THE UNIVERSITY OF SYDNEY

Research Study: Communicating Cancer Risk with Family Members – a qualitative co-design study

We are carrying out a research study to review and develop information resources to support people with identified hereditary (genetic) cancer risk variants. Researchers at the University of Washington in the United States have developed a website (**www.connectmyvariant.org**) of information resources to assist patients start a conversation with relatives to tell them about their potential hereditary cancer risk. These resources provide information on how to spread awareness among families about inherited cancer risk and include instructions about communication with family members following a diagnosis with a hereditary cancer risk variant.

The study aims to review the existing *ConnectMyVariant* resources and adapt resources to improve and facilitate family communication regarding inherited risk of cancer in an Australian population.

This study is looking for feedback to help us make sure that the words, phrases and examples used in the University of Washington *ConnectMyVariant* resources are suitable and understandable for Australians who have an identified hereditary cancer risk variant(s) and their family members. The content of the resources will then be changed to make it suitable for an Australian population, the changes made will also be reviewed to make sure the changes are understandable and acceptable. The study will also explore if people feel there are any information resources missing that they think would be helpful related to having conversations with family about inherited genetic risk.

Taking part in this study is voluntary.

You can take part in this study if you:

- Aged over 18 years,
- Informed of genetic risk (either yourself or a family member) within last 10 years, i.e. since 2014.
- have an identified risk of hereditary cancer due to the detection of a clinically significant gene mutation (variant) OR you are a family member of someone with an identified risk of hereditary cancer due to the detection of a clinically significant gene mutation (variant)
- Speaks English,
- With access to an internet connection for a Zoom interview.

Taking part in this study will involve:

1. Completing an online survey which asks for demographic (e.g. age, gender) and health information (e.g. cancer and genetic variant) and health literacy questions.

2. You may be asked to take part in up to two Zoom interviews to provide verbal feedback on the wording, phrases and examples used in the *ConnectMyVariant* resources, and how understandable and acceptable for an Australian population.

The online survey is expected to take 10 minutes to complete, Interview 1 may take up to 1 hour and interview 2 may take up to 45 mins.

If you have any questions or would like further information about this study, please contact:

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To take part in this study, please click the following link which will take you to the study information sheet, consent form, and survey questions:
https://redcap.sydney.edu.au/surveys/?s=KTCWAMXNAECRY8KE

This study has been approved by the Human Research Ethics Committee (HREC) of the University of Sydney [2024/HE001427].