



## **CAN-THUMBS UP (CTU)**

### **Data Sharing and Publications Committee Policy**

**Version 1.0**

***Approved by the CTU Steering Committee on [July 9, 2021]***

## **1. Principles**

- 1.1. The CAN-THUMBS UP (CTU) program is being conducted as a part of the Canadian Consortium on Neurodegeneration in Aging (CCNA), with funding from the Canadian Institutes of Health Research (CIHR) and other CCNA funding partners. This document outlines the guiding principles and rules of engagement for the Data Sharing and Publications Committee (DSPC) policy (“the Policy”) developed by the CAN-THUMBS UP Steering Committee (CTU SC) and CTU Co-Principal Investigators (CTU Co-PIs) for DSPC, a sub-committee of the CTU SC.
- 1.2. The DSPC establishes policies and procedures to implement sharing CTU data, as well as, policies and citations for publications for the use of CTU data. The intent of these policies is to facilitate data sharing with all qualified investigators, to encourage academic productivity, and to provide a mechanism for tracking and archiving data requests, intended analyses and publications related to, and resulting from, CTU data. It delineates how the Policy will be operationalized to ensure the appropriate use and dissemination of CTU data and appropriate credit for said use and dissemination;
- 1.3. The Policy is necessary to protect the reputations, interests and work undertaken by all CTU investigators, their institutions, the CIHR, the CCNA and other CCNA funding partners, and to foster and maintain trust between CTU investigators and research participants;
- 1.4. The Policy aims to be fair, transparent and explicit, while enabling decisions and publications in a timely manner. It will anticipate the majority of publication types and common publication scenarios but the CTU SC will retain the right to make decisions, after consultation with the DSPC, for unforeseen publication scenarios;
- 1.5. The DSPC will develop and oversee the implementation of the Policy. Intended publications using CTU acquired data must be reviewed by, and discussed with, the DSPC although this discussion need not require an in-person meeting (i.e., it could be conducted by email, telephone, WebEx etc.);
- 1.6. The DSPC will consist of a Chair and up to 6 CTU SC members and invitations to those with particular expertise, who will be rotated as required; and
- 1.7. The DSPC will report to the CTU SC.

## **2. Aims**

- 2.1. To facilitate and expand possibility of publications of CTU and coordinate a fair process in publications and authorship arising from CTU data.
- 2.2. To encourage best practices for the quality and reproducibility to maximize impact and visibility for CTU and to publish in a way that recognizes the individual efforts;

- 2.3. To facilitate and liaison with knowledge translation platform
- 2.4. To ensure each publication follow the rules of publication set by CTU
- 2.5. To track publication productivity and for CCNA central administration to maintain a central record of research outputs which is required for reporting to CIHR and other funding partners.

### **3. Expectations**

- 3.1. Those who have contributed to the work should be fairly represented and all papers will be published in accordance with the International Committee of Medical Journal Editors (ICMJE) authorship criteria (<http://www.icmje.org/recommendations/>);
- 3.2. All CTU co-investigators have the opportunity to be on all papers. An authorship block, named CCNA-CAN-THUMBS UP Study Group, will be used to involve and acknowledge all investigators who contributed to CTU.
- 3.3. CTU publications will be in line with the CIHR, NIH, and European Association of Science Editors guidelines for reporting on sex differences, and where appropriate gender differences, in human participants, cell lines, and experimental animals.

### **4. Revisions of the CTU Publications and Data Access policy**

- 4.1. The Policy will be formally reviewed annually by the DSPC and the CTU SC to confirm alignment with the CTU's overall mission, objectives and policies and procedures;
- 4.2. The Policy will be reviewed and may be revised by the DSPC at any other time or as requested by CTU SC.

### **5. Data use and analysis**

- 5.1. A distinction is made between publication and data analysis.
  - 5.1.1. The Policy does not in itself restrict analysis of CTU data, which might be with a view to publication but which might also be for training purposes, quality control, exploratory analysis, methods development or other reasons; and
- 5.5. A list of CTU protected planned projects and publications to be undertaken by the CTU Co-PIs, CTU co-investigators or CTU SC members using CTU-acquired data will be posted in LORIS publication module. Any CCNA investigator who wishes to analyze and subsequently publish data related to a question already listed in the "Protected planned projects and publications" 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 “embargo period” (see 5.6) has passed;

56. 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 published, hereby referred to as “the embargo period”. The embargo period will be in effect for any investigators who are not participating as a member of the CTU SC or as a CTU co-investigator.
57. Following the end of the embargo period and at the earliest possible time prior to pursuing a specific project based on CTU-acquired data, qualified persons as determined by the DSCP may make a request for use of CTU datasets on the LORIS publications module or via email to CCNA; Central Administration [ccna.admin@ladydavis.ca]. Data will only be released after approval of project in the LORIS publications module by the DSCP. If approval for the CTU Data Request is granted, the requestor will have 6 months to produce a first draft after which another internal investigator will have an opportunity to publish;
58. If there is overlapping research interest about granting access to data, the case may be referred to the CTU SC.

## **6. Publication and authorship**

### **6.1. Manuscript publication**

- 6.1.1. All manuscripts must undergo an administrative review by the DSCP before they can be submitted. This review will ensure that confidentiality is protected; that the publication is not a duplication of the aims and methods of another CTU publication; CCNA and of the contribution of investigators. It will also provide advice and feedback to authors where it may be helpful;
- 6.1.2. All authors considering publications of research conducted as part of CTU are to submit publications form according to LORIS publications module guidelines.
- 6.1.3. The DSCP will review all such material at scheduled monthly meetings and confirm approval to submit for publication, subject to any necessary amendments, to the lead author(s). It will be the responsibility of the lead author(s) to (i) notify the DSCP (through CTU Central administration) of the acceptance of any manuscript and forward a copy of the final version, together with details of the name of the journal where the manuscript has been accepted, and (ii) to ensure that all conditions with respect to publication have been met and appropriate acknowledgements are included;

- 6.1.4. Publications will follow CIHR policy regarding Open Access.  
<http://www.cihr-irsc.gc.ca/e/46068.html>.
- 6.2. Conference participation (including presentations, posters, and conference papers)
  - 621. All authors considering submitting conference abstracts based on data from the CTU study will need to submit publications form according LORIS publications module guidelines. Responsibility for the presentation materials lies with this PI, who must give final approval of materials to the lead author(s) before the conference. The lead author(s) shall notify the CTU Central administration of the acceptance of any conference abstracts with the date of the meeting and presenting author;
  - 622. The lead author(s) shall upload a late copy of any poster presentation and final abstract to the LORIS publications modules; and

## **7. Indigenous Data Access & Publication Policy**

### **7.1. Accessing Indigenous self-identifiers**

- 7.1.1. 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.
- 7.1.2. Data access requests that include Indigenous identifier will undergo an additional review, as part of the submission process, to ensure that meaningful and respectful engagement with relevant Indigenous Peoples is integrated throughout the research process. The DSPC will seek guidance from Indigenous persons with knowledge of Indigenous data sovereignty principles for the additional review process.
- 7.1.3. Access and use of Indigenous data must respect and act in accordance to 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](https://ethics.gc.ca/eng/tcps2-eptc2_2018_chapter9-chapitre9.html)

72. All manuscripts or other reports that include Indigenous identifiers must involve Indigenous Peoples to ensure that the analysis and interpretation of the CTU data are respectful and reflect Indigenous understandings and knowledges.

## **8. Publicity**

- 81. Any publications should go through the established publications module and adhere to the policy as mentioned above.
- 82. Press releases must refer to CTU and CCNA. Any parties considering dissemination (including press releases) of the details of the research and/or

results should notify via the publications module with oversight from DSPC of such intent and submit a draft for approval;

83. The DSPC will review all such outlines at regularly scheduled meetings, and notify of approval, subject to any necessary amendments, to the lead author;
84. In situations where a faster response is required (e.g., unexpected press interest), the request should be made directly to the CTU Co-PIs (with cc to the CCNA Central administration) for executive decision;
85. It will be the responsibility of the lead author to notify the CCNA Central administration with cc to the DSPC of the intended date of any such publication and to ensure that all data conditions with respect to publication have been met and appropriate acknowledgements are made (see section 8 for details); and
86. All members of CCNA and investigators requesting use of CTU data must adhere to publications embargos.

## **9. Acknowledgements**

91. The public web address for the CTU study may be given as [www.canthumbsup.ca](http://www.canthumbsup.ca)
92. Statements and acknowledgements to be included in publications
  - 9.2.1. Funding of CTU and CCNA by CIHR and other funding partners must be acknowledged;
  - 9.2.2. Exact wording may vary depending on the journals and the type of publication, but a default statement is: *The CAN-THUMBS UP Program and the Canadian Consortium on Neurodegeneration in Aging is supported by a grant from the Canadian Institutes of Health Research with funding from several partners.* The CCNA Central administration will ensure that the relevant funding partners are acknowledged in the manuscript when reviewing the document before it is submitted to journals;
  - 9.2.3. Other acknowledgements may refer to local or national bodies that have significantly contributed to the research in the form of students, participants, special groups, etc.

## **Signed acceptance of the CTU Data Sharing and Publications Policy**

After reading this document, please sign and return an electronic copy to the CCNA Central Administration [[ccna.admin@ladydavis.ca](mailto:ccna.admin@ladydavis.ca)] to confirm that you agree to its content.

Name (please print): \_\_\_\_\_

Institution: \_\_\_\_\_

I, the undersigned, acknowledge that I have read and understood this document and agree with its terms and conditions.

Signature: \_\_\_\_\_

Date: \_\_\_\_\_