Participating in Research: What You Need to Know

What is a research study?

Research studies are done to discover new information or to answer a question about how we learn, behave, and function. Some studies might involve simple tasks like completing a survey, being observed among a group of people, or participating in a group discussion. Other studies, sometimes called clinical trials, involve more risky procedures like testing a new drug or medical device.

Who can participate?

Each research study has its own set of criteria to determine who can participate. This depends on the research question being asked and may include restrictions based on age, behaviors, health status, or other traits.

Why should I participate?

Research is designed to benefit society. This might include learning how to live healthier lives, how to better treat conditions or diseases, why we do the things we do, or how we learn and develop. And while there are several reasons why people choose to participate in research, most people participate based on the possibility of helping themselves or others.

Will I benefit from participating?

It's important to understand that you may not directly benefit from participating in research. In fact, with a lot of research, you will not receive any benefit. For some types of research however, there may be a *possibility* that you *could* receive benefit, but there is no guarantee.

How am I protected?

Research studies involving humans must be approved and monitored by an Institutional Review Board (IRB). An IRB is a committee of individuals responsible for reviewing research to ensure adequate protections are in place to protect the people who take part. For each study reviewed, the IRB checks to see that

- there is a good reason to conduct the study
- the risks related to participating are the least possible
- the risks related to participating are reasonable given the knowledge that will be gained from conducting the study
- the plan for selecting subjects to participate is fair
- subjects will be provided enough information about the study, in an understandable manner, to make an informed decision about participation.

What can I expect if I decide to participate?

To start, you will be given information about the study so that you can make an informed decision about whether or not to participate. You will also be given an opportunity to ask questions about the study. This process is called informed consent. Before you can start the study, you need to agree to participate (i.e., consent). Participation is always voluntary.

Once you provide consent, the specific procedures or activities you'll be asked to complete can vary widely and depend on what is being studied. Regardless, all the activities you will be asked to complete will be described during the consent process.

How will my information be protected?

Protecting the information you provide to researchers is a high priority, particularly if you provide health-related or sensitive information. As part of the IRB approval process described above, all researchers must provide a plan to adequately protect the information they plan to collect in order for the study to be approved. This might include assigning a code to the information collected instead of using your name or other identifiable information and storing the information in a secure manner.

What are the risks of being in a study?

Most studies involve some risk, though the risks can range from very small to very serious. Some examples of risks include

- side effects or reactions to experimental drugs, treatments, or procedures
- feeling anxious or uncomfortable
- breach in confidentiality or invasion of privacy.

Side effects or other risks you might experience may be temporary or go away with treatment, but in rare cases they may be permanent, cause disability, or be life threatening. There may also be risks in participating that we don't know about.

Can I change my mind about being in the study once I start?

You are free to withdraw from a research study at any time, for any reason. Your relationship with the hospital, clinic, academic institution, or employer will not be affected and you will not lose any benefits to which you are entitled.

Note that in some cases, a researcher may decide to end your participation in the study early. This may happen if the study is no longer in your best interest, if you can no longer complete study activities, or if the study ends early for some other reason.

How much time will it take?

Each study is different, so time requirements will vary. Some may require very little of your time, perhaps only 5–10 minutes, while others may require multiple visits over an extended period of time, sometimes up to several years. Your time commitment for a particular study will be described during the consent process.

What do I need to know before I agree to participate?

Before you agree to be in the study, make sure you have a solid understanding of the following:

- the voluntary nature of the study
- why the study is being done
- who is doing the study
- the procedures, activities, tests, or treatments involved (including how long they will take, how often they have to be completed, and whether there are any other treatment options available rather than being in the study)
- potential risks, discomforts, or side effects
- potential benefits to participating, if any
- how your privacy will be protected
- how long your participation will last
- what will happen if you are injured while participating
- the costs to you, if any
- what to do if you change your mind about participating
- whom to contact with questions, concerns, or problems

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Questions, concerns, or feedback about human subject research conducted by the University of Rochester can be directed to the Research Subjects Review Board: 265 Crittenden Blvd., Box CU 420628, Rochester, NY 14642; or telephone (585) 276-0005 or (877) 449-4441.