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 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, 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 social and behavioral research before you decide whether to take part in a research study. You may want to ask the following questions:

- 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?
- How will my privacy be protected?
- What happens if I decide to leave the study early?

Health Research

SOCIAL & BEHAVIORAL RESEARCH

Participating in research is your choice. Be informed. Ask questions. Get answers.

Social and behavioral research explores how and why people behave the way they do in certain situations and how this might impact human health.

Questions? Call us at

This material is the work of the New England Research Subject Advocacy Group, with contributions from the affiliated universities and academic healthcare centers of member institutions. Funded by the NIH National Center for Advancing Translational Sciences (CTSA) Program UL1 TR001102. For more information see: http://catalyst.harvard.edu/regulatory/language.pdf

This brochure contains general information for educational purposes and is not intended to provide medical advice. Talk with your own doctor or research team for advice about your personal situation and health concerns.
What is social and behavioral research?

Social and behavioral research explores how and why people behave the way they do in certain situations and how this might impact human health. Researchers look at individuals or at larger groups, such as families, communities, and societies to find ways to solve social problems and improve health.

Researchers may pose questions such as:

- Why some people don’t take medicines prescribed by their doctor
- How communities respond to gang violence
- What helps children make healthy food choices
- Why some teenagers engage in risky behaviors
- What helps senior citizens live independently
- Why people live longer in some countries than in others

Who takes part in social and behavioral research?

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

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

Participating in a social and behavioral research study often involves filling out a questionnaire or responding to a researcher’s questions over the phone. In some studies, researchers will want to interview you and ask you questions about how you feel about a particular subject. In other studies, researchers might observe you while you do a certain activity. Some studies might involve reviewing your medical records.

What are the benefits of taking part in social and behavioral research?

Some studies will not benefit you as an individual, but taking part may help others in the future. 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 taking part in social and behavioral research?

One common risk of taking part in social and behavioral research 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 if 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 the interview at any time.

The informed consent form for your study will describe any specific risks. Make sure you understand these risks before you agree to take part.