



U.S. Department of
Health and Human Services
Centers for Disease
Control and Prevention



NORC
at the UNIVERSITY of CHICAGO

FREQUENTLY ASKED QUESTIONS

Who should complete the study?

This survey should be completed by a woman in the household diagnosed with ovarian, fallopian tube, or primary peritoneal cancer.

How long will it take me to participate in this study?

It will take about 45 minutes to complete the survey.

Why are you doing this study?

We are doing this research study to understand how to help women with ovarian, fallopian tube, and primary peritoneal cancer as they are diagnosed, receive treatment, and begin to recover.

Who is funding this study?

This study is paid for by the Centers for Disease Control & Prevention (CDC).

How much will I be paid for participation?

For this survey, you will receive a \$10 Amazon gift code via email or mail upon completion.

How was I selected to participate?

If a registry participant: Your name was obtained from the [STATE] Cancer Registry which supports research to understand and reduce the burden of cancer, including contacting patients on behalf of researchers. Every cancer diagnosed in [STATE] is required by law to be reported to the [STATE] Cancer Registry. Information on individuals with cancer can only be released for research purposes to qualified researchers who have obtained approval for the study from a federally-approved Committee for the Protection of Human Subjects, and have agreed to maintain the confidentiality of the information they collect.

If an RDS participant: Your name was provided as someone who may have interest in participating in this study. All information you provide will remain confidential.

How do I know this study is real or valid?

Please contact Dr. Mary Puckett at the CDC at (800) XXX-XXXX with questions, complaints or concerns about this research.

Who is NORC at the University of Chicago?

NORC at the University of Chicago (NORC) is an independent research organization that is conducting this study. Additional information on NORC can be found on its website (www.norc.org).

Who will see my answers?

Only a few people who work on the study ever see any personal information. Answers that could identify you in any way are separated from your other answers. Study findings are put into summary reports that contain no names or other information that identifies you.

Will you ever sell my name, address, telephone number, or other information?

No. Your information is kept confidential, and your answers are used for research purposes only. If you have questions about your rights as a study participant, you may call 1-866-309-0542, toll-free, and leave a message asking to speak to the Chairperson of the Institutional Review Board.

Are there any risks to me if I decide to be in this study?

There are minimal risks to participating in this study. You may find some of the questions make you feel uncomfortable. You may skip questions you do not want to answer and you can stop the survey at any time.

Are there any benefits from being in this study?

You taking the survey will help us understand issues important to women who have been diagnosed with ovarian cancer. Findings from this study will help inform future development of tools and resources to improve women's lives as they are diagnosed, receive treatment, and recover from ovarian cancer.

Will the information I give you be kept private?

All answers to survey questions will be kept private to the extent allowed by law. Only NORC study staff will ever see any personal information that could identify you as a participant. Information that could identify you in any way will be kept separate from answers to survey questions. We will combine your answers with answers from others participating in the study when writing summary reports or papers. Your name or other information that identifies you will never be reported.

No information that could identify you will be given to CDC. CDC staff will only have access to responses to survey questions. All identifying information will be destroyed once the study is complete.

Will my answers be safe online?

We will do our best to protect all the information we collect from you, but no one can guarantee complete confidentiality for data that is sent over the Internet. Information collected is encrypted at all times. Our secure servers use "HTTPS" to ensure encrypted transfer of your data between your browser and our servers. The survey link is also independently verified by Network Solutions as a secure website.

If I need to step away, can I return and complete the study online at a later time?

Yes, by using your PIN in the invitation letter.

I'm having technical issues with the survey form.

You may call our study partner, NORC, toll free at <<toll-free>> or email Ovarian-Survey@norc.org for assistance.