

Letter of Information (online)

Project Title: OurBrainsCAN: University of Western Ontario's Cognitive Neuroscience Research Registry

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In this Consent document, “you” always refers to the study participant. If you are signing up as a substitute decision maker (SDM) (i.e. for a minor or an adult for whom you are legal guardian of), please remember that “you” refers to the participant though you are being asked to review this letter and consent on behalf of the participant.

Many research groups at Western study cognitive functions like learning, memory, perception, attention and language in children and adults. These studies teach us how the brain works. They provide crucial information that may allow researchers to develop novel therapies for brain and mental disorders, as well as more sensitive tests so disorders can be identified and treated sooner. BrainsCAN is a neuroscience research initiative funded by the Government of Canada that aims to transform the way brain diseases and disorders are understood, diagnosed and treated.

Volunteers like you are key partners in this research: without you, this essential work can't happen. The goal of OurBrainsCAN, which is supported by BrainsCAN, is to establish a registry of potential participants for health-related research at the University of Western Ontario. Our brains can work together to understand how we learn, think, move and communicate in order to reduce the burden of brain disorders. We aim to enrol 50,000 volunteers over a period of 5 years.

If you agree to participate in the registry, we will collect some information about you, including contact details. You are free to leave any question on the questionnaire following the registration portion unanswered, and you may request to have your name and details removed from the registry at any time. Your information will be stored in a secure, password-protected database using Ripple Science software. Ripple is a participant recruitment and management software committed to ensuring the confidentiality, privacy, integrity, and availability of the information. All the information that you choose to share will be kept private and confidential with access limited to cognitive neuroscience researchers affiliated with BrainsCAN. The records are used only for the purpose of recruiting research

participants and will not be released to any third party. The registry coordinator(s) will administer the registry and match potential participants to individual studies according to eligibility using the information you provide. The researchers will also use Ripple to access their own studies and get contact information to invite potential participants.

When you are invited to participate in a research study, you will be given a full description of what your involvement would entail. You are, of course, free to turn down any request. You can also browse through the active studies in this website without registering and contact the study personnel directly.

There are no known or anticipated risks or discomforts, or direct benefits, associated with your participation in this registry. You may be invited to participate in future research studies because of the information you enter. The risks and benefits of these studies will be explained to you before you decide whether or not to participate.

If you have any questions about the registry, or would like more information, please contact ourbrainscan@uwo.ca.

You can also contact us at any time to change your preferences (e.g. frequency of invitations) or to delete your information from our registry.

If you have any questions about your rights as a research participant you may contact the Office of Research Ethics (519) 661-3036, email: ethics@uwo.ca.

Thank you for your interest and support of our research.

You can register as a participant by filling in the OurBrainsCAN online questionnaire (~15min to complete). By clicking on either button below you are indicating your consent to participate. I am signing up for:

Myself

As a Parent/Legal Guardian

If you are consenting on behalf of a minor or an adult for whom you are legal guardian of who has the capacity to assent but cannot read the main Letter of Information please also review the [Letter of Assent](#) with them.