Ovarian Cancer Study Fact Sheet

Researchers

Kaiser Permanente Washington Health Research Institute	Geisinger Health System	Mid-Atlantic Permanente Research Institute
Nora Henrikson PhD KPWA Study Lead Researcher 206-287-4675	Alanna K Rahm, PhD, CGC Geisinger Study Lead Researcher 1-866-207-3289, option 3	Cabell Jonas, PhD KPMAS Study Lead Researcher 202-594-7836

We are asking you to be in a research study. This form explains the details of the study.

Please take as much time as you need to read through this information and make your choice. Ask questions if anything isn't clear or if you would like more information.

You do not have to be in this study. If you say yes, you can quit the study at any time.

What is this study about?

You have been asked to participate in this study because you are a person with ovarian cancer, an ovarian cancer survivor, or a family member of someone with ovarian cancer. Ovarian cancer is the deadliest gynecologic cancer (cancer of the female reproductive organs). It is the fifth leading cause of cancer death in US women. Guidelines recommend genetic testing for all women with ovarian cancer and their at-risk relatives. However, fewer than a quarter are tested.

This study will help us learn more about your thoughts on genetic testing for hereditary cancer risk (cancer that runs in your family). We hope this will help Kaiser Permanente Mid-Atlantic States to offer better support to patients who need genetic testing for hereditary cancer and their families.

What will happen if I take part in this study?

If you join the study, we will ask you to:

Take part in an interview that will last about 90 minutes. Your interview will take place by phone or video call at a time and date of your choice. During the interview, the study researcher will ask you questions about:

- genetic testing,
- the best way to share information about genetic testing for ovarian cancer risk,
- and how Kaiser Permanente Mid-Atlantic States might help you in this process.

You will be given some information to review before the call, which should take about 20 minutes. The interview will be recorded and transcribed (we will write down what was said) so that we will have an accurate record of what was discussed during the interview. Recordings will be stored on a secure server at the Mid-Atlantic Permanente Research Institute. Only the research team will have access to recordings and transcripts. Recordings will be deleted after transcription is completed but no later than 6/30/2025. You must consent to have your interview recorded in order to join this study. Any information you provide us is voluntary, and you are free to refuse to answer any questions you do not want to answer. Anything you say that could identify you will be removed from the written transcripts.

After the interview, you will receive $25 to thank you for taking part in the interview.

How do I know if I can participate in this study?

You are eligible to participate in this study if you:

A. Are currently a member of Kaiser Permanente Mid-Atlantic States
B. Have ever been diagnosed with ovarian cancer OR are a blood relative of someone who has ever been diagnosed with ovarian cancer
C. Are willing to have your interview recorded and transcribed (written down)

Will there be any costs to me?

There is no cost to you to take part in this study.

Will being in this study help me?

This study will not help you personally, but we hope the results of this study will help improve care for ovarian cancer patients and their families in the future.

Can anything bad happen to me from being in this study?

You might feel uncomfortable answering some study questions or having your answers recorded. You may skip any questions you don't want to answer.

It's possible that someone other than the researchers could find out you were in the study or see your private study information. The steps we take to keep this from happening are described below.

How will you protect my confidentiality?

All researchers sign a confidentiality pledge that requires them to keep your information private. The researchers listed on the first page and their staff will use your study information for research only. We will not use your name in study reports or in any transcripts (written records of what was said). Instead, we will label your responses with a code number only. We will not tell your healthcare providers about your participation in this study. We will not add information to your medical record.

We plan to keep your study information as described in this form until 6/30/2025. At that time, we will destroy any study records that include your name or other information that points to you.

Do I have to be in this study?

No, being in this study is up to you. You are free to say no now or to leave the study at any time later. Either way, there will be no penalty. Your decision won't affect the health care you receive or benefits that you are entitled to.

What happens if I say yes, but change my mind later?

You may change your mind any time about letting us use your information for this study. If you change your mind, you may take back your consent by writing to:

Anna DiNucci (OC Study)
Mid-Atlantic Permanente Research Institute
2101 E. Jefferson St
Rockville, MD 20852

If you take back your consent (your agreement to join this study), it will not affect your health care or benefits at Kaiser Permanente Mid-Atlantic States. Once we receive your letter asking to withdraw, your information will be destroyed, and we will not use it. We will destroy any record of your name or other information that could identify you.

Who do I call if I have questions?

- If you have questions or concerns about the study, please call the Research Associate, Anna DiNucci, at **202-923-6990** or email **OCstudy@kp.org**.
- If you have questions about your rights as a research participant, please call the Kaiser Permanente Mid-Atlantic Permanente Medical Group's Institutional Review Board for the Protection of Human Subjects at **301-816-6572** or toll-free at **1-877-258-0017**.