

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.

Other types of registries

Other types of registries have lists of clinical research studies, which do not include personal information about people who participate in research.

In the US, [ClinicalTrials.gov](https://clinicaltrials.gov) is an online registry that contains information about studies around the world. It does not include every study because not all studies must be registered.

At [ClinicalTrials.gov](https://clinicaltrials.gov), you can:

- > Learn about studies happening in your community and elsewhere
- > Contact researchers if you want to join a study
- > Learn about the results of studies that have ended

[ClinicalTrials.gov](https://clinicaltrials.gov) is maintained by the National Library of Medicine (NLM) at the National Institutes of Health (NIH).

Questions to ask

You have the right to ask questions about a research participant registry before you decide whether to take part in it. Below is a list of questions you might want to ask before you agree to participate in a registry.

- > How does the registry work?
- > Does it cost anything to join?
- > How do I find a study I can participate in?
- > What types of studies will you contact me about?
- > Who will contact me?
- > How will you contact me, and how often?
- > How will you use and store my information and protect my privacy?
- > What if I want to remove my information from the registry?
- > Does this registry have information from my medical records?
- > Who do I contact if I have other questions?



RESEARCH PARTICIPANT REGISTRY



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

A research participant registry collects information on people who might want to be in research studies. A registry might collect general information, such as your name and contact information. It might also collect specific information, such as diseases and health conditions you have, or even connect to your medical records.

Questions? Call us at

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

What is a research participant registry?

A research participant registry is a place for information, usually online. A registry collects information on people who might want to be in research studies. Two groups of people use registries:

- > People who want to find research studies or learn more about research, and
- > Researchers looking for people to participate in their studies.

A registry might collect general information, such as your name and contact information. It might also collect specific information, such as diseases and health conditions you have, or even connect to your medical records.

Benefits and risks of joining a research participant registry

You may benefit from joining a registry by learning about research studies that might interest you, or someone you know.

There is a risk that someone outside the registry may access your personal or health information and use it for purposes you have not agreed to. Registries have ways to keep this from happening. In most cases, only specially trained staff can see your personal information or other details that may link back to your identity. Each registry has specific privacy policies. Before you join a registry, be sure to ask how researchers protect your information.

Why join a research participant registry

You might join a registry 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 the same medical condition as you
- > The available treatments have not helped your condition; you may want to try an experimental treatment that researchers are studying

No matter what your reasons are, joining a registry makes you an important part of medical research.

By joining a participant registry, you may:

- > Learn about opportunities to be in research studies
- > Learn more about a specific disease or condition
- > Have the chance to try experimental treatments or drugs; these might benefit you, or they might not

What happens if I join a research participant registry?

Before you join a registry, you should understand how the registry works. You should also learn how researchers will use your information and protect your privacy. If you have any questions, please be sure to ask.

After you join a registry, researchers can ask you to be in a specific study. You might get an email, letter, or phone call about studies you could join. In some registries, you can contact researchers who are looking for research volunteers.

Joining a registry does not mean you have to join a study. If a study interests you, you have the chance to ask questions. You might also need to give researchers more information than you did when you joined the registry. This helps researchers understand if you are able to participate in the study.

Researchers will give you all the details so that you can decide if you really want to take part in a specific study. This process is called “informed consent.” As a study volunteer, you can change your mind at any time about participating. This includes during the informed consent process and even after the study starts.

