

Office of the Privacy Commissioner of Canada



Prairie Health Information Privacy Day
Regina, Saskatchewan
April 16, 2007



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Commissariat
à la protection de
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Health Research & Privacy: Can they co-exist?

*Presentation by:
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Co-Existence ?

Co-existence

A Travelling Exhibition
of the Museum on the Seam

<http://www.coexistence.art.museum>



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Conclusion

**Health Research & Privacy:
Can they co-exist?**

Yes.



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Health Research & Privacy

Zooming IN



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Health Research: Relevant Laws

- Health Sector legislation
 - *Alberta, Manitoba, Saskatchewan*
- Public Sector legislation
 - *Federal, Alberta, Saskatchewan, Manitoba*
- Private Sector legislation
 - *Federal, Alberta*

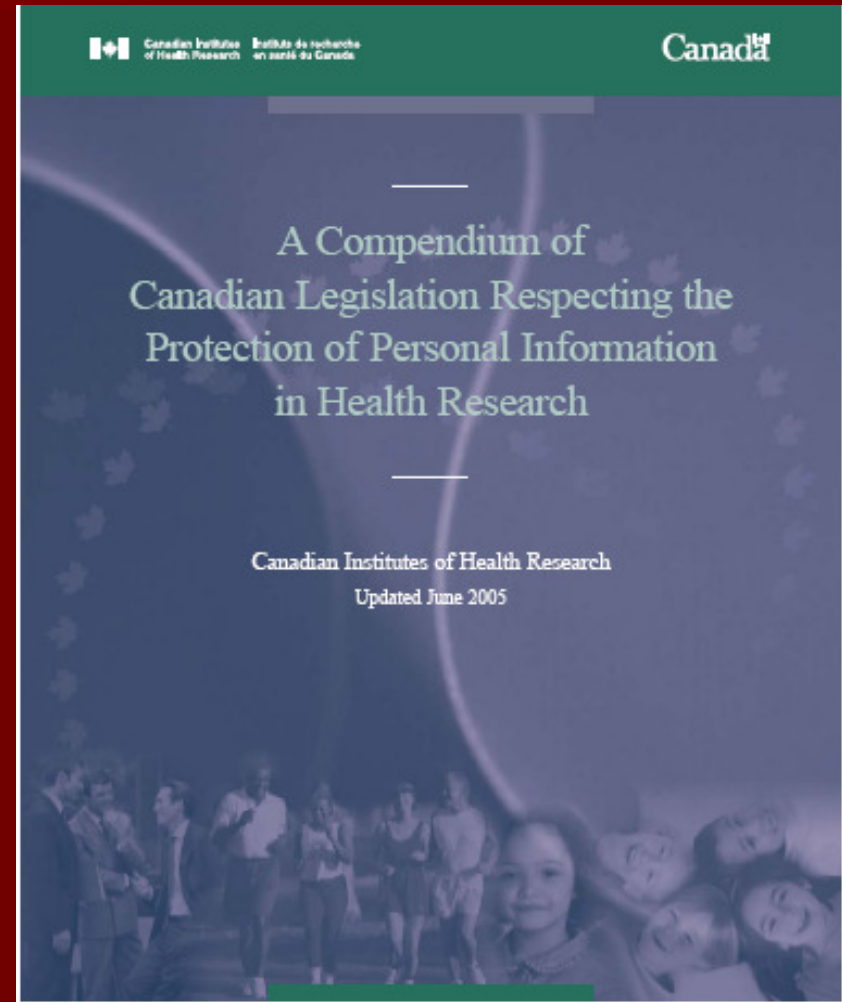


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Health Research: Privacy Laws

- Reference:
http://www.cihr-irsc.gc.ca/e/document_s/ethics_privacy_compendium_june2005_e.pdf

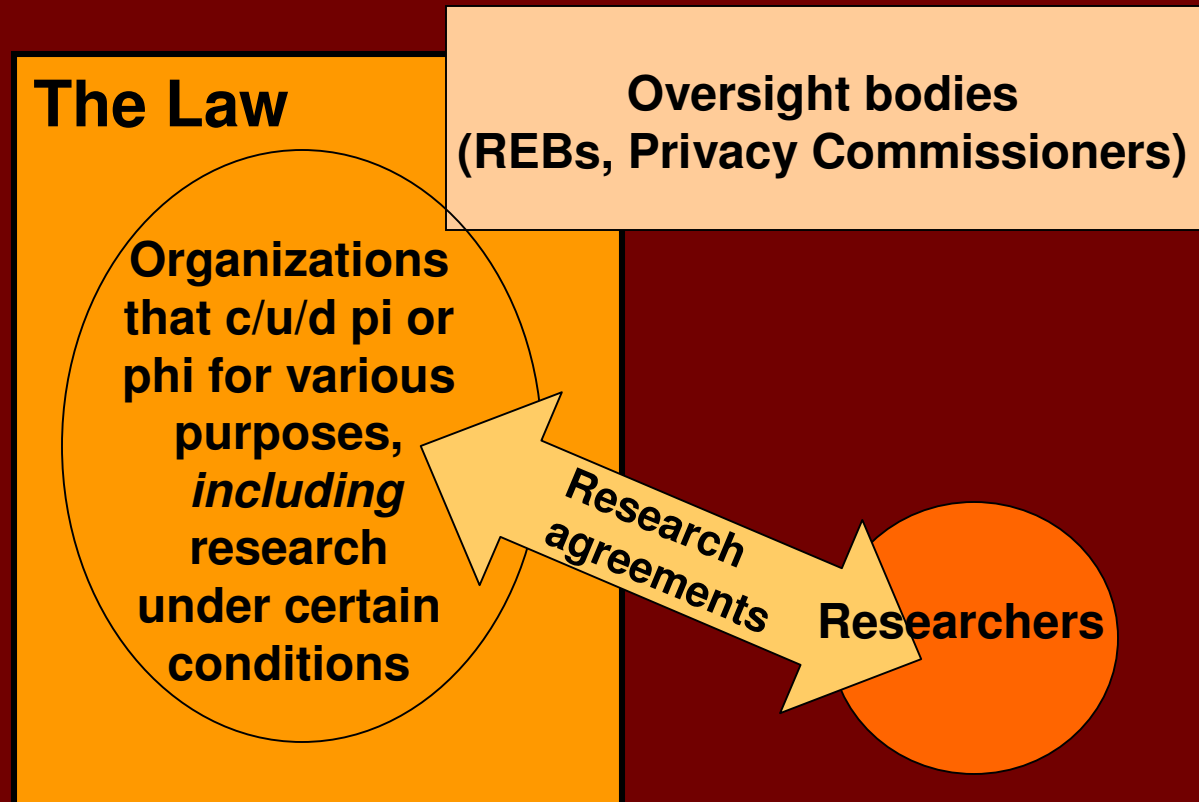


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Health Research: Privacy Laws

Typical Construct



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Health Research: Privacy Laws

General Overview

- Fair Information Principles form the backdrop of most Canadian laws
- Laws cover information about *identifiable* individuals
- Purpose must be legitimate, appropriate, reasonable
- Necessity/justification principle limits C/U/D of p(h)i
- As a general rule, C/U/D of p(h)i for research purposes requires informed consent
- Form and elements of consent may vary



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Health Research: Privacy Laws

- Non-consensual c/u/d of p(h)i for research purposes is allowed subject to conditions:
 - Obtaining consent is impracticable, unfeasible, unreasonable
 - Some harms/benefit analysis or public interest test
 - Researcher must be qualified to carry out the research
 - No contacting individuals without prior authorization
 - Some specific rules for data matching and linkage
 - Adequate safeguards for the security and protection of p(h)i
 - Research Confidentiality agreements to ensure compliance
 - Authorization/approval by health information custodian, REB and/or Privacy Commissioner



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Health Research: Privacy Policies

TCPS on Research
Involving Humans

CSA Model
Code

F/P/T
Legislation



CIHR
Best Practices
For Protecting
Privacy in
Health Research

Researchers

ICES & MCHP
Privacy Best
Practices for
Secondary
Data Use

Research
Ethics Boards

Health data
custodians



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Health Research & Privacy

Zooming OUT



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The “Bigger” Picture

- Health Research as a “Secondary Use”
- The New reality of an EHR world
- Creating longitudinal research databases: offering, respecting and *managing* consent preferences over the long-term
- Publicly available databases: assessing the possibility & *probability* of re-identification



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The “Bigger” Picture

- The growing threat and prevalence of ID theft : authentication and breach notification requirements
- “Sleepwalking” into a surveillance society: commercial exploitation, law enforcement and national security



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Questions / Discussion ?



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