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 possible risks and benefits. They will also explain the rules they follow to protect your safety and privacy. Ask for help if you don’t understand something or 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 you understand the study, you can agree to take part by signing a document called an “informed consent form.” You can change your mind at any time, for any reason, even after you sign.

The risks and benefits of research studies

Research studies try to answer questions that have not been previously asked. Because the answers are unknown, there may be some risk. An experimental drug, device, treatment, or procedure might not be better than the drug, device, treatment, or procedure used currently in health care. The study might also cause side effects that researchers do not know much about.

Also, researchers hope to help people in the future. So you might not get any direct benefit from joining a study. Before agreeing to be in a research study, you need to understand the possible risks and benefits.

Questions to ask

You have a right to ask questions about a research study. Below is a list of questions you might want to ask before you agree to take part in a study.

- How are the procedures in this study different from the health care I receive for my personal needs?
- Why am I being recommended for this research study?
- What do researchers expect me to do in this study?
- Do I need any of the study drug/device/treatment/procedures as part of my health care? Or will they mainly help researchers answer a scientific question?
- Will the study, drug/device/treatment/procedure help me feel better? Will it cure my disease or condition?
- What are the potential risks and benefits of being in the study?
- Should I keep seeing my health care providers during the study?
- Will the study team have access to my health care records?
- Will the drug/device/treatment/procedure being studied be available to me after I complete the study?

Improving health care for the future is the focus of health research. Health research helps doctors and researchers learn about human health and disease. They also learn better ways to prevent and treat diseases. Participating in health research is not the same as receiving health care. There are several important differences to understand.
How is health research different from health care?

Why is it done?

To help you with personal health care needs.

You are called...

A patient.

Who benefits and when?

People in the future. You might benefit or you might not.

How certain is the result?

Researchers do not know if what they are studying works better or worse than current treatments.

Why participate in a research study?

You might choose to participate in a research study for one or more of the reasons below.

- You want to help others
- You like to volunteer
- You want to help researchers develop new treatments and drugs
- You want to help others who have your medical condition
- The available treatments have not helped your condition