

National Cancer Institute

Providing Your Tissue for Research: What You Need To Know



U.S. DEPARTMENT
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You have been asked to provide some of your tissue for medical research. Tissue helps researchers find new and better treatments for people. Before you make a decision to let researchers use your tissue, it is helpful to learn more.

What is tissue?

Tissue can include materials from your body such as skin, hair, nails, blood, and urine.

Why do people do research with tissue?

Research with tissue can help us prevent and treat diseases such as cancer, diabetes, and Alzheimer's. By giving your tissue, you could help researchers gain knowledge that may possibly save lives.

Your tissue may be used in all types of research, such as finding the causes of disease, developing new tests or new drugs. Your tissue may also be used for genetic research, or research looking at diseases that are passed on in families. This research will help scientists better understand how genes affect health and illness.

You do not get to decide what kind of research your tissue is used in, just as you do not get to decide who gets your blood when you donate at a blood drive. You will not profit from any of the products developed from the research. Products are not often developed from just one person's tissue. However, you will have the reward of knowing you helped researchers find new ways to prevent and treat diseases.

How do you collect the tissue that I give to research?

The tissue that you give to research is leftover tissue from a medical test, for example a blood test. Even though your doctor only takes the amount of tissue he or she needs for the medical test, there may still be some leftover tissue. Doctors usually destroy this unneeded tissue, but you may choose to allow this leftover tissue to be stored and used for future research. Regardless of your decision, it will not affect your care. Remember, your tissue cannot be used for research without your written consent.

What happens to my tissue after it is collected?

After your doctor completes all your medical tests, he or she will send the leftover tissue to a tissue bank along with some information about your general health. (A tissue bank is a place where the tissue is protected and stored.)

Will I find out the results of the research using my tissue?

You will receive the results of your medical test (e.g., biopsy, blood test), but you will not get the results of the research performed with your leftover tissue. Tissue research takes a long time and requires tissue samples from many people before results are known; results may not be ready for many years. These results do not affect your care when you donate the tissue.

Why do you need information from my health records?

In order to do research with your tissue, researchers may need to have some information about you. This information helps them learn more about specific diseases. Information that researchers ask you for may include:

- Your gender
- Your racial or ethnic group
- Your age
- Whether you smoke.

Researchers may also need information about:

- The date of your diagnosis
- Treatment you have received
- Your family history
- Your medical history.

How is my privacy protected?

To protect your privacy, your tissue will be coded with a random number instead of your name. Your name, address, phone number, Social Security number, date of birth, and anything else that could identify you will be removed before the records are sent to the researcher. The researcher will not be able to identify you.

The tissue bank is in charge of keeping your information private. They will take careful steps to prevent the misuse of records. People will not have access to your personal information. Tissue banks are not allowed to release your personal information without your consent.

What are the risks to me if I give my tissue to research?

There are few risks to you. The greatest risk is the release of information from your health records, but the tissue bank will protect your records so that your name, address, and phone number will be kept private. The chance of these personal facts being given to someone else is very small.

In some cases, health records can be used against patients and their families. For example, insurance companies may deny a patient insurance, or employers may not hire someone with a certain illness. However, since personal information is removed from research samples, the risk of your privacy being violated is very small.

Can I change my mind?

Yes. You can change your mind about letting researchers use your tissue at any time. Contact your doctor if you do not want your tissue to be used in any future research. The doctor will contact the tissue bank and ask them to destroy or return the rest of your tissue. However, tissue already used for research cannot be returned, and the data resulting from a study of this tissue may be used in published research. The tissue bank will return or destroy all the rest of your tissue.

What if I have more questions?

If you have any questions, talk to your doctor or nurse. Or call the research review board listed on the informed consent form.

Visit National Cancer Institute's Web site :

www.cancer.gov

or call

1-800-4-CANCER



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