How Can Parents Be Involved in Child Health Research?



How can I be involved?



As a parent, you might be asked to be a research participant. But this is only one way that you can be involved! Parents can also partner with researchers to plan & carry out research projects. Parents can help researchers decide what topics are important to study, how to run the study, and what questions to ask participants.

What are the benefits of partnering with researchers?

Everyone benefits when parents with real life experience partner with researchers. Partnerships help make sure that research is relevant, meaningful, and addresses parents' needs and concerns. Parents can also learn new skills (like writing or presenting at conferences) or use their existing skills in a new way to help other families who are on the same journey.

But what if I don't have any research training?



Perfect! Parents bring something to the table that researchers don't have: real life experience. Because of this, parents can advise researchers on things like what is important to families of children with medical conditions, and how to best engage parents to participate in research.

What will I be asked to do as a research partner?

It depends on the project and your own interests and skills! Be sure to discuss roles and expectations with the research team ahead of time. Some research projects offer stipends to cover parents' expenses of partnering (such as travel and childcare) as well as to acknowledge your time.



Where can I learn more?

Talk to your child's healthcare team about potential partnership opportunities. In Canada, there are also a number of research networks that involve patients and families through the Strategy for Patient-Oriented Research (SPOR): <u>http://www.cihr-irsc.gc.ca/e/45854.html</u>

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