



## Research Team Memorandum of Understanding

# Data Sharing and Data Security

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These Memorandum of Understanding documents are intended to guide the work of the Trans Youth CAN! Study. While each team member agrees in principle with the Memorandum of Understanding, it is considered a set of 'living documents', which may be revisited and revised throughout the life of our project. **Revisions to this document may require REB approval.**

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## Data Management and Confidentiality

Control of the full multi-site data set will be retained by the lead PI. Data ownership will be retained by the lead PI's institution, unless otherwise specified in interinstitutional agreements. Full copies of the data set may be retained by research team members who are core analysts, provided any necessary REB approvals and data transfer agreements are in place. Partial copies of the data set containing variables needed for specific analyses may be obtained by research team members through the procedures outlined above. Research team members who are clinicians may obtain raw data for specific analyses, provided their patients are not identifiable. These sets will not contain full date of birth, postal code, identifiable write-in text, or clinic. All team members may access aggregate data from statistical program outputs.

Each research team member (including trainee members) with access to raw data will sign a Data User Agreement. This will specify appropriate/inappropriate uses of data to maintain confidentiality, as well as details on access to, storage and destruction of data. Data sets must be encrypted during transfer, and may be stored only in approved secure locations.

## Data and Data Analysis Request Procedure

- a. Researchers requesting access to Trans Youth CAN! data must be members of the research team, as defined by the team's membership policy.
- b. All analyses using Trans Youth CAN! Data must be first approved by the Steering Committee. This includes analyses by team members who already have access to the data set. Research Team Members must submit a Concept Sheet containing the following (a template is available):
  - i. Provisional authorship team for the research, with lead(s) identified
  - ii. Research questions/objectives
  - iii. Rationale
  - iv. Proposed methodology

- v. Potential impacts of the research on trans youth, their families or communities, and other stakeholders
  - vi. Integrated knowledge translation and exchange strategy, including stakeholder involvements and type(s) of research products to be produced
  - vii. How the researchers' backgrounds and capacities will enable them to complete the project as planned
  - viii. A list of variables that will be needed to complete the analysis
  - ix. Which team members will have access to the raw data set
  - x. Whether any additional REB approvals or data transfer agreements are required
- c. The Concept Sheet will be submitted to the Project Coordinator, who will review the form for completeness, and upon acceptance will circulate it to the Steering Committee for review. Review will be based on the following criteria:
- i. Strength of the research objective(s)
  - ii. Alignment of the proposed analyses with the aims of the project
  - iii. Assessment that the project will benefit and not harm the communities under study
  - iv. Methodological appropriateness and rigour of the proposed analyses
  - v. Capacity of the researchers to undertake the project
  - vi. Lack of overlap with topic areas committed to other team members
  - vii. Capacity of the research team to provide the requested data and guidance for the project, given competing priorities
  - viii. Degree and quality of community and stakeholder involvement
  - ix. Quality of the knowledge translation plan
  - x. Potential for actionable impact
- d. Additional team members may be added by the Steering Committee to the project, in consultation with the authorship team, as deemed appropriate.
- e. The Steering Committee will have ten working days to review and discuss, and to either approve, request modifications, or deny the request.
- f. If the data request is approved and those who will complete the statistical analysis do not already have access to the full data set, the lead research team member on the Concept Sheet will be contacted by a data analyst from the team in order to discuss the analysis plan and confirm which variables are necessary for the project and the format in which the data set will be produced. Once the required data items have been identified, and Data User Agreements are signed and any additional REB approvals are in place, the data analyst will have ten working days to provide the research lead with the encrypted data, limited to variables needed for the analysis.
- g. At this point, the authorship team will have six months (with the option of a three month extension, pending approval from the Steering Committee) from the date of receiving the data (or from approval of the Concept Sheet, if data are already accessible to the researcher) to prepare and submit the research product(s) (e.g. a manuscript, conference presentation). Alterations to this timeline may be made by the Steering Committee if needed to fit the timelines of student thesis work. If the research team members do not submit their research product(s) within the allotted time, responsibility for analysis of that research topic may be re-assigned to other team members in order to ensure the team's priority research is conducted in a timely manner.

- h. Research outputs such as manuscripts, conference presentations, pamphlets or website materials will be reviewed and approved by the Steering Committee as per the team's policy.