

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.

How should I get ready for a telemedicine study visit?

Talk with the research team. They can tell you how to get ready and what you need. You usually need a communication device, such as a computer, tablet, or smartphone, and an internet connection. Sometimes, you might need a web camera and a sound source, such as computer speakers. Your research team will let you know what to expect before, during, and after your telemedicine visit.

Questions to ask

You have the right to ask questions about the use of telemedicine in your research study. Below is a list of questions you might want to ask before you decide whether to take part in a study using telemedicine.

- > What are the steps I should take to get ready for a telemedicine research study visit?
- > Do I still need to travel to the study site for study visits? How often will I be expected to go there?
- > Could using telemedicine change how long it will take to get my study treatment or procedure?
- > Will I need my own equipment (telephone, tablet, computer) to participate in this study? Will I need to provide my own internet access?
- > Will I have to pay for the telemedicine equipment used in this study?
- > What are the benefits of using telemedicine in this study?
- > What are the potential risks of using telemedicine in this study?
- > How will my health information be protected?
- > Who should I call if I have a question about using telemedicine in this study?
- > What if I decide to stop using telemedicine during the study? Can I still participate in this study?

USING TELEMEDICINE IN A RESEARCH STUDY



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

Telemedicine uses technology such as computer or video to provide services and health care. Health care providers can use telemedicine to learn about patients and treat them from a distance. Some researchers also use telemedicine to gather information for a specific research study.



What is telemedicine?

Telemedicine uses technology devices, such as computer or video, to provide services and health care. Health care providers can use telemedicine to learn about patients and treat them from a distance. So if you live a long way from a health care provider or cannot get to one when you need to, telemedicine can help. Telemedicine is not a separate medical specialty. Many specialists, such as allergy or skin doctors, can give care through telemedicine. Health researchers can also use telemedicine to gather information from research volunteers (also called “research participants” or “research or study subjects”).

Some ways researchers use telemedicine

- Researchers can check in with research participants who are at home.
- Research participants may wear devices or use mobile technology to record and send medical information to study staff.
- Research participants may use computers, mobile devices, and other technology to tell study staff about any concerns or side effects. For example, pictures or videos can be shared with researchers, and researchers can see side effects while they are happening.

What types of telemedicine are used in research?

There are three main types of telemedicine used in research.

- **Interactive telemedicine** – A research participant and a researcher share information, usually by audio or video. The participant is at one location and the researcher is somewhere else.
- **Non-interactive telemedicine** – This type of telemedicine sends information from one location to another. A camera or similar device is used to record information and send it somewhere else for review. For example, a researcher might send an x-ray for another doctor to review.
- **Remote monitoring telemedicine** – A researcher keeps track of a participant from a distance. For example, a participant with diabetes might wear a device that sends her blood sugar level to a research nurse every day. With remote monitoring, the participant does not have to visit the clinic as often.



What are the benefits and risks of participating in research that uses telemedicine?

Benefits

- Being able to participate in research from your home – This might make it possible for you to participate in a research study even if the study center is far away.
- Potentially saving time and money with less frequent travel to the study site.

Risks

- Researchers cannot absolutely guarantee your health information will stay private and secure when you send it by computer or another device.
- Computers and other devices sometimes have delays or other problems.
- Some parts of a medical examination cannot be done by telemedicine. You will probably still need to go to the study site sometimes.

The informed consent form for your study will explain any specific risks related to participation in the study. The researchers will also explain how they protect against or reduce these risks.