PARTICIPANT INFORMATION

Oncology health professionals’ attitudes towards treatment-focused genetic testing for women newly diagnosed with breast cancer

The study is being conducted by the following researchers:

Professor Christobel Saunders, University of Western Australia, Perth
Associate Professor Bettina Meiser, Head of Psychosocial Research Group, Prince of Wales Hospital, Sydney
Dr Kathy Tucker, Head, Hereditary Cancer Clinic, Prince of Wales Hospital, Sydney
Dr Gillian Mitchell, Familial Cancer Service, Peter MacCallum Cancer Centre, Melbourne
A/Professor Judy Kirk, Familial Cancer Service, Westmead Hospital, Sydney
A/Professor Kristine Barlow-Stewart, Director, Centre for Genetics Education, Sydney
Ms Belinda Rahman, Research Assistant, Psychosocial Research Group, Prince of Wales Hospital, Sydney
Ms Stephanie Burcher, Master of Genetic Counselling Student, University of Sydney, Sydney

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

What is the purpose of the study?
The purpose is to explore the current attitudes and experiences of Australian surgeons, medical oncologists, radiation oncologists and breast care nurses towards treatment-focused genetic testing (TFGT) via a web-based survey. TFGT refers to genetic testing for mutations in the breast cancer genes, BRCA1 and BRCA2, done around the time a woman is diagnosed with breast cancer to help her and her doctor decide on the best surgery. The survey aims to investigate oncology health professionals' attitudes towards the use of TFGT as part of the health care of women with breast cancer. The survey will take about 15-10 minutes to complete.

Do you have a choice?
Participation in this study is voluntary. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason. However, please note that it may not be possible to withdraw your data from the study results as the survey responses are all anonymous. Only individuals who give their informed consent will be included in the study.

If you agree to participate in this study, we will ask that you:
1) Read this Participant Information and the Consent page;
2) Click on the ‘I consent’ button located at the end of the Consent page. If you do not wish to participate, click on the ‘I do not consent’ button;
3) Follow the instructions to complete the survey
Are there any risks?
We do not expect there to be any risks or discomforts associated with this study. However, there may be risks associated with this study that are presently unknown or unforeseeable.

Are there any benefits?
We cannot guarantee that you will receive any direct or indirect benefits from participating in this study. However, it is hoped that the results from this study will assist with the integration of TFGT into the future clinical care of women with breast cancer.

Confidentiality / Privacy
Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. The study will be conducted online on a secure website administered by Stephanie Burcher, a Master of Genetic Counselling student. All participant data will be kept strictly confidential and participants’ email addresses will be stored separately from their questionnaire responses. Only the researchers will have access to participants’ data and these will be stored securely in a password protected database at the Psychosocial Research Group, Prince of Wales Hospital, Sydney, NSW.

Will taking part in this study cost me anything, and will I be paid?
Participation in this study will not cost you anything. You will not be paid for participating in this study but the first 60 participants from each professional group to respond will receive a $30 Amazon voucher. Participants will be notified by email when the quota has been exceeded and they are no longer eligible for the incentive. At the end of the survey the first 60 participants from each professional group will be asked for their email address and an online voucher will be sent to them.

What happens with the results?
If you participate in this research, the results will be used to write a thesis. We also plan to publish the study findings in a peer-reviewed journal, and to present a summary of the findings at appropriate conferences or other professional forums. In any publication, information will be provided in such a way that you cannot be identified. You will be offered a copy of the journal article, once published, to provide you with feedback on the findings.

Who should I contact if I have concerns about the conduct of this study?
This study has been approved by the SESLHD – Northern Sector HREC. Any person with concerns or complaints about the conduct of this study may contact the Research Ethics Secretariat, SESLHD – Northern Sector, Prince of Wales Hospital, Randwick, NSW 2031 Australia (phone 02-9382 3587, fax 02-9382 2813, email ethicsnhn@sesiahs.health.nsw.gov.au).

Contact details
If you have any questions after reading this information, or if you would like to know more at any stage, please do not hesitate to contact the coordinating investigator, Ms Stephanie Burcher on 0404124642

Thank you very much for taking the time to consider this study.

You may print this information if you wish.