



NOTICE OF YOUR RIGHT TO DECLINE FUTURE SAMPLE RESEARCH, INCLUDING ANONYMOUS OR CODED GENETIC RESEARCH

OHSU collects, stores, and distributes human biological samples (such as tissue, blood, or body fluids) and associated health information, including genetic information, for use in future research projects. Gathering and storing many human biological samples and associated health information together can help future researchers by having more samples available, having samples ready to go, and avoiding the need to re-collect samples and information from participants. Research with the stored samples and information can help us understand more about how the human body works, develop new tests to diagnose diseases, find new ways to treat and prevent diseases, or develop new products, such as drugs.

DONATION OF UNUSED SAMPLES

“You,” “your” or “I” refers either to you or to the person for whom you are making healthcare decisions. If you consent to a treatment or procedure as part of your healthcare at OHSU, there may be biological samples collected to help diagnose a condition or as part of the treatment. All biological samples will first be used for this purpose. There may or may not be biological samples left over after the treatment or procedure. If there are extra biological samples, you can authorize OHSU to store those extra biological samples and any associated health information indefinitely for use in future research.

By allowing the storage of your biological samples, you are also permitting the use of your biological samples for research, and use of your biological samples and health information for anonymous and coded genetic research. The samples will be used by OHSU, as well as public or private entities with which OHSU collaborates. This may include for-profit companies that conduct research, including research to develop products such as drugs and diagnostic tests. These biological samples and health information may be used to make a discovery that could be profitable to OHSU or another company. You will not be financially compensated if this happens. However, you will have no responsibility or liability for any use made of your biological samples or health information.

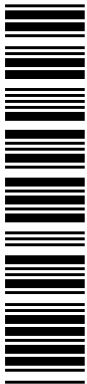
PRIVACY & CONFIDENTIALITY

The health information that we gather about you for research is personal and will be used and disclosed by OHSU in compliance with the law.

Your health information may be shared with others outside of OHSU for research purposes. Research records may be reviewed and/or copied by government oversight agencies or others authorized by law. Whenever possible, biological samples and information will be maintained in a form that is either anonymous or coded. In anonymous research, personal information that could be used to identify you, like your name or medical record number, cannot be linked to your biological samples or health information. In coded research, personal information that could be used to identify you is kept separate from your biological sample or health information so it would be very difficult for someone to connect it back to you. Both methods protect your identity. Unless there is a scientific need for them to be identifiable (for example, labeled with your name or medical record number), researchers will be given only the anonymous or coded biological samples or health information. The main reason identifiable information might be needed for research is to link information from different sources, such as linking information from your healthcare record with your biological sample.

ABOUT RESEARCH AT OHSU AND GENETIC RESEARCH RIGHTS

The federal government has laws to ensure that research conducted at institutions like OHSU is safe and ethical. Consistent with these laws, OHSU has an Institutional Review Board that reviews research before it begins to make sure those requirements are met. Research at OHSU using biological samples or your health information may involve genetic research. The State of Oregon has laws to protect the genetic privacy of individuals. These laws give you the right to refuse to have your biological samples or health information used for genetic research. In addition, you



MR-4960



Oregon Health & Science University
Hospitals and Clinics

Health Information Services

3181 SW Sam Jackson Park Rd.
Mail Code: **OP-17A**
Portland, OR 97239-3098
(503) 494-8521, Fax (503) 494-6970

ACCOUNT NO.
MED. REC. NO.
NAME
BIRTHDATE

can also choose to not allow use of your extra biological samples for any research. The choice is yours. Your decision will not affect the care you receive from your health care provider or OHSU, or your health insurance coverage, and there will be no penalty or loss of any benefits to which you are otherwise entitled.

HOW TO PARTICIPATE

If you agree to allow your biological samples to be stored and used for research, and your biological samples and health information to be used for anonymous and coded genetic research, **you do not have to do anything else.** We will consider this to be your decision to donate your biological samples to OHSU and to allow future research using your biological samples and allow anonymous or coded genetic research using your biological samples and health information without further notice to you.

IF YOU DON'T WANT TO PARTICIPATE

If you do not want to have your biological samples stored and used for future research, or your biological samples and health information used for anonymous and coded genetic research, **you must tell OHSU by completing this form and:**

- Giving it to your OHSU health care provider; or
- Mailing it to Health Information Services,
3181 SW Sam Jackson Park Rd., Mail Code OP-17A
Portland, OR 97239-3098.

If you decide not to participate, your decision becomes effective on the date OHSU receives this form.

No matter what you decide now, you can always change your mind later. If you change your mind, complete this form and mail it to the above address at any time. If you change your mind, that decision will apply only to biological samples and health information collected after OHSU receives this completed form.

If you have questions or want more information about anything in this notice, please read our educational brochure "Why Sample Donations Matter: What You Need to Know," call the OHSU Research Integrity Office at 503-494-7887 or visit us online at www.ohsu.edu/xd/research/about/integrity.

By checking the box and signing below, I am not allowing or I am limiting the use of my biological samples or health information for research, as follows:

- I do not want my extra biological samples stored and used for future research.
- I do not want my biological samples and health information to be used for anonymous or coded genetic research.

Printed Name of Patient

Printed Name of Legally Authorized Representative (if applicable)

Signature of Patient or Legally Authorized Representative

____/____/____ : am pm
Date (required) Time (required)