Form to decline participation (continued)

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

Printed name _____ Signature _____

Birth date _____ Health record number _____

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

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KAISER PERMANENTE®

All plans offered and underwritten by Kaiser Foundation Health Plan of the Northwest.
500 NE Multnomah St., Ste. 100, Portland, OR 97232.

You are receiving this letter because you or someone in your household is a Kaiser Permanente member or patient who could be getting care at a Kaiser Permanente facility in Oregon. The state of Oregon has passed laws about anonymous and coded genetic research. These laws give you certain rights if you receive medical care in Oregon. You may decide if you want your health information or biological samples to be available for use in future anonymous or coded genetic research. You also have the right to tell us not to use this information or these samples in research. It's your choice.

This letter discusses the issues involved in making your decision. It also explains what you need to do. Your decision will not affect the care you receive from Kaiser Permanente. It also will not affect your health insurance coverage.

Notice of your rights: anonymous or coded genetic research

Under Oregon law, you may decide if you want or do not want your health information or biological samples to be used in research. These Oregon laws apply to anonymous or coded genetic research.

This type of genetic research uses patient health information or biological samples gathered as a part of clinical care. It requires no further effort from you. It also does not require any extra contact with you.

Some definitions

Biological sample. This could be a blood sample, a urine sample, or some other bodily material.

Anonymous research. In this type of research, your health information or biological samples cannot be linked to anything that identifies you. For example, your name and health record number cannot be linked to your cholesterol information.

Coded research. Personal information that could be used to identify you is kept separate from your health information or biological sample. This makes it extremely difficult for someone to link them.

Your identity is protected in both types of genetic research.

Information about research

Research gives us information on how to improve health. Through research, we can learn new ways to prevent disease or improve treatment for heart disease, diabetes, and cancer. Here are a few examples of important breakthroughs that genetic research could bring.

- People who have diabetes also have a risk of heart disease. Research can aid us in finding new ways to reduce this risk.
- Some people inherit a high risk for cancer. Research can help us find better ways to reduce breast cancer and colon cancer risks and deaths in these people.

Medical breakthroughs can't happen without research. And this research requires information from thousands of people. Researchers study the health information or biological samples. Through this study, they can validate their discoveries.

Kaiser Permanente Building
500 NE Multnomah St., Suite 100
Portland, OR 97232

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How research is monitored

Oregon law requires that all genetic projects be reviewed before they start. An institutional review board (IRB) does this review. The board is made up of a team of independent scientists, physicians, and community members. At Kaiser Permanente, our IRB reviews every proposed study. Each research project must have procedures to protect the privacy and confidentiality of the people involved. Our IRB reviews and approves these procedures. A research project begins only after it passes this review.

To participate

If you make this choice, you don't have to do anything. Your health information or biological samples may be used for anonymous or coded genetic research at any time without further notice.

To decline participation

If you do not want to participate, you must tell us. By declining, your health information and biological samples **will not** be available for use in anonymous or coded genetic research. If this is your decision, please fill out the attached form. Then, mail it to the address shown at the bottom of the form. Your decision is effective on the date we receive this form.

If you change your mind

No matter what you decide now, you can always change your mind later. If you change your mind, please send a letter to Attn.: GPN-CHR, Kaiser Permanente, 500 NE Multnomah St., Ste. 100, Portland, OR 97232

Your new decision takes effect on the day we receive your written notification. We will honor your new decision for all future health information or biological samples that we collect.

For other Kaiser Permanente members in your family

We are sending one notice to each household. Please make sure that all Kaiser Permanente members on your health plan (18 and older) receive a copy of this notice. You may copy this notice as needed.

Questions?

If you have questions or would like more information, call Membership Services, 8 a.m. to 6 p.m., Monday through Friday. From Portland, call 503-813-2000; from all other areas, call 1-800-813-2000. For TTY, call 1-800-735-2900. For language interpretation services, call 1-800-324-8010. You may also sign on to **kp.org** and send us an e-mail.

This notice is available in additional languages and large print. Please contact Membership Services to receive a copy.

Вы можете получить данный документ на других языках или напечатанный крупным шрифтом. Пожалуйста, обращайтесь в Отдел услуг по участию в плане (Membership Services), чтобы заказать экземпляр. В районе города Portland звоните по телефону 503-813-2000. Из всех остальных районов звоните по телефону 1-800-813-2000.

Este documento está disponible en otros idiomas e impresión con letra grande. Por favor llame a Servicio a los Miembros para solicitar una copia. En el área de Portland, llame al 503-813-2000. Todas las demás áreas, llamar al 1-800-813-2000.

Tài liệu này đã được phiên dịch qua nhiều ngôn ngữ khác và bản in bằng chữ lớn. Xin liên lạc với Dịch Vụ Thành Viên để hỏi xin. Vùng Portland xin gọi số, 503-813-2000. Tất cả mọi nơi khác, gọi số 1-800-813-2000.

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Form to decline participation

Please check the box below and complete this form. Then return this form to the address shown below.

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

Printed name

Signature

Birth date

Health record number

Street address

City State ZIP code

If you are the parent or legal guardian of a child younger than 18 years or the legal guardian of another individual who is a Kaiser Permanente member and you want to decline on his or her behalf, please list his or her name, birth date, health record number below. We encourage you to discuss this notice with teenage children or other individuals before making a decision on their behalf. We are sending one notice and form to each household. Please make sure that all Kaiser Permanente members on your health plan (18 and older) receive a copy of the notice and form. Make copies as needed.

Printed name of minor or other person on whose behalf you are signing

Signature of parent or legal guardian

Birth date

Health record number

Printed name of minor or other person on whose behalf you are signing

Signature of parent or legal guardian

Birth date

Health record number

Please mail this form to:

Attn.: GPN-CHR
Kaiser Permanente
500 NE Multnomah St., Ste. 100
Portland, OR 97232

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