

KNOW YOUR RIGHTS

7 ETHICS TIPS FOR FAMILIES PLANNING TO PARTNER IN RESEARCH

1

How do I know that I will be treated fairly and with respect?

Researchers do not need ethics approval to partner in research. However, when partnering in research you are an equal member of the research team and are working with researchers throughout the research process, and thus are not a participant in the study. Researchers do require completion of the Tri-Council Policy Statement 2 Tutorial, meaning that they should have a full understanding of proper ethical conduct.

2

What if I am too shy to speak up?

Discuss the importance of mutual respect, active listening, and safe, open lines of communication. Any concerns should be discussed right away in an open manner. Ask if there is a key contact person on the research team for you to talk to if you have specific questions.

3

How do I know my role on the research team?

Ensure you have an open conversation about your role on the research team. Know what is expected of you and others at the beginning. Ask as many questions as you need!

4

What if I don't want to partner on the project anymore?

You can stop partnering in the research project at any time. If you are not comfortable executing a certain research-related task, or require more information, speak up. Remember, the researchers want you to feel comfortable and succeed! If you feel overwhelmed at any point, don't be afraid to say.

5

Will I be compensated for my time?

If compensation for your time (and reimbursement of any costs incurred) hasn't been discussed, address these concerns before partnering in the project. The Canadian Institutes of Health Research recommends that researchers provide patient partners with appropriate compensation for their time. If you are not comfortable receiving payment, you can also make this clear to the research team beforehand.

6

How do I know I can trust the research team?

Suggest creating a document of understanding or a research agreement. You can outline the expectations related to respect, trust, honesty, and communication. As well, to document and clarify your specific role on the research team.

7

What if I forget things along the way?

It is important to revisit these ethics tips throughout the research project and partnership. These points can be discussed any time and at multiple times throughout the research project.

This infographic was created by Amanda Carrington & Vanessa Tomas as a requirement for the Family Engagement in Research Certificate through McMaster University.

