

What happens to my donated samples?

After your doctor completes all your medical tests, any remaining tissue will be sent to a repository at OHSU. The tissue may be associated with personal and medical information such as age, sex and ethnicity as well as information about any disease affecting the tissue.

Your tissue will be coded with a number. Your name, address, phone number, Social Security number and date of birth will never be used to label your donated tissue.

Tissue is handled and stored carefully. It may be frozen, prepared as microscopic slides, fixed in paraffin wax or used for its DNA. It may be used, for a fee, by other researchers in public institutions or private, for-profit companies. Excess tissue may be used immediately in research projects or it may be stored indefinitely for future use.

How is my privacy protected?

The health-related information that is gathered about you for research is confidential. OHSU is required by law to protect the privacy of this information and takes careful steps to safeguard all records.

There are, however, reasons why your health information would be used or shared. It could be required by researchers at OHSU because of the nature of their investigation. Like all health institutions, OHSU may be required by law to provide the information to government agencies for public health reporting purposes.



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OREGON HEALTH & SCIENCE UNIVERSITY

Why tissue sample donations matter

What you need to know

"There is something appealing to me about collectively working toward advancements in medicine."

— Oregon resident



You have the choice to allow OHSU to use your excess tissue samples for medical research. Tissue helps researchers develop new and better medical treatments for people. Before you make your decision, it is helpful to know more.

What are tissue samples?

Tissue samples can include materials from your body such as skin, blood and other bodily fluids. Tissue donations can come from common medical procedures, like blood tests and biopsies. Often parts of your samples remain after the medical test. These samples are usually destroyed, but may be stored for future use by researchers. You can also give permission for additional samples to be taken for research.

Why is tissue so important for research?

OHSU collects, stores and distributes tissue and associated health information for use in research projects. Researchers need both healthy and diseased tissue.

Tissue samples help researchers:

- Find new ways to treat or prevent diseases such as cancer, diabetes or Alzheimer's
- Develop new drugs and other products
- Learn more about how the human body works



Are there costs or risks associated with donating tissue?

There is no cost to you for the storage and use of your tissue for research purposes. There is a small risk your information could be disclosed, but OHSU makes every effort to protect your identity. There are no additional health risks.

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

You will receive results of your medical test (for example, your biopsy), but you may not get the results of research performed with your remaining tissue. Research is different than tests used for your health care. Results from research take a long time and require samples from many people. Results may not be known for many years.

Does this permission extend to all research at OHSU?

No. OHSU has many other research projects for which you may be asked to grant permission for your tissue to be used. Those will be explained by your nurse, doctor or researcher.

What are examples of the types of research conducted on tissue?

Many types of research are done on tissue samples. Diseased cells can be exposed to new drug compounds to see if they live or die. Tissues can be examined under a microscope to look for physical changes, or to see if tumor cells are in blood. Other research looks for clues in your genes for health conditions, such as obesity or Alzheimer's disease.

In anonymous research, samples contain no personal information and cannot be linked back to a donor. In coded research, samples are labeled with a number, rather than personal information such as name or Social Security number. This allows

researchers to use medical information without knowing a person's identity. In identifiable research, researchers know who donated the sample and have direct access to the donor's medical history, only to accomplish the research.

Will I be able to decide how my tissue is used?

No, just as you do not decide who gets your blood when you donate at a blood drive. Tissue is used in research for nearly all diseases. You **can** decide that your tissue may not be used for specific types of research, such as genetic research.

What happens if I decide not to donate my tissue?

OHSU understands that donating your tissue is a personal choice. If you don't want OHSU to save and use your tissue for research, just complete a "Notice of Your Right to Decline Future Sample Research" form. Your clinic staff can help you with this. Your decision will not affect the health care you receive at OHSU.

What if I change my mind?

If you decide in the future that you would no longer like your tissue to be kept for research, you may contact OHSU and we will destroy your donated tissue and any information associated with it.

Or, you may choose to have personal information removed and let us continue to use your samples for anonymous research only.

Will I be compensated for my tissue?

No. Tissue donation is a way you can contribute to science. You will not be paid for your tissue or from products that might be developed from research. The benefit to you is knowing that you helped researchers find new ways to prevent and treat disease.

TO LEARN MORE about tissue and cancer research, visit the National Cancer Institute: <http://biospecimens.cancer.gov/patientcorner>

FOR QUESTIONS about research at OHSU, call the OHSU Research Integrity Office at **503 494-7887** or visit www.ohsu.edu/xd/research/about/integrity

