

# Privacy and Sharing Information for Public Health Purposes: a Commissioner's view.

Frank Work, QC  
Information and Privacy Commissioner  
Alberta

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# Assumption:

- The technology exists to link, create, assemble and effectively use health information databases for public health purposes.
- What are the privacy issues from a regulators point of view?



# The issues:

- Statutes
- What phi is being collected?
- Why is it being collected?
- What other uses will it be put to?
- Who will it be disclosed to?
- Is it secure?
- Outsourcing

# The statutes

- PIPEDA consent, “circle of care”.
- Quebec, B.C., Alberta private sector privacy statutes (substantially similar).
- Provincial health info statutes:
- Public health statutes.
- PIPEDA still applies to trans-border data flows and FWUB activities



# The statutes

- All privacy statutes deal with the:
  - Collection,
  - Use, and
  - Disclosure
  - Of Personal Information
  - By someone.



# The statutes

- In Alberta: HIA, FOIP, PIPA
- HIA ss 57, 58.
- Collect, use and disclose with the highest degree of anonymity possible.
- Collect, use and disclose the least amount of info needed.



# Relevant decisions

- Alberta Cervical Cancer Screening Program (H2005-IR-002)
- Direct disclosure of lab tests to AB Cancer Board by labs.
- AB Cancer Board has authority to collect, use and disclose.
- They did a PIA!



# Planning Surveillance systems

- Prepare a privacy impact assessment!
  - Required in AB
  - OIPC-AB has received over 700
  - See our website: [oipc.ab.ca](http://oipc.ab.ca)
- Leadership is critical: someone has to be in charge; someone has to enforce the rules.
- Oh, yeah, there have to be rules.



# What phi is being collected?

- Is it the least amount of info needed for the purposes?
- Is it accurate?



# What is the purpose of the collection?

- It is critical to analyze and define the purposes of the collection at the outset.
- This will determine collection, use and disclosure issues.
- Prepare a privacy impact assessment.



# What other uses?

- There will be requests/demands to use the phi for other purposes:
  - Research
  - Law enforcement
  - Security
- How will these be dealt with?
- Who is in charge?



# A note on research...

- My opinion: existing processes for approving research are inadequate and out of date (ie overworked, under-resourced REBs).
- Databases like this are very attractive to researchers.
- There are ways of facilitating research while protecting personal health information:
  - CIHI
  - Statistics Canada
  - Among others.



# Planning: Who will the phi be disclosed to?

- Public health authorities
- Health care workers
- Law enforcement
- Security/intelligence
- Foreign governments
- Researchers

# Planning: Is it secure?

- Alberta law requires “reasonable” safeguards.
- Portables should be encrypted.



# Planning: Outsourcing

- The organization/custodian is responsible.
- Lots of materials available on outsourcing due diligence.



# Planning

- Given the number of laws and agencies involved, there should now be work being done on planning the systems or systems, working out the protocols and identifying the players.

# Privacy Resources

- Office of the Information and Privacy Commissioner
  - Telephone (780)422-6860
  - Toll free (888)878-4044
  - [www.oipc.ab.ca](http://www.oipc.ab.ca)
- Access and Privacy Branch Government Services
  - Telephone (780)644-7472
  - [www.psp.gov.ab.ca/pipa](http://www.psp.gov.ab.ca/pipa)

