661 University Avenue, Suite 460
MaRS Centre, West Tower
Toronto, Ontario
M5G 1M1 Canada
www.ctontario.ca

Documented Institutional Ethics Requirements
Neurocentre of Eastern Ontario (NEO)

Scope

At the Neurocentre of Eastern Ontario (NEO), our multi-centered clinical trials focus on advancing treatments for a wide range of neurological conditions. Our Clinical Investigation Hub (CIH) areas include epilepsy and seizure disorders, stroke prevention and management, Parkinson's disease and movement disorders, multiple sclerosis, cognitive disorders such as dementia and Alzheimer's disease, neuropathy and peripheral nerve disorders, migraine and headache management, tremor and essential tremor, neurocognitive and psychological health impacts of neurological conditions, balance and gait disorders, and chronic pain syndromes.

Our research in these areas integrates innovative therapeutic approaches and advanced medical technologies, ensuring a focus on improving patient outcomes and advancing neurological care.

Missions and Values

At the Neurocentre of Eastern Ontario (NEO), we aim to align our research objectives with our clinical mission. The integration of patient care with scientific innovation allows our investigators to recruit from a large and diverse patient population, enabling the production of high-quality and timely research that benefits both science and the patients we serve. Our research priorities are based on: (a) projected patient outcomes, (b) scientific relevance, (c) cost-benefit analysis, (d) available capacity and resources, and (e) safety considerations. Our investigators frequently publish in leading medical journals, and our extensive network of partnerships spans regional, national, and international research collaborations.

Privacy Considerations

The **Neurocentre of Eastern Ontario (NEO)** is committed to upholding the highest standards of privacy and confidentiality in the management of personal health information (PHI). We recognize the importance of protecting patient information and ensuring it is handled responsibly and in compliance with the Ontario Personal Health Information Protection Act (PHIPA) and other relevant laws and regulations.

Our primary goal is to ensure that PHI is used only for the purpose of providing or supporting personalized health care. This includes collecting, using, and sharing PHI when necessary to deliver appropriate medical services and treatments. All members of our staff are bound by strict privacy policies and can only access or use PHI to the extent required by their specific job duties. This ensures that patient information is handled responsibly, securely, and only by those who are directly involved in the patient's care.

The policies and procedures at NEO apply to all forms of PHI, which include:

- **Electronic records**: Data stored and managed in electronic medical records (EMR) systems, online patient portals, and other digital platforms.
- **Verbal information**: Conversations about patient care among healthcare providers, which are conducted in a confidential and secure manner.
- **Written records**: Physical documents, including medical charts, test results, and consent forms, that are stored and handled according to strict security protocols.

Consent Model

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NEO operates under an **implied consent** model for health care, meaning that by seeking medical services at our facility, patients are generally understood to have consented to the collection, use, and sharing of their PHI for the purposes of their care. However, **informed and knowledgeable consent** is always obtained in specific situations where it is required by law or involves the disclosure of sensitive information to third parties.

Disclosure Without Consent

While NEO seeks patient consent whenever possible, there are certain situations where PHI may be collected, used, or disclosed without patient knowledge or explicit consent. This occurs only in cases where it is **permitted or required by law**, such as:

- **Public health and safety reasons**: In situations where PHI is needed to address public health concerns, such as reporting certain infectious diseases to public health authorities.
- **Legal obligations**: When required by court orders, subpoenas, or other legal proceedings.
- **Emergencies**: If it is necessary to protect the life or health of a patient or another individual in urgent circumstances.

Informed Consent Form Requirements

Consent to access medical records for research purposes is a standard requirement. All patients are required to sign the “Consent for Release of Health Care Information” form. This consent covers “health care information,” which includes, but is not limited to, all details related to a patient’s healthcare, such as appointment records, medication instructions, authority to access laboratory tests, medication lists from pharmacies, consultation notes, progress notes, radiology reports, and laboratory test results. Patients are also encouraged to review the privacy policy carefully.

Access to Medical Records and Obtaining Consent

For the duration of the clinical study and up to 25 years after its conclusion, clinical trial staff at the sites will require access to medical records strictly for trial-related purposes. During this period, records may be reviewed at the request of the Health Canada, Study sponsor or Ethics Committee to gather additional information or clarify any serious adverse events. While the study is ongoing, only authorized study personnel will have access to specific health information, solely for the purpose of verifying study-related data.

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SRERS Administration
Neurocentre of Eastern Ontario (NEO)

Reminder: Institutional Research Administration Requirements

The CTO Streamlined System provides a streamlined approach to research ethics review. Each participating site must ensure that all necessary institutional authorizations and contracts/agreements are in place prior to beginning the research.

CTO Stream

Collaborators:

The following collaborators must be given a role on all Provincial Initial Application (PIA) forms and Centre Initial Application (CIA) forms.

Email: ramanaappireddy@neoclinic.ca
Role: Institutional Representative

This access is automatically granted when the Centre Initial Application is created. **When Neurocentre of Eastern Ontario is the Provincial Applicant site the research team should immediately create the CIA for Neurocentre of Eastern Ontario (right after creating the PIA)**. This will ensure that access is automatically granted as required above, otherwise the research team will need to manually add these roles to the PIA prior to submission.

Institution Representative in application forms

The Primary Institution Representative must be indicated as follows in the applications within CTO Stream:

Title:	Dr
First Name:	Ramana
Surname:	Appireddy
Organization:	Neurocentre of Eastern Ontario
Address:	722 Arlington Park Place
City:	Kingston
Province/State:	ON
Postcode/Zip:	K7M8H9
Telephone:	613-383-2393
Fax:	613-542-0610
Email:	ramanaappireddy@neoclinic.ca