University of Kentucky Biobank and Research Registry:  
Frequently Asked Questions for Patients

Doctors at the University of Kentucky have developed a Kentucky Research Registry & Specimen Bank. They intend to collect leftover samples of tissue, blood or other fluids that are obtained during your visit. These leftover specimens will be frozen and saved in a bank and may be used for future research.

Q. Do I have to sign this form?
A. No, participation is voluntary and your care will not be impacted should you choose to say no.

Q. Will anything extra be done?
A. No, only leftover specimens will be collected and stored.

Q. What kind of specimens?
A. These specimens may be blood, urine, tissue, or other excess specimens that would otherwise be discarded are not needed for clinical care.

Q. Will it cost anything?
A. No, there is no cost to participate, and no payment for participating.

Q. Will the researcher know that they are working with my specimen?
A. No, your name and all other identifiers will be removed from the medical record information or specimens before they are shared with doctors and scientists conducting the research.

Q. Is there any way that I can be identified by this research?
A. Safeguards and security measures are in place to protect your identity and confidential information, however there is always a small risk that confidentiality may be breached.

Q. What will the specimens be used for?
A. Specimens may be used to help scientists understand the role that cells, tissues and genes play in human diseases.

Q. Will this research benefit me?
A. Although the knowledge gained may benefit everyone, this research will not likely have any direct benefit to you.

Q. If I change my mind, can I withdraw consent?
A. If you choose to consent but then change your mind, you should contact the Research Participant Registry Office by phone (859)-323-2615 or write to the Registry Office [c/o UK Center for Clinical and Translational Sciences, 800 Rose Street, Pavilion H, Lexington, KY 40536. After receiving your
withdrawal request, we will not collect future specimens from you, and we will discard any specimens that have not been used.

**Children**

**Q. Can samples be obtained from children?**
A. Yes. A parent or guardian must provide permission and sign the consent form for children up to the age of 18. In addition the consent form asks parents to obtain verbal assent from any child over age 11.

**Q. What happens after a child turns 18?**
A. After the age of 18, a child must sign the consent form again.

**Q. What if I am uncertain or have additional questions?**
A. If you are concerned or have reservations then you do not need to sign the consent. If you would like to speak to someone and obtain more detailed information, you may call the Research Participant Registry Office by phone (859) 323-2615.