

Lifelines

from the National Cancer Institute



How You Can Help Medical Researchers

By the National Cancer Institute

There are many ways to participate in medical research. One of those is to join a clinical trial. Another is to donate a sample of your tissue—materials from your body such as skin, hair, nails, blood, and urine. Such samples, called biospecimens, are carefully analyzed and stored for future use by researchers working to prevent and treat diseases such as cancer, diabetes, Alzheimer's and other diseases.

Opportunities to donate a biospecimen arise when you are scheduled for surgery; for a biopsy, which is a procedure to look for cancer; or for some other medical procedures, even a simple blood test. The process is entirely voluntary, and you can change your mind and withdraw permission for use of your biospecimen at any time. Whether or not you decide to donate, there will be no impact on the medical procedure itself.

Keeping your identity private

It is understandable that people worry about the privacy of their medical information. You are entitled to ask any questions you may have about donating your sample, and then decide not to donate if you are not satisfied for any reason. It is important for you to understand as much as possible about donating your tissue in order to make an informed consent.

But you should know that the process has been carefully designed to make certain that your personal information will be secured as effectively as possible. This means that any scientist who uses your sample for research purposes will not be given your name, social security number, or any personally identifying information when the sample is transmitted. Federal laws protect your privacy by limiting who can have access to your private medical information. Federal law also prohibits employers or health insurers from discriminating against you or your family members based on your genes.

Your privacy is protected by the tissue storage facility, known as a tissue bank or biorepository, where your sample will go to keep it safe and in good condition after you donate it. The professional collecting the biospecimen may need your name, address, phone number or social security number in order to associate your sample with relevant information from your medical

record, but the sample itself will not be stored with any of this information. A computer assigns a random identifying number to your sample, and no researcher can ever learn the name of the person who was the donor.

To make the best use of your specific tissue, researchers may need to know your age, gender, race, or ethnicity--or even your family history and the details of your medical condition and treatment. But these are all ways to describe your biospecimen, they do not refer to you as a person with an identity. The privacy wall is erected by the random number, and the biorepository is the broker that makes certain that wall is never breached.

A patient education booklet, *Providing Your Tissue for Research: What You Need To Know*, is available online at <http://www.cancer.gov/clinicaltrials/learningabout/providingtissue>. A fact sheet on donating tissue for research is also available online, at <http://www.cancer.gov/cancertopics/factsheet/Information/donating-tissue-research>. Copies of both can be ordered by calling NCI at 1-800-4-CANCER.

NCI leads the National Cancer Program and the NIH effort to dramatically reduce the burden of cancer and improve the lives of cancer patients and their families, through research into prevention and cancer biology, the development of new interventions, and the training and mentoring of new researchers. For more information about cancer, please visit the NCI web site at www.cancer.gov or call NCI's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237). More articles and videos in the culturally relevant Lifelines series are available at www.cancer.gov/lifelines.