

UF Consent2Share Information Sheet

How is my Medical Information and Contact Information used for the Consent2Share Research Contact Registry?

What is a research study?

A research study is a scientific way to improve or develop new methods of health care. Studies are designed to answer specific questions on how to prevent, diagnose, or treat diseases and disorders. Many types of research studies exist. For example, clinical trials test new medicines or devices. Other studies use interviews or surveys to understand health or behavior.

Why are research studies important?

Research studies are important because they contribute to knowledge and progress on diseases and disorders. Research is the fastest and safest way to find treatments that work. That's why UF Health has created the Consent2Share Research Contact Registry.

What is the Consent2Share Research Contact Registry?

The Consent2Share Research Contact Registry is a voluntary database of people who are willing to have their medical records flagged as someone who is interested in hearing about research opportunities, and then allow UF Health to share their name and contact information with UF researchers when their medical records show they might qualify for a future research study. Its goal is to bring the advancements of medical research faster and more directly to those who can benefit.

What types of participants are needed?

Research studies need participants of all ages, genders, races, and ethnic groups. Some studies need healthy participants, while other studies need people with specific health problems.

Why should I join?

- to learn about ways to possibly improve your health
- to help in the evaluation of medications, tests, or programs that may not be available outside of research
- to potentially help others
- to further knowledge of scientific research and medical care

What happens once I join?

- Your medical record will be flagged as someone who is interested in hearing about research opportunities
- Your name and contact information will be shared with researchers once the researcher has an approved study and your medical records show that you potentially qualify for the study. Studies are approved by the Institutional Review Board (IRB), which is a committee of scientists, ethicists and community members.
- If you are contacted, you will be told about a specific research study at that time. At that time, you can choose whether or not to be involved in that research project.

If I agree to be in the Consent2Share Research Contact Registry, can I change my mind later?

Yes. You may choose to stop your involvement at any time. You will not be penalized or lose any benefits to which you are otherwise entitled. You can call the Consent2Share Helpline at (352) 265-3282 to have your name removed from the “re-contact” list.

Why do you need information from my health records?

To determine whether you might qualify for a specific research study, researchers may need to know some things about you. The information used to identify you as a potential participant for a research study may include your age, sex, race, diagnosis, treatments, or family history. (For example: Are you male or female? What is your race or ethnic group? How old are you? Have you ever smoked?) This information is collected by your hospital from your health record.

Will my name be attached to the records that are given to the researcher?

Yes. If you agree to participate in the Consent2Share Research Contact Registry and your medical records show you potentially qualify for a new research study, your identifying information will be given to the researcher so they can contact you about the study. None of your identifying information will be given out to anyone else and will never appear in any publication.

How could the records be used in ways that might be harmful to me?

Although every effort will be made to keep your information confidential, there is a small risk that an unauthorized person may obtain your information. Therefore, there is a very slight risk that a test result could be linked to your identity and inadvertently disclosed to a third party.

Your participation is completely voluntary and confidential. UF Health uses extensive methods to ensure the privacy of your information. The Federal government has regulations and policies to protect the rights and safety of all research participants. Before taking part in any study, you will receive complete information about the research. You will have to give your informed consent before participating. You may choose not to participate in a study and may leave any study at any time and for any reason.

Are there other things I should know?

- Your medical information will be kept in a very safe location (on a password-protected and encrypted computer server).
- If you do not agree, you will not be denied or refused any treatment, payment or enrollment in a health plan, or lose any benefits that you would otherwise be entitled.
- There will be no cost to you for your involvement in this research contact registry.
- Your involvement in this research contact registry might not result in any benefit to you.
- There may be other research studies that involve the review of your medical information, any of which you can choose to participate in.
- By signing this document, UF Health will be allowed to collect, use and/or give out your contact and medical information, but only to other researchers whose research is approved by an IRB.

What if I have more questions?

If you have any questions, please contact the Consent2Share Helpline at (352) 265-3282.