

# Community Research

In some cases consent is not just an individual process but a collective one. This happens most often with research involving Indigenous communities, but it may also include research of social movements, institutions, workplaces, or other community organizations. It is important in these scenarios to ensure that, where appropriate, the research has been approved by those in positions of leadership in the community. As such, individuals should feel free to talk with their community about what they believe is best to share, or whether the community may benefit from the research, before they agree to take part.

Even in cases where the community has agreed and others have taken part in a study, individuals still have the right to decide not to participate.

Where the community is a collective being studied, researchers must respect any decision-making and oversight processes the community may have in place before they may proceed with research.

**Rights of Research Participants, including communities, are outlined in full in the Tri-Council Policy Statement: Ethical Conduct for Research Involving Human Participants**  
[www.pre.ethics.gc.ca](http://www.pre.ethics.gc.ca)

# Questions to Ask Researchers

Before you agree to participate in a study, you should ask questions about anything that is not clear to you, such as those below .

- What is the study about? What are the researchers trying to find out?
- Is there any compensation for the study?
- Are there any risks to the study?
- How much of my time am I expected to commit?
- Will I be recorded, or quoted?
- Will I be asked to provide personal information? If so, will it be kept confidential and how?
- How long will the data be kept?
- Is there any chance of me being identified?
- Will characteristics such as names, age, location of the study be removed to protect my identity?
- Can I change my mind to be in the study after you have my data? Can it be removed?
- Could my employer find out any of the information that I provide in the study?
- Can I have a copy of my data?
- How can I see the results of this study when it is complete?
- Could this data be used for any studies other than this one?
- Am I able to see the results before any kind of publication?
- Can I leave or stop whenever I feel I need to?
- What is your contact information?

# Doing Research Together: Rights of Research Participants

Office of the Vice-President  
(Research)

# What is Research?

Research involves investigating issues, topics, and problems to learn more about them. In the case of research with individuals, this often involves asking people their opinions, questions about their life experiences, or trying out new products or medication, providing feedback, and/or sharing information. These are just some ways that researchers collect data for research.

Research can happen anywhere. Sometimes researchers contact people directly and ask questions, over the phone, in a mail, or via an online survey. Sometimes they seek participants by putting posters in public places and asking people to contact them, and sometimes researchers ask employers, organizations or communities to help them contact people whom they would like to ask to participate in their research.

In all of these cases, researchers are looking to collect data from you to advance their studies. These studies can produce new techniques, services, critiques, products, or understandings. It is your decision as a potential participant if and when you choose to allow researchers to collect or use your data, and you have the right to refuse research, to ask questions, and to fully understand the process and the study. Research is, at its best, a collaboration between researchers and participants.

**Researchers must respect the welfare, rights, needs, boundaries, and circumstances of participants.**

# Research Risks and Rewards

Research can help to develop services, treatments, and products, or find answers to important intellectual and practical questions. That being said, research may have risks and drawbacks. It can, for example, sometimes cause participants anxiety or discomfort, take up a lot of their time, or be unable to protect their privacy.

Risks in research can be emotional, physical, financial or social. The risks of every study are different, so researchers must discuss the possible risks with participants. For example, it may be difficult to protect someone's confidentiality regarding what they've said in an interview in a smaller community where people may know details of that person and be able to identify them. Participants can always refuse to be part of a study if they feel they do not want to take on the potential risks. No research can take place before a participant consents, which includes being briefed on all foreseeable risks.

**While research can involve risks to the participants, researchers work with Research Ethics Boards (REBs) to create procedures to protect participants as fully as possible.**

Research can also produce measurable benefits. This can take the form of skill building, or developed services, products, and initiatives. However, there are often no direct benefits to individual participants. Researchers also often use incentives, such as cash honoraria or gift cards, to thank participants. It is important to consider how research may or may not align with your priorities as a participant, and balance these priorities with the potential risks.

# Consent

Researchers must tell potential participants what will happen during the research before they can agree to it. Participants are given consent forms that explain what they are being asked to do, and researchers talk through the process until participants indicate that they understand. Usually participant consent is documented by their signature on the consent form. Sometimes consent is given in other ways, like a recorded voice memo or checking a box on an online survey. But no matter how it is done, you should know what the study will require you to do, and what possible harms or benefits could come from the study before you give consent. **As a participant, no action can be taken without your full and informed consent.**

No participant is obligated to consent, and consent is not a one-time agreement. If for any reason you are unsure about the research, you can withhold consent and either take time to think about it or discuss concerns with the researcher (or others), reach out to the REB, or not participate in the study.

Even if the study is done and you feel you no longer consent or don't want the data used, you can request to have your data removed in many cases. Other cases, like anonymous surveys, or if the research has already been published, may not be able to remove your data.

**All participation in research must be voluntary, and you can stop participating if you change your mind partway way through.**