Canadian Consortium on Neurodegeneration in Aging

Data Access Committee Policy

Version 1.0 approved by the CCNA Research Executive Committee (REC) on December 1, 2025

This document outlines CCNA's Data Access Committee Policy, which was previously part of the combined *Publications and Data Access Committee (PDAC)* Policy. For information specific to publications, please refer to the [Publications Policy](). *Note*: There may be some overlap in content across Policies.

Questions regarding the Data Access Committee Policy can be directed to CCNA Central Administration: ccna.central@gmail.com.

Principles

1.1. This document outlines the guiding principles and rules of engagement for the Data Access Committee (DAC) policy ("the Policy") developed by the Canadian Consortium on Neurodegeneration in Aging (CCNA). It delineates how the Policy will be operationalized to ensure the appropriate access and use of CCNA data;

1.2. The Policy guides the CCNA DAC in making fair, transparent, and explicit decisions on data access requests, while rendering decisions in a timely manner. Based on input from the CCNA Themes, Platforms, and Dementia Research Support Hub ("Hub") leaders, the DAC renders decisions on researchers' requests to access CCNA controlled data. The DAC must render their decision in accordance with the Policy, the DAC Terms of Reference, and its associated Evaluation Criteria. It consults with the Research Ethics Committee (REC) as needed to fulfill is functions;

1.3. The DAC will develop and oversee the implementation of the Policy. All researchers requesting CCNA data must adhere to the Policy;

1.4. The DAC is considered an overarching/unifying term, encompassing both COMPASS-ND (CND) and CAN-THUMBS UP (CTU): the CND-DASC and the CTU-DASC, respectively. Each subcommittee will manage data access requests relevant to their platform (see DAC Terms of Reference for details); and

1.5. The REC will have final approval of the Data Access Committee Policy.

2. **Revisions of the CCNA Data Access Policy**

2.1. The Policy will be formally reviewed every three (3) years by the DAC to confirm alignment with CCNA's overall mission, objectives, policies, and procedures; and

2.2. The Policy will be reviewed and may be revised by the DAC at any other time, for approval by the REC, if there are:

2.2.1. Changes in the CCNA research sites;

2.2.2. Changes to relevant CCNA policies and procedures or other aspects of CCNA, as deemed relevant by the DAC or the REC; or

2.2.3. Other ethical, legal, or operational changes that motivate or require its revision.

3. Data Use and Analysis

COMPASS-ND Specific Data Use and Analysis

3.1. The coded clinical, neuropsychological, imaging, biomarker, and genomic data from each COMPASS-ND testing site or laboratory within CCNA will be managed and uploaded centrally to the LORIS database. Other types of data, such as those derived from *in vitro* or *in vivo* model systems will also be uploaded to the LORIS database. Access to coded data and tissue samples for analysis is subject to the COMPASS-ND Data Use Agreement (for data) and to the CCNA Biological Sample Access Committee (BSAC) Policy (for biosamples) overseen by CCNA DAC and the BSAC, respectively. Both policies can be found on CCNA's website: https://ccna-ccnv.ca/policies/;

3.2. Internal analyses at each participating COMPASS-ND CCNA site may be undertaken on locally-acquired data for the purposes of quality control, training, or exploratory purposes. These analyses must be overseen by a COMPASS-ND site PI, and any ensuing Publication should adhere to the Publications Policy;

3.3. Access to and analyses of CCNA-acquired data by CCNA members, stored in LORIS and as part of the COMPASS-ND study, will be granted to researchers affiliated with Canadian Learning Institutions upon review and approval of a digital Data Access Request (available on LORIS). All Data Access Requests undergo a thorough review that includes the following steps: verification of researcher credentials, assessment of research feasibility, evaluation of the completeness of the request form, and relevance determination of the selected instruments to the stated research objectives. Requests that do not meet one or more of the criteria outlined above may be declined or returned to the applicant with a request for modification. Accordingly, any Data Access Request that has successfully completed the review and approval process shall be referred to as an "approved project";

3.4. The released data and the release dates will be announced on the LORIS Welcome Page, the COMPASS-ND website, newsletters (including CCNA's *La Capsule* and the COMPASS-ND Newsletter), and in e-mail communications;

3.5. The list of approved projects is available to researchers through a downloadable link in the Data Access Request Form on LORIS. Researchers submitting a new project proposal are encouraged to review this list and, where appropriate, establish communication with relevant investigators. To foster collaboration, researchers will be invited to collaborate in the use and analysis of COMPASS-ND acquired data in case of an overlap with an existing approved project. Nevertheless, in alignment with COMPASS-ND's commitment to promoting transparency and reproducibility in research, researchers are welcome to submit requests addressing research questions included in the approved project list. Data requests for all projects using COMPASS-ND data must be submitted via the Data Access Module on LORIS. For any assistance related to data access, please contact the COMPASS-ND Data Coordinator;

December 1, 2025	CCNA REC	V1 approved by CCNA REC

3.6. A subset of the broader COMPASS-ND data will be made available to the international research community through a registered-access platform to be first released by the end of 2026. Specific details pertaining to this process are being developed and will be made available on the CCNA website's COMPASS-ND page; and

3.7. Publication guidelines for manuscripts using COMPASS-ND data, including authorship acknowledgement of the "CCNA COMPASS-ND group" and the methodological papers that should be cited, are outlined in the section "COMPASS-ND Related Acknowledgements" in the Publications Policy.

CAN-THUMBS UP Specific Data Use and Analysis

3.8. A list of CTU protected planned projects and publications to be undertaken by the CTU Co-PIs, CTU co-investigators or CTU Steering Committee members using CTU-acquired data will be posted in the LORIS publication module. Any CTU investigator who worked on the project and wishes to analyze and subsequently publish data related to a question already listed in the "Protected planned projects and publications" will have priority to work on said project. Any other researcher must receive approval to join the designated writing group for that project to avoid duplication of the aims and methods of another CTU publication or wait until the "quarantine period" (see 3.11 has passed);

3.9. Access to and analyses of CTU-acquired data, stored in LORIS, may be granted to qualified persons 12 months after the principal paper(s) answering primary research questions is/are posted, hereby referred to as "the quarantine period". The quarantine period will be in effect for any investigators who are not participating as a member of the CTU Steering Committee or as a CTU co-investigator;

3.10. Following the end of the quarantine period and at the earliest possible time prior to pursuing a specific project based on CTU-acquired data, qualified persons as determined by the DAC may make a request for use of CTU datasets on the LORIS publications module or via email to CCNA Central Administration (ccna.central@gmail.com). Data will only be released after approval of project in the LORIS publications module by the DAC, with consultation from CTU leadership where necessary. If approval for the CTU Data Request is granted, they will only be granted access to data related to the project outlined. The requestor will have 6 months to produce a first draft after which another internal investigator will have an opportunity to publish;

3.11. If there is a competing research interest about granting access to data or publication, the case may be referred to the CTU Steering Committee for adjudication; and

3.12. Publication guidelines for manuscripts using data from the CAN-THUMBS UP study, including authorship acknowledgement of the "CCNA CAN-THUMBS UP Study Group" and the methodological paper that should be cited, are outlined in the section "CAN-THUMBS UP

Related Acknowledgements" in the Publications Policy.

4. Indigenous Publication and Data Access

4.1. An additional review process is required for accessing Indigenous (First Nations, Métis, and/or Inuit) self-identifiers in COMPASS-ND and CAN-THUMBS UP;

4.1.1. Indigenous Nations and populations have inherent rights to self-determination in research and data. This means that the Indigenous self-identifier variable must only be used when Indigenous Nations, populations or organizations are involved in the governance of the project and the research is reflective of the needs and priorities of Indigenous Peoples, as described and defined by Indigenous Peoples and/or communities;

4.1.2. Data access requests that include Indigenous identifiers will undergo an additional review to ensure that meaningful and respectful engagement with relevant Indigenous Peoples is integrated throughout the research process. The DAC and subcommittees will refer such data requests to a designated Indigenous Publication and Data Access (IPDA) review committee convened by the Indigenous Cognitive Health (ICH) program; and

4.1.3. Access and use of Indigenous data must respect and act in accordance to Tri-Council Policy Statement (TCPS) 2 Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada, https://ethics.gc.ca/eng/tcps2-eptc2_2018_chapter9-chapitre9.html.