

# Streamlining the Review and Resolution of Privacy Issues



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# What I am not addressing today...

- × Bioethics literature concerning research privacy
- × Critiques of current compliance requirements

✓ **Operationalizing research  
privacy procedures**

# Research privacy in BC: Key points

- Break down the silos that lead to “creeping” and compliance gaps.
- Refocus on proportionality and value added to the lifecycle of scientific research.
- Consider the benefits of research to the health care system and patients. Inaction is not value neutral.

# Research privacy in BC: Current state

- It can take years to compile required data from various data sources (if they ever get it).
- Researchers are often forced to pull data together in an ad hoc way, reduce the scope of their studies, modify their research questions, or exclude data from certain patient groups that are difficult to access.
- Not unusual for the informed consent of participants or REB decisions to be disregarded.

# Conceptual framework (participant centered)



Substantive ethics



Procedural ethics –we must hold up our end (we must demonstrate and maintain our expertise and be accountable!!)

# OIPC guidance regarding FIPPA and research



# Thoughts on rule following...



# Current focus of privacy review





# Autonomy and informed consent

➔ Full disclosure, individualistic models or consent to good governance (SREs, public engagement)?

*"My view is that the focus on consent in contemporary biomedical research has become the modern equivalent of a fetish"*

*- Barbara A. Koenig*

# Pan Canadian Research Privacy Network

- Goal: To facilitate efficient privacy reviews for Canadian multi-site research projects.
  - Hoping to develop guidance, tools, papers.....
- We are pleased to announce that the VPR Committee of HealthCareCAN endorses our Network and supports our efforts.

# Network members

Name	Role	Organization
Holly Longstaff	Chair	Research Privacy Advisor, Provincial Health Services Authority
Shelly Rempel-Rossum	Member	Research Ethics Board Coordinator, University of Manitoba
Karen Meelker	Member	Privacy officer, University of Manitoba
Stacey Page	Member	Assistant Professor, Dept. of Community Health Sciences, Cumming School of Medicine Chair, Conjoint Health Research Ethics Board University of Calgary
Shawna Weeks	Member	Interprofessional Practice, Education & Research, Saskatoon Health Region
Sandra Veenstra	Member	Ethics Director, Health Research Ethics Authority NL
Donna Roche	Member	Centre for Health Information (NLCHI) in NL
Susan Marlin	Member	President & CEO, Clinical Trials Ontario
Christina Popovich	Member	Privacy Specialist, Privacy & FOI Office, Hamilton Health Sciences
Madelaine Saginur	Member	Executive Director at Centre for Law, Technology and Society, University of Ottawa Office of the Privacy Commissioner of Canada
Jacquelyn Legere	Member	Regulatory Compliance Manager Research Services Horizon Health Network / Réseau de santé Horizon Providing services in New Brunswick, northern Nova Scotia and Prince Edward Island.

# Thank you

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