



Research Team Memorandum of Understanding

Data Sharing and Security

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These Memorandum of Understanding documents are intended to guide the work of the Trans PULSE Canada 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.

Data Collection

Survey data collected or entered online will be encrypted for transmission via REDCap to a server at Western University. In the case that participants consent to recontact, they will be redirected to provide their information in a separate form, which will store the directly identifiable information in a separate database from the survey; both databases will contain a participant ID to allow for linkage for recontact for future studies. In the case of online data collected on a Peer Research Associate (PRA) tablet, tablets will be programmed to save an encrypted copy of the survey, in case of poor internet connection. Tablet encrypted copies will be digitally shredded immediately following confirmation of data receipt at Western University, which should occur within 2 business days of data collection. In cases where encrypted survey data are stored on the tablet and a participant wishes to consent for recontact, recontact information will not be stored on the same tablet, but collected via paper form and entered by the PRA directly into the REDCap recontact database when next connected to a network. The paper copy will be shredded.

Survey data collected via paper form will be returned by mail in pre-stamped, pre-addressed envelopes, and then entered into REDCap. If participants completing the survey on paper consent to recontact, they will complete a brief paper form matched to their paper survey by randomly-generated temporary potential participant ID number (separate from REDCap's sequential participant IDs). This form will be mailed to Western University in a separate pre-addressed and stamped envelope from the survey, either by a PRA or by the participant themselves.

During data collection, PRAs will store project cell phones, tablets, completed surveys, and consent forms according to Western University's Confidentiality and Data Security Policy. Paper surveys completed and returned to PRAs will be mailed to Western, and then entered digitally by

study staff. In the case that a paper survey returned to a PRA is accompanied by a completed recontact form, the recontact form will be mailed to Western in a separate envelope.

During PRA-administered data collection, participant confidentiality will be protected by a mandatory participant confidentiality agreement signed by all PRAs prior to contact with participants. This agreement is in addition to a mandatory confidentiality training for PRAs, to be completed in-person at Western University. Furthermore, in order to address potential power differentials between PRAs and participants, PRAs cannot recruit or administer surveys to individuals to whom they are currently providing one-on-one health or social services; we will endeavour to avoid hiring PRAs who may be in such conflict of interest situations to avoid having this become an issue.

Participants will have an option of completing the survey via telephone with a language interpreter, if needed, or via video call with an ASL interpreter. Professional interpreters are contracted through Access Alliance, and will sign confidentiality agreements.

Data Storage & Retention

During data collection, data will be stored in REDCap in servers on-site at Western University. After digital entry of paper survey and recontact data is completed, and following quality control testing, all paper will be physically shredded. Tablets will be collected from PRAs, and the drives will be securely wiped. Study data will be retained indefinitely on secure Western research servers, and for limited periods of time during data analysis on encrypted USBs or servers at other universities, as approved by institutional REBs. Encrypted participant recontact information will be stored in a separate database on secure Western servers for a period of 3 years after data collection (the maximum recontact period), at which time it will be digitally shredded. Only the PIs and the Project Coordinator will have access to decrypt this database.

Data Access

Only members of the study team's Data Analysis Working Group will have access to the full survey dataset. Access at sites other than Western University will be via encrypted USB, sent via courier, with data storage either on USB or other REB-approved locations. Data Transfer Agreements and Data User Agreements will be signed.

Team members requesting access to the data for a particular project must follow Trans PULSE Canada's internal data request procedure. In the case that investigators external to the research team wish to access Trans PULSE Canada data, they must first be approved by the Steering Committee to join the research team (including the Data Analysis Working Group), then proceed with the data request procedure. Should any application include a request for recontact, the lead applicant must demonstrate REB approval for the planned new study.

Conditions of Use

Data will be used for:

- Advancement of knowledge;
- Identification of future research questions;
- Making recommendations for policy and service provision; and
- Supporting knowledge transfer, advocacy in relation to social justice and the social determinants of health, organizational development and the promotion of leadership and involvement.

The data will not be used for:

- Individual or agency interests that are not related to the goals of the research
- Identification of individual data for personal or non-research use.

Data/Recontact Request Procedure

Please see [Application for Participant Recontact](#) and [Application for Data Access or Analysis](#).

Trainee Projects

Undergraduate, graduate students, and postdoctoral fellows under the supervision of a Trans PULSE Canada investigator are eligible to submit Concept Sheets. The investigator must guide and supervise all stages of the project, approving all materials before they are submitted to the Project Coordinator. Trainees must complete the Data Request Procedure before accessing data, even if the supervisor already has the data on-site.

Any presentations, posters, or manuscripts, produced by students using Trans PULSE Canada data must be reviewed first by the supervisor, and then by the Steering Committee. Note that trainee theses are not required to undergo final review by the Steering Committee, but any resultant publications in the grey or peer-reviewed literature must be approved.

Trainees are expected to create their own Terms of Reference document in conjunction with their supervisors. This document should explicitly outline:

- Proposed authorship and acknowledgement for all components of their project, following the Trans PULSE Canada [Authorship and Acknowledgement Policy](#).
- A commitment to create specific knowledge translation outputs (e.g., manuscript, community fact sheet) that will benefit the community, in accordance with community-based research principles.
- An agreement decreeing that if the trainee does not submit their research product(s) within a reasonable time frame, responsibility for completing the research project and its outputs may be reassigned to other team members in order to ensure the team's priority research is conducted in a timely manner. In these cases, the trainee may be moved to a secondary author.