








Should My Child Join a Study?

As a parent or guardian, the decision to allow your child to participate in a *clinical study*  may be a difficult one. Many parents are concerned that their child may not benefit from being in a study or that some tests may hurt or be uncomfortable. Parents want to know what the *side effects*  may be for certain study treatments and how much extra time or visits to the research site it will take to be in a study. The [Children and Clinical Studies](#) website can help you to identify "[Questions You Should Consider Asking](#)"

Some studies just observe a child over time and others test a medication, treatment or device. But most studies are required to give you a *consent form*  before you agree to join a study. This form describes the research and many of your questions will be answered there. When you meet with a member of the *research team* , you will want to listen carefully and ask several questions about the study. To begin, some questions you may ask are:

- Why is this study being done?
- Why do the doctors think this treatment may work?
- Has this treatment been tested before?

Some studies might divide the participants into groups. For example, if a new medicine is being tested, one group might get the "experimental medicine" and another group might get a medicine that is usually used. In this way, doctors can see which medicine works better. Or sometimes there is no treatment for a certain problem. In this case, one group might get an "experimental treatment" and another group might get a *placebo*  or no treatment. Questions you might ask are:

- How will the study team decide who gets the experimental treatment?
- What are the possible risks and side effects in this study?
- How will my child's safety be monitored in this study?
- Could my child's condition get worse and what happens if it does?
- How will I know if the treatment is working?
- How can I reach the research team if I have questions?

It is important to know what your responsibilities are once your child enters a study (See "[Rights and Responsibilities in a Study](#)".) You will need to make sure that you and your child are following the study instructions in order to keep your child safe and for the study to have meaningful results. You will also want to know if there will be extra costs or visits to the study site. Some questions to ask are:

- How many children are in the study and when did it start?
- How long will the study last?
- How might this affect my daily life and my child's?
- How many extra visits will I need to make to the hospital or study site?
- Will I be reimbursed for parking, travel expenses or childcare?
- Who will pay for the experimental treatment?
- Will it cost me anything to be in the study?

You will want to consider all of your choices when deciding if your child should enter a research study or not. You may want to let your



Print PDF of
this page



Download
PDF Reader

 = glossary definition


child participate or you could allow your child to receive the standard care. An important question is:

- What are my other choices if I choose not to participate in the study?

Before deciding to join a study, it's important to get information from people like the *principal investigator* and *research coordinator*, family members and friends and your child's regular doctor. Some hospitals or clinics offer the services of a social worker or patient advocate who is not directly connected with any study and who can talk with as you make a decision. There are resources such as this website and the [Children and Clinical Studies](#) website to help you make a good decision. Depending on your child's age and ability, his or her opinions will also be important - and your child's *assent* may be necessary. Read the information and watch the video at "[Do Kids Have Say](#)" and "[What Do Kids Say about Being in a Study](#)" for more details about children's views of research.

There is no "right" or "wrong" answer about participating in research, only the answer that seems right for you and your child.

 [Why Include Children in Research?](#)

[Rights and Responsibilities in a Study](#) 

Adjust Text



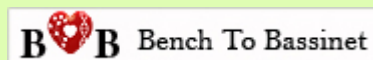
Department of Health and Human Services



National Institutes of Health



National Heart, Lung, and Blood Institute



Please disable any pop-up blockers to take full advantage of all of the features of this website.

Last updated: June 2, 2010 10:42 AM