



Investigator Toolkit

Note to the investigator. Leveraging on a partnership with C-OPN when applying for a grant provides several benefits:

- 1) Demonstrating the feasibility of accessing data and biospecimen samples through our existing biobank (DNA, serum and PBMCs only) and data bank, as well as the possibility of collecting new specific samples and data rapidly through our highly efficient team across ten current sites in Canada.
- 2) Demonstrating connexion to the research community, enhanced visibility, as well as impact (C-OPN can broaden reach and can help disseminate research findings)
- 3) Demonstrating data or samples collected will have a second utility.
- 4) Demonstrating access to specialized Infrastructure: advanced laboratories through members, data repositories (LORIS, C-BIG, REDCap), computing clusters, specialized research equipment through our network members.
- 5) Access to increased funding opportunities through C-OPN (internal grants, fellowships, announcement on external grant opportunities and other forms of financial assistance)
- 6) Additional opportunities for collaboration with other C-OPN members who may have complementary skills or access to unique data, equipment, or facilities can also be achieved. This collaboration can enrich the research project and lead to more innovative and impactful outcomes.
- 7) Demonstrating knowledge sharing and training (workshops, conferences, seminars, and training programs organized by the network).

1. Ethics

C-OPN approval includes de-identified data and biospecimens from the following sites:

- University of British Columbia (Vancouver, BC)
- University of Calgary (Calgary, AB)
- University of Alberta (Edmonton, AB)
- University of Ottawa/The Ottawa Hospital (Ottawa, ON)
- University of Toronto/University Health Network/Toronto Western Hospital (Toronto, ON)
- Western University (London, ON)
- McGill University (Montreal, QC)
- University of Montreal (Montreal, QC)
- University of Laval (Quebec, QC)
- Clinique Neuro-Lévis (Lévis, QC)

- University of Sherbrooke (Sherbrooke, Qc) *future site (2023)
- Dalhousie University (Halifax, NS) *future site (2023-24)

Note that the researcher does not need to be affiliated with one of the above-mentioned sites in order to utilize C-OPN resources.

2. Existing infrastructures

The Canadian Open Parkinson Network (C-OPN) is currently recruiting for the following categories:

- People living with Parkinson’s disease,
- People with atypical forms of Parkinsonism (i.e. Progressive Supranuclear Palsy, Multiple System Atrophy, Corticobasal Syndrome, Dementia with Lewy Bodies, Frontotemporal Dementia, Essential Tremor, REM Sleep Behaviour Disorder, Other),
- Healthy volunteers (healthy controls).

3. Database

Researchers gain access to de-identified data from approximately 1500 participants enrolled in the Canadian Open Parkinson Network (C-OPN). The following information is collected via REDCap by C-OPN:

- Demographics (ethnicity, race, gender, age, etc.)
- Epidemiology (living and work environment, environmental exposures, alcohol consumption, etc.)
- Clinical data (date of disease onset, first symptoms, current symptoms, symptom asymmetry, etc.)
- Current medications
- MDS-UPDRS
- MoCA

4. C-OPN /C-BIG Biobank

Researchers gain access to de-identified DNA/serum/PBMC samples (extracted from whole blood) from close to 1500 participants enrolled in the Canadian Open Parkinson Network (C-OPN). All biobank samples can be linked to de-identified data of each C-OPN participant.

C-BIG Cost Recovery Fee Schedule*

	McGill (60% discount)	Academia outside McGill (40% discount)
PBMC	\$600.00	\$720.00
Serum	\$140.00	\$210.00
DNA	\$180.00	\$270.00

*Fees are subject to change

5. Registry

Researchers are able to expediate subject recruitment via the Canadian Open Parkinson Network (C-OPN) Registry, which facilitates study promotion to close to 1500 participants enrolled pending approval of the C-OPN Review Committee of their study. C-OPN reports a 20-30% positive response rate, which means if 1500 participants are emailed about the study, approximately 280 participants may be recruited to participate and complete the study protocol.

Researchers are encouraged to contact the National Manager of C-OPN for publication policies and all other inquiries at national.manager@copn-rpco.ca