Participating in research is a choice

Joining a research study is an important personal decision. Before you join, researchers will talk with you about the goals of the study and the possible risks and benefits. They will also explain the rules they follow to protect your safety and privacy. Ask for help if you have questions.

You should never feel rushed or pressured to make a decision. Being part of a research study is completely voluntary - it's your choice.

After the study is presented to you and if you decide to take part, you will be asked to sign a document called an "informed consent form." You can change your mind at any time, for any reason, even after you sign.

Questions to ask

You have a right to ask questions about the research before you decide whether to take part in a research study. If you forget the answer to any of your questions, ask again. If you need additional information, ask the researcher. You may want to ask the following questions:

- Who is doing this study?
- What is the purpose of the study?
- What will happen if I participate?
- What kinds of questions will you ask me?
- How long will the study last?
- What are the risks of participating in this study?
- Will taking part in this research benefit me?
- Will there be any costs to me?
- What will you do with my study information?
- Who will know that I participated in this study?
- How will my privacy be protected?
- Will I be told the results of the study?
- How do I end my participation in this study if I change my mind?
- What happens if I decide to leave the study early?
- Who has reviewed and approved this study?

If you have questions, concerns, or complaints please call, email, or mail the Human Subjects Protection Program managers at:

Department of Energy
Human Subjects Protection Program 1000 Independence Ave SW Washington, DC 20585
301.903.7693 / 202.586.1444
DL-DOEHSPP@hq.doe.gov
https://science.osti.gov/ber/human-subjects

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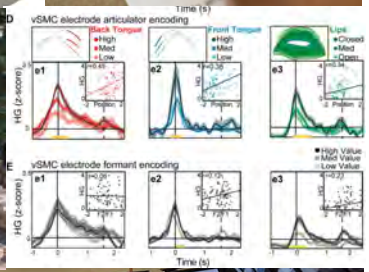
U.S. DEPARTMENT OF ENERGY

NNSA

National Nuclear Security Administration

Should I Participate in a Research Study?



What is a research study?

A research study is an organized activity to learn more about a problem or answer questions. Scientists conduct many different kinds of studies. For example, a research study may explore how and why people behave the way they do in certain situations and how this might impact human health. A research study may test if a treatment or device is safe and effective. A research study may be done to find out what practices work best. A research study may be done to determine the best way to prevent an illness. A research study may use a survey or an interview to understand feelings people have about specific topics.

Researchers may pose questions such as:

- Why don't some people take medicines prescribed by their doctor?
- How do communities respond to gang violence?
- How well do you sleep?
- How much confusion did you experience when conducting the research task?
- What was the comfort level of the research device?

Who takes part in research?

- Adults and children
- Families
- Communities
- Regional, cultural, or social groups
- Employees

What does it mean to take part in a research study?

Your role in a study will depend on what type of research is being conducted. The researcher for your study will explain it to you. A research study may require you to fill out a questionnaire or respond to a researcher's questions. In other research studies, researchers may observe you while you perform a specific activity. Another research study may require you to try a treatment or device to make sure it is safe and effective.

What are the benefits of taking part in a research study?

Some studies will not benefit you as an individual. No one can predict what will happen with a research study or how it might affect you. The research study may result in information that will help others in the future. For example, researchers may be able to improve the health of a community or help a group with a particular disease or condition.

What are the risks of participating in a research study?

One common risk of taking part in a study is that private information you share with the researchers could accidentally be shared with other people. Researchers will explain the ways they guard against this. Most of the time, even it the researcher writes an article about the study, your name will not appear.

You might feel uncomfortable answering some questions the researchers ask you. You can decide not to answer any questions that make you uneasy and you can stop at any time.

Some research procedures and treatment may cause discomfort and bad side effects. Some of these effects may not be known at the beginning of the study.

The informed consent form for your study will describe any specific risks. Make sure you have been informed of known risks before you agree to take part in the study.