected or used in the course of analysis should be:
  - conceptually related to the subject-matter under study, and
  - directly informed by the question asked.
- All big data projects should be reviewed and approved by a REB, or a similar body where permitted under *PHIPA*.
- Describe projects with public notification on organisation's website.
- Consider privacy risks associated with publicly available personal information.
- Throughout data integration, analysis, and predictive profiling, organisations and researchers should work to minimise privacy and other ethical issues that arise, by following best practices issued by the IPC/O and any further limitations set by REB.

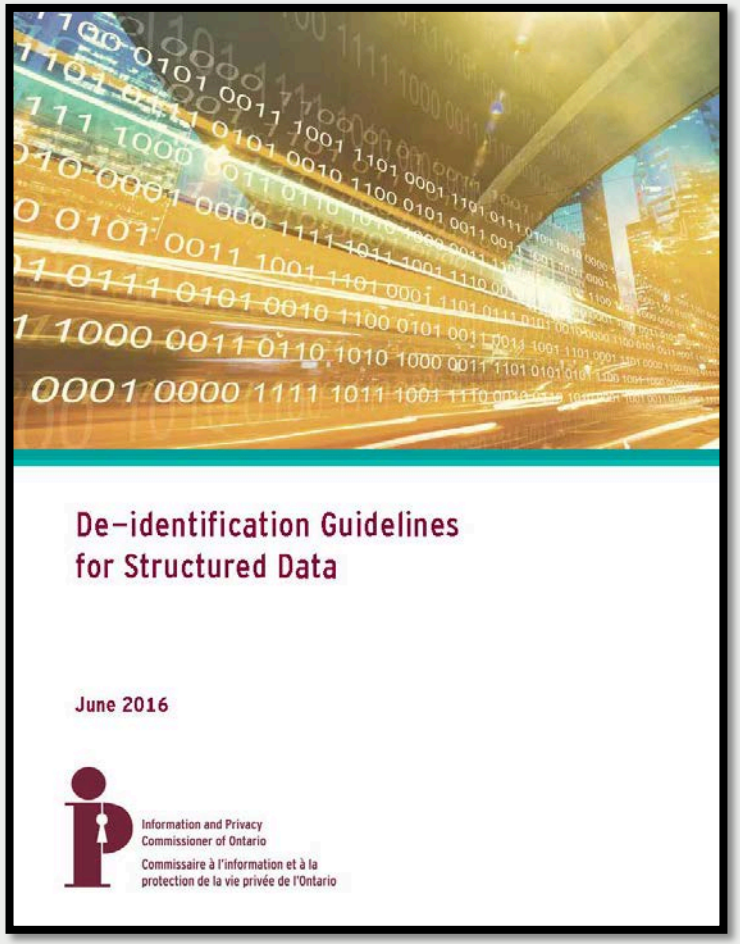
Big Data Guidance



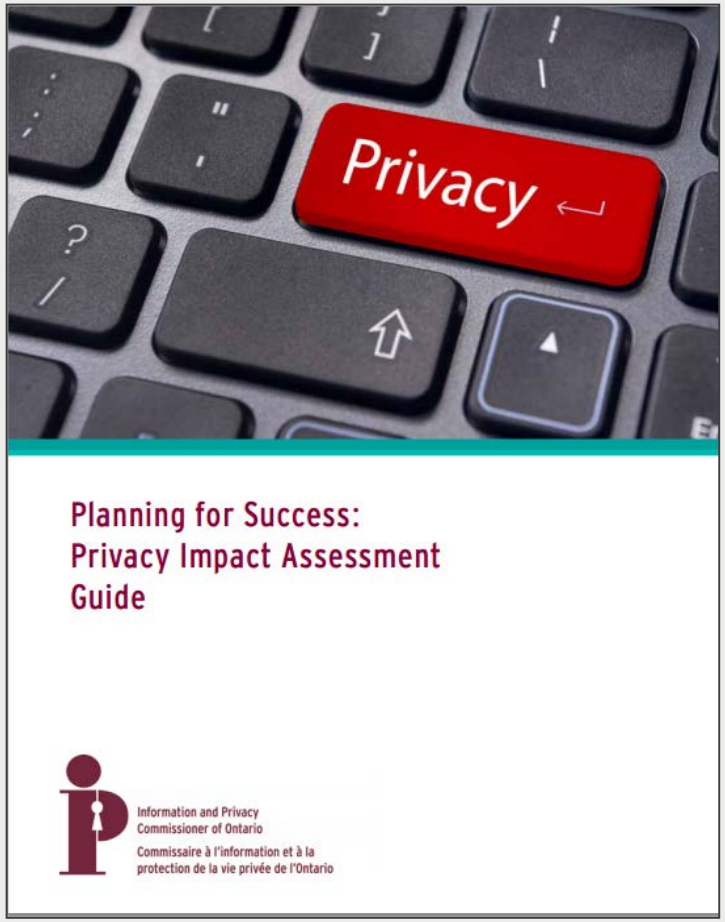
- Key issues, best practices when conducting big data projects involving personal information.
- Considerations at each stage:
  - collection
  - integration
  - analysis
  - profiling.

De-identification

- Risk-based, step-by-step process to assist organisations to de-identify.
- Key issues when publishing
  - release models
  - types of identifiers
  - re-identification attacks.
- IPC wins global privacy award for excellence in research [International Conference of Data Protection and Privacy Commissioners, Hong Kong 2017].



Planning for Success: Privacy Impact Assessment Guide



- Tools to identify privacy impacts and risk mitigation strategies.
- Step-by-step advice on how to conduct a privacy impact assessment
- Not required by legislation, but considered privacy best practice

HOW TO CONTACT US

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