

Informed Consent Form

Name of Study: Accessible Information for Intellectual and Developmental Disabilities: Advancing Canadian Communications Standards

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Introduction

Thank you for your interest in this research project. This form includes information you should know before you decide if you want to do the study, including:

1. Why we are doing this project;
2. What you will be asked to do;
3. Benefits (the good things that can happen if you do the study);
4. Potential risks (things that might be hard about doing this study);
5. Information about privacy and confidentiality (how we will keep your information private and secure);
6. Information about the optional raffle for prizes; and
7. Who to contact with questions.

You can take as much time as you need to make your decision. Before you make your decision, feel free to talk about this study with anyone you want to, such as a friend or a family member. You can also contact the research staff listed on the first page; they can explain anything that you do not understand and make sure that all of your questions have been answered before continuing with the survey.

Please contact Sabrina Campanella (research staff) listed on the first page if you require assistance via phone or WebEx.

Participation in this study is voluntary and you can stop at any time. That means you are deciding to do it on your own and you do not have to do it.

1. Why are we doing this project?

A group of researchers is doing this project to learn about how people with intellectual and developmental disabilities find, understand, and use information from the Government of Canada.

It is important that the information the Government shares is easy to find and easy to understand. We also want to make sure that people are given the information they need in a way that helps them to take action. We want to know:

- Where do you go when you want to find Government-related information?
- How do you like to receive that information – for example, information that is easy to read, found online or printed, and that uses pictures, video, or audio recordings?

- How do caregivers of people with intellectual and developmental disabilities support their loved one or client when finding, understanding, and using Government information?

The information you provide will help us tell the Government of Canada how to create and share information for people with intellectual and developmental disabilities that is easy to find, understand, and use.

2. What will I be asked to do?

- If you decide to participate, you will be asked to fill out a survey that will take around 20 to 30 minutes to complete.
- You can complete the survey online, or you can contact us for a paper copy of the survey.
- The survey is anonymous and we will not be able to connect your name to your survey answers.

Voluntary Participation

- Participation in this study is voluntary. This means it's your choice on whether you want to fill out the survey.
- You can choose to skip any of the questions if you don't want to answer them.
- If you change your mind, you can stop the survey at any time and it will not affect services you or your caregivers get at CAMH.
- Your health care providers will not know if you do this or not.

3. Benefits: What are the possible good outcomes in participating in this study?

We hope this project will make things better for people with intellectual and developmental disabilities who want to find and use government information. The benefits or results of this study may help you and other people in the future.

4. Potential risks: What are the possible harms of participating in this study?

There should not be any problems in being part of this research project. Finishing the survey will not take a lot of time. You can take as much time as you need to answer questions. You can skip any questions you do not feel comfortable answering.

There is a small chance that some survey questions may remind you of frustrating experiences. If that happens, you can skip the questions, talk to someone you trust, or contact the research team for guidance and support.

We cannot guarantee the security of information sent by email. Please do not communicate personal sensitive information by email.

5. What will happen to my responses and personal information?

- The study is anonymous. This means the researchers will not know which survey belongs to you.
- Only some researchers at CAMH will have access to your responses. This includes the people listed on the contact information page of this form and other select staff from CAMH research departments, including the Research Ethics Board and the Research Quality Assurance Office.
- CAMH researchers will look at the data or information for research-related purposes (for example, analyzing or studying survey responses).

How will my information be kept confidential?

- We will not collect any personal identifying information in our survey, including birthdate, email address, mailing address, health card, or medical record number.
- You may ask for our help over the phone or by email; our contact information can be found on Page 1. We will not ask for any personal information.
- Because the survey is anonymous we will not be able to remove your responses from the project once you submit them.
- If you request a paper survey, we will delete your mailing address from our records once we mail you the research package.

6. Compensation

At the end of the survey, you will have the opportunity to enter a raffle to win one (1) of twelve (12) prizes consisting of \$25 e-gift cards from various retailers (e.g. Walmart, Amazon, Loblaws, Tim Hortons).

How do I enter the raffle?

- After you finish the survey, you will have an option to enter a raffle for an e-gift card.
- If you would like to enter the raffle, you will click on a link that will take you to a different webpage, separate from your survey responses. You will be asked to provide your email address or phone number to enter the raffle.
- Your survey responses will not be connected to your email address or phone number.
- You will also be asked if you are interested in receiving additional resources or being contacted about future studies
- If you choose to have your contact information used only for the raffle draw, once we announce the winners of the raffle, we will delete your email or phone information.

Publication of Results

At the end of the study, the researchers will share the results through conferences and/or academic publications. No one will know who you are from anything we write or present about this study. If you want to receive a copy of the results of this study, please email Dr. Yona Lunsky (yona.lunsky@camh.ca) and we will be happy to send the results to you at the end of the study.

Conflict of Interest

The researchers want to do this study. But just because they want to do this study doesn't mean you have to want to be part of the study. It is still your choice if you want to participate or not.

7. Study Contacts for Questions and Concerns

You may contact Dr. Yona Lunsky (yona.lunsky@camh.ca / 416-535-8501 x 37813), at any time if you have questions about this research or if you decide to withdraw from this research.

If you have questions about your rights as a participant or about ethical issues related to this study, you can talk to someone who is not involved in the study at all. That person is the Chair of the Research Ethics Board (REB). The REB is a group of people responsible for the ethical oversight of this study. The Chair of the REB can be reached by telephone at 416-535-8501 ext. 34020.

Informed Consent

If you consent to participate in this study, click “Yes” below. Afterward, press “Submit” at the bottom of this page to continue the survey.

If you click submit, it means that:

- You voluntarily agree to take part in the survey and have your anonymous responses recorded and studied.
- You have been given enough time to consider whether or not to take part in this research study.
- You understand that you may choose not to participate in this research study at any time. This will not have any negative consequences or affect any future involvement with CAMH.
- You understand that your consent does not take away or waive any of your legal rights, nor does it take away or relieve the research team from any legal responsibility.
- You have read and understood this entire consent form.

Please download a copy of this consent form for your files before clicking on your choice. Your email address will not be saved.

Would you like to participate in this study?

Yes, I **CONSENT** to participate in the survey for this research study.

Do you agree to have your research data analyzed for other related studies at CAMH?

Yes, I **CONSENT** to have my anonymous data analyzed for other related studies at CAMH.

No, I do not want my data to be analyzed for other studies at CAMH.

If you do not wish to take part, please close this window and do not complete this consent form.

Click submit to proceed to the survey.