

Genomic Experience Project: HBOC and Fertility Study Information Sheet



What is this research study about?

The goal of the Genomic Experience Project: HBOC and Fertility Study is to learn more about how young adults with a hereditary risk of cancer make decisions about fertility preservation and family building. We are hosting two tweet chats and will use the information we gather to better understand what is meaningful to young adults with genetic cancer risk.

What are you asking me to do?

- **Join us for a tweet chat!** During the tweet chat, we will tweet questions about your experience with genetic testing and fertility preservation or other forms of family building. You will be asked to use the designated hashtag in your tweets related to these questions. Participate in the tweet chat as much or as little as you like. The tweet chat will last about 60 minutes.
- **Fill out the anonymous survey online.** The survey will ask general questions about your age, gender, genetic testing, and choices you have made about fertility preservation or family building. It will take about 5-10 minutes to complete.

You can skip any questions you don't want to answer. We will save the comments we gather during the tweet chat and survey. These comments may be used in presentations, publications and grant applications. However, we will never list your name or Twitter handle with any quotes and will not provide details that would identify you. You must be at least 18 years old to join this study.

Who is leading this study?

The following researchers at Kaiser Permanente Washington Health Research Institute are leading this study:

Marlaine Figueroa Gray, PhD	Karen Wernli, PhD	Nora Henrikson, PhD
Marlaine.S.Figueroagray@kp.org	Karen.J.Wernli@kp.org	Nora.B.Henrikson@kp.org
206-287-2620	206-287-2934	206-287-4675

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 in the future.

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

You might feel uncomfortable answering some questions. You may skip any questions you don't want to answer. Our tweet chat is a public conversation that is available to all Twitter users. Therefore, you should not share anything that you don't want known publicly.

How will you protect my confidentiality?

All Kaiser Permanente Washington researchers sign a confidentiality pledge that requires us to keep your information private. The researchers and their staff will use your study information for research only. We won't use your name or Twitter handle in study reports. We plan to keep your study information as described in this form until five years after the study ends. At that time, we will destroy any study records that include your name, Twitter handle or other information that points to you.

Information shared by e-mail and social media (Twitter, Facebook, etc.) is not considered secure. We cannot guarantee the privacy of e-mail or social media, and we will be careful to limit the amount of personal information included in messages we send you.

Do I have to be in the study if I want to join the tweet chat?

No, you can join the tweet chat and tell us not to use your comments for research. If you opt-out, we will delete your tweets from the comments we collected. If you want to opt-out, private message us on Twitter @frommarlaine, or email tara.c.beatty@kp.org or Marlaine.S.Figueroagray@kp.org.

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 any benefits that you are entitled to.

What happens if I join the tweet chat, but change my mind later?

You may change your mind any time about letting us use your comments for this study. If you change your mind, you may leave the study by writing to:

Marlaine Figueroa Gray, PhD
Kaiser Permanente Washington Health Research Institute
1730 Minor Ave, Suite 1600
Seattle, WA 98101

If we have already shared your comments publicly (never including your Twitter handle or other information that identifies you), we will not be able to take back what has already been shared. But we will destroy any record of your Twitter handle, 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 project manager, Tara Beatty at **206-442-4012**, or one of the researchers listed on the first page.
- If you have questions about your rights as a research participant, please call the Kaiser Permanente Washington Human Subjects Review Office at 206-287-2919.