Data Access



The <u>Indigenous Cognitive Health (ICH) Program</u> is part of the CCNA's Dementia Research Support Hub and its purpose is to promote respectful engagement between Indigenous communities and/or organizations and researchers. Researchers who are requesting permission to *access* or *publish* Indigenous data held by the CCNA will be asked to provide evidence of Indigenous engagement. Note: 'Indigenous data' includes any Indigenous-identified data or research related and relevant to Indigenous communities.

Are you requesting access to Indigenous data held by the CCNA? (this may include the base parcel of data)

- If yes, researchers will be expected to provide supportive documentation demonstrating the following:
 - Evidence of a strategy to ensure that the research project will benefit, and not harm,
 Indigenous Peoples and communities, both now and future generations;
 - o Meaningful engagement and support from relevant Indigenous communities;
 - That meaningful and respectful engagement with relevant Indigenous communities will continue throughout the duration of the project (i.e., data analysis, interpreting results, knowledge translation and exchange);
 - The existence of culturally safe data management plans, including: proof of necessity of access; recognition of Indigenous self-determination, data sovereignty, and the right to control what happens to Indigenous data throughout the research process (including its use, storage, and destruction); and accountability metrics.

Would you like to know more? Here are some relevant resources:

- Tri-Council Policy Statement
- CARE Principles for Indigenous data governance
- Dementia Indigenous Health Research Position Statement
- First Nations Data Centre Policies and Procedures
- Principles of Ethical Métis Research
- Inuit Qaujimajatuqangit

Publication



The <u>Indigenous Cognitive Health (ICH) Program</u> is part of the CCNA's Dementia Research Support Hub and its purpose is to promote respectful engagement between Indigenous communities and/or organizations and researchers. Researchers who are requesting permission to *access* or *publish* Indigenous data held by the CCNA will be asked to provide evidence of Indigenous engagement. Note: 'Indigenous data' includes any Indigenous-identified data or research related and relevant to Indigenous communities. Please indicate 'yes' below if your analysis will report Indigenous data as a (sub)category in the demographics or outcomes or elsewhere in the analysis.

Are Indigenous data included in the manuscript?

- If yes, researchers are expected to include an "Indigenous Engagement" section in the manuscript that outlines the following:
 - Any project-related Community- or Nation-specific approvals and/or letters of support;
 - Any project-related Community partnership, research, or data management agreements;
 - The role and contributions of Indigenous people and/or Communities with regards to each of the following project stages:
 - research question development,
 - study design and conduct (including choice of outcome measure and participant recruitment),
 - data analysis,
 - and disseminating results (namely, overall approach and knowledge translation, exchange and mobilization activities/outputs, including the writing of this manuscript).

Additionally, authors are encouraged to discuss the publication process with any relevant partners and collaborate on a plan that Indigenous communities and/or organizations support. This may include:

- Submitting to an open access journal;
- Ensuring the contributions of Indigenous people and/or Communities are reflected in authorship and/or acknowledgements. Indigenous authors are encouraged to include their Nations and/or Communities as well as academic affiliations;

• Ensuring any institutional and/or journal copyright requirements or implications have been discussed with Community partners.

Would you like to know more? Here is a list of relevant resources:

- Indigenous Community Research Partnerships Course (Queen's University)
- Dementia Indigenous Health Research Position Statement
- Canadian Journal of Public Health adopts requirement for meaningful engagement of First Nations, Inuit, Métis, and Indigenous Peoples
- Rural health journals collaborate on author cultural identity and Indigenous-centred research National Rural Health Alliance