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Health research in children: What parents need to know

Health research is the study of what makes us healthy or unhealthy. It can help us understand why some children become sick, and may help to improve their health.

Research gives health care providers the best information possible to prevent illness and to treat children who are sick.

How do people get asked to take part in research?

You and your child may be asked to take part in research in a number of ways:

- A researcher may contact you directly because of a specific condition that you or your child has. To respect your confidentiality, that type of contact will almost always come from someone who already knows you.
- You may also find out about research opportunities through newsletters, bulletin boards, phone calls or other media.

No matter how you are asked, you always have the right to decide not to take part in the research.

Who sets the rules about research?

All researchers in Canada must follow Canadian rules on human research. Most human research in Canada must be approved by a research ethics board. Their job is to make sure the research is performed in a way that respects and protects the rights of children and youth involved in research studies.

This board is made up of doctors, scientists, lawyers, ethicists (people trained in ethics) and members from the community. All hospitals and universities use research ethics boards.

What are my and my child's rights in health research?

- You and your child do not have to take part in health research. It is your choice.
- You will be asked for permission (consent) for your child to take part in the research, if your child cannot give his own consent.
- Your child will be asked for her permission (assent) if she is old enough to understand parts of the research.

- You will be told about all the possible benefits and risks of taking part in the research. This will help you decide whether to take part in the research.
- You can decide to stop taking part in the research at any time.
- Your child's health care will not be affected if you decide not to take part in the research.
- Your child has a right to confidentiality. The researcher will keep your child's personal research information private.
- You and your child have a right to know about new information that may change your mind about taking part in the research.
- You and your child have a right to be offered a summary of the results of the research.
- You will be provided with a copy of a consent form for your records.

What does 'consent' and 'assent' mean?

Consent is the permission a parent or guardian gives for their child to take part in the research. Older children or youth may give their own consent if they are mature enough to fully understand the research. Local laws may require children to reach a minimum age before they can provide consent. There are 3 things needed for consent to be valid:

1. You must make the decision freely – it is entirely your choice.
2. You must have enough information to make a choice.
3. You must understand the information.

Assent is an agreement to take part in the research when your child cannot give full consent. Children often can understand some, but not all parts of a research study. Assent is their way to say they agree to take part, as much as they understand.

What should I do if I have questions?

You or your child may have questions about the research you are being asked to take part in. You should ask the research team to explain any issues.

If you have more questions about taking part in the research, speak with a health care provider you trust, such as your doctor, or someone from the research ethics board that approved the study. Most hospitals have information about their research ethics board on their Web site, or you can contact your hospital's general inquiry line for information on how to reach the board.

For more information

[Ethical issues in health research in children](#), a position statement by the Canadian Paediatric Society

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This information should not be used as a substitute for the medical care and advice of your physician. There may be variations in treatment that your physician may recommend based on individual facts and circumstances.

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