

[Name of Entity]

Notice of Your Right to Decline Participation in Future Anonymous or Coded Genetic Research

The State of Oregon has laws to protect the genetic privacy of individuals. These laws give you the right to decline to have your health information or biological samples used for research. A biological sample may include a blood sample, urine sample, or other materials collected from your body. You can decide whether to allow your health information or biological samples to be available for genetic research. Your decision will not affect the care you receive from your health care provider or your health insurance coverage.

Research is important because it gives us valuable information on how to improve health, such as ways to prevent or improve treatment for heart disease, diabetes, and cancer. Under Oregon law, a special team reviews all genetic research before it begins. This team makes sure that the benefits of the research are greater than any risks to participants.

In anonymous research, personal information that could be used to identify you, like your name or medical record number, cannot be linked to your health information or biological sample. In coded research, personal information that could be used to identify you is kept separate from your health information or biological sample so it would be very difficult for someone to link your personal information to your health information or biological sample. Your identity is protected in both types of research.

If you want to allow your health information and biological sample to be available for anonymous or coded genetic research, **you don't have to do anything**. If you make this choice, your health information or biological sample may be used for anonymous or coded genetic research without further notice to you.

If you want to decline to have your health information and biological sample available for anonymous or coded genetic research, **you must tell your health care provider** by: [Fill in relevant options below]

- Completing this form and giving it to your health care provider
- Completing this form and mailing it to the address provided
- Going to [Website] and completing the form provided

Your decision is effective on the date your health care provider receives this form.

If you have any questions or concerns about this notice, please contact [Fill in name or title of a person or office] at [Fill in phone number or other contact information].

No matter what you decide now, you can always change your mind later. If you change your mind, tell your health care provider your decision in writing by [sending a letter, include mailing address] [sending an e-mail to **] [going to **website address**]. If you change your mind, the new decision will apply only to health information or biological samples collected after your health care provider receives written notice of your new decision.

OAR 333-025-0165, Appendix 2

EXAMPLE Notification and Opt-out Statement & Form

(Other statements and formats may be developed and used that meet requirements)

- I decline to have my health information and biological samples available for anonymous or coded genetic research.

Printed Name

[Add other identifying information as relevant (e.g., birthdate, medical record number, address) and necessary to make sure the statement is recorded for the correct person]