HDRN Canada Guidelines

How Privacy Compliance and Research Ethics Board Review/Approval Work Together



## Who are these guidelines for?

These guidelines are for researchers or research teams requesting access to administrative data held at HDRN Canada partner data centres or equivalent for the purpose of secondary use for research.

## What information do these guidelines provide?

These guidelines were developed to facilitate navigating between privacy legislation compliance requirements and the Canadian Tri-Council Policy Statement Ethical Conduct for Research Involving Humans TCPS2 2018 (TCPS2) as well as local Research Ethics Board requirements.

What is the relationship between privacy compliance and Research Ethics Boards?
Legislative privacy compliance and research ethics review are commonly two separate processes when requesting access to administrative data for research. Each review serves a unique but complementary role to protect research participants and their personal information.

While privacy compliance primarily addresses the right of the individual to control the information about oneself, research ethics policy provides an ethical lens balancing core principles of autonomy, beneficence, non-maleficence and justice.

The two elements work in tandem and reference each other in guiding documents. The TCPS2 states with respect to research ethics and law:

*“In addition to the principles and guidelines in this Policy, researchers are responsible for ascertaining and complying with all applicable legal and regulatory requirements with respect to consent and the protection of privacy of participants (Chapter 5). These legal and regulatory requirements may vary depending on the jurisdiction in Canada in which the research is being conducted, and who is funding and/or conducting the research. They may comprise constitutional, statutory, regulatory, common law, and/or international or legal requirements of jurisdictions outside of Canada. Where the research is considered to be a governmental activity, for example, standards for protecting privacy flowing from the Canadian Charter of Rights and Freedoms, federal privacy legislation and regulatory requirements would apply.”*

Conversely, various pieces of provincial/ territorial legislation reference the requirement to operate in conformity with the Tri-Council Policy Statement and or/or to have data access requests reviewed by area view body that meets the Tri-Council requirements.

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| **Where can I get more information or help with my REB and privacy compliance questions?** |
| For **research ethics** contact your local Research Ethics Board. | For **general inquiries** about privacy compliance please contact HDRN | info@hdrn.caSend us an e-mail |