

TOP 10 MISUNDERSTANDINGS

How Privacy Compliance & Research Ethics Board Approval work together for research using administrative data.



Réseau de recherche sur les données de santé du Canada
Health Data Research Network Canada

	<div>✕</div> <div>MYTH</div>	<div>✓</div> <div>FACT</div>	<div>i</div> <div>RESOURCES</div>
Privacy Compliance	<div>✕</div> <div>I have REB approval to access administrative data. I don't need to be concerned about privacy compliance/ REB approval by default.</div>	<div>✓</div> <div>Administrative data access requires both REB approval and privacy legislation compliance.</div>	<div>i</div> <div>Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS2 (2018)</div>
Participant Consent	<div>✕</div> <div>My region has a legislation consent waiver clause for secondary use of data, so I don't need to get consent from participants.</div>	<div>✓</div> <div>Legislation permits consent waivers only when compliance to a series of requirements has been met.</div>	<div>i</div> <div>Consent requirements - Privacy Legislation by Province or Territory</div>
Default REB Approval	<div>✕</div> <div>My data access request meets all the requirements in my region's legislation; so, by default, I will have REB approval.</div>	<div>✓</div> <div>Privacy compliance and REB requirements are not one and the same. They are addressing different obligations to ensure the rights and protection of human subjects in research.</div>	<div>i</div> <div><div>Always consult regional REB requirements.</div></div>
Multi-Regional Approval	<div>✕</div> <div>I have local REB approval, so I don't need to worry about REB or Privacy for other regions in my multi-region study.</div>	<div>✓</div> <div>Privacy requirements may be different across regions; requirements need to be met for each region in the study. In addition, regional REBs will ask to see confirmation of any other REB approvals granted.</div>	<div>i</div> <div>Privacy Legislation by Province or Territory</div>
Data Protection	<div>✕</div> <div>I do not need to list all the privacy safeguard details used to protect administrative data in my REB application or informed consent form.</div>	<div>✓</div> <div>Transparency of privacy safeguards is a requirement for both REB applications and informed consent. Details of data access and linking must be included in both.</div>	<div>i</div> <div>Guidelines: Informed Consent Wording for Administrative Data Linking</div>
Legal Compliance	<div>✕</div> <div>The obligation to protect the autonomy of my participants is more important than meeting legal compliance.</div>	<div>✓</div> <div>Legal compliance must be met.</div>	<div>i</div> <div>Guidelines: Informed Consent Wording for Administrative Data Linking</div>
Privacy vs. Confidentiality	<div>✕</div> <div>Privacy and confidentiality are the same thing.</div>	<div>✓</div> <div>Privacy is understood to be a human right while confidentiality describes information practices followed to ensure that privacy is protected.</div>	<div>i</div> <div>United Nations Declaration of Human Rights - see Article 12</div>
Data Access & Custody	<div>✕</div> <div>I have REB approval to access the data requested, so the data steward must give me access to the data.</div>	<div>✓</div> <div>Project approval by an REB does not guarantee access to data. In addition to REB approval, data stewards must ensure all the terms and conditions of access to data in their custody are met.</div>	<div>i</div> <div><div>Reach out to your data providers at the beginning of your research to ensure all terms and conditions of access can be met. Consult with the appropriate REB for clarification of requirements.</div></div>
Quality Assessment Requirements	<div>✕</div> <div>My work is a quality assessment; by default, I don't need REB approval.</div>	<div>✓</div> <div>Only an REB can determine if a project is considered research or not. In some cases, projects assumed to be quality assessment or other non-research activity may require REB approval depending on study objectives and other regional requirements. Always confirm if REB is required.</div>	<div>i</div> <div><div>Consult with the appropriate REB for clarification of requirements.</div></div>
Safeguarding Research	<div>✕</div> <div>Privacy and REB compliance requirements present barriers to my research work.</div>	<div>✓</div> <div>Requirements set for privacy and REB compliance are safeguards to protect human subjects, but they should not present barriers to research.</div>	<div>i</div> <div><div>HDRN is working to identify and find solutions towards facilitating better access to data for research use.</div></div>