

Research Fact Sheets Series

Fact Sheet #4

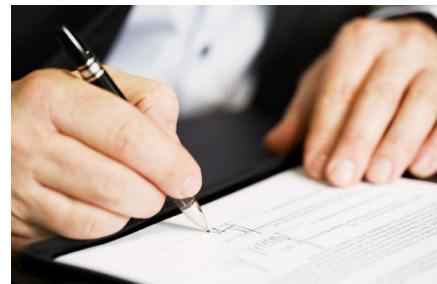
Informed Consent

What is informed consent?

Giving consent means that you agree to something. For example, if a friend knocks on your door and asks if they can come in and you say yes, you consent to have them enter your home.

Informed consent is a bit different than regular consent. It means that you have been prepared with information and knowledge before you give your consent, or agree. For example, when you open a bank account, you agree to follow the banking rules; when you go to the doctor's you review all the information about the treatment options with your doctor and give your informed consent to be treated.

Anyone taking part in research also gives informed consent before they begin participating. To make sure the participant is giving informed consent the researcher will explain information about the project and answer any questions the participant may have.



The type of information the researcher explains usually includes:

- the purpose of the study
- what the researcher will be asking the participant to do
- how much time participating will take
- the possible risks, harms, discomforts, and inconvenience for the participant
- the possible benefits to the participant, or society, from the study
- information about how the researcher will keep the participants personal information confidential
- letting you know that taking part in the research project is voluntary, and there will be no punishment if a person changes their mind about participating
- confirming that participants can stop their involvement at any time
- the contact information of the researcher

Why is informed consent important?

Informed consent is important for both the participants and the researchers. Participants must have all the information they need in order to make an informed decision about whether they want to be involved in the research project. Researchers must follow rules to make sure their research is done properly and ethically*. Giving your informed consent makes sure that you know exactly what you are being asked to do and what it is for.

Asking for support:

Before deciding if you want to become involved with a research project you can ask the researchers to talk to you about informed consent and ask them any questions you have about the project. You can also ask someone you trust to support you in deciding if you want to take part in the research project, for example your representative, a family member or a friend.

How do researchers get informed consent?

Informed consent can be done in different ways.

- It can be a paper form that participants are expected to sign. This is usually done when the researcher is meeting with participants in person.
- It may be given verbally. For example, if someone calls you to do a phone survey.
- It may be a form online with a button you click to give your consent. For example, when you do an online survey.

“Our analysis indicates that adults with intellectual and developmental disabilities want to engage in research to improve their quality of life and to have greater access to a worthwhile activity through more active participation. Our results also highlight trust as a critical ingredient in the success of research with this group.”

-McDonald, et al. (2013)

*Starred words are explained using plain language in the Fact Sheet Series Glossary on the CIC website: cic.arts.ubc.ca

McDonald, K., Kidney, C. & Patka, M. (2013). ‘You need to let your voice be heard’: research participants’ views on research. *Journal of Intellectual Disability Research*, Volume 57, 3, 216–225.

If you need any help to read or understand this document please ask someone for support. You can also call or email the Centre for Inclusion and Citizenship to ask questions.

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