

Joining a Study?

Please Ask Questions!

Research tries to find answers. Research can benefit human society by improving people's understanding of the world and its diversity. People's participation makes this research possible.

People are often asked to join a research study as participants.

Ask questions so that you can tell if a study is the RIGHT research study - for YOU!

Even if you agree to participate, you can always change your mind.

It's all up to **YOU** Only **YOU** can:

- decide to join a research study
- choose whether to continue in a research study
- consider how this research will affect your life

Ask all the questions that matter to you at any time, even if they are basic or feel embarrassing.

The Policy and the Panel

This brochure was developed by the Panel on Research Ethics (PRE). PRE manages the ethics policy of Canada's research agencies. It is called the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, or TCPS 2. You can learn more at:

www.pre.ethics.gc.ca

TCPS 2 is based on respect for human dignity.

The core principles of TCPS 2 are **Respect for Persons, Concern for Welfare, and Justice.**



The welfare of participants is more important than the goals of researchers.

TAKING PART IN RESEARCH



Some Key Questions to Ask About Participating in Research



What is the research study about?

- What is the researcher trying to understand in the research study?
- Why did the researcher invite me to take part in the research study?

What will I be asked to do?

- What steps will I be asked to follow?
- What tests or medications will I be asked to take?
- What information will be collected from me?
- How much time will the study take?

What will happen to my information?

- Who gets my information and who uses it?
- How will my information be protected?
- How long will my information be kept?
- Can I change my mind about how or whether my information will be used?

What are the risks?

Some research studies have little risk. Others have higher risks. Some risks are unknown.

- What kinds of risks are possible (for example physical, emotional, social)?
- Are the risks common or are they rare?
- Will the risks have small or major consequences for me?
- How will the risks be managed?
- How might the risks impact me in my life?

What are the possible benefits?

Some research studies may benefit participants directly. Others do not offer any direct benefits, but the results may help others, or add to existing knowledge or practices.

- Do the possible benefits matter to me?
- Do I want to help improve existing knowledge or practices?

Learn More About a Research Study

Ask the researcher or a member of the research team any questions you may have about the research study. They are responsible for the design and conduct of the research study.

The researcher(s) must give you a contact phone number or email address for any questions or concerns you may have.

Ask the Research Ethics Board (REB) questions about the ethics of a research study. A major role of REBs in their review of research studies is to protect the welfare of participants.

If you have other questions or concerns, you may **ask the ethics office staff** at the organization responsible for the research study – university, college, hospital or other.

Contact information for the REB or ethics office should be provided in the research study material.

Answers to Common Questions

www.pre.ethics.gc.ca/eng/education/FAQs_participants/