

Plain Language Statement

Melbourne School of Population and Global Health,
The University of Melbourne



Project: International Twins and Breast Cancer Study

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Introduction

Thank you for your interest in participating in this research project. The following few pages will provide you with further information about the project, so that you can decide if you would like to take part in this research. Please take the time to read this information carefully. You may ask questions about anything you don't understand or want to know more about. Your participation is voluntary. If you don't wish to take part, you don't have to. If you begin participating, you can also stop at any time.

What is this research about?

This National Institutes of Health (USA) funded international research project is being conducted collaboratively at the University of Melbourne by Professor John Hopper and the University of Southern California by Professor Thomas Mack and their associated colleagues. The study aims to research genetic and environmental risk factors for breast cancer. We aim to recruit twin pairs in which at least one twin who has either had breast cancer themselves, or their twin sister has had breast cancer, to collect information on their medical, reproductive and environmental histories. De-identified data collected from Australian twins will be pooled together with data from twins from the USA for the analysis. This study may help answer questions around why only one twin in a pair with a similar familial background develops breast cancer. It may help identify environmental factors that are protective against breast cancer that could help prevent breast cancer worldwide.

Professor Hopper has been studying twins for over 20 years and is director of Twins Research Australia (TRA) based at The University of Melbourne. He has been an active researcher in breast cancer and has previously established the Breast Cancer Family Registry. Professor Mack has also been a productive researcher in breast cancer, also through twin and family studies. You have been approached regarding this study because you have previously participated in research conducted by Professor Hopper through Twins Research Australia.

What will I be asked to do?

Should you agree to participate you will be asked to complete an online questionnaire about your health and lifestyle. We will email you a link to an online survey where you will be asked a series of health-related questions about you and your twin sister. This should take about 30-45 minutes to complete. The survey includes questions about your co-twin, although we will only collect such data in our study if both you and your co-twin agreed to participate in the study. You will be also asked to provide consent for us to contact you again in the future regarding possible collections of digital mammograms and blood or saliva samples. Participation in all parts of this study is voluntary, so you can agree to just complete the questionnaire.

What are the possible benefits?

This research could benefit all women by clarifying the genetic and environmental risks of developing breast cancer. It will help identify risk factors for breast cancer and support the establishment of effective preventive strategies.

What are the possible risks?

The risks associated with this study are minimal. If participating in this study causes concern about a family or personal history of cancer, the researchers will be able to provide information about access to government-funded Familial Cancer Clinics.

Do I have to take part?

No. Participation is completely voluntary. You are able to withdraw (quit) at any time.

Will I hear about the results of this project?

Yes, if you tell us that you are interested in receiving a report of the final study results we can email or mail this to you. You can indicate if you are interested on the consent form.

What will happen to information about me?

The information you provide in this study will be 'de-identified', meaning that it will be stored separately from your name and contact details so that you cannot be identified by anyone outside the direct research team and authorised Twins Research Australia staff. All data will be stored securely in password-protected computer files. Your 'de-identified' data will be shared with Prof Mack's team at the University of Southern California only for data analysis purposes of this study, using a secure digital transfer process. Your data, updated contact details, and any zygosity updates will be returned to Twins Research Australia, where it will be kept indefinitely and your de-identified data may be made available for other ethically approved research projects. The results of the research will be published in a form that will not allow individuals to be identified.

Who is funding this project?

This project is funded by the National Institutes of Health (USA). The reason for utilising funding from the NIH is due to the decades-long collaboration between Prof Hopper and Prof Mack, who is currently funded by the NIH.

Where can I get further information?

If you would like more information about the project, please email the study coordinator Lucas Ferreira by email lucas.cf@unimelb.edu.au or mobile 0478 652 768. Alternatively, you may wish to call Twins Research Australia on 1800 037 021.

Who can I contact if I have any concerns about the project?

This research project has been approved by the Human Research Ethics Committee of The University of Melbourne. If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Manager, Human Research Ethics, Office of Research Ethics and Integrity, The University of Melbourne by phone 8344 2073 or email humanethics-complaints@unimelb.edu.au. All complaints will be treated confidentially. In any correspondence please provide the name of the research team or the name or ethics ID number of the research project.