

The Clare Project

Study Information Sheet



What is this study about?



The goal of the Clare Project is to learn more about how young adults with cancer make choices about medical care, including fertility preservation and other forms of family building. We will do this by talking with young adults with cancer who were diagnosed between the ages of 15 and 39. We will also talk with clinicians who care for these patients.

We plan to conduct a total of 20 interviews in 2017. We will use the information we collect to better understand how fertility planning for young adults with cancer is aligned with what patients say they want.

What are you asking me to do?

Do a phone interview. If you agree to do the interview, we will schedule a time to call you and ask you questions about your experience making decisions about fertility preservation and family building, and how care can improve to meet patients' needs.

The phone call will take about 60 minutes. You can skip any questions you don't want to answer. We will audio record the phone call to make sure we have listed your answers correctly. We will send the recording to a transcription company via secure website. They will listen to the recording, write down what you said and securely transfer the files back to us. A study team member will delete your name and any names you mention before sharing the written copy with the researchers listed below. We will destroy the audio recording by the end of the study.

We will mail you \$50 after you finish the interview. 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 Gray, PhD
gray.m@ghc.org
206-287-2620

Karen Wernli, PhD
wernli.k@ghc.org
206-287-2934

Evette Ludman, PhD
ludman.e@ghc.org
206-287-2917

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 study questions. 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 information. However, there are many things that we do to keep your study information safe and secure.

How will you protect my confidentiality?

All Kaiser Permanente researchers sign a confidentiality pledge that requires us to keep your information private. We will share your audio recording outside of Kaiser Permanente Washington only with a transcription company that has signed an agreement not to disclose any information.

The researchers and their staff will use your study information for research only. We won't use your name in study reports or write it on the information gathered in your interview. Instead, we will label everything with a Study ID number only. We will store your transcript and audio recordings in locked offices and password-protected computers. We won't tell anyone whether or not you join this interview study.

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 or other information that points to you.

Information shared by e-mail and social media (Facebook, Twitter, blogs, 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 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:

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

There is no penalty for taking back your consent. We may still use the study information we collected before we received the letter taking back your consent. But 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 project manager, Tara Beatty at **206-442-4012**, or one of the researchers on the first page.
- If you have questions about your rights as a research participant, please call the Kaiser Permanente Washington IRB Office at 206-287-2919.