



FAQ:

research ethics

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Intro

For many of us, scientific research seems mysterious and raises plenty of questions. What are the practical purposes of research? How do research projects take place? Which specific issues must researchers consider? Though a far cry from lab rats and the iconic white coat-clad, disheveled scientist, we invite you for a second time to come along as we take a closer look into the world of autism neuroscience research.

Introduction of the article

Research ethics is a large and indispensable part of developing and conducting research projects on human beings. It is a code of conduct of sorts, meant for researchers and based on values of respect, justice, personal well-being, and all other principles underlying human dignity. In order to ensure that ethical considerations are taken into account in research projects involving human beings, all projects without exception are subjected to rigorous assessment by a Research Ethics Committee (REC).

Here are five questions related to research ethics, which are often asked by people who participate in projects conducted by the Montreal Cognitive Neuroscience and Autism Research Group.

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Références:

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Gouvernement du Canada. (2014). Énoncé politique des Trois Conseils: Éthique de la recherche avec des êtres humains. Repéré à http://www.ger.ethique.gc.ca/pdf/fra/eptc2-2014/EPTC_2_FINAL_Web.pdf

Questions and answers

1 How can I make sure that a project I would like to participate in has been approved by an REC?

When an REC approves a research project that will take place in one of its establishments, it stamps the consent form with a seal of approval, which includes the date of final approval.

2 Why is it important to read the information and consent form prior to participating in research?

It is crucial that you take the necessary time to read the information and consent form before participating, in order to give *informed consent*. This form contains all the information you need to understand what your participation implies, such as what will be required of you, benefits of participating, risks and inconveniences, and freedom to withdraw at any point. If anything remains unclear or you have any questions about the form, do not hesitate to address all questions to the researcher or their representative, until you receive satisfactory answers that allow for an informed decision to participate in the study. Signing the consent form confirms that you have read and understood it, that your questions have been answered and that you consent to participate in the study according to the described terms and conditions... which is why it is so important to read them!

3 I would like for my child to participate in a research project. My child is underaged, must they still provide consent?


Underaged participants are considered a vulnerable population, which includes any person with diminished

decision-making abilities, due to their young age or mental state. Therefore, a parent or guardian must consent for the child to participate in the study. However, in cases where a child is able to comprehend the nature of their participation, their verbal or written assent will be taken into account.

4 If I participate in a research project, will my personal information be made publicly available?

La confidentialité et le respect de la vie privée sont des principes cruciaux en éthique de la recherche. Le chercheur ne peut communiquer les données recueillies sur un participant à une autre personne sans son consentement et se doit de protéger ces données. Les mesures prises par le chercheur pour respecter la confidentialité varient selon la nature des projets de recherche et sont énoncées dans le formulaire d'information et de consentement. Concrètement, il pourrait s'agir par exemple de « coder » les renseignements personnels, c'est-à-dire d'attribuer un code au participant pour remplacer son nom, ou de recueillir les données de façon anonyme, de sorte qu'aucun renseignement permettant d'identifier la personne ne soit consigné.

5 Why do some studies financially compensate participants?

Monetary compensations are provided in certain research projects in order to "compensate" for any inconveniences, such as travel and time commitments. For example, this could be a fixed sum of money, reimbursement for parking or travel, or sometimes an hourly sum. 



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