

Frequently Asked Questions

UT Southwestern Volunteer Research Participant Registry

1. What is the UT Southwestern Volunteer Research Participant Registry?

The Volunteer Research Participant Registry is a database of people who have indicated that they would like to be contacted about future clinical research opportunities. This is a voluntary database and you are not required to participate. The purpose of this registry is to make it easy for people interested in participating in research to be matched with study teams who are seeking volunteers.

2. What is clinical research?

Clinical research is medical research that involves people like you. People volunteer to participate in carefully conducted studies that ultimately uncover better ways to treat, prevent, diagnose, and understand human disease. Clinical research includes trials that test new treatments and therapies as well as long term natural history studies, which provide valuable information about how disease and health progress. UT Southwestern conducts many different kinds of clinical research, from studies on behaviors and attitudes to investigation of new therapies.

3. Why is the UT Southwestern Volunteer Research Participant Registry important?

The most essential part of clinical research is the volunteer. The Volunteer Research Participant Registry is important because it will help link UT Southwestern researchers with people interested in participating in clinical research. Researchers at UT Southwestern have made important discoveries which would not have been possible without research volunteers.

4. How can I join the UT Southwestern Volunteer Research Participant registry?

You can join the Registry via MyChart or in person at UTSW clinics or outpatient services.

5. If I consent to participate in the registry, who will contact me, and how often will I hear from them?

The Registry office will send you information about the Registry 2-4 times per year. This information will contain contact information for the Registry Office and for the Research Participant Advocate. Recruitment Specialists in the Registry Office or the Research Participant Advocate may contact you with new study opportunities, information about the registry, or to update your contact information.

If you potentially qualify for a research study, study team members from individual research projects who are authorized to receive your contact information may call, email, or write you to request your participation. Study teams may contact you frequently, rarely, or not at all, depending on your eligibility for research studies. There is no way to accurately know how often you will be contacted.

6. How will I be matched to research studies?

Researchers at UTSW submit their research projects to an ethics committee which reviews them to make sure the participants are protected. This committee is called an Institutional Review Board (IRB) and is comprised of scientists, physicians, and community members. If the IRB approves a researcher to recruit participants from the Registry, we will use information from

your electronic medical record (EMR) to match you to studies you may qualify for. You are under no obligation to participate in any research study; it is completely voluntary. Each study will have its own enrollment process. If you choose to participate in a particular study, you will be fully informed and learn about the benefits and risks. If you choose not to participate, your information will be given back to Participant Registry staff and you will not be asked again to participate in that study (you may still be contacted for future studies).

7. How will this impact my care if I see a physician at UTSW?

You are under no obligation to participate in the Volunteer Research Participant Registry. Your physician will treat you the same if you agree to participate in the registry or if you decline.

8. Will my information be kept confidential?

Every possible measure will be made to keep you and your information safe and confidential. Your information will be stored in a secure, internal UT Southwestern database. Participant registry staff will not share your information with researchers who do not have IRB approved projects or to researchers outside of UT Southwestern. Anytime information is collected, there is a potential risk for loss of confidentiality. However, every effort will be made to ensure your personal information remains private and secure.

9. Can someone else sign me up for the registry?

No, you must personally agree to be in the Volunteer Research Participant Registry.

10. Will I find out the results of research that I participate in?

If you qualify for a particular study and decide to participate, it may be possible to find out results of the research by contacting the study team directly. You can ask the study investigator or staff what type of information may be available to you after the study is finished. In the future, we may highlight publications resulting from use of the Registry on our website. These publications will not contain identifying information.

11. Can I stop participating in the Volunteer Research Participant Registry?

Yes, you can stop participating at any time. If you choose to stop participation, your name will be removed from the registry and registry staff will no longer contact you about research studies at UT Southwestern. To stop participating in the Registry, please contact our office at: 214-648-5005.

12. Where can I learn more about research at UT Southwestern?

<http://www.utswmmedicine.org/researchregistry>

13. Whom can I contact if I have more questions?

For more information, contact the Participant Registry at:

researchregistry@utsouthwestern.edu

214-648-5005

For more information regarding the research approval process and your rights as a participant, contact the IRB at:

irb@utsouthwestern.edu or 214-648-3060

For information regarding confidentiality of your information, contact the Privacy Office at 214-648-6080