

PREVENT-Breast video transcript

Amara and Pria have both been invited to take part in a study to learn about their future risk of developing breast cancer and how to reduce that risk.

They're wondering why they've been invited and what they would need to do if they decided to take part.

The purpose of the study is to find women who may be at increased risk of breast cancer but don't know about it. These women can then be offered additional screening or preventative treatment. Most women at increased risk do not have a family history of breast cancer. If you decide to take part, you will need to complete the following steps, which can all be done at home.

You can use any smartphone, tablet, laptop or desktop PC to complete the online elements.

First, scan the QR code in your invitation letter. Then enter your participant ID and PIN. You will then be asked to give your consent and agree to take part in the study and complete an initial questionnaire about yourself. Within two weeks, the study team will contact you by email or letter if you request that and you will be asked to complete an online questionnaire which is called MyCanRisk.

Before completing MyCanRisk it might be helpful for you to ask your relatives about any breast or ovarian cancer that has affected people within your family. You will be asked about this as well as questions about yourself. Completing MyCanRisk can take up to 20 minutes but could be much quicker if you don't have any family history of these cancers. MyCanRisk is in English but if you need one, you can contact us to arrange for an interpreter to help you answer the questions.

You will have the option to provide a saliva sample so that researchers can assess how your genes affect your risk of developing breast cancer. If you do want to provide a saliva sample, a free kit will be sent by post and it should arrive within two weeks of you completing MyCanRisk. Instructions for completing the saliva sample will be provided in different languages. You must complete and return the sample within 14 days. The postage is free. Your saliva sample will be destroyed at the end of the study.

Now, behind the scenes, researchers will be calculating your risk score, and you should receive your results by email within six months. You can ask for a letter if you prefer. There will be links in the email or letter to view your risk results in different languages.

Your breast cancer risk results will place you in one of three risk categories. Near population risk, moderate risk or high risk. Most women will be at near population risk. If

you are found to be at moderate or high risk, you will have the opportunity to speak with your GP to discuss your results. If needed, you may be referred to a specialist for a consultation in person, by phone or by letter. If you are at a high risk, you may be eligible for additional screening or preventative treatment.

Lastly, the team will contact you with the option to complete follow-up questionnaires and take part in an interview. If you require any assistance throughout this process, we will always be on hand to help you.