



Privacy present and future state: Considerations for research and program evaluation ARECCI Ethics Forum October 2017

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## Overview

- Background
- Who is the OIPC
- Alberta's privacy legislation
- How we intersect with research, program evaluation and quality improvement
- Current State
- Information sharing
- Future possibilities
  - Predictions?





#### Office of the Information and Privacy Commissioner of Alberta

- Commissioner Jill Clayton
  - an officer of the Legislative Assembly
  - independent of government
- Oversight of Alberta's access to information and privacy laws:
  - Freedom of Information and Protection of Privacy Act
  - Personal Information Protection Act
  - Health Information Act
- Provincial government is responsible for legislation



## What we do

- Resolve access and privacy complaints
  - Mediation, investigation, adjudication
- Order compliance
- Conduct investigations to ensure compliance with any provision our access and privacy laws
  - Including offence investigations leading to prosecution
- Review Privacy Impact Assessments
  - Mandatory for health sector in Alberta
  - Common under FOIP
- Issue Breach Notification decisions
- Give advice and recommendations
- Inform the public



#### How we intersect with research

- Health Research Ethics Boards
  - File their approvals with us
  - Duty to review research proposals and assess whether adequate safeguards are in place
- Privacy Impact Assessment review
  - including data matching
  - Recommended for multi-stakeholder initiatives
- Investigations
  - Unusual, most people aren't aware, or have consented



access to data without agreement

#### Program evaluation, and quality improvement and PIAs

- Privacy Impact Assessments
  - Required under the Health Information Act
  - Risk assessment
  - Ability to comment



# Current state of information sharing in Alberta

- Privacy regulators understand benefits of information sharing and analytics
  - Advancement of science, health
  - Convenience
  - Harmonized, coordinated, targeted services
  - Efficiency, cost containment
- Privacy statutes allow appropriate information sharing and data matching



#### Things privacy laws allow you to do

- Research
- Planning
- Resource allocation
- Policy development
- Quality improvement
- Auditing
- Evaluation
- Data matching
- Share personal information for service delivery



## **Information Sharing**

Alberta Privacy Legislation allows for information sharing; how to get it right

- Transparency
- Legal Authority
- Privacy Impact Assessment (PIA)
- Access and Correction
- Accountability

https://www.oipc.ab.ca/media/820663/advisory\_information\_sharing\_may2017.pdf



## Current Challenges

- We live in a federation and have international partners
- Managing privacy among multiple stakeholders (governance)
- Transparency
- Managing consent, citizen expectations
- Trans border legal demands
- Bureaucratic fear, uncertainty and doubt



#### Future state

- Near future
  - Breach notification
  - Reasonable security requirements
  - Increasing complexity with information sharing
  - Gargantuan data
  - Autonomous machine learning
  - Surveillance think 1984



## Predictions?

- Privacy Impact Assessments are here to stay
- There will be more breaches and notification requirements
- More regulation
  - Larger role for research in privacy
  - Rules for data mining, artificial intelligence



Curriculum How can you stay up to date

- Privacy training, in house or other
- Privacy risk assessment and mitigation strategies
- Information security
- Access to information
- Records management
- Agreements and contracts



### Tips for success

- Talk to us
  - We are happy to consult on any initiative
  - Early consultation prevents last-minute pitfalls
- Build privacy into your initiative from the start
  - Last-minute, bolt-on privacy is expensive and inefficient
- Conduct a privacy impact assessment
  - Our Office is pleased to review and provide comments
  - Consider making your PIA public
- Develop privacy expertise



#### **OIPC sponsored research on information sharing**

Government Information Sharing Is Data Going Out of the Silos, Into the Mines?

- <u>http://www.oipc.ab.ca/Content\_Files/Files/Publications/R</u> <u>eport\_GovtInfoSharing\_Jan2015.pdf</u>
- Case studies
- Citizen expectations
- Examining risk in data sharing projects



### Your questions





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#### **THANK YOU!**

