

REST-KY Study Privacy Statement

Updated 05/30/2023

HOW WILL YOUR PRIVACY AND CONFIDENTIALITY BE PROTECTED?

We will take careful steps to keep your information confidential. We will remove your name or other direct identifiers from your blood samples. We will label your samples with a code and will store the key separately from the master code list. Only select staff will have access to the list that links the code to you.

WHO WILL SEE THE INFORMATION THAT YOU GIVE?

When we write about or share the results from the study, we will write about the combined information. We will keep your name and other identifying information private. We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. We label your information with a unique identifier (i.e., a number) in all of our databases. This number is kept separate from your name. We further password protect our computers and lock our file cabinets. Our research staff are the only ones with access to your information, and our staff undergo training in confidentiality.

You should know that there are some circumstances in which we may have to show your information to other people.

For example, the law may require or permit us to share your information with:

- a court or agencies, if you have a reportable disease/condition;
- authorities, such as child or adult protective services, if you report information about a child or elder being abused or neglected;
- authorities or a mental health professional if you pose a danger to yourself or someone else (e.g. suicidal thoughts). If you share with us that you are having thoughts of suicide during one of the surveys, a member of our research team will attempt to reach out to you to ask about your safety and to ask if you need help connecting to any additional resources or support. If at that time, you tell us that you are planning to harm yourself or someone else, we may be required to call 9-1-1 and share that information with authorities.

Also, to ensure the study is conducted properly, officials from the National Institutes of Health or the University of Kentucky may look at or copy pertinent portions of records that identify you.

If at any time you have questions about the situations that would require us to share information about your participation, please discuss these with the research team.

We will be using mEMA, a data collection software app for daily surveys. It is important to note that any data collection process undertaken through the use of third-party software comes with potential risks. Included among these risks is a potential breach of confidentiality. The study team will take all available precautions to prevent this from occurring, although we cannot guarantee that your identity will never become known. The mEMA app will collect information from sensors on your smartphone to share details with us about your sleep environment. This includes information about the level of noise and whether your phone can detect voices speaking. No actual voice or sound recordings are ever shared with mEMA or the research team, only measures about noise levels.

We will make every effort to safeguard your data, but as with anything online, we cannot guarantee the security of data obtained by way of the Internet. Third-party applications used in this study may have Terms of Service and Privacy policies outside of the control of the University of Kentucky.

REDCap is a secure, web-based program to capture and store data at the University of Kentucky that will be used to complete the surveys every six months. We will make every effort to safeguard your data in REDCap.

However, given the nature of online surveys, we cannot guarantee the security of data obtained by way of the Internet.

To help us protect your privacy, this research has a Certificate of Confidentiality. The researchers can use this Certificate to refuse to disclose information that may identify you to anyone not connected with this study, or in any legal proceedings. The exceptions to this rule are release of information:

- you have requested us to provide, for instance, to your insurance company or doctor;
- to the sponsor (e.g., National Institutes of Health) or agency auditing the research (e.g., Food and Drug Administration);
- about child or elder abuse, neglect, or harm to yourself or others; and
- about you if it involves a reportable disease.

This policy does not prevent you from releasing information about your own participation in this study.