

Participating in research is a choice

Joining a research study is an important personal decision. Before you join, the researcher 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.



Questions to ask

You have the right to ask questions about the research team and about the research study before you decide whether to take part. Research team members are there to answer your questions and help you find answers to questions they cannot answer. Below is a list of questions you might want to ask the research team before you agree to take part in a study.

- > Who is the principal investigator for this study?
- > Who else is part of the research team?
- > Which research team members will I work with?
- > What will each research team member do?
- > How is the research team trained to do this study?
- > Which research team member(s) should I contact with questions? How do I get in touch with them?
- > If I do not feel well, should I call my primary care physician? Or someone on the research team?
- > Who should I contact if I want to leave the study?
- > Besides the research team, should I contact someone else with questions or concerns?

MEET THE RESEARCH TEAM



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

Research studies collect information to answer scientific questions. They help researchers find better ways to prevent and treat disease and improve health care in the future. Every study has a research team. Team members work together to follow a detailed plan for the study, called a protocol.



Members of a research team

A research team may include scientists, doctors, nurses, and staff who help coordinate and perform the study. The research team might be very large, with many people at different hospitals. Or it might include just a few people. Let's meet some research team members.

The **principal investigator**, or PI, is the person responsible for the entire study. Every study has a PI. This person is often a doctor or scientist. The PI plans the study and makes sure the activities are done safely and correctly. He or she decides what each research team member does. The PI supervises all the research activities and all of the members of the study team. The PI also makes sure everyone on the team has the right training.

Co-investigators are researchers who work with the PI. Many studies have co-investigators. They are often doctors, scientists, or people with other training who are important for the study. Co-investigators might help the PI design the study or supervise it. But they are not responsible for the entire study. They might work on just one part, such as doing a lab test or studying research information.

A **research nurse** often has special training and experience in research. Many studies that involve medical or clinical research have a research nurse on the team. He or she helps carry out the study, focusing on the care and safety of the research participants. A research nurse is often involved in coordinating daily study activities.

A **research coordinator / research assistant** is a person who works with the other research team members to organize and help with daily study tasks.

A research team works together

Whether the research team is large or small, all of the members work together to keep you as safe and well as possible while you are in a study. The PI leads the research team, but all team members work together to make sure the study is done correctly and safely.

Research team members have many assigned duties based on their role(s).

Some of these tasks include:

- > Making sure research participants are eligible to be in the study
- > Making sure all participants get clear instructions
- > Giving or supervising study procedures
- > Making sure participants stay as safe and healthy as possible during the study.

In addition to their training as doctors, nurses, or scientists, research team members get additional special training for research. They learn how to do research studies in a way that is correct, safe, and follows the law.

Many other people also help with a research study. For example, a study can include:

- > Pharmacists who give out a study drug
- > Lab technicians who take blood and other samples
- > Dieticians who help with participants' dietary needs
- > Social workers who provide support and may diagnose and treat mental, behavioral, and emotional issues
- > Office staff who help collect and review information

The important part that research participants play

By being in a study, you play an important part in improving health care.

You and other people who take part in research are called "research participants," "research or study subjects," or "research volunteers." Researchers could not develop new treatments without the help of the people who choose to participate in studies.

In some studies, research participants are healthy volunteers. In others, they have the disease or condition researchers are studying. Some studies include both groups. The research protocol says who is eligible to join a study.

What do research participants do?

Every study is different. A member of the research team will explain what your role, rights, and responsibilities are in the study. Your main contact may be the research coordinator, research nurse, or another team member. Before you agree to participate, make sure you know who your main contact is and how to reach him or her.

For more information about being a research participant, please see our educational materials, videos, and resources.

Visit us at: catalyst.harvard.edu/services/rsa/.