

Data Use Agreement - Canadian Open Parkinson Network (C-OPN)

I request access to data collected by the Canadian Open Parkinson Network (C-OPN) for the purpose of scientific investigation, teaching, or the planning of clinical research studies and agree to the following terms:

1. I will receive specific de-identified data for the purpose of an ethics board approved project, and I will be using the data only for the purpose of the approved project by a C-OPN Review Committee.
2. I will receive de-identified data and will not attempt to establish the identity of or attempt to contact any of the C-OPN participants.
3. I will not further disclose these data beyond the uses outlined in this agreement and my data use application.
4. I will require anyone on my team who utilizes these data or anyone with whom I share these data to comply with this Data Use Agreement and provide a signed Agreement to the National Manager.
5. I will accurately provide the requested information for persons who will use these data and the analyses that are planned utilizing these data.
6. I will comply with any rules and regulations imposed by my institution and its institutional review board in requesting these data.
7. I will respond promptly and accurately to annual requests to update this information.

If I publish abstracts using data from C-OPN, I agree to the following:

8. I will cite C-OPN as the source of data in the abstract.

If I seek to publish manuscripts using data from C-OPN, I agree to the following:

9. In manuscripts utilizing C-OPN data, I will acknowledge the work by C-OPN personnel that went into accumulating the data. On the by-line of the manuscript, I will include the phrase “for the Canadian Open Parkinson Network*” with asterisk referring to the following statement and list of names:

**Data used in the preparation of this article were obtained from the Canadian Open Parkinson Network (C-OPN) database (www.COPN-RPCO.ca). As such, the investigators within the C-OPN contributed to the design and implementation of C-OPN provided data but did not participate in analysis or writing of this report. We gratefully acknowledge the funding support for this research from Parkinson Canada. A complete listing of C-OPN investigators can be found at: <https://copn-rpco.ca/>*

10. I will include language similar to the following in the methods section of my manuscripts in order to accurately acknowledge data gathering by the C-OPN personnel. Depending upon the length and focus of the article, it may be appropriate to include more or less than the example below, however inclusion of some variation of the language shown below is mandatory.

Data used in the preparation of this article were obtained from the Canadian Open Parkinson Network (C-OPN) database (<https://copn-rpco.ca/research/>). The C-OPN was launched in 2020 as a unique pan-Canadian initiative bridging people, resources, and data to accelerate Parkinson's disease discoveries through generous contribution from Parkinson Canada and Brain Canada. C-OPN study data were collected and managed using REDCap electronic data capture tools hosted at the University of Calgary. For up-to-date information see <https://copn-rpco.ca/>

11. I will ensure that Investigators who utilize C-OPN data use appropriate administrative, physical, and technical safeguards to prevent use or disclosure of the data other than as provided for by this Agreement and will promptly report any use or disclosure of data that does not comply with the guidelines established by this Agreement.
12. I will submit all manuscripts to the C-OPN National Manager before submitting them to a journal to track the usage of C-OPN database for reporting purposes. This process is intended to ensure that items 6-11 above are correctly implemented.

Finally, due to the dynamic nature of the C-OPN database, in the event that I receive data from the C-OPN for the purposes of analysis and future publication in the form of abstracts and/or manuscripts, I will note the version of the data I receive, and I will check the database to determine if updated data has been provided prior to submission of any material for publication.

I understand that failure to abide by these guidelines may result in termination of my privileges to access C-OPN data.

☐ I agree

☐ I disagree

First and Last Name

Name of the Institution

Signature _____

Date: _____