



Consent and Authorization to Participate in a Research Study

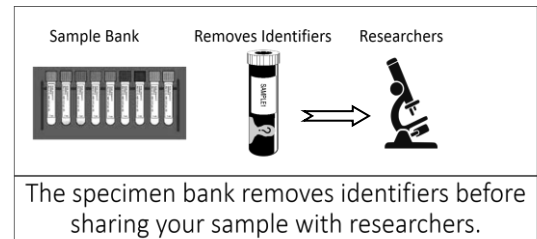
KEY INFORMATION FOR THE ACME SAMPLE BANK

We are inviting you to take part in a research sample bank. The purpose of the bank is to collect and store specimen samples for general future research use. This page is to give you key information to help you decide whether to participate. Detailed information follows this page. Ask the research team questions. If you have questions later, the contact information for the research investigator in charge of the bank is below.

WHAT IS THE PURPOSE, PROCEDURES, AND DURATION OF THIS STUDY?

If you agree to participate, the bank will obtain a small sample of blood, urine, nails, hair, and saliva. See Appendix 1 for amounts. The bank will store your samples forever, in a secure area along with some basic information (race, diagnosis, ethnic group, geographic region, sex, and age range).

Only bank staff can access your samples. Researchers can request stored samples and basic information for future research studies. The bank will remove all information that could identify before sharing with researchers.



Researchers may do genetic studies with your sample. They may use your genetic material (DNA, RNA) or your genome (the entire set of genetic instructions in a cell). They study these to learn about the role genes play in health and disease. Genetic studies help explain why traits are passed down in families. Researchers may use your sample to create a “cell line” which is cells grown in the laboratory. This allows researchers to have an unlimited supply of your cells in the future without asking for more samples from you. A cell line may be kept forever.

Researchers can do studies that are more powerful when they share the results of studying genomes. Researchers may place the genomic results into large scientific databases. The results will not include your name or information that could identify you.

WHAT ARE REASONS YOU MIGHT CHOOSE TO VOLUNTEER FOR THIS STUDY?

There is no direct benefit to you for participating. Some people like knowing they have contributed to research that may help others in the future. The bank will take careful steps to keep your information confidential. The researchers who obtain samples from the bank sign an agreement promising not to try to identify you. In addition, there are laws that make it illegal to discriminate against you based on your genetic information. See the Detailed Consent for additional information on privacy protections.

WHAT ARE REASONS YOU MIGHT CHOOSE NOT TO VOLUNTEER FOR THIS STUDY?

In spite of the security methods we use to protect your information, we cannot guarantee that your identity will never become known. Genetic information is unique to you. While unlikely, it is possible for someone to trace genetic data back to you. Genetic information used improperly to discriminate or support negative stereotypes could cause you or your family distress. Generally, tests done for research purposes are not meant to provide clinical information. We will not provide the research findings or results from genetic tests.

DO YOU HAVE TO TAKE PART IN THE STUDY?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any services, benefits, or rights you would normally have if you choose not to volunteer.

WHAT IF YOU HAVE QUESTIONS, SUGGESTIONS OR CONCERNS?

The person in charge of this research bank is (Name). If you have questions, suggestions, or concerns about the bank, his/her contact information is: (Phone/Email).

If you have any questions, suggestions or concerns about your rights as a volunteer in this research, contact staff in the University of Kentucky (UK) Office of Research Integrity (ORI) between the business hours of 8am and 5pm EST, Monday-Friday at 859-257-9428 or toll free at 1-866-400-9428.