

Privacy Notice for Research Participation

The University of Tennessee, Knoxville (UT) is committed to protecting and respecting your privacy.

This privacy notice sets out how UT processes the personal data of:

- participants in research conducted by UT; and
- individuals whose data may be processed indirectly as part of research conducted by UT (examples of circumstances where this may occur are provided at section 5 below).

This notice applies to the personal data we collect from you and personal data which is passed to us by third parties. Please read the following carefully to understand how we process your personal data.

The information in this privacy notice about the uses of your personal data is intended to be combined with the information provided in the research informed consent form when you agree to participate this research study.

What is research?

It is generally understood by universities that research makes an original contribution to knowledge. Research conducted by our staff and students is always intended to make an original contribution to knowledge.

What is 'personal data'?

'Personal data' means any information which relates to or identifies an individual. This includes information which may not explicitly identify you (e.g. where your name has been removed) but which does make it possible to identify you if it is combined with other information that is readily available. For example, this might be because the information available contains a postcode, your gender and date of birth, and in these circumstances it might be possible to identify you by using other information available elsewhere. We would therefore treat the details we hold as personal information and protect it accordingly.

UT's Data Protection Obligations

When we design and manage research studies, UT will usually be the controller for the purposes of data protection law, which means that we will decide how your personal information is created, collected, used, shared, stored and deleted (processed). We will do so in line with the objectives of the research, ensuring we collect only what is appropriate and necessary and we have informed you of what we are collecting.

UT researchers may collect and use the following categories of Personal Data for this research study:

[Include any of the following that apply to the research. Add any additional categories of information that may be collected.]

- Name, email address, and phone number
- Information about your responses to the interview questions
- Your racial or ethnic origin
- Your political opinions
- Your religious or philosophical beliefs
- Your sexual orientation or beliefs
- Health information
- Genetic data
- Trade union membership
- Criminal Offenses or Convictions

The lawful basis for collecting and processing your personal information is performance of a task in the public interest.

[Include this statement if any of the following special categories of personal data may/will be collected: racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation.] The lawful basis for collecting and processing special categories of personal data is for scientific and historical research or statistical purposes.

[Include this statement if information about participants' criminal convictions and offences may/will be collected.] The lawful basis for processing personal data relating to criminal convictions and offences is for scientific and historical research or statistical purposes.

Your personal data will be processed so long as it is required for the research study. If we are able to anonymize or code (pseudonymize) the personal data you provide, we will do so. Additionally, we will minimize the processing of personal data wherever possible.

The researchers will transfer your personal data to our research site in the United States. Although the United States does not have the same laws to protect your Personal Data as EU/EEA Member States, the research team is committed to protecting the confidentiality of your Personal Data. Additional information about the protections we will use is included in the research consent form.

Although rare, there are times when others may need to see the personal data we collected or created about you: *[Delete any of the following that do not apply to the research or add any others that apply.]*

- Members of the research team so they properly conduct the research
- People at UT who oversee the research to see if it is conducted properly
- Representatives of the U.S. Office of Human Research Protections (OHRP) who oversee the research
- *[If applicable, include:]* Other researchers, so they can conduct additional research on this topic
- *[If applicable, include:]* The research Sponsor who will monitor the study and analyze the data

Your Rights

- You have the right to see the information being collected about you in the study. To ensure integrity of the study, you will not be able to review some of the data until after the study has been completed. For example, if you are in a blinded study, neither the researchers nor you will be able to know the study arm in which you participated until after the study is over.
- You have the right to request corrections to your personal data if it is inaccurate.
- You have the right to limit the collection and use of your personal data under certain circumstances (for example, if you think that the information is inaccurate).
- You have the right to request the deletion of your personal data if you are no longer participating in the study. However, there are limits on your ability to request deletion of your personal data such as if deletion would seriously impair the integrity or the efficacy of the research study or if your personal data is needed to comply with legal requirements.
- You have the right to file a complaint with a data protection authority (http://ec.europa.eu/justice/data-protection/article-29/structure/data-protection-authorities/index_en.htm).

Withdrawal from the Study

If you withdraw from the study, you will no longer be able to participate in the study. No new information or samples will be collected about you or from you by the study team. Your withdrawal has no effect on the lawfulness of the data processing that occurred prior to your withdrawal.

After your withdrawal, your personal data may still be maintained to maintain the integrity of the study, to satisfy any legal or regulatory requirements including reporting and retention requirements, and/or for any other purposes permitted under applicable data protection and privacy laws. Your Personal Information also may be anonymized so that the information does not identify you personally, and the anonymized information may be used for further research.

As noted in the research consent form, you are free to stop taking part in this study at any time by telling the researchers.

If you stop taking part in the study but do not withdraw your consent, your personal data will continue to be used in accordance with the information in research consent form, this privacy notice and applicable law. If you withdraw, no new information or samples will be collected about you or from you by the researchers, unless you have agreed to provide them.

If you decide to withdraw your consent:

- You will no longer be able to participate in the research study;
- No new information or samples will be collected about you or from you by the researchers;
- The researchers may still need to report any safety event that you may have experienced due to your participation in the research study;
- Your personal data, including Coded Information, that has already been collected up to the time of your withdrawal will be kept and used by the research study to guarantee the integrity of the study, to satisfy legal or regulatory requirements, and/or for any other purposes permitted under applicable data protection and privacy laws; and
- Your personal data, including Coded Information, will not be used for further scientific research. However, if permitted by applicable law, your personal data may be anonymized so that the information does not identify you personally, and the anonymized information may be used for further research.

Security

We implement technical and organizational measures to ensure a level of security appropriate to the risk to the personal information we process. These measures are aimed at ensuring the ongoing integrity and confidentiality of personal information. We evaluate these measures on a regular basis to ensure the security of the processing. Additional information about the protections we will use is included in the research consent form.

Contact

If you have any questions about a specific research study you are participating in, use the contact details you were provided with in the research consent form to contact the researchers leading the study.

If you have any general questions about how your personal information is used by UT, or wish to exercise any of your rights, please consult [UT's Data Privacy](#) webpage or the UT Data Protection Officer, Joel Reeves, Associate Vice Chancellor and CIO. You can contact Mr. Reeves at privacy@tennessee.edu.

Changes to the Notice

You may request a copy of this privacy notice from us using the contact details set out in the research consent form. We may modify or update this privacy notice from time to time. You will be able to see when we last updated the privacy notice because we will include a revision date. Changes and additions to this privacy notice are effective from the date on which they are posted. Where changes to this policy will have a fundamental impact on the nature of the processing or otherwise have a substantial impact on you, we will give you sufficient advance notice so that you have the opportunity to exercise your rights (for example, to object to the processing).